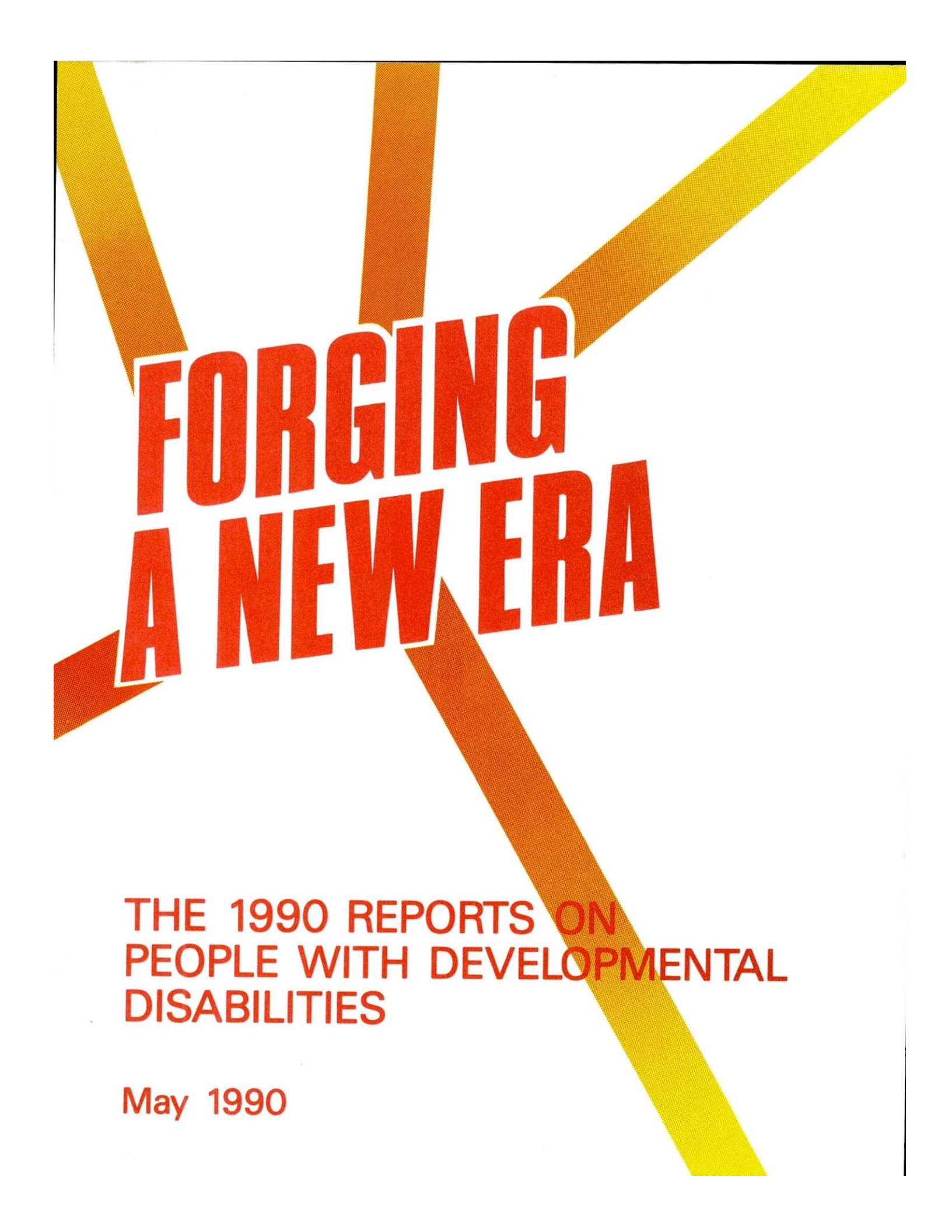




FORGING A NEW ERA

**THE 1990 REPORTS ON
PEOPLE WITH DEVELOPMENTAL
DISABILITIES**

May 1990

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The 1990 Reports on People
With Developmental Disabilities

APPENDIX

This publication was support in part by grant number 90DD0162 from the Administration on Developmental Disabilities, Office of Human Development Services, Department of Health and Human Services.

PREFACE

This volume contains statements of barriers/critical issues and recommendations from the individual Developmental Disabilities Councils 1990 reports, as submitted by the governors of the states and territories to the Secretary of Health and Human Services in January 1990. The statements are provided verbatim with the exception of conversion to "people first" language, i.e., "people with developmental disabilities" rather than "the developmentally disabled."

The barriers and recommendations have been grouped by life area, based on the primary focus of the statement. Cross-cutting statements, such as those related to coordination, overall program effectiveness, human resources, funding, etc., have been grouped by their primary focus. Readers also will note that some statements could be seen as either a barrier or a recommendation. Many of the decisions on placement have been arbitrary, based on our best understanding of the Council's meaning.

Each section is organized in alphabetical order by state, based upon their two-letter state abbreviation, (i.e., "AK" for Alaska precedes "AL" for Alabama.) Any statements found in two or more reports precede the alphabetical list, to further assist readers in finding individual states of interest. Most of these "multi-state" statements were adapted by Councils from the Sourcebook for Developmental Disabilities Councils' 1990 Report, distributed by the National Association of Developmental Disabilities Councils in July 1989 as a resource to Councils in preparing their reports.

It is inevitable that a few errors in abstracting and transcribing these statements from the individual 1990 reports will have been missed, despite our best and repeated efforts at checking. Readers are encouraged to read the individual 1990 reports in relation to specific statements of interest, for a better understanding of the context as well as for confirmation of the text.

The section on cross-cutting barriers and recommendations does not contain all such items; rather this chapter focuses on items which are not specific to; a program or to a life area or which refer to multiple programs in life areas. Cross-cutting items are areas such as funding, personnel, quality assurance, etc.

There are two reports which accompany this appendix, Forging A New Era: The 1990 Reports on People With Developmental Disabilities which is a compilation of the policy barriers identified and recommendations made by DD Councils, and a summary of that compilation. Copies of these publications can be obtained from NADDC.

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INDIVIDUAL SUPPORTS: BARRIERS

Multiple States

There is an overall lack of data on the needs and preferences of individuals with developmental disabilities for various kinds of supports and their relative significance in helping people reach greater levels of independence, productivity and community integration. <LA,MT,UT,WY>

Despite its critical role in financing supports to individuals with developmental disabilities and their families, there are no data available on Medicaid services and expenditures in this area other than broad estimates. <LA,MT,UT,WY>

There is almost no current information available on the federally-supported Independent Living Program regarding services being provided and the characteristics of those being served. <LA,MT,UT,WY>

Few data are available on supports provided to people with developmental disabilities through "generic" support programs such as child welfare and aging services, primarily because of the lack of reporting requirements that would include such information. <AZ,ID,MT,UT,WY>

There is a need for an overall shift in thinking from facility-based services to a "facility-free" system of supports. To accomplish this, public attitudes will need to include recognition of the significance of this approach in the quality of life for people with developmental disabilities and the viability of this approach for people with challenging and severe disabilities. <LA,MT,UT,WY>

The majority of personal assistance programs do not emphasize consumer control. <CA,IN,WA>

Most of the federal programs which currently finance supports are included in the administration's "flexible freeze" group in its FY 1990 federal budget request, including Supported Employment State Grants, Independent Living State Grants and Centers, the Social Services Block Grant, Children with Special Health Care Needs/Material and Child Health Block Grant, the Alcohol, Drug Abuse and Mental Health Block Grant, Title IV-B Child Welfare Services, the Foster Grandparent Program, Technology-Related Assistance Grants, Temporary Child Care and Crisis Nurseries, and the Early Infant Intervention Program (special education.) No funding is proposed for the Special Recreation Grant Program. <CA,FL,ID,IN,MT,TN,UT>

The appointment of a guardian can be the most intrusive form of state government intervention for a person with a disability, potentially reducing the capable adult with a disability to the status of a child. Guardianship is often granted when it is neither an

appropriate nor adequate means to provide the assistance needed for people with developmental disabilities to achieve their fullest potential. <CA,ID,MT,UT,WY>

Because there is a lack of support and assistance available in the community to enable people with disabilities to make choices most citizens take for granted and as more people move into the community, resources will be needed to sustain their independence. As this happens, there is a fear that states will tend to appoint more guardians rather than provide needed support services to promote independence and true integration in the community. <MT,WA>

The overriding issue is the relative lack of resources for supports to individuals with developmental disabilities and their families despite their critical importance to the promotion of independence, productivity, and community integration. <ID,IN,MT,UT,WY>

There is an increasing number of people with functional limitations in their activities of daily living, especially associated with the significant growth in the number of people who are elderly. There is no corresponding rate of growth in the availability of supports to individuals. <ID,IN,LA,MT,UT,WY>

Almost none of the supports to individuals with developmental disabilities and their families are considered entitlements. Most federal funding that is available is at state or local option, including Medicaid waivers, optional services, and extension of Medicaid eligibility to children with disabilities who would otherwise only be eligible if they were institutionalized; and discretionary grants for "demonstration" programs and special projects, including special recreation programs, independent living centers, community support programs for people with serious mental illness, and the development of statewide systems to make assistive devices and services available. <MT,TN,UT,WY>

For both individual and family supports, there is frequently a lack of involvement and focus on the consumer. Individual supports are seldom available that can be directed by the person with the developmental disability or selected from an array of supports to provide a "package" of supports tailored to the needs and preferences of the individual. <HI,IN,MT,UT,WY>

Reinforcement of the emphasis on consumer control in the Independent Living Program is still awaiting publication of the federal performance standards. <LA,MT,UT>

Federally-financed supports to individuals and families tend to be tied to medical care needs, because of their basis in health finance programs. For example, "personal care" services provided through the Medicaid program are defined as "medically-oriented" tasks having to do with a patient's physical requirements", must be prescribed by a physician and supervised by a registered nurse, and be in accordance with the recipient's "plan of treatment". <ID,IN,LA,MT,UT,WY>

Almost none of the supports to individuals with developmental disabilities and their families are considered entitlements. Most federal funding that is available is at state or local option, including Medicaid waivers, optional services, and extension of Medicaid eligibility to children with disabilities who would otherwise only be eligible if they were institutionalized. <ID,IN>

Many Independent Living Centers (ILCs) restrict services to people with only certain kinds of disabilities. Over 40 percent do not serve people with mental retardation, and 70 percent do not serve people with mental illness. <IN,LA,MT,UT>

Many older people with developmental disabilities find it difficult to obtain services in the programs funded through the Older Americans Act. <LA,MT>

Limited funding is available for home and community-based supports to individuals with developmental disabilities and their families. Expenditures for supports are consistently much lower than those for institutional and facility-based care, despite the fact that these expenditures broaden the availability for services to many more people than the facility-based programs that serve relatively few individuals. <ID,MT,UT>

There are gaps reported across the nation in the availability of supports to individuals with developmental disabilities and their families living in rural areas, supports for consumers with the most severe disabilities, and supports that can be obtained in an emergency. <ID,MT,UT,WY>

The Social Services Block Grant, a major source of funding for supports to individuals with developmental disabilities and their families in many states, has been significantly underfunded for the past several years in comparison to its original authorization levels. <IN,LA,MT,UT,WA>

In the current era of deficit reduction, increased costs for existing facility-based services, such as those provided in large state institutions, frequently leave few resources for individual and family supports — without regard to their relative cost-effectiveness and their significance in the promotion of independence, productivity, and community integration. <MT,UT,WY>

The individuals with developmental disabilities who receive supports are inadequately involved in their monitoring and supervision. <ID,LA,MT,UT,WY>

The potential benefits of the Medicaid Home and Community Based Services (HCB) Waiver are limited by the "cost-neutrality" requirement, which prevents states from using the HCB waiver to finance home and community-based supports to all people with developmental disabilities who need them. In addition, the waiver is not available in all states. <ID,IN,MT,WY>

Access to supports financed through the general Medicaid program is limited by several factors. <ID,IN,MT>

Individual state regulations on coverage may limit Medicaid reimbursement to an inadequate number of units of support services. <MT,UT>

Individual States

Federally-financed supports to individuals and families tend to be tied to medical care. Funding for assistive devices is very limited in Alaska. It is usually tied to services through the Division of Vocational Rehabilitation or through special education programs in the school districts. The ELKS HELP program advises people in the selection of adaptive equipment and loans out devices for trial use, but the eventual purchase of the device is often up to the individual. <AK>

Weather issues make Alaska a logical location for testing of all types of assistive devices. To date, little or nothing has been accomplished toward making assistive devices operable in cold weather climates. <AK>

Alaska's guardianship law is considered a model statute by the American Bar Association. Due to under staffing and high client caseloads, the high standards set in the law are impossible to maintain. <AK>

Becoming a guardian can often be an expensive undertaking. Under the current practices and rules of the court, a family member who wants to become the guardian for a person who experiences a disability usually must hire an attorney to initiate the process. Guardianships for people living in institutions and for young people under supervision of the Division of Family and Youth Services are paid for by state. <AK>

New developments in adaptive devices and equipment are often costly and therefore not always available to people who experience disabilities. Medicaid and Medicare, rehabilitation agencies, insurance companies, etc., are often reluctant to fund newer, more technologically advanced, and more expensive items. <AK>

Fifty-six percent (56%) of Americans who experience disabilities say that their disability prevents them from getting around, attending cultural or sports events, or socializing with friends outside their home as much as they would like. <AK>

The personal care option is the only addition to the mandatory Medicaid program offered by the state. Consumers report that the state will need to increase the number of personal care hours allowed in order for this to be a viable alternative to institutionalization. <AK>

Some funding exists for assistive devices (such as adapted toys, computers, communication devices, powered wheelchairs, environmental controls, and ramps and other modifications made to the home to make it more accessible), but much of it is tied to specific purposes of activities (e.g., education or rehabilitation) and is subject to age, income, type of disability or other eligibility requirements. Some equipment may also be so expensive as to be out of reach for all but a few families or organizations. <AK>

Access to Alaskan state parks is extremely limited for people who experience disabilities, especially mobility impairments. <AK>

People who live outside Anchorage, Fairbanks and Juneau have limited access to guardianship or protection and advocacy services. <AK>

Case coordination (CC) services in Alabama have become a major concern, particularly with regard to young children with handicapping conditions. Part of Public Law 99-457 in 1986 mandates case coordination services. This is a new facet in the spectrum of services to these children and their families. <AL>

Perhaps more than other service, the area that includes recreation and leisure services prompted one of the largest responses. Of the 225 people who responded to the question, what is your level of need for recreation/leisure service?", 177 people indicated somewhat of a strong need, and 110 were not receiving any recreation or leisure services. These Alabama findings are consistent with national trends in the area of recreation. <AL>

There is a need for a central information and service referral agency. <AL>

Isolation extended into the lives of the family members as well. For example, one family reported that, due to negative and stereotypic attitudes expressed by some members of the community (including extended family members), they became even more isolated because they were hesitant to participate in regular community activities such as attending church, having visitors in their home, or shopping at the mall. <AL>

The consumer survey item asked respondents to state their single most important need. An examination of those important "miscellaneous" needs focus largely on a variety of urgent needs relating to social interaction and integration. Respondents did not ask for "bowling for the handicapped" or "handicapped day at the movies" but rather basic human interactions (e.g., a friend, love, someone to talk with). <AL>

Respite care was a problematic area for many consumers in the state. Over a third of those surveyed did not know what respite care was or that these services were available. However, approximately one-third indicated a strong need for both in-home and out-of-home respite care. <AL>

The financial drain of supporting a disability (costly medical tests, treatments and therapies; expensive adaptive and support equipment for people with various impairments; expensive vital adaptations to dwellings and vehicles, and costly attendant care) often means that people with disabilities have insufficient funds for the regular expenses of daily living. <AL>

One of the findings from the demographic data reveals that 91% of the sample had never married and at least 45% of the sample was old enough to marry. Being single in 1990 and attempting to establish new relationships can be financially expensive. It is also known that having a developmental disability typically means earning far less than most individuals, thereby complicating the issue of access to social situations (e.g., movies, theatre, sporting events). It is no wonder, then, that far too many people with developmental disabilities report that they are isolated and lonely. <AL>

The need for information and referral services consistently appears at points of transition (from infant to preschool settings, from preschool to school age environments, and particularly from secondary school settings to adult services). <AL>

Services such as physical, occupational and speech therapy; medical equipment supplied; and home health care are the least likely to be fully covered by public or private funding, require higher co-payments than other services, and are subject to more limitations than inpatient services. <AL>

The most startling finding of the study concerned with permanency planning was that more than half of the sample had made no concrete plans for the future care of their adult children with mental retardation. Many of the responses regarding future planning consisted of statements to the effect that "God will provide." Planning was less likely when the sex of the dependent child was male and when the child displayed higher functioning abilities. The lack of planning by families for their members who are mentally retarded poses a serious problem for the mental retardation service system. The need for services, especially residential, for this group of individuals with mental retardation is likely to be sudden and critical, creating a situation in which less than appropriate intervention is effected. <AL>

A number of individuals frequently requested PT, OT and/or speech therapy. Parents in particular mentioned that although their child might have been scheduled to receive those services, often it was on a very limited basis. <AL>

In many cases, services are needed from several programs and agencies. While some individuals of the target population may have knowledge of the system, most individuals with severe developmental disabilities do not have the resources of time, money, and energy to investigate and obtain needed services. <AL>

In Arkansas, case management is typically provided by case managers who are employed by and housed in institutional facilities and by community providers who also provide direct services to individuals with disabilities. While there has been no formal evaluation of the case management services provided through the community provider network, advocates indicate that this system does not necessarily function free of the many problems that may stem from a conflict of interest. <AR>

A service deficit that needs immediate attention in Arkansas is called "Follow Along". Currently the service provides 30 minute units of transportation, personal finances, counseling and service acquisition services. The growing need for this is a tribute to every community program in the state. There are currently at least 175 people identified as having moved into the community living on their own after receiving training in residential programs. They usually need very little continuing support. However, they must have the support available in order to maintain their independence. Many people with disabilities will need access to that support all their lives. If follow along support were more readily available more people could move from existing community residences. Three community residential service providers, Life Styles, Independent Living Services-Conway, and Pathfinders have been unable to move more people out because of their inability to provide proper support in the community. <AR>

In Arkansas, there currently exists no state.-wide integrated information and referral system to assist individuals with developmental disabilities and their families in their efforts to obtain quality services. Organizations and efforts that do exist do not provide broad referrals nor do they follow up to insure that needed services are received. <AR>

The current guardianship program in Arkansas, Guardianship, Inc. indicated as of February 1988 that only 70 persons with developmental disabilities were currently involved in that project, leaving hundreds of individuals presently residing in state and private institutions with no effective representation. <AR>

It is important to note that a progressive guardianship law, which provided for limited guardianship, was enacted by the Arkansas State Legislature in 1983 (ARC/USA, 1988). However, in the aftermath of the law's passage, the Legislature has effectively eroded some of the safeguards and requirements. <AR>

In Arkansas, a preliminary effort to initiate a statewide system of local DIRECTION SERVICE sites was organized through the Arkansas Disability Coalition. Unfortunately, however, the funding has not yet been obtained to accomplish the development of this system. <AR>

Based on the known number of individuals who are now served or who are on waiting lists, case management, with a maximum case load of 35 persons for each case manager, for all 7,371 would require the full time equivalent of 210 case managers. Such a system would, based on the qualification level of case managers and an anticipated salary of

\$17,500, with fringe benefits equivalent to current state costs, and travel and administrative overhead, require an expenditure in excess of \$5,000,000. Given current resources in Arkansas, a case management system which utilizes a combination of providers and independent case managers which gives each client a choice would appear to be likely for the near term future. <AR>

The levels of reimbursement for service vendors should be increased to encourage more provider participation and increase the availability of support services. <AZ>

The Governor's Council needs to work with state agencies to develop ways to address problems in filling case manager positions, especially in the rural areas of the state. <AZ>

Arizona's regulations on covered services should allow Medicaid reimbursement to more than a limited number of units and categories of support services. <AZ>

The Arizona Executive and Legislative branches need to develop additional funding to address the growing waiting list. <AZ>

Arizona should have an established policy for waiving parental income in extending Medicaid eligibility to children with developmental disabilities who remain in their family home. <AZ>

For both individual and family support, there needs to be more involvement and focus on the consumer and family members. Individual support must be guided by the person with the developmental disability or selected from an array of supports to provide a "package" of services tailored to meet the needs and preferences of the individual. Participation by the individual in his or her IPP development must be a priority. <AZ>

There needs to be more resources for supports to individuals with developmental disabilities and their families despite the critical importance of family support to the promotion of independence, productivity, and community integration. <AZ>

Qualified people should be hired for the case management positions so that individuals and their families can expect a certain level of competence. <AZ>

The management system, although a valuable tool in managing services to assure the most effective and coordinated services possible, has not been strongly supported with funding. This is a serious problem because it is through case management that people with developmental disabilities receive an evaluation and a plan of services to assist them in becoming more independent, productive, and integrated into the community. <AZ>

DDD's case management system is overloaded — both in terms of caseloads and range of responsibility. There is also a lack of authority to carry out necessary functions. Caseloads are too large and clerical support is lacking. In some areas, attending Individual

Program Planning (IPP) meetings has been given a very low priority or totally eliminated. <AZ>

New case managers are inundated with too much information for a person to absorb in the quick, brief training they receive. These people do not receive the training they need to obtain a good understanding of the various programs in the service system. <AZ>

Recreational opportunities are often non-existent for people living in residential care homes. Due to fiscal constraints on providers and a caretaking approach to the provision of services, many individuals spend their free time in the group home, watching television or listening to music. <CA>

Publicly funded programs to assist individuals in living independently through the use of attendants offer only limited service. No central resource exists to help people find attendants when they need one. <CA>

Attendants often do not receive adequate training in the handling and care of individuals with developmental disabilities, and there needs to be better and more uniform training to provide more consistent and better quality attendant services. <CA>

Many people with developmental disabilities have only a few, if any, friends, and many have no friends that do not have disabilities. Few supports are available to encourage and promote the building of friendships. <CA>

Case management services are available to people who meet the state eligibility requirements, but caseloads are often extremely high; for people with developmental disabilities who meet the federal definition of developmental disabilities, but not the California state definition, no case management services are available. <CA>

At the Consumer Forums, people with developmental disabilities indicated that turnover among case managers is a real problem. To understand an individual and the associated developmental disabilities unique to that person, considerable time is often needed on behalf of the case manager. When people meet infrequently with their case managers, there may be little continuity due to high case manager turnover. <CA>

Liability and certification are significant barriers to the recruitment of people willing to provide attendant and/or respite services. Respite workers are required to carry liability insurance which may be prohibitively expensive relative to the compensation. <CA>

No adequate funding mechanism exists to purchase state-of-the-art, high technology equipment for people with developmental disabilities. <CA>

Social and recreational opportunities are scarce for people with developmental disabilities, even though it is an entitlement under the Lantherman Act. Without adequate transportation, many individuals are isolated and segregated within the community. <CA>

Attendant services are often poor in quality, not assessable or not affordable, and people with developmental disabilities often have little control over their attendants. <CA>

Law enforcement officers are often not trained to understand developmental disabilities and how to protect and serve people who have developmental disabilities. <CA>

Independent living supports and training are in extremely short supply, and many individuals are not being given the opportunity to live independently because this support is not available. <CA>

Not all people with developmental disabilities have the opportunity for social interaction and participation in community activities. <CA>

Family and individual support services must be designed to fit the needs of the family as a unit. They must be appropriate to the family's lifestyle, number of children, ethnic and cultural preferences, economic status, and parents' work schedules. There must be more flexibility within the service system to provide needed supports in a manner which will alleviate family stress and help the family to successfully maintain a home for their children with developmental disabilities. <CA>

Many of the aging system service providers were either unaware that persons with developmental disabilities were eligible for their programs, or reported that aging persons who did not have developmental disabilities were not receptive to having these persons in their programs. Little outreach from the aging system to persons with developmental disabilities occurred. <CO>

In all areas of the state, if the family has no money to purchase therapy and other services, children may go without speech and language therapies because most health insurance does not cover these therapies. <CO>

The need for flexible, family- and consumer-directed services. <CO>

The primary need cited by ILC staff was funding for case management services. <CO>

Rather than providing supports which include a full spectrum of paid and unpaid activities for people who want to contribute to society, supports are aimed almost without exception at income-producing activities; i.e., "substantial gainful activity." This focus excludes many people from being valued members of society, and also leaves untapped a reservoir of talent that could be channeled into productive activities that would benefit society as well as its members who can and want to make this type of contribution. <CO>

All the literature and existing programs for DD offenders agree that it is essential to provide services that will prevent further criminal behavior and lead to a positive self-image, as well as enhance the offender's ability to be self-sufficient and independent. Although the numbers of persons in Colorado justice system who have developmental disabilities is unknown, it will be essential to develop appropriate treatment programs for these people as they are identified. <CO>

There is a need for physical therapy, including massage and exercise programs, for adults with cerebral palsy. <CO>

Another example of the lack of funding to provide for the level of services needed by those with cerebral palsy and severe disabilities is found in the three group homes operated by the Center, where therapies have **been cut back due to the low reimbursement** rate currently available for residential programs. <CO>

Family support services are needed for families with children who have cerebral palsy but whose disabilities are not severe and who do not have intellectual impairments, as well as counseling and crisis intervention for these young people, many of whom are experiencing severe emotional problems. <CO>

A respite care facility to provide crisis care, assessment, family support, and training is critically needed for persons with autism. <CO>

The independent living centers can serve only a fraction of those in need of services. <CO>

Although technology has been a great aid in helping to ameliorate the medical disabilities of children with special health care needs, their social needs have yet to be addressed satisfactorily. Family support services are generally not available for many families whose children live at home. <CO>

Effective, comprehensive case management throughout the life span is lacking outside the dedicated developmental disabilities system. Many persons with epilepsy feel that the dedicated service system is not appropriate for their needs. <CO>

Appropriate recreational opportunities are often lacking for younger children with hearing impairments. <CO>

If additional funding were available, more dogs could be trained to provide people of all ages with hearing impairments with assistance through the Hearing Dog program which would make them more independent. <CO>

The state Essential Services program is not an entitlement. For people with severe and multiple disabilities, personal assistance is a basic condition for a dignified life and active participation in the community. It should be an entitlement. <CT>

The annual subsidy for personal assistance must increase, especially for people who have the most intense personal assistance needs. It was documented in 1986 that it was not unusual for people with severe and multiple disabilities who require full-time attendants and services to pay \$13,000 to \$15,000 per year for personal assistance. In 1988, Graphic Futures has documented that people who have extensive needs require \$12,000 to \$18,000 per year for personal assistance. <CT>

The medical model represents an obstacle to people's realization of their potential for self-direction, because the attitude is conveyed that people with disabilities are possible patients who need to be taken care of. <CT>

The Division of Rehabilitation Services is hampered by federal regulations requiring a commitment of long-term support before providing services under Title VI-C or regular case service funds (Title I). <CT>

Nearly 8 out of 10 providers agreed that: 1) access to supports is tied to proving ability to work; b) having the disability condition under control may affect access to services and c) long waiting lists and waiting periods frequently preclude access to service. <DC>

Nearly eight out of 10 providers said that there is resistance to integrate older persons with developmental disabilities and seven of 10 said that there are not adequate provisions in service plans which cover life span transition points. <DC>

The ten Department of Recreation and Parks persons interviewed called for more budget allocations, and a majority said there was a need to conduct more outreach activities, complaining that there was a lack of data on who is being served by the program. Several felt that the lack of transportation was the greatest deterrent to the participation of people with disabilities in recreation activities. <DC>

The District has been constantly optimistic about the point at which its inmate population would level off. Its last several budgets have been developed based on assumptions that the variety of measures taken to reduce prison population would achieve the desired effect. However, despite the number of inmates who have been diverted from the existing, overcrowded facilities, the prison population has reportedly continued to climb dramatically. The department is mandated to provide educational training and counseling services within a healthful and humane institutional environment. This has become extremely difficult in the face of the escalating growth of the District's inmate population, the shortage of adequate funds to operate the system, and the inability to recruit and to retain sufficient and qualified staff. <DC>

The results of analysis conducted on the provider survey indicates that there are 903 persons incarcerated who have been diagnosed as having developmental disabilities. Out of the 903 inmates with developmental disabilities, 600 had an emotional disorder, 150 suffered from asthma, 22 had a speech/language impairment, 18 had AIDS, and 10 suffered from epilepsy. It was reported that the developmental disorders of 50 of the inmates were drug related. <DC>

Such circumstances lead several providers to conclude that most inmates with developmental disabilities are not identified by the system, and that the support services for those that are identified are inadequate. They also complain that insufficient information on the condition and whereabouts of these inmates make it difficult to provide them with adequate representation. It would appear that only the education and medical services are specifically targeted for the inmate with developmental disabilities. There are no special provisions in recreational programs that are available to all inmates. <DC>

The provider survey administered to corrections personnel produced comments and responses from individuals who felt there was a serious need to focus attention on the offender with developmental disabilities. A main concern was that those offenders with developmental disabilities were often overlooked because of their low visibility in an overcrowded prison system and the shortage of qualified personnel who could identify and address their particular problems. <DC>

Planning for attendant service is only at initial stages: demonstrations of model services are indicated, and mobilization of consumer awareness and advocacy is needed. <DE>

A large number of Stockley (state facility) residents require guardianship, either permanent or substituted decision making in most areas of treatment and personal life. <DE>

The population of people with developmental disabilities is aging at a faster pace than the general population and new programs need to be developed, within current resources if possible, to meet their needs which are vastly different from the general population especially in the area of health care. Currently 24% of the Division of Mental Retardation population is over the age of 50. <DE>

Consumer Satisfaction Survey respondents indicate that "respite care in the home, needed by half the children, is not being received by about three-fourths of those who have the need. Outside respite care, needed by about one-third of the children, is not being received by about half who express the need." A need also exists to expand respite services to include children who are also medically dependent and require specialized medical care. <DE>

Of those participating in the Consumer Satisfaction Survey, about half indicated a need for information and referral services and said they were not receiving those services. This

was found to be particularly true in Kent and New Castle Counties. Survey findings further indicate that some participants simply did not know where to turn in order to receive such services. <DE>

The Consumer Satisfaction Survey indicates that 28% of total survey participants report needing case management services, and also report that they are not receiving them. Children and adults are almost equal in their need for case management services (56% and 59%). The survey also found that persons with mental disabilities are much more likely than persons with other types of disabilities to report needing case management services (71% vs. 49% for sensory/emotional, 48% for physical). In each case where case management services were indicated as a need, about four in ten reported their need as strong or critical. <DE>

Lack of in-home care as well as the lack of programs which are specifically designed to address the person's health, behavior or level of skill were identified as needs by advocates and providers. <FL>

Recreation opportunities are limited. <FL>

Funding for individual and family supports is inadequate. <FL>

Inability to receive effective behavior management training was a frequent consumer complaint. <FL>

Many individuals who need guardians do not have them. <FL>

Almost no attention is given to social/leisure needs of individuals with developmental disabilities. <FL>

Follow along services connected across age spans are also needed. <GA>

Very limited resources are available to provide attendant care for persons with developmental disabilities. <GA>

There is a need for an increase in the amount and coordination of Case Management service providers. <GU>

There is a need to expand and improve long-term care services in the area of family and community support services for individuals with developmental disabilities. These support services include cash incentive program, housing subsidy, cash assistance, community living training, homemaking assistance and training, and personal assistance and other services for people with blindness. <GU>

There is a need to provide adequate communication/language services for individuals with developmental disabilities who need such services. <GU>

There is a need to upgrade and improve Guam's recreational facilities so that individuals with developmental disabilities can have access to them; develop recreational programs suitable to these individuals. <GU>

Medicaid funds can be a significant resource to programs providing personal assistance services. New York and Michigan use this optional Medicaid coverage to fund supported services in community residences and in an individual's home. But Hawaii, like most states, limits this coverage to avoid substantial budget impact. <HI>

The majority of personal assistance service programs do not emphasize nor involve the consumer. <HI>

Programs need to include a social component to facilitate movement into the community so that independence does not equal isolation. This concern was expressed in all focus groups with discussing barriers to independence for people with developmental disabilities. <HI>

Most "generic" recreation programs are not designed to integrate persons with disabilities. Most public parks in the state of Hawaii are not accessible to persons with physical disabilities that are in wheelchairs. <HI>

The state Medicaid plan requires that the purchase or repair of a prosthetic device over the cost of \$50 be authorized in advance. This restriction applies to almost 100 percent of all assistive devices needed by people with developmental disabilities. This restriction often means that a person is without an essential device required to move about, and worse, a device which will assist in the rehabilitative process. <HI>

There is a poor communication between the agencies trying to facilitate the process of reimbursement for assistive devices and the state Medicaid agency. There is no education of the physicians as to the requirements of obtaining reimbursement for a particular device. Often, whether or not the device is approved depends on how the physician writes the prescription. <HI>

HCB waiver eligibility standards restrict participation on the basis of family resources, may not actively promote more community involvement by clients of the program, and do not explicitly cite integration as a goal of the program. <IA>

The results of the consumer satisfaction survey reinforce the conclusions drawn from the policy analyses. As expected given eligibility requirements that limit the number of clients to 200, relatively few respondents use, or have access to, HCB waiver program services. Among those who are served by this program, more than three of four express

some dissatisfaction. Specific areas of concern include limits on services available through the program, eligibility restrictions, and a lack of individual choice of appropriate services. <IA>

In two areas policy is seen as inhibiting independence. First, the HCB waiver policy presents in-home services as a waiver option, rather than the preferred option for service delivery. As a model waiver program, the number of participants is limited to 200 in Iowa. Second, policy offers individuals very little choice in the type and level of services to be provided. <IA>

Only one-third of those surveyed report the HCB waiver program provides enough individual choice. Surrogates feel they have insufficient input into the selection of appropriate services. Consumer satisfaction with the program's support of productivity and integration is also relatively low, with responses identifying restrictions that limit access to the full range of program services. <IA>

The HCB (model) waiver program is often confused with the discontinued Katie Beckett Waiver and other similar programs. The area of greatest confusion centers on client age and eligibility. Many parents mistakenly believe that the HCB Waiver is only for persons under the age of 19. This program actually provides services to any child, adult, or elderly person who meets the eligibility requirements and is at-risk for institutionalization. <IA>

Although the HCB Waiver program serves relatively few families, significant comment about it arose at the public forums. At the forums, comments did not center on issues related either to integration or to independence, but on issues of eligibility, complexity, and lack of awareness of the program by professionals who serve the families. These are system-wide issues which arise with other programs as well, but they are particularly evident in this program because the families served are often those already inundated by the complexities of their child's medical condition. It is also clear from the comments about unmet needs that the services offered under this program are very much needed by families still attending to, or wanting to attend to, adult family members with developmental disabilities living at home. <IA>

Analysis of the Congregate Meals program policy indicates a lack of promotion of independence through support for individual choice regarding when and where services are provided; and second, that independence is not cited as a goal in the program policy. The Home-Delivered Meals program policy lacks language in the policy that would promote individual choice with respect to who provides services, when it is provided, and how often it is provided, and thus inhibits client independence. <IA>

Consumers report feeling that providers are reluctant to follow up on requests for information about other programs or services. Sometimes providers seem to discourage application to other programs because they feel the consumer has little chance of being

served by that program. Other consumers report that once local service personnel have the proper information, they are often very helpful; the key issue is simply getting the information. <IA>

The consumers and their surrogates who were interviewed consistently report they encounter serious problems when they try to discover what services are available. For example, many commented on the basic problem of finding out where to go to begin the search for information about programs or services. No single source of information is currently available; different programs are administered by different agencies, and often one agency is not well informed about the services of another. Once an individual learns a program exists, it is then necessary to find out whom to contact for eligibility and application information. <IA>

Surprisingly, less than ten consumers and surrogates, out of the 384 surveyed, reported using the services of either the Congregate Meals or Home-Delivered Meals programs. It would seem that the most important issue raised by the survey is the lack of utilization of this service by persons with developmental disabilities. Whether this reflects a very small population of elderly persons with developmental disabilities, a problem with informing eligible persons about the availability of this service, or simple under-utilization of these programs needs to be examined. <IA>

In terms of productivity, Congregate Meals policy does not include language promoting productivity as a goal of the program. Need based criteria applied to determine eligibility for program services are vague, and may inhibit productivity as an outcome. The policy for the Home-delivered meals program does not explicitly cite productivity as a goal of the program. Congregate Meals policy is, however, found to be 100% promotive of integration. <IA>

Idaho does not have case management services to assist in establishing and maintaining a coordinated service relationship among two or more agencies or organizations serving people with developmental disabilities. Case management should be available to help the individual identify services to meet his or her needs, assisting in completion of eligibility applications and processes, coordinate multiple services, advocate, and assess services and transition issues, which are appropriate for their individualized plans. <ID>

There is no formal statewide information and referral system, supported by state funds, which can be accessed at the local level. There is no single source for information on different types of disabilities or training opportunities. <ID>

Independent living skills supports should be made available in the home. Training should be provided to help people with disabilities learn to live more independently. <ID>

Long range plans need to be developed to move toward a more individualized system of support services. <ID>

Individual supports are seldom available, are not directed by the person with a developmental disability, nor are they selected from an array of supports to provide a "package" tailored to the needs and preferences of the individual. <ID>

Idaho's involvement with the Home and Community Based Service (HCB) Waiver is among the least comprehensive in the United States. It is one of the primary Medicaid sources for community services and provides funding for supports not directly tied to placement in an ICF/MR facility, therefore, these supports can be matched to the individual person and can vary in amount, frequency, and duration based on individual needs. Although almost a dozen waivers are available, Idaho has chosen to offer only personal care services under its HCB waiver. <ID>

Respite care services provided by the Idaho Department of Health and Welfare regional Adult and Child Development Centers was limited to \$70,000 in FY 1988-1989. Respite service funds are easily transferred to other programs within regional service areas, thereby reducing the program's effectiveness. More in-home respite care is needed. Although Health Districts also provide respite care services through the Children's Special Health Care Services (formerly Crippled Children's Program) they are even more limited. <ID>

The need to verify the quality of training for respite care providers was noted during dialogue at the public forums and the focus group. The Idaho Needs Survey concurred with this concern, as 83.6% of the respondents noted the same need. <ID>

During the Idaho Public Forums, the lack of trained personnel in the areas of physical, occupational, and speech therapies was cited as a barrier to the delivery of effective service. The Idaho Focus Group pointed out that we have recruiting problems associated with a shortage of staff for speech, occupational, and physical therapy. <ID>

Idaho will need to make a strong commitment to cover these lost federal funds [re: Social Services Block Grant] with state revenues. <ID>

One of the primary federal funding sources for individual and family supports, the Social Services Block Grant, has lost 50% of its "purchasing power" over the last ten years. Idaho puts just over 10% of its federal funds into disability related services. <ID>

The fact that more individuals are not working or living independently or in supported environments directly relates to the lack of financial commitment by the state to fund adaptive technology rather than dependent center and facility-based programs. <ID>

Increased costs for existing facility-based services, such as those provided in large state institutions, leave few resources for individual and family supports which are much more cost effective and significant in the promotion of independence, productivity, and community integration. <ID>

Low levels of reimbursement for Idaho Medicaid vendors have discouraged provider participation and reduced the availability of support services. <ID>

The Idaho Focus Group noted one problem with Personal Care Services (PCS) is that you can only qualify for the service if you qualify for placement in a nursing home or ICF/MR. It's a Catch 22 problem. If you need ICF/MR services, how can you live on your own? <ID>

The Idaho respite care program continues to be underfunded, lack providers or provider training, and is not adequately marketed to families or individuals who have a developmental disability. This can often create serious problems when family members must attend to their own needs or the needs of other family members. Too often, family members don't get the respite they need and eventually place their child out the home to maintain the rest of the family. <ID>

There is an overall lack of data gathered by key Idaho agencies on the needs and preferences of individuals with developmental disabilities for various kinds of supports and their relative significance in helping people reach greater levels of independence, productivity and community integration. <ID>

A major concern of the Idaho Focus Group was the loss of support services when there is a loss of program service. <ID>

Services in Illinois usually are done to or for rather than with people with developmental disabilities and their families. <IL>

In the Consumer Satisfaction Survey, families chose case coordination as the second most supportive service they could receive. Two other Illinois studies indicated that the need for case coordination services was critical for both people with developmental disabilities or mental illness who were reentering the community or trying to remain in the community. <IL>

The Council finds that, in Illinois, most of its citizens with developmental disabilities act as their own primary caregiver or have a family member who does so, yet services to support individuals and families are far less common than out-of-home services. <IL>

Deemed status limits for families may need to be changed so that MR/DD support for the individual family member in need of Medicaid could be accessed. Families and/or individual MR/DD family members who could afford to pay for the programs and services would not be eligible for Medicaid. <IN>

It is believed that limited guardianships would be more appropriate for a substantial number of wards of the state. There is a need for greater understanding and use of limited guardianships by service providers in Indiana. <IN>

There is a great need for guardianship services in Indiana for individuals who have no family members willing or able to undertake this responsibility. Respondents in the 1987 study estimated that a total of 6,553 persons statewide are currently in need of some type of guardianship. The greatest reported need is for guardianship of the persons, with an estimated 2,664 individuals in need. Respondents also indicated that 1,146 individuals need guardianship of the estate and 1,768 need guardianship of both. In addition, 975 individuals are in need of something other than full guardianship, such as a limited or temporary guardianship. The County Departments of Public Welfare provided the highest estimates of services needed (37.6%) followed by the state hospitals (26.6%) <IN>

The vast majority of guardianships in Indiana are assumed by a family member. Unfortunately, there is also an increasing number of cases in which a client's family has been abusive or exploitative, as documented by the involvement of Adult Protective Services workers in removing endangered adults from their home and working to enlist non-family members to become guardian. <IN>

The 1987 survey on guardianship revealed that a large number of agencies are misinformed about the responsibility of the Department of Public Welfare to become guardian of the person if no other guardian can be found. Only 26 percent of county welfare departments surveyed indicated that their agency would become guardian of the person in emergency cases. The Department of Public Welfare should not be viewed as the appropriate auspice for guardianship services. <IN>

In comparison to neighboring states, Indiana supports most of the services under Title XX through federal allocation; Indiana's state share is small compared to other states and represented only 23 percent in FY 1989. The trend nationally is a reduction in the absolute amount funds available to the states through the Social Services Block Grant program from the federal government and in turn, a reduction by the states in the number of service included under the SSBG. In Indiana, the costs have increased, the number of recipients declined, and so the cost per recipient has increased over the past two years. <IN>

Children with disabilities are more likely to be abused than neglected. According to the reported data, over the three year period, 1987-89, over the three year period, 57 percent of substantiated or indicated incidents with children with physical, mental or emotional disabilities concerned abuse, and that was statistically significant. Accordingly, it can be argued that there is a relationship between the prevalence of abuse and neglect and having a disability. <IN>

In most communities, the media was faulted for failing to cover adequately the recreational and cultural programs for persons with disabilities, and for not paying sufficient attention to informing them about benefits for which they might qualify. <IN>

The overall sixth-rated problem was the lack of reasonably priced assistive devices, such as wheelchairs, orthopedic appliances, phone amplifiers, hearing aids, and the like. While assistive devices are considered available to buy or rent, they are not considered affordable to own or (less so) to rent by persons who often need special (and costly) adaptations. <IN>

The very few Independent Living Centers (ILCs) in Indiana restrict services to people with only certain kinds of disabilities. <IN>

There is a lack of funding for obtaining and maintaining assistive devices. <KS>

An emphasis on funding and developing integrated leisure options is lacking. Such programs are needed as people with developmental disabilities often do not have the funds to access existing recreational options. <KS>

Access to Special Olympics is available to all who want to participate, or alternatively, it is the only option. <KS>

Many people with developmental disabilities are lonely and do not have friendship and other needed supports. <KS>

Coordination and case management services for people with developmental disabilities and their families is inadequate. <KS>

Families need qualified and affordable help to deal with guardianship, conservatorship, wills, and trusts. There is a backlog of legal aid and trained advocates are lacking. <KS>

There is a lack of qualified interpreters for people with deafness. <KS>

There is a lack of consistency from court to court concerning guardianship and conservatorship. Accountability laws are not uniformly enforced. <KS>

Too many families, attorneys, and judges are under-informed about limited guardianship. <KS>

There are no specialized services for adults with developmental disabilities who are in state or community corrections programs. <KS>

Courts can effect admissions for people on criminal charges with mental illness to MH facilities only. People with mental retardation may be inappropriately placed and may need maximum security for their protection. <KS>

The overriding issue is the relative lack of resources for supports to individuals with developmental disabilities and their families despite their critical importance to the

promotion of independence, productivity, and community integration. A related issue is the bias in many publicly-supported programs toward funding services in facilities and institutions, but not in homes and communities. <LA>

For both individual and family supports, there is frequently a lack of involvement and focus on the consumer. <LA>

Almost none of the supports to individuals with developmental disabilities and their families are considered entitlements. <LA>

The potential benefits of the Medicaid Home and Community Based Services (HCB) Waiver are limited by the "cost-neutrality" requirement, which prevents states from using the HCB waiver to finance home and community-based supports to all people with developmental disabilities who need them. In Louisiana, the HCB Waiver, when approved, will serve 224 individuals with developmental disabilities in the first year, increasing to 442 by the end of the third year. These figures fall far short of meeting the need for adequate individual and family support services. <LA>

Guardianship is often granted when it is neither an appropriate nor adequate means to provide the assistance needed for people with developmental disabilities to achieve their fullest potential. <LA>

In Louisiana, individuals with hearing impairments experience a profound lack of sign language and interpreter services. <LA>

In Louisiana, as in most other states, the availability of data on services to people with developmental disabilities through "generic" support programs is practically non-existent. <LA>

More children who are medically fragile are surviving than in the past. They and their families need specialized support to participate in community life and attend local schools. <MA>

Technology is playing an increasing role in assisting persons with disabilities to live and work independently. The state needs to support efforts by business, communities and schools to use technology that will help persons with disabilities attain the highest degree of independence, productivity and integration. <MA>

Supporting individuals with disabilities and their families to live in the community makes common sense - however, in Massachusetts this support is far from commonplace. Support services are considered a "soft service" and have been an early target of budget cuts. Cutbacks in other parts of the service system put additional pressure on this relatively new and fragile system, which is forced, then, to "pick up and slack." However, the needs

of persons with disabilities and their families do not diminish, even in times of fiscal crisis. <MA>

Even when laws and policies are enacted which support persons with disabilities, lagging implementation can be a barrier. For example, Massachusetts has yet to expand its Personnel Care Attendant Program to persons with mental disabilities, despite an adoption of regulations over a year ago authorizing this change. <MA>

Massachusetts needs an act establishing a Public Guardianship Commission in order to provide guardians and conservators for elderly persons and people with disabilities who are not legally competent to decide where to live, what medical care they need or how to manage their money. Often, when no family or friends exist to act as guardian or conservator and volunteers are hard to find, an incompetent person cannot get the services or benefits s/he deserves. <MA>

The service coordination system should be streamlined so that individuals who are already receiving services are not required to receive case management services, if they do not request and require these services. <MD>

There are too few qualified interpreters for persons who are deaf residing in rural areas. <MD>

Concerning Medical Day Care, quality and monitoring are needed to make the system flexible and responsive to needs. <MD>

The processes involved in terminating the rights of parents are often stonewalled by Departments of Social Services. There is no protection for social workers nor for physicians who will testify that parental rights should be terminated. Something needs to happen to protect the child in this circumstance. <MD>

Sexual and physical abuse is considered by many as severely under reported and acted on. <ME>

Community and family based support systems are often not available and not encouraged by the existing system of professional services. <ME>

Case management services (coordination of resources in behalf of individuals and families), when available are often sporadic and subject to high staff turnover and inattention to individual needs. A major factor is large caseloads. <ME>

Independent living programs can and do provide information, assistance, and many of the supports that people with severe physical disabilities often are unable to find. However, they are underfunded and are not available in all areas of the state. <MI>

People with developmental disabilities who become involved in the criminal justice system are vulnerable to abuse and do not receive appropriate intervention. <MI>

Services providers and policy makers consistently express frustration about lack of coordination of services, confusion of responsibility for provision of services, and problems with access to appropriate services. They see particular problems for people who need several kinds of ongoing services from a number of different agencies. Effective case management is often proposed as the appropriate way to deal with these problems. <MI>

The Social Services Block Grant (Title XX), is one of the primary federal funding sources for individual and family supports. Title XX has lost 50% of its purchasing power in the last 10 years because of actual reductions and the failure of appropriations to keep pace with inflation. <MI>

Case management, which should enable access to services, is too often more oriented toward payment and gatekeeping than to consumer empowerment. <MI>

People with disabilities across the country report gaps in the availability of supports for people with developmental disabilities and their families who live in rural areas. Shortages are especially acute for people with the most severe disabilities. Supports that can be obtained in an emergency are also scarce. <MI>

Centers for Independent Living are not widely and equitably available to consumers. <MI>

Personal Assistance Services are not consistently available when needed to help handicappers who are trying to achieve greater independence and community integration. Many people who could benefit from PAS do not receive them. <MI>

Most personal assistance programs do not emphasize consumer control. <MI>

People with severe disabilities at the Consumer Response Initiative Forums reported that current levels of reimbursement for personal assistance services (PAS) make it impossible for them to get services at the level they need. It is very difficult to find personal assistants who have adequate training, and little or no help is available in finding personal assistants. <MI>

New developments in adaptive devices and equipment are often costly and therefore not always available to handicappers who need them. Medicaid and Medicare, rehabilitation agencies, and insurance companies are often reluctant to fund newer, more technologically advanced, and more expensive items. Information about simple, low cost adaptations is not readily available. <MI>

Much new technology is available in assistive devices. However, access problems (primarily funding) mean that people with disabilities are often unable to obtain them, or must do so with their own funds-if possible-at great personal sacrifice. <MI>

People with disabilities who are eligible for Medicaid, their families, and advocates are often unaware of the optional services available under Medicaid that can be used to obtain supports for independent, integrated lives. <MI>

Some new developments in adaptive devices and equipment may be costly. Handicappers on limited incomes, especially those who need sophisticated assistive devices, cannot always afford the equipment they need. <MI>

The greatest problem currently facing case managers seems to be the delivery of increased and more effective services while struggling with large caseloads. <MN>

Many case managers have not been prepared to perform the functions required by Rule 185 during the process of change from counseling and advising roles to those of team planning, negotiation, coordination, and advocacy. Compliance with Rule 185 was highly correlated with service quality, informal supports, consumer satisfaction, least restrictive environment, and community integration for a sample of 300 people. <MN>

There are serious deficits in the availability of personal support services for individuals who can appropriately be considered developmentally disabled and for many other Minnesotans who have limitations in these activities. <MN>

The public hearings, consumer satisfaction survey, and our own analysis of the current situation indicates that there are serious problems in the availability of both categorical and generic services in the following areas: transportation, recreation, personal support services, and technology. <MN>

Without Medicaid reform there is little incentive to shift funds to families and support services. The Medicaid program historically has relied on institutional and large congregate case settings. Institutional services consumed 33 percent of service expenditures while community services received nearly 67 percent of service dollars. In-home family support received less than one percent of these dollars. <MN>

Medicaid funds do not start with family support nor move with persons from congregate care settings to support service. <MN>

In Missouri there are very few services which provide older people with developmental disabilities opportunities to choose how they would like to spend their retirement years. <MO>

The social support network of individuals with developmental disabilities is often limited to immediate family and a few other individuals who generally also have a disability. More opportunity needs to be extended to individuals with disabilities to develop social support networks in the community at large. <MO>

Support groups for individuals with developmental disabilities, such as "People First" groups, need to be fostered throughout the state. <MO>

Training is needed to assist service providers and administrators on how to implement a full array of individual and family supports which facilitate independence and integration into communities. <MO>

If Missouri chooses to expand community based support services they will need somehow to anticipate the increase in consumer and family expectations for these services. <MO>

Individual supports for interdependent community living are very limited for individuals with more severe disabilities, particularly resources for assistive devices. <MO>
Consumer and family needs for support services can be intermittent or continuous, may be needed at various levels of intensity at different times, and may be different for different communities. In other words, the provision of support for community living is fundamentally different from many of the existing service approaches used to assist people with developmental disabilities. Missouri, in the 1990s, will be challenged to identify mechanisms which will address some of the fundamental differences identified above. <MO>

Involvement by people with severe disabilities in recreational and other community based activities continue to be limited and often segregated. <MO>

There will be a greater need for training on community living skills, such as how to make choices and how to communicate, as people with disabilities continue to move into community based settings. <MO>

Centers for Independent Living (CIL) provide a much needed community based resource for individuals with disabilities and for families. However, to date the CILs have placed more emphasis on providing services to people with physical disabilities than to all people with disabilities. <MO>

Research on the nature and functions of case management and case managers is needed. <MO>

The increasing rate at which technology is impacting upon rehabilitation service delivery is overwhelming. In order to deliver the best possible service to clients, family training and case management staff and managers must make a tremendous effort to bridge the gap between knowing what is out there and applying that knowledge successfully. For

service agencies, the environmental data fed into the service delivery process arises from consumers, other community agencies providing services, federal and state rules and regulations regarding persons with disabilities' right to treatment, the numerous employee rights acts, and adaptive equipment technology sources and application methods. That provides one of the major challenges of today's service providers and the managers in the field of developmental disabilities. They must harness the enormous wealth of information and efficiently utilize it in combination with the information they are generating to achieve maximum benefit for their consumers. <MT>

Low levels of reimbursement for Medicaid vendors may discourage provider participation and reduce the availability of supports. <MT>

Current "individualized plans" are piecemeal and too short-term to be effective guides for persons with developmental disabilities. <NC>

Consumers indicated in the survey and the public hearings that accessible, appropriate and integrated recreational services are generally not available for people with developmental disabilities. While some of the funding aimed at providing services for people with developmental disabilities includes provisions for recreation programs, there is no funding specifically earmarked for this purpose, nor are recreational programs a required component of any federal or state funded program. <NC>

Family members are in desperate need of some relief as they struggle to provide a loving, challenging and safe environment for individuals with developmental disabilities. Respite care is an essential service for these families. Consumers indicate problems with in-home and out-of-home services ranging from total lack of respite services in some areas to poorly trained personnel, poor reliability of personnel and prohibitive cost in many areas which do have services. <NC>

Causes for this shortage of personnel include limited training opportunities, limited opportunities for career advancement for those working in the field, low salaries and the undesirability of living and working in some remote areas. <NC>

There is an identified shortage of professionals with expertise regarding developmental disabilities in both the public and private sectors. This includes interpreters, recreational therapists, cognitive retainers, speech/language therapists, physical therapists, occupational therapists and augmentative communication specialists. <NC>

Concern was expressed that restrictive eligibility requirements (regarding income and severity of disability) limited access to adaptive equipment or assistive devices. <NC>

Quality and type of adaptive equipment and assistive devices provided for individuals with disabilities are more than not dictated on the basis of what vendors are trying to sell rather than by what individual clients actually need. Such vendor-driven procurements can

result in excessive expense and acquisition of equipment or devices that are non-usable because of their inappropriateness to individual client need. <ND>

Many DD clients residing in community facilities throughout North Dakota are unable to have their adaptive equipment needs met in a timely manner. Theoretically, the adaptive equipment unit of the State Developmental Center at Grafton is ideally suited and responsible for addressing the adaptive equipment needs for clients in community facilities. However, because its first priority is meeting the adaptive equipment needs of individuals still residing at the Center, the adaptive equipment unit is unable to respond to client needs in the community as quickly or as effectively as it would prefer to respond to those clients. <ND>

Many adults with disabilities who need adaptive equipment or assistive devices have limited financial means and no health insurance, yet are ineligible for Medical Assistance benefits. Often these same persons do not qualify for Vocational Rehabilitation services. As a result, they must rely on the generosity of private charitable organizations to meet their needs or else do without. <ND>

Medical Assistance expenditures for durable medical equipment have increased substantially in North Dakota over the past five years. For the 1987-89 biennium, such expenditures approximated \$1.5 million compared with about \$400,000 for the 1983-85 biennium. All too frequently, such equipment is purchased without the benefit of genuinely competitive bidding. <ND>

Although recreation programs are seldom funded by federal or state monies, their repeated mention in the "Other" category on the Consumer Satisfaction Survey bears a comment. There is a need for appropriate leisure time activities for persons with developmental disabilities. Current community recreational activities may not encourage participation by persons with disabilities. Transportation to these activities may be an obstacle in some communities. The survey indicated that there is a continuing need for appropriate recreational activities. Communities must become aware of the need for not only specialized activities but also making real efforts to include persons with developmental disabilities in those open to the general public. <NE>

Attendant care which is typically paid by Title XX (sic) Medicaid funds is another sensitive issue for persons who need this support. Several problems come up when this service is discussed. One of the basic one involves the relationship of the personal care attendant to the individual. There seems to be some confusion as to who is in charge. It seems reasonable that the person receiving the service should be considered the employer. Yet, since the payment is made through the Department of Social Services, it is often perceived as the "real" supervisor. This confusion in roles can cause problems when individuals with disabilities need to correct problems with their personal care attendants. Whenever problems with work performance arise, the individual with disability faces a potential dilemma. Many persons rely on their personal care attendants to enable them

to live independently. Unfortunately, the job is low paying and attendants are not easy to locate. A person may accept poor performance, even neglect or emotional abuse, from an attendant because if they fire the attendant they will have no assistance at all. Finally, there is a concern expressed by some about the federal regulation against a family member receiving Medicaid payment as an attendant. This seems to be a particular problem for those in rural areas where attendants are hard to locate. They argue that a family member cannot afford to not work and provide this service. However, with the Medicaid payment they would be able to serve as the attendant. <NE>

There are additional sub-populations of persons with developmental disabilities who have difficulty in obtaining appropriate support services. Families may find that locating respite providers for their children as they age becomes an increasing problem. Not only respite for an occasional break, but routine day care for all ages, preteen, teenage youth, and adults can be difficult to locate. Traditional day care providers usually phase out their service for school age children around elementary grades. Youth with developmental disabilities may still need supervision throughout their adolescence. This problem can be exacerbated for working parents during the summer months when school is out. <NE>

Another population that faces difficulty in accessing services are those persons whose developmental disability includes behavioral problems. These individuals may require intensive one on one interaction. This may be extremely draining to families and other care providers. The needed staff ratio is so high that appropriate care is expensive wherever the individual resides. This inappropriate behavior may severely limit options that individuals have as far as housing, employment, and education opportunities. <NE>

Persons with high medical needs may have a difficult time getting needed services. Both children and adult programs may have limited access to nursing care and medical services. Support services such as respite care, day care, and transportation may not have the capacity to handle services to persons with high medical needs. <NE>

Difficulties in obtaining intensive supports for children at risk of an out-of-home placement, and a lack of community residential options for children who cannot be maintained at home, were concerns. <NH>

Recreation and leisure are an important aspect of community membership. But because leisure activity is not a reimbursable service, it is specifically excluded from most service plans. <NH>

People who bring specific complaints and service problems to the attention of the Council commonly report having no experience with or information about advocacy organizations. Most of these organizations have either an explicit or implied responsibility to conduct outreach activities. But as with other services, the needs of recipients far exceed the availability of personnel and funds. Greater attention to outreach, and coordination of

outreach efforts, could be a source of information about services and appeal processes that would result in greater empowerment of consumers and their families. <NH>

There is little evidence that people with developmental disabilities are able to make use of generic community resources for leisure and recreation. Evidence of membership in organizations, clubs, or community groups of any kind is rare. One consumer attempting to sign up for a swimming class at her local community recreation facility was told that she had to use the pool during "handicapped hours." Few developmental service agencies have made a concerted effort to develop working relationships with community facilities to meet the socialization needs of their clients. <NH>

The single greatest need reported by consumers surveyed is for companion/friend/advocate assistance in the development of personal relationships and closer ties to the community. <NH>

One difficulty frequently mentioned by consumers who attempt to secure services is an initial difficulty locating the responsible agency in their area and obtaining basic information. Many Area Agency names, for example, do not refer to developmental services and many local phone book entries do not make an association between the agency and the services it provides. Since many more people are eligible for services than any Area Agency has the funding to serve, there is little incentive for an agency to conduct an extensive outreach campaign. The difficulty is exacerbated by the fact that regional boundaries bear no relation to those of other services state Agencies or any natural political subdivisions of the state. <NH>

Levels of community participation and friendships are markedly lower for people with developmental disabilities than for other citizens. <NH>

Consumers have not found that social integration automatically accompanies placement in a community setting. Far too often, "community living" is experienced as loneliness and isolation from the community. While people are far better off in community as opposed to institutional settings, much more needs to be achieved. One parent describes the evening activities at the group home where her daughter lives as follows: "They get in their pajamas right after dinner and sit and watch TV. If someone gets up they are told to sit back down. Then at 9:00 they are sent to bed." <NH>

Services are not evenly distributed through the state; more services are available in populated areas than in less-populated rural areas. <NJ>

State-provided case management is subject to bureaucratic decisions and policies. Job descriptions, pay scales and salary increases may be difficult to change, while imposed changes or restrictions may adversely affect the delivery of case management. In 1989, for example, the state's hiring freeze impeded the Division of Developmental Disabilities' ability to meet the increased demand for case management. <NJ>

Agencies may define and restrict the availability of services according to specific policies or practices. For example, an agency may provide respite care between the hours of 9 a.m. and 5 p.m. on weekdays, but the family's greatest need may be between 6 p.m. and 9 p.m. on weekends. In addition, respite care may only be available as an in-home service when an out-of-home situation is really needed. <NJ>

Case management may be affected by a variety of barriers including: unrealistic caseloads, unstable staffing patterns, piles of paperwork, inadequate staff training, a lack of cohesion and coordination among different agencies, demands for direct service, conflicting roles for case managers involved with monitoring and quality assurance, and inflexible, prescriptive models for delivering services. <NJ>

Four counties have not yet established Offices of the Handicapped/Disabled: Burlington, Cape May, Hunterdon, and Warren Counties. <NJ>

There is considerable confusion about the respective roles of these county offices and the independent living centers. Both promote independent living, consumer participation and advocacy. Centers are nonprofit voluntary agencies while county offices are agencies of government. Each has its own strengths and weaknesses. Both are needed. <NJ>

As government entities, the county offices have limitations to advocacy and can be subject to political control. The offices also cannot engage in fund raising, since they are public agencies. <NJ>

The PAS program (DYFS) is now administered by the Division of Youth and Family Services, the state's "Title XX" social services agency. Using the standard social service limit of 80 percent of New Jersey's 1983 median income as the cut-off for free services, DYFS has established a cost-share formula with considerable flexibility. Exceptions can be requested from a reduction where disability or work-related expenses present a problem for a consumer. However, the "family" income standard may be applied to a person with a disability living with a spouse, despite the fact that the spouse usually provides significant personal assistance for which no payment is expected or allowed. The net effect penalizes both parties inappropriately, in effect increasing the dependence of the person with a disability on his or her non-disabled spouse. <NJ>

The most serious barrier at the present time is qualified personnel to perform the direct services. There is an additional need for training and support of the consumers to use the services efficiently, effectively and responsibly. <NJ>

The implementation period for the Personal Attendant Services Program has revealed some difficulties that require remediation. Some counties have been slow to initiate the program, while those involved in the demonstration phase may already have waiting lists. <NJ>

There is a need for flexibility so that the personal attendant is permitted to perform essential personal services made necessary by the disability. This includes not only such household tasks as cooking, but also driving a car. In some programs, the aide may drive the client's car, but is not permitted to convey the client in a car owned by the aide. Current refusal by insurance companies to provide coverage in these instances must be further addressed. <NJ>

The need for expansion of the interpreter services for the deaf, identified by the Governor's Task Force on Persons with Disabilities, continues. The fact that community agencies that may wish to accommodate deaf individuals, whether for service or recreational/social purposes, must pay the full cost of interpreter services is a distinct barrier to community participation of people with developmental deafness. <NJ>

Although the Adult Protective Services Program is now fully operational, state legislation has never been enacted to specifically provide the Department of Human Services with statutory authority to render such services - hence there are no promulgated rules and regulations. A bill passed both houses of the legislature in spring 1988, but was vetoed. <NJ>

Another problem relates to ownership of equipment needed by an individual. If the equipment is purchased by a school or employer, the owner wishes to keep it on site; it does not go home with the student or worker, even though it is equally useful in daily living or for homework. This is particularly true of communication equipment. <NJ>

Funding for further expansion will be a problem. Despite active collaboration among interested parties, New Jersey was not successful in its first round application under the Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407). This funding source, however, is not long-term. A revised application for second round grants was filed on December 1, 1989. <NJ>

Because of the shortage of case manager positions, even individuals who have been declared eligible by the Division are increasingly being assigned to "social supervision," a minimal contact or follow-along service. <NJ>

By law, the population eligible for services from the Division of Developmental Disabilities includes those of any age who meet the federal definition, plus those with uncomplicated mental retardation who may not meet the "functional definition." The division provides either case management or "social supervision" without full case management to all individuals accepted for functional services. Unfortunately, at this time, the Division is declaring ineligible those individuals who have met the functional definition but who are seen by the Division as not requiring another service that is not currently offered by the Division, even though case management may be what the client needs to access services from other agencies. <NJ>

The lack of a comprehensive case management system in New Mexico means that, on an individual level, the ability to access services is extremely variable and not necessarily based on the needs of the individuals. <NM>

Many find the case management available oriented toward payment and gatekeeping rather than consumer empowerment. <NM>

People seeking services must find the appropriate point of entry by trial and error. If the individual/family has the skills or stamina to conduct the search, they may find supports and services that may be available. <NM>

Services such as physical, occupational, and speech therapy; medical equipment and supplies; and home health care are the least likely to be fully covered by public or private funding, require higher co-payments, and are subject to more limitations than inpatient services. <NM>

New developments in adaptive devices and equipment are often costly and therefore unavailable to people who need them. <NM>

Recreation and leisure programs for individuals with disabilities tend to be in metropolitan areas and are limited because of access to facilities and existing programs. <NV>

The lack of experience with Centers for Independent Living may also indicate lack of information about recreation and leisure programs which do exist through the Las Vegas adaptive recreation program, Alpine Meadows Handicap Ski School, Silver State Highrollers wheelchair basketball team, wheelchair tennis, Bureau of Services to the Blind recreation program, as well as limited track and field club opportunities for young adults. <NV>

The fact that there is no one agency or entity that provides information on recreation and leisure programs for persons with disabilities or pursues the expansion of opportunities for programs is significant in consumer responses as indicated by 82% of the 164 respondents expressing a need for these services. <NV>

Inadequate attendant care and meal, chore and respite services. <NV>

Every assessment of need conducted and all direct experiences, regardless of disability group, age, location, experience with "the system" or professional background, point to one fact as possibly the single most critical current barrier to fulfilling any of the seven objectives established in the purposes of the Technology Act: most professionals simply are not aware of enabling technology let alone its potential and proven benefits. <NV>

The capacity of Nevada's agencies, community service providers, employers and service organizations to provide and pay for enabling technology is severely hampered by outdated attitudes relevant to the potential of people with disabilities, lack of cross-disciplinary

information and training relative to the proven potential of technological application, and insensitivity to cultural and age related aspects of rehabilitation and outreach. <NV>

Coordination in planning for enabling technology breaks down, however, at the local level where many agencies, school personnel and agency staff maybe involved. Additionally, there is a great need for collaborative planning between state and local entities whether or not they currently provide technology services. Included among those are potential service providers excluded only by internal or legislated policy, and many potential private sector providers who are currently unknown and/or untapped by traditional service providers. <NV>

Services to Nevada's rural areas are so limited in the area of technology they can be said not to exist. The Divisions of Rehabilitation and Special Education provide minimal assessment services and the Developmental Disabilities Council assists in procuring devices in exceptional circumstances. Nevada's large Indian population residing on reservations does without any services at all in this area. Expanded service delivery to our rural counties and reservations is all the more critical due to their isolation and inability to quickly access urban area facilities and resources. <NV>

The lack of assessment and application of technology related services in a holistic approach to rehabilitation seriously inhibits the probability that Nevadans with disabilities will secure and maintain enabling devices which transcend the continuing transitions of lives. This is particularly true for older people with disabilities and those with severe disabilities because of the multiplicity and intensity of their disabling condition(s). <NV>

Parents who are employed are frustrated by the lack of day care, after school, and recreation programs for their children. Not having these supports seriously affects the stability of the family situation. <NY>

The results of the Consumer Satisfaction Survey, as well as other consumer input, indicated that the types of supports needed were often unavailable, not available when needed, or the service was not suited to their individual needs. This forces consumers to accept and "fit into" what exists. Many people feel this is the result of providers not listening to them when they expressed their needs for individualized supports. <NY>

Parents and individuals with developmental disabilities want information about community resources, entitlements and rights, in language they can understand. <NY>

Those activities currently referred to as case management or case coordination must be reexamined and changed so that individuals with developmental disabilities have, instead of numerous case managers, a designated individual who will help locate and provide those supports or services the individual or the family needs. <NY>

A major barrier to expanding these guardianship and protective services has been funding limitations - the Ohio Department of MR/DD's budget for protective services has increased by only 8% over the past 4 years which has not allowed Advocacy and Protective Services, Inc. to significantly increase its services. An additional complication comes from the fact that the sole source of funds for protective services is the Ohio Department of MR/DD, which results in a conflict of interest in that the Department is a major provider and funder of service programs for persons with developmental disabilities. <OH>

A problem is that state funding for protective services is limited to adults with developmental disabilities, particularly for those with mental retardation. There are no publicly funded protective services for adults who become disabled solely because of mental illness. <OH>

The appointment of a guardian can be the most intrusive form of state government intervention for a person with a disability, potentially reducing the capable adult with a disability to the status of a child. <OH>

Oklahoma is not unique nationally in that the need for certain therapist services exceeds the supply of trained professionals. However, Oklahoma does have a relatively low population density that creates three problems: (1) there is insufficient market size and density to economically justify the presence of these professionals in or near many counties and communities; (2) this requires the clients to travel long distances to receive services; (3) the expense of services, coupled with transportation and lost work time, creates significant financial hardships in many cases. <OK>

The need for accessible and accurate information on services for people with developmental disabilities was mentioned more than once at each of the eight public forums. The need is also expressed by agency representatives whose job it is to locate services and resources for families and persons with developmental disabilities. <OK>

Providing an individual with up-to-date, complete information on all appropriate public and private resources available and how the services may be accessed has been addressed in Oklahoma, but no program addresses all ages, all disabilities nor uses an aggressive marketing approach statewide to provide information on available services, where they are located and how to contact them. <OK>

Many assistive technology devices are not well known, disseminated and/or are prohibitively expensive for use by citizens with disabilities. <PA>

Although there are a variety of sources of technical, assistive devices (rehabilitation hospitals, vocational rehabilitation, universities doing research in the area) a very large problem is insufficient knowledge among consumers and professionals about what devices are actually available, how they work, and how they can be obtained. <PA>

Once persons turn age 60, attendant care becomes the responsibility of the Department of Aging. This transition can be disruptive and may result in a more dependent model of support. <PA>

There is a 500 person waiting list for the Attendant Care Program for services and some persons have had their number of hours of attendant care cut back as a result of funding shortages. Moreover, there are citizens with disabilities living in rural parts of the state that are unaware of the program. <PA>

Lack of related services, such as speech therapy, at the community level. <PR>

People who are elderly in isolated communities cannot receive some services available due to transportation or someone who may serve as his/her companion. <PR>

Services are fragmented making them hard to access. Eligibility for support services is restrictive. <SC>

Private insurers are less likely to cover kinds of auxiliary health services persons with developmental disabilities require, i.e., speech therapy, physical therapy and occupational therapy. <SC>

Funding for assistive devices is often not a covered services. <SC>

Growing concerns are being expressed concerning gaps in service delivery. For example, the state offers relatively few in-home support services for either children or adults. The lack of availability of funding for such services is viewed as significant service gap. <SD>

The lack of locally-based advocacy and guardianship services was viewed as a significant systematic weakness by a surprisingly large number of the individuals interviewed. While recognizing the efforts of the South Dakota Advocacy Project in seeking to develop a statewide network of citizen advocates and organizing a proactive guardianship program, several persons pointed out to us that, in many communities, both advocacy and guardianship services are not readily available or are available only on a limited basis. While ODDMH has attempted to alleviate this problem by applying for a Medicaid state plan amendment to provide guardianship as an adjunct to case management services, that amendment has been rejected by HCFA. <SD>

A number of individuals commented that South Dakota's service delivery system places too little emphasis on the provision of supportive services in contrast to furnishing what might be termed "comprehensive" services. For example, within the ODDMH-administered service delivery system, the role of follow-along services has receded and facility-based programming has become more important. Also, as previously commented, the state lacks a distinguishable family support services program. <SD>

South Dakota's means of providing case management services to persons with developmental disabilities has significant limitations. South Dakota lacks a distinct case management system focused solely on persons with developmental disabilities. In addition, case management services are not routinely available to children and their families. Unless confronted with a crisis, such services usually are not available. For adults who are receiving community-based services, "internal" case management services are available. For adults not receiving services, the provision of case management services is again triggered principally by the occurrence of a crisis. South Dakota's present system of provider-based, internal case management services, coupled with crisis-oriented "independent" case management services delivered principally through DSS local area offices or via direct crisis intervention by ODDMH staff, is out-of-step with contemporary practice which emphasizes the importance of independent case management as a means of assuring access to services and oversight of client services. <SD>

Tennessee does not include personal care services in its Medicaid program, and in 1987, 53 percent of the Medicaid funds in Tennessee were expended for the most expensive forms of medical care, inpatient hospitalization, and nursing home services. <TN>
Tennessee has two independent living centers (ILCs) funded through Part B of the ILC Program administered by Rehabilitation Services. The Memphis Center was funded in 1983 and the Chattanooga Center was funded in 1987. Applications from Nashville and Knoxville have not been funded due to small amount of federal funding available for this program. <TN>

Tennessee's Medicaid plan mainly covers costs related to physician care, hospital care, and prescribed drugs. It does not include services such as therapy for speech, hearing and language disorders, or personal care services, which have the potential for allowing persons with developmental disabilities to function with greater independence, productivity and integration into the community. <TN>

It is estimated that an additional 80 percent of persons with developmental disabilities could benefit from community-based publicly funded personal assistance. In Tennessee, this means about 60,000 more people need such assistance in order to increase their independence, productivity and integration into the community. <TN>

There is a lack of resources for supports to individuals with developmental disabilities and their families, including continued support for persons who have achieved partial independence. <TN>

The lack of available and accessible communication options continues to be a major obstacle blocking people with disabilities from full participation in society. Barriers in communication limit social and community involvement and also place severe restrictions on educational and employment options. <TX>

People in Texas have a tremendous amount of difficulty accessing services because of a sheer lack of information about where to go to find out about programs. It's not uncommon for a person to make a dozen or more calls all over the state to track down information on services for a family member. <TX>

There are concerns that case managers have such large caseloads that they are unable to provide enough individual attention to their clients and that they are experiencing "burn-out." Personnel issues include adequate training and pay. <TX>

Case management has become a major policy issue in Texas as the number of agencies providing case management services has grown. On the state level, there are concerns that case management services are fragmented and duplicative. Questions are being raised about whether limited resources are being wasted. At the same time there are concerns that many people who need case management can't access it because eligibility criteria differ between programs. <TX>

Not one of the state's 254 counties has a court investigator responsible for making visits and ensuring the information in the accountings filed by guardians accurately reflects the monitor the required accountings to ensure prompt filing, and there are no sanctions provided for failure to comply. <TX>

Currently, there are no state records that indicate how many guardianships exists. <TX>

According to a 1988 survey conducted by the Associated Press, half of all Texas guardianships were granted without a medical statement. More than 41% of the files surveyed contained no medical statement and 72% of the people in the files surveyed had no legal representation. The Associated Press study stated that people who need guardianship are afforded fewer rights than criminal defendants. <TX>

Families expressed concern about the future of their adult children in their oral and written testimony to the Council. Who will care for their child when they can no longer do so? How can they be assured their child will not become a victim of abuse, neglect or exploitation? Where will the money come from to pay the legal fees for obtaining guardianship when their child reaches age 18? What does the law really say about guardianship? <TX>

As the population of Texas continues to increase, so will the need for an array of guardianship options. The Associated Press study found that people who deal with guardianship issues believe that greater oversight in the guardianship process is needed and will become critical in the future. State laws to improve due process and court monitoring will need to be enacted. <TX>

Many people with disabilities live in the community with the assistance of family and friends. However, families face enormous obstacles when dealing with the legal issues of

guardianship which are so important to people with disabilities who are unable to make decisions for themselves. <TX>

When not conducted appropriately, guardianship can strip individual rights to self-determination. Mounting evidence suggests that many people with disabilities are being poorly served and are often victimized and exploited by the very persons or agencies appointed to protect them. <TX>

Texas laws are vague in defining who needs guardianship. Only in rare instances do Texas courts investigate the respondent's situation and condition. The Probate Code does not require expert testimony to establish a permanent adult guardianship. <TX>

In conversations with case managers, the one complaint they have about the state services to targeted people is the problem of documentation. Workers are required to document their time every fifteen minutes to assure a Medicaid eligible service to a medically eligible client. Workers consider this rigorous documentation as time wasted with no way of tracking credibility. In their estimation, this is a "bureaucratic nightmare." However, Utah and other states were required to add this tracking method which is based on the medical model by federal officials. <UT>

The HCBS Waiver policy on case management has not been entirely implemented for a number of reasons. First, many agencies have case managers, which results in a person who is receiving a variety of services from different agencies having that many case managers. There is presently no system that assigns one case manager for each client. Second, many case managers are not comfortable in their new role of designated advocate. Third, case managers also claim that their case loads are too high to deliver the kind of intensive services that this model requires. <UT>

The critical issue with support services is availability, especially in the rural areas. <UT>

While satisfaction with Virginia's direct services is generally high, satisfaction with supports (that are often needed to use services effectively) is much lower. <VA>

The social support networks of most consumers are extremely limited. <VA>

Case management services are viewed as inadequate to meet current demand, too rigid and inflexible to meet individualized needs, insensitive to individual choice, and ineffective given the current gap in service availability. <VA>

Much of the issue of comprehensive case management is structural in nature. Currently, case management is provided by Community Service Boards (CSBs) to assist individuals living in the community by making available to them various services or programs available. Concomitantly, the CSB is also providing the services or supports identified by the case manager. Such a situation obviously presents great potential for conflict of

interest to occur as case managers must not only concern themselves with their client's needs, but those of the CSB, their employer, as well. <VA>

The number of consumers serviced by a case manager needs to be carefully monitored. It is unrealistic to assume that a case manager can effectively support persons living in the community with a caseload of 50 - 100 persons. <VA>

Personal assistance services are desperately needed across the Commonwealth to address primarily the needs of Virginians with developmental disabilities who have physical impairments. Many of these individuals do not need ongoing training or supervision. They simply need someone to assist them with personal care or with household-related activities which they are physically unable to do without help. Many individuals are able to lead normal, productive lives with the use of intermittent services from a personal attendant who may provide assistance for only part of the day. Currently, personal assistance services are in extreme short supply and not funded. As a result, many individuals with physical disabilities are confined to convalescent centers, nursing homes, training centers, or other restrictive and costly residential service programs. <VA>

Lack of affordable, accessible and appropriate community-based recreation/leisure option statewide. <VT>

Supports of other kinds, such as the supports that come from friends, families and communities are critical to people with developmental disabilities. Public policy has too often made the needs of people with developmental disabilities appear to be so specialized that they become deprived of the natural responses and supports upon which people without disabilities depend. <VT>

Lack of trained, qualified and readily available personal care attendants. <VT>

Lack of programs in the state correctional system to deal effectively with people with disabilities. <VT>

As of July 1988, 114 case managers provided services to 11,987 clients. Nationally, the current accepted caseload is no more than 50 clients per caseworker. <WA>

In Washington State, personal services are offered under several different titles and all have their own unique eligibility rules and particular area of services offered. A lack of communication between these various programs often prevents the development of a comprehensive and accessible system. <WA>

In Washington State alone, of the 14,500 people determined eligible for appropriate individual support services, approximately 3,600 are not receiving the appropriate support because of inadequate funding. <WA>

One of the more pervasive barriers to full use of guaranteed civil and human rights are guardianship statutes. Guardianship laws are set and implemented by each individual state. The federal government can intercede only when a Constitutional right is denied by a state guardianship law. <WA>

The high incidence of child abuse and neglect (3,800 such complaints are received by Child Protective Services each month), substance abuse, homelessness, babies born with alcohol and substance addictions, and the growing incidence of HIV/AIDS further compound the issue. <WA>

Futures planning needs to start early and must focus on ability rather than disability. Professionals, parents and students need to work together to encourage participation at all levels. Attention needs to be focused on successful transition to jobs, expansion of statewide programs, and easy access to factual information. <WA>

In spite of all the positive aspects of community integration, appropriate day activities for older people with developmental disabilities are not a reality. At this time, few people use regular senior center facilities and training is needed by staff in order to understand how seniors with special needs fit into programs. <WA>

There is an increasing number of families who need support services because of the developmental disability of one or both parents. <WI>

In 1987, there was a total of 29,456 reports made in Wisconsin under the Child Abuse and Neglect Act. Information is not collected on the number of children with disabilities who are abused or neglected or on the number of children who become disabled due to abuse or neglect. <WI>

There are presently many adults who need guardians but don't have them. In some situations, these are individuals who are institutionalized for long periods of time and may no longer have family members actively involved who are willing to serve as guardians. <WV>

Proponents of an independent case management system argue that the current system is undermined by the inherent conflict of interest that exists when the case manager works for an agency that also provides direct services to the same consumers. The case manager is no longer an independent broker of services and may not feel free to advocate for services from another provider. In West Virginia, the situation exists where case managers usually work for the largest, and sometimes only, service provider in a given area. Others argue that creating a system of independent case management would be costly and would not result in any substantive changes. An independent case manager will still need to work within the confines of the resources available, which are often limited. They contend that the independence of the case managers is meaningless if there's still "only one store to shop at". <WV>

West Virginia recently applied, but did not receive a technology development grant for FY 1990. <WV>

Ninety-eight percent (98%) of the people reporting that they needed case management were either not receiving it or not receiving enough. It appears that people generally feel positively about their case managers, but still do not feel that their needs are being adequately met by the service system. <WV>

There is a general lack of services for persons with mental retardation who are aged and there is a lack of agreement as to whether the responsibility for services should fall to programs for aged, programs for persons with mental retardation, or a special new set of programs. <WY>

In Wyoming the independent living program does not report the number of individuals with developmental disabilities and the number of adult individuals with disabilities served in the program. <WY>

INDIVIDUAL SUPPORTS: RECOMMENDATIONS

Multiple States

Supports to individuals with developmental disabilities that promote their independence, productivity and integration in the community should be a major policy goal in the 1990s. <MS,NM>

Supports to individuals with developmental disabilities that promote their independence, productivity and integration in the community should be a major policy goal in the 1990s, embodying the following principles: maximum consumer control and direction, priority for community based services, and availability to people in all areas, of all ages, and with all types and levels of disability. <ID,LA,MT,WY>

Funding levels for discretionary programs that stimulate the development of supports, including grants for recreation programs, assistive devices, community support systems in mental health, temporary child care/crisis nurseries, and independent living centers, must be maintained — and expanded where possible. These programs should not be sacrificed to the budget crisis while expenditures for more costly facility-based services continue to increase. <ID,LA,MT,WY>

Coordination assistance ("case management") must be available to individuals with developmental disabilities and family members to facilitate arrangements for supports and their monitoring. Sufficient funding must be available to permit small enough "caseloads" for effective help with coordination; additional resources must be available for systems-level coordination. <ID,LA,MS,MT,WY>

The availability of supports to individuals with developmental disabilities and their family members should not be limited to "medically necessary" services; public funding of supports should not be governed by health care finance requirements that favor medically-related and facility-based care. <ID,LA,MT,WY>

Guardianship as a means of assistance should be considered as a last resort for persons in need of decision making guidance and then only limited in length and scope as necessary for independent living. <ID,MT,WA,WY>

Federal funding for the Social Services Block Grant should be increased, as proposed in the Social Services Block Grant Restoration Act of 1989 (S. 704); proposals to earmark increased SSBG funding for specific services, rather than maintain state flexibility in the use of these funds to meet state-defined priorities in social services, are not recommended. <LA,MT,WY>

Supports to families which include a family member with a developmental disability should be a priority in the 1990s, with emphasis on supports that reinforce the primary role of families in providing care and support to younger people with developmental disabilities and their ongoing role as part of the support system for adults with developmental disabilities and that involve families in the design, implementation and monitoring of family support systems. <ID,LA,MT,WY>

Comprehensive education efforts should be undertaken to help translate the concept of a facility-free support system into reality, including: supports to the participation of communities, neighbors and informal organizations; an orientation for professionals in the service system to assist them in providing supports to individuals with developmental disabilities, family members and communities; and information from the consumer perspective on the significance of support. <LA,MT,WY>

The revived interest in reports on federal expenditures, such as the recently enacted requirements for state reports on Social Services Block Grant expenditures, should be expanded to provide additional information on how supports are financed and the availability of supports to people with developmental disabilities. This information should be complemented by consumer-based research on the relationship between supports and the ability to reach greater independence, productivity and community integration, building on the consumer survey undertaken for the 1990 Report. <LA,MT,WY>

Develop a long term home care benefit under Medicare which would be available to current Medicare beneficiaries and children with disabilities on the basis of functional limitations. In addition, working-age people with disabilities should be eligible for long term home care on the same basis as elderly people and children. <LA,MT,WY>

The federal government should remove the arbitrary exclusions in Medicare coverage on assistive devices and environmental controls which enable a person to improve his or her functioning or replace the function of a body organ. <ID,LA,MT,WY>

Individual States

There should be uniform national standards to protect persons under guardianship from abuse or denial of civil and legal rights which provide incentives for other forms of assistance in decision making such as individual and family support and advocacy in both the community and in institutions and less restrictive protective interventions such as increased case management for persons in the community. Standards should state that in any adjudication of competency or capacity which may result in the appointment of a Public Guardian, must be hired immediately to bring individual caseloads down to 30-35 clients per Public Guardian. This would require five new positions for Anchorage and one each for Juneau and Fairbanks. <AK>

The Division of Vocational Rehabilitation (DVR) should continue to pursue funding for a statewide system of providing assistive technology to all Alaskans who need it. DVR has submitted a proposal for funds available under the Technology-Related Assistance for Individuals With Disabilities Act of 1988, P.L. 100-107. <AK>

Public Guardians must receive orientation and on-going training on disabilities issues and be prepared to provide assistance to private guardians. In addition, they must give priority to identifying family members and friends who, with advice and support, would be willing to be guardians of individuals with disabilities. <AK>

Supports to people with disabilities should promote independence, productivity and integration and embody the following principles: maximum consumer control and direction; priority for community based services; availability to people in all areas of the state, of all ages and with all types and levels of disabilities; individually determined to meet the unique needs of the family and the community in which they live. <AK>

The state should join in the partnership with people who experience disabilities to explore ways to make state parks more accessible. This will benefit others who use state parks, such as older Alaskans, families with young children, inexperienced hikers, etc. <AK>

The Department of Health and Social Services should increase the number of hours of personal care attendant services available to consumers. <AK>

A long-term, stable interdepartmental funding base should be established to support parent and primary consumer groups, and family support networks. <AK>

The Division of Vocational Rehabilitation (DVR), with the assistance of the Department of Education, private providers and support groups, should continue to pursue funding for a statewide system for the provision of adaptive equipment that would serve all Alaskans needing this service, not just those in school or eligible for DVR services. <AK>

The Department of Administration and Advocacy Services of Alaska, in consultation with the Governor's Council, should publish a guide for people wishing to become guardians that makes the process more understandable and provides information on how to initiate guardianship proceedings and, if necessary, the statute should be revised to be more "parent friendly". <AK>

There should be a Public Guardian office in each of the state's four judicial districts. Public Guardians are currently located in Anchorage, Fairbanks and Juneau. A Public Guardian should be placed in Bethel as soon as possible. The Department of Administration should consider further regionalization of Public Guardians to such communities as Nome, Kotzebue, Barrow, Dillingham and Ketchikan, so that smaller communities in Alaska have equal access to guardianship. <AK>

Interventions such as educational programs and assistive devices must be provided for people of all age groups. <AL>

Of optimum importance is a state-wide respite care system that is flexible enough to meet the diverse needs of persons with developmental disabilities and their families. <AL>

An information, referral, and tracking system should be implemented. This system should cut across all state agencies providing services to people who have developmental disabilities and should be easily accessible as appropriate (e.g., consumers, general public, professional to information; selected offices to tracking). <AL>

A case management system separate from the service providing agencies should be developed and become operational immediately. <AL>

Support services such as the provision of technology, personal attendants, architectural modifications, and transportation must be provided as needed for the individual to live in the community. <AL>

Alabama should take advantage of state and national expertise and develop a consumer-responsive assistive device/technology program. <AL>

The DDS service system is based upon the developmental theory, that is "All persons with appropriate training and habilitation can progress." The Rehabilitation Services system is geared for persons who had skills and lost them due to accident or injury. Hence, it is appropriate that persons with head injuries be served by Rehabilitation Services through their Independent Living Services. <AR>

Other disabilities with low incidence, such as Tourette syndrome and others, should also be served by a case manager from the Division of Developmental Services (DDS) who brokers service from other divisions as needed. <AR>

Support the expansion of the independent case management effort across the state. These case managers can and should serve as monitors of community and institutional services and can provide a valuable resource of the Council in its role to monitor the provision of services. It is unrealistic to consider that the case managers who are employed by and have an inherent loyalty to direct service providers could provide this type of monitoring. <AR>

Explore the potential to employ regular Medicaid personal care dollars to support persons living on their own or with families or as an element of a strategy to "blend" various sources of funding to finance community residences. <AR>

Work with generic providers of recreation services and professional physical education and recreation associations to encourage them to incorporate as part of their organizational goals the inclusion of persons with developmental disabilities in their activities. <AR>

Persons with physical impairment and normal intelligence should be provided with an independent case manager under contract to but independent of the Division on Developmental Services (DDS) with services being brokered from other divisions by the case manager as needed. Example: Rehabilitation Services should be responsible for the independent living piece, including needed technological devices, modifications to living and work settings. <AR>

Revise the existing guardianship law so that it underscores the presumption of competency, requires that the person who is alleged incompetent be informed of less restrictive alternatives to guardianship, and ensures that guardianship is used to enhance the lives of persons with disabilities rather than to benefit the proposed guardian, service providers, even families or others. <AR>

Recognize the unique support needs of adults and their families. Many adults who are advancing in years and who may still reside with their aging parents receive no formal supports in transition planning for the time when their families can no longer meet their needs. There is a need for such supports and for a concerted effort in the area of services for senior citizens with developmental disabilities. <AR>

DDS should proceed with its plan to submit a case management plan amendment under Section 1915(g) of the Social Security Act to provide more broad-based case management services for persons with developmental disabilities, including those persons on waiting lists but not currently receiving services. <AR>

Persons with physical impairment and mental illness should be provided an independent case manager, under contract to but independent of the Division of Developmental Services (DDS) with service being brokered from other divisions by the case manager as needed. Example: Mental Health should be responsible for services pertaining to the disability of mental illness, including follow-up and support when returned to the community. DDS should provide that portion of support that pertains to the developmental disability. In this way, funding for supports would come from both agencies, with the case manager coordinating services and funding. Persons with other dual diagnoses should be served in the same way. <AR>

Make readily available to all people with developmental disabilities and their families, independent, broad-based, consumer-centered case management services of their choice. Case managers and management teams should effectively serve, not as determiners of services, but as communicators of service options and as brokers of services that consumers and families select. <AR>

Improve interagency cooperation in the development of consumer-responsive policies and procedures regarding funding and delivery of technology services. <AR>

Expand those support services needed by persons with developmental disabilities to live and thrive within the community. <AR>

Match service types to personal support needs more effectively in order to make service delivery more efficient and more cost-effective, and to extend the most intensive supports to those who may need them most. <AR>

The DDD must assure that each person is served by a case manager who is properly trained to manage the implementation of the individual's Individual Program Plan; maintain negotiated ratios regarding caseloads for all persons, both state and federally funded; establish performance standards for case managers which are uniformly applied, and assure that case managers are properly trained; and assure that case managers have the authority, accountability, and responsibility which will enable them to perform according to standards. The Executive branch and advocacy groups need to advocate for, and the Legislature needs to support adequate funding to implement the above recommendations. <AZ>

There should be adequate supports and a monitoring plan to support persons with developmental disabilities who are in an independent environment. <AZ>

An effective Individual Program Plan process must be implemented and used by the Division of Developmental Disabilities (DDD) as a basis for an individual support system. <AZ>

Independent living training and appropriate supports must be provided to all individuals with developmental disabilities to enable them to progress toward full independence and integration. This should include knowledge about subsidized housing and residential options, and support services available in the community. <CA>

People in need of attendant services should have more direct control over the training and employment of their attendants. Reimbursement rates for attendant services should be adequate to attract and retain quality attendants. Licensure and certification should not be required for attendants and respite care providers as this results in unnecessary barriers to their availability. <CA>

Case management services should be provided for individuals who meet the federal but not state definition of developmental disability, in order to maximize the services available to meet their individual needs. <CA>

For families with children living at home, the case management and assessment of family and in-home support needs must be focused on what is appropriate for the family unit and

not solely on the individual needs of the child. More resources must be focused on supporting these families, in order that they may maintain their children at home as long as possible. <CA>

Service plans (IPP, IEP, etc.) must be consumer-driven and reflect the real service needs of the individual, and must be monitored to assure full implementation. <CA>

Social and recreational opportunities must be considered on an equal basis with other program resources in providing for full life experiences for people with developmental disabilities. This form of full integration should help enable people with developmental disabilities to make friends and establish support groups among people without disabilities. <CA>

A mechanism to provide state-of-the-art technological assistive devices must be developed at the state level in order to provide them to people in need. <CA>

The costs and benefits of alternatives case management models (such as independent service brokers) should be researched, and models piloted in order to more fully empower consumers to make their own service choices. <CA>

Create a mandate for services and develop state funding for case management services for those not in the specialized developmental disabilities system. <CO>

Support a special state income tax deduction for people with severe disabilities who do not receive publicly funded services and their families who are in the low and middle income categories, to partially offset increased costs of care. <CO>

Support increased access to personal care and other support services via Medicaid Reform legislation at the federal level. <CO>

Encourage state agencies and the judicial system to develop a statewide plan for corrections system diversion of offenders with mental retardation. <CO>

Establish a statutory right to protective services and guardianship for all people at risk, including those with disabilities. <CO>

Encourage development and use of both high and low technology applications for community living and employment. <CO>

Consumer control is a policy to be maintained and enhanced. Consumers are the best experts on their needs and must be able to decide with what activities they need assistance and how many different persons are to be employed. Their power to recruit, hire, schedule, pay and, if necessary, fire their staff must be preserved. <CT>

The non-medical model and the concept of consumer control must be maintained. The Personal Care Assistance Program has been continually threatened by professionalism, commonly health care related trade unions and administrators, who believe certain in-home assistance should be provided by licensed and regulated personnel. Personal assistants, who are directed by the person with a disability to carry out a wide variety of duties, are more appropriate to matching the needs of people with disabilities than professionals who are skilled in narrow duties. Second, accredited, certified, licensed and regulated health care "professionals" are more expensive than personal assistants and they are guided by their professional expertise rather than the person with a disability. Third, in-home professionals are hard to find, generally, let alone on a live-in basis. In addition, when agencies deliver professionals, they are often different people each day. Training must occur on a daily basis, thereby undermining consistency, reliability and quality. <CT>

The maximum payment for Essential Services (personal assistance) is \$650 per month or \$9800 per year. People with severe and multiple disabilities have extensive needs costing \$12,000 and \$21,200 annually. Payments should be expanded to a range of \$15,000 to \$20,000 annually, plus, use of up to \$3,000 of these funds should be permitted for the purchase and installation of an emergency system and a monthly monitoring fee, adaptive technology or rehabilitation engineering. <CT>

Essential Services (personal assistance) excludes receiving support from other programs. By design these "exclusive" provisions virtually prohibit anyone labeled mentally retarded, in particular, from using Essential Services. Excluding support from other programs should be eliminated. Many people face a major gap between the amount of support that is available and the amount of support they need. This gap can be overcome if people are able to combine programs with Essential Services. <CT>

Abandon the use of sheltered settings to train people in basic living skills and to provide appropriate maintenance therapies. Instead, support people in independent living until resources are made available to provide appropriate on-the-job support. <CT>

Personal services must be made available to all people with disabilities. Medicaid can be expanded to include more people as Medicaid-eligible but all people with disabilities still will not become Medicaid eligible. In order to make personal assistance available to all people, Medicaid needs to be used in conjunction with other state and federal programs that provide personal services. <CT>

Identification and development of informal supports (e.g., circles of support) for people who are living and working in the community. <CT>

Eliminate maximum limits on use of personal services and prohibition on use with other supports. <CT>

Revise the State Medicaid Plan to include more persons with special health care needs who are presently served by medicaid waivers. <CT>

Medicaid reform, if it is to fund case management services, must require the service to be independent of local service providers and with "caseload" size to assure monthly visitation by the case manager. <CT>

Essential Services (personal assistance) should be divorced from the medical model. Medical data and other statements from a doctor, therapists, or other health therapists should not be necessary to receive authorization for the program. <CT>

The Department of Human Resources must examine its role in providing "case management" to people with disabilities. Many people do not wish to be considered a "case" nor do they wish to be "managed." Rather than providing the "direct service" of "case management," the Department can be more effective regarding its caseworkers as "field coordinators" who are responsible for coordinating the programs of the Department with programs from other public and private agencies. <CT>

Essential Services (personal assistance) is poverty-making. "Excess" income is directed to first pay medical bills and then to help pay for Essential Services. Remove the "spend-down" provisions. <CT>

Eliminate the prohibition against one's spouse serving as a personal assistant. Enabling funds to be used with one's spouse makes the Personal Care Attendant Program function more like an entitlement. In addition, a spouse is most familiar with day-to-day care and that care is consistent, reliable and of the highest quality. <CT>

Change federal policy on health care and family members. Personal assistance must not require at least one health care related activity for eligibility nor prohibit family members from providing personal assistance. <CT>

Essential Services (personal assistance) is income-limited (i.e., means-tested). It should not be means-tested. Means-tested eligibility can act as an effective deterrent for gainful employment. Coverage of the costs of Essential Services may be regarded by the general population and people with disabilities as a welfare payment. Welfare is stigmatizing. <CT>

Eliminate requirements tying personal assistance to work or work potential. Personal assistance should be an entitlement. <CT>

Personal Care Services are not required by state statute to be certified and this noncertification must be maintained. There are many threats to the nonprofessional nature of personal services and more threats will arise as the independent living movement and consumer control grows. <CT>

The Department of Human Resources must take advantage of its core funding relationships with the Institute of Human Resources Development to discover lessons from its Personal Care Assistant Program to create supports for people not eligible for support by some other human service agency. A videotape should be produced, and updated quarterly, describing the relationship amongst various state and federal benefit programs to employment. Grant funds should be used to experiment with "peak" packages enabling people to shelter part of their income as "corporate benefits," personal trusts, or savings accounts, in order to get off public assistance programs. <CT>

The Personal Care Advisory Council should study, and issue a report with recommendations for change in legislation, regulations and appropriations one, the legal status of personal assistants with regard to employer/employee relations, labor law, fringe benefits, insurance and liability, unemployment compensation, and the Internal Revenue Service. <CT>

Medicaid reform legislation must mandate that certain services - individual and family support services with assistive technology and independent case management - be provided by a date certain. <CT>

The Council should include, as part of its monitoring process discussed in other chapters of this report, procedures for determining the extent to which the Department of Recreation and Parks is effectively meeting the needs of individuals with developmental disabilities. <DC>

The Council should, in collaboration with consumers, plan and implement procedures for increasing professional, family and social networks of individuals with developmental disabilities. <DC>

The annual budget of the Government of the District of Columbia should be prioritized to allow for personal assistance services specifically designated for individuals with developmental disabilities and their families. <DC>

The Council should contribute to or co-sponsor current efforts on developing legislative history on the Social Services Block Grant Restoration Act of 1989 (S.704). <DC>

The Council should identify and select a cadre of articulate, knowledgeable individuals with developmental disabilities who avail themselves to speak out on individual support and other critical DD issues. <DC>

A data bank should be established and kept current on the types of support services available to individuals with developmental disabilities and their families. <DC>

The Council should develop and implement procedures for publishing and disseminating on a regularly scheduled basis, information on support services currently and potentially available for individuals with developmental disabilities and their families. <DC>

The Council should put into place an early warning system, in collaboration with the appropriate human service delivery systems in the District of Columbia for individuals with developmental disabilities. Such a system would track, monitor and intervene to reduce the potential of subsequent incarceration. <DC>

The Council, working in collaboration with its constituency and advocacy groups, should augment procedures for increasing quality of service delivery, including personnel, for incarcerated individual with developmental disabilities. <DC>

The Council, working in collaboration with the Department of Corrections and other agencies and organizations, should develop procedures for meeting the special needs of inmates with developmental disabilities during their incarceration in general and post-release in particular. <DC>

The Council should establish procedures for making an in-depth examination of the agency's "Annual Recreation Action Plan" for the purpose of insuring that the plan includes action strategies designed specifically for individuals with developmental disabilities. <DC>

The Council should take action to assure that a representative with developmental disabilities be included as a member of the D.C. Advisory Committee on Recreation. <DC>

Consumers in the satisfaction survey emphasized the need for a system of respite services, especially for children. Include support for respite for persons who are medically dependent. <DE>

Establish priorities in the area of guardianship for residents of Stockley Center from the recommendations made by the working group established to review this problem. <DE>

1992: Assess the need for and access to outpatient speech, occupational and physical therapy services for the elderly and persons with disabilities within the catchment areas of the three Long Term Care facilities run by Public Health. <DE>

Provide Alzheimer's and Medical Adult Day Care in all three counties. <DE>

Investigate the need for funding for provision of day care for elderly persons with DD. <DE>

Gradually expand eligibility under the Social Services Block Grant to cover non-elderly persons with disabilities up to 200 percent of poverty and elderly people up to 150 percent of poverty. <DE>

Identify funding sources for the provision of personal care attendants to persons with physical disabilities to enable those persons to live in the community. <DE>

Encourage consumers to aid in educating the legislature and the public on the need for attendant services. <DE>

Public hearing participants recommend the establishment of a central coordinator for respite services, in order to better control the quality and delivery of services. <DE>

Public hearing participants recommend the expansion of day care and respite services throughout the state and identification of program models which have proven successful in other states to develop a program for implementation in Delaware. <DE>

Advocate for legislative action to develop and fund attendant care services for persons with disabilities. <DE>

Increase fund-raising efforts in order to provide meals for more homebound elderly. <DE>

Expand respite service. <DE>

Public hearing participants recommend the expansion of services such as the Harvest Senior Program which provides for food shopping services for seniors living in Dover. This type of program needs to be expanded throughout the state along with appropriate guidelines which include a greater proportion of those who are in need of such services. <DE>

Encourage transportation and meal preparation for homebound elderly. Implement creative incentive programs for volunteers. <DE>

Increase publicity and outreach to those people who are elderly and persons with disabilities who depend upon homemaker service. <DE>

Explore alternative systems of implementing homemaker services which prove to be more cost-effective. <DE>

Parents and consumers attending the public hearings recommend that standards for quality of services provided by homemakers be established. Standards will help in providing consistency in the delivery of services. <DE>

Explore the feasibility of adding case management for people who are elderly and persons with disabilities as an eligible service within the state's Medicaid Program. <DE>

Fund (\$6,300) the Division of Mental Retardation request in FY 1991 for one additional senior case manager position to provide case management for the expected increase in clients who are referred for active treatment services through the OBRA screening process. The federal government will pay 75% of the total cost. \$6,300 is the state's 25% match. <DE>

Fund the 1990 Legislative Budget Request for \$6.5 million for the Florida Family Care Program. Ensure that these funds are used to provide specifically designed supports needed by individuals and their families, based upon an IHP which includes a long-term view of where and how the individual should live, learn, work and play in one to three years. <FL>

Encourage the expansion of Foster Grandparent Programs to capitalize on the valuable resource available in Florida's population of older citizens. Many young people with developmental disabilities and their families could benefit from the young person having an ongoing, personal relationship with an older adult. <FL>

Develop a computerized data base which will enable efficient matching of the individual's characteristics and needs with the programs and services and their eligibility criteria. Install this resource at the local HRS Service Center. Provide training for case managers on use of the system. Evaluate the impact of the service to determine its improvement of service delivery and consumer satisfaction. <FL>

Habilitation plans alone fail to ensure that individuals obtain the services needed to achieve a good quality of life. An adequate number of qualified case managers must be made available and empowered to ensure that services are organized, delivered and evaluated to determine their effectiveness. Without adequate case management services, individuals will continue to face barriers to exercising choices and barriers to obtaining services. Lack of case management will continue to result in fragmented outcomes for individuals. <FL>

Ensure that all individuals with developmental disabilities who are in need of legal guardians receive this needed support. <FL>

Expand individual support services tailored to each individual situation. <GA>

Case management services must be available to all who need it, must span across agencies, and must focus on persons who fall through the cracks in agency services. <GA>

Specific individual therapies necessary for independence and productivity should be available. <GA>

Expand independent living services. Responsibility for provision of these services should be clarified and coordinated. <GA>

An education program for physicians and hospital social workers is needed. The training should include medical students as well as current physicians, especially obstetricians, pediatricians, and family practitioners. <GA>

Establish resource centers to maintain and disseminate information related to developmental disabilities, technology, and available agencies and services and develop accompanying directories of information, including telephone information service. <GA>

Advocate for accessible information and communication (large print, tapes, TDD, interpreters, and Braille) at all public events. <GA>

The Council recommendation is to seek and attract qualified speech therapists and certified interpreters in order to provide adequate services in this area. <GU>

The Council recommendation is to upgrade, improve and develop recreational programs accessible and suitable for individuals with developmental disabilities. <GU>

The governor will create a Technical Assistive Devices Task Force which will develop options for generating resources to assist people with developmental disabilities in obtaining the necessary assistive devices which will allow for independence, productivity and integration. <HI>

By 1992, the federal and state governments should increase funding to support independent living programs. <HI>

The legislature should allocate funding to agencies providing assistance to people with developmental disabilities for personal assistant services. <HI>

All agencies working with people with developmental disabilities on employment plans should address the recreation and social needs of that person. <HI>

Expand the mechanisms for claiming reimbursement for assistive devices for persons with developmental disabilities. <HI>

Develop the mechanism and apply for inclusion of targeted case management services for the Zero-to-Three Project and the Developmental Disabilities Division's services. <HI>

Enhance HCB waiver program effectiveness through policy that explicitly cites integration and productivity as a goal. <IA>

Enhance HCB waiver program effectiveness through policy that requires significant consumer/family/guardian control in the selection of services. <IA>

Study the effects of expanding of the population eligible for HCB Waiver services to include persons in addition to those categorized by Medicaid as "medically needy." <IA>

Revise the HCB waiver application process in order to make it less complicated and less embarrassing to potential clients. <IA>

Increase policy as well as funding support for more effective dissemination of information about the HCB Waiver program to individuals, families, and providers. <IA>

Develop a statewide information and referral system to assist consumers in locating and gaining access to needed services. <IA>

Investigate the reasons why so few elderly persons with developmental disabilities use Older Americans Act nutrition programs in Iowa. <IA>

Study the effects of revising the policies of both Older Americans Act nutrition programs to incorporate greater responsiveness to consumer choice regarding what services are provided; when, where, and by whom. <IA>

Enhance the effectiveness of both Older Americans Act nutrition programs through policy that explicitly cites productivity and independence as program goals. <IA>

Enhance the effectiveness of the Home-Delivered Meals program through policy that explicitly cites integration as a program goal. <IA>

The state must replace lost federal dollars for disability services in the Social Services Block Grant. <ID>

Reports on federal and state expenditures should be expanded to provide additional information on how supports are financed and the availability of those supports to people with developmental disabilities. This information should be complemented by consumer-based research on the relationship between supports and the ability to reach greater independence, productivity and community integration, building on the consumer survey undertaken for this 1990 Report. <ID>

Comprehensive education efforts should be undertaken to help translate the concept of a facility-free support system into reality, including state funded community connection supports for participation in communities, with neighbors and informal organizations;

increased community supported employment by moving away from facility-based vocational or re-vocational program; orienting professionals in the service system to assist them in providing supports to individuals with developmental disabilities, family members, and communities; legislation allowing more comprehensive Home and Community Based Service programs and use of Medicaid to fund creative programs and individual supports; and information from the consumer perspective on the significance of outside supports. <ID>

Increased independence and less tax dependency will be enhanced with an improved self image. Integrated recreation opportunities build positive perceptions of people with disabilities and should be supported with state dollars. <ID>

Beyond access to services and supports, exercising civil rights requires receiving those supports. Idaho should revise its Medicaid Plan to include as regular options those individualized supports. <ID>

People with disabilities should continue to be eligible for medical support service while in gainful employment. Disincentives and loss of medical services have no place in the field of community supported employment. <ID>

Illinois should create a system of independent case coordination entities which will be available to all citizens with developmental disabilities, including severe mental illness, and their families. This system should act as a central point of entry and access to the service system for consumers and families with service needs or concerns. <IL>

Indiana shall require that parks, recreational facilities, and programs funded by the state include accommodations needed to serve people with cognitive, physical, and sensory disabilities. <IN>

Indiana shall enact standards and provide tax credits, low interest loans, or other incentives to ensure that theaters, sports arenas, cinemas, health clubs, and other places of public accommodation are accessible. <IN>

Leisure and recreation training objectives shall be included in individual plans and shall focus on support and resources needed by the individual to access existing community programs and associations of their interests. <IN>

Indiana shall provide family and individual support services including respite care, counseling, crisis intervention, attendant care, technology assistance, financial counseling, and other services designed to maintain and foster maximum independence and community integration. <IN>

Indiana shall create a centralized information and referral system that provides full up-to-date information on all programs, has a statewide 800-number, and has local outreach and support. <IN>

Indiana shall provide a system of services designed to preserve maximum independence in living and decision making, including follow-along, futures planning, friend/advocate programs, alternatives to guardianship (such as representative payee) and guardianship. <IN>

Indiana shall assign to each person with a disability an individual case manager who has authority to secure services from any agency, program, or entitlement appropriate to the individual's needs. <IN>

Indiana shall require the use of a uniform system of symbols for public buildings so that all people can use and understand their surroundings. <IN>

Telephone companies shall provide TDD relay services to enable people who are deaf to communicate with non-TDD users. <IN>

Public utilities, social services agencies, and government offices shall tailor billing statements and information on services to provide accessibility for people with disabilities (such as recorded information for people who are blind, and TDD services for people who are deaf.) <IN>

Communications systems and services (radio, television, telephones) shall provide adaptive equipment for people with disabilities, such as captioning for people who are deaf, narration for people who are blind, and shoulder rests for accessible public pay phones. <IN>

Restaurants and other places of public accommodation shall be encouraged to provide information through picture symbols for those persons who have a reading impairment. <IN>

Indiana shall develop a professional training program designed to insure that certified interpreters are available to all who request them. <IN>

Indiana shall develop and promote a statewide network of Independent Living Centers to further empower people with disabilities. <IN>

Social Service Block Grant funds should be restored to the level originally authorized with provisions for inflation. <IN>

Indiana shall develop policies and funding mechanisms to enable people who use or need adaptive and assistive devices to have access to equipment that promotes their highest level of independence in communication and mobility. <IN>

Indiana shall assure access to integrated community recreation and leisure activities for people with disabilities. <IN>

Indiana shall establish a coordinated, interagency information and referral system for all people with disabilities that is easily accessible, cost free, and educates users on how and where to obtain information and access services. <IN>

The National Guardianship Act of 1989 should be enacted and states should adopt its guidelines in the conduct of guardianship proceedings and in the determination of a person's competency. <LA>

Generic support programs in Louisiana, such as child welfare and aging services, should begin to collect data on the number on individuals with developmental disabilities receiving those services. <LA>

The Office of Human Services (in the Louisiana Department of Health and Hospitals) should take responsibility for the expansion, maintenance, and management of public and privately funded case management services for all persons with developmental disabilities, including persons with mental illness. <LA>

The Department of Health and Hospitals and the Department of Social Services should implement the Community and Family Support System Plan as developed by the Developmental Disabilities Council. <LA>

Interagency efforts (Department of Health and Hospitals, Department of Social Services, State Department of Education) should be directed toward determining case management programming needs and appropriate models of independent case management, including a single point of entry, for addressing identified needs. In order to facilitate these efforts agencies should develop compatible data collection mechanisms. <LA>

Congress should enact Medicaid reform to provide funding for community and family support services. State officials should support this recommendation by communicating with Louisiana's Congressional delegation. <LA>

The Departments of Education, Health and Hospitals, and Social Services should jointly fund a statewide system to provide technical assistance, training, and advocacy to increase integrated social/recreational activities in the community for persons with severe disabilities. <LA>

Examine state initiatives to make sure that eligibility is inclusive of the people at need. For the Kaileigh Mulligan Home Care Program, remove the current low cognitive functioning limit to be more inclusive of children with severe health needs. <MA>

Address the beyond-the-classroom needs of children and their families, e.g., after-school and summer programs, recreation and leisure family supports, human service programs and career planning. <MA>

Maximize an array of individualized personal supports and other independent living services (e.g. attendants, health aides) available in the home and workplace, funded as much as possible by third-party payors (e.g. Medicaid, health insurance). Create uniform eligibility for such services, regardless of whether a person "enters the system" via MRC, DMH, DMR, etc. <MA>

Ensure that all services and supports for families and individuals are flexible, coordinated, consumer-driven, connected to the community and culturally sensitive. <MA>

Develop a statewide interpreter pool accessible to all human service agencies; this service is essential if services are to be truly accessible to linguistic minorities. Interpreter training and certification should be established by the state legislature. <MA>

Establish a statutory entitlement to publicly-funded but client-directed independent case management/service coordination, as an option for persons/families desiring help in accessing, planning and coordinating resources to meet disability-related needs. <MA>

Establish a centralized system of information and referral that is efficient, accurate and easily accessible to all families and individuals with developmental disabilities. It should include the capacity to aggregate program data and link to other computerized systems, as needed. <MA>

Publicize and use technology in all areas of life to promote independence, productivity and integration for all persons with disabilities. Support present work of Mass. Commission for the Deaf and Hard of Hearing (MDCHH) to access federal resources and coordinate state efforts around technology resources. <MA>

The present guardianship law should be amended to create and fund a public guardianship commission that can provide a trained fiduciary when no one else is available, by passage of Senate Bill 663. Other reforms are needed: periodic review of competence should be mandated for persons deemed incompetent due to mental retardation and/or mental illness; representation for prospective wards; and individually tailored limited guardianships. <MA>

Establish a policy on support services for adults with developmental disabilities which assures that supported independence outside of parental/family homes in a typical and accessible Developmental Disabilities Administration service options. <MD>

Provide an independent services coordination system - not involved in the direct operation or purchase of services - to assure that persons with developmental disabilities are linked with services that respond to their abilities and choices. <MD>

Expand Medical Assistance program covered services to include augmentative communication devices. <MD>

Include retirement pursuits and other options for older persons with developmental disabilities, as part of an array of services promoted and offered by the Developmental Disabilities Administration. <MD>

Actively support congressional passage of the Medicaid Home and Community Quality Services Act (the Chafee bill, S.384) allowing states to receive federal financial participation for an array of services - including occupational and speech therapies and dental services, and structural and environmental modifications, such as grab bars, ramps, and environmental controls - for persons with severe disabilities without the requirement to extend similar benefits to the entire Medicaid eligible population. <MD>

Include children with chronic conditions and their families in a comprehensive case management program, such as the family service planning process being developed under P.L. 99-457 or the service coordination system through the Developmental Disabilities Administration, to ensure their access to services which are available to other persons with disabilities. <MD>

Seek an amendment to the Maryland Home and Community Based Services waiver to broaden the array of services eligible for federal reimbursement under Medicaid. Include services which are available in the Intermediate Care Facilities for the Mentally Retarded program which are not covered under the present waiver, including speech and audiology, environmental controls, attendant services and respite care, and occupational therapy, in order to broaden options for persons who leave institutions under the Maryland waiver. <MD>

Limit growth of Medical Day Care for persons with developmental disabilities because its nursing/medical model thwarts opportunities for community integration, as well as progress toward vocational potentials. <MD>

Ensure that the Division of Vocational Rehabilitation allocates Independent Living funds to private non-profit organizations with a goal to maximize direct supports available to eligible persons, while streamlining center-based personnel providing "core" information and counseling services. <MD>

Continue vigorous efforts to increase state funding of Independent Living Services. <MD>

Continue efforts to attract more federal funding under the Centers for Independent Living program. Foster development of more community based organizations with federally required consumer composition in governance, management and staffing and formulate more competitive proposals to advance the state's ability to leverage new federal funding, depending on availability. <MD>

Determine the Maryland Rehabilitation Center's capacity to export, to disperse new revenues through grants to local community based organizations which offer options for integrated, community based services, and to increase accessibility of assistive technologies to more effectively encourage employment and independent living. This capacity is especially important for persons with very severe disabilities who cannot take advantage of the Center's on-site resources. <MD>

Provide supplemental funding for interpreter services, both for on-the-job support and for sign language training of counselors in the Independent Living Services program. <MD>

Consider within the Developmental Disabilities Planning Council a demonstration project to encourage community based integrated services, therapies, technologies, and technology try-outs. <MD>

Increase flexibility in the use of Medical Assistance Personal Care dollars to bring attendant wages to a decent standard and allow for back-up services while maximizing federal financial participation. <MD>

Enable Development Disabilities Administration funds to be used to supplement Medical Assistance dollars so that persons served by community-based agencies may receive Medical Assistance Personal Care services. Developmental Disabilities Administration individual support service funds would supplement low Medical Assistance wages, and allow for payment of mileage, holidays, benefits, and other items not covered by Medical Assistance. <MD>

Change state regulations to allow temporary personal care attendants to fill in when the primary attendant is unavailable. <MD>

Change state regulations requiring an independent nurse case manager to allow nurse case managers to work for the same agency as persons providing Medical Assistance personal care services in order to avoid intrusive, expensive and duplicative levels of supervision. <MD>

Examine the impact of the current Medical Assistance reimbursement rates on quality of Medical Assistance Personal Care services. <MD>

Make respite services available to temporarily replace attendant as well as unpaid care. <MD>

Tie eligibility for respite care to the individual, not the family. Amend regulations to allow families to access the full number of respite care days for each family member with a developmental disability. <MD>

Provide respite care as one part of a flexible and ongoing support system which is available and accessible to all eligible persons. The ideal organizational location for respite care is within that agency which is responsible for administering other support services for persons with developmental disabilities. Relocation of respite care would increase the visibility and potential for growth of respite services in Maryland. Assure that the program remains available on a first-come, first-served basis. <MD>

Explore the feasibility of administering all personal assistance services through a single agency. The single agency would administer funds to finance an array of choices: agency-based, traditional Medical Assistance, and subsidized employer-employee arrangements. Such an arrangement could improve access and assist service recipients in choosing the most appropriate services for which they qualify. <MD>

Provide training to judges and petitioning attorneys on the adult guardianship portion of the state Family Law article in order to ensure that they act in the individual best interests of vulnerable adults. <MD>

Require private guardians of adults to meet with review boards to assure that they are properly carrying out their duties, and, that the scope of their duties is revised when necessary to at least limit the rights and choices of persons for whom guardianship is held. Prohibit service providers from being selected as guardians for their service consumers. <MD>

Clarify the definition of disability in the Adult Protective Services law. <MD>

Expand adoption and foster care recruitment through increased efforts such as the One Child, One Church program, corporate involvement, and greater media involvement. <MD>

Provide for adequate wages to respite providers (Department of Human Resources-funded home health aides and Division of Vocational Rehabilitation-funded attendants earn over \$7.00 per hour) in the program's budget supported by state general funds. <MD>

Establish as the highest priorities in Children's Protective Services timely investigations and prompt delivery of support services. Focus provision of more family support services before families reach crisis situations. <MD>

Review and amend as necessary the guardianship law pertaining to adults in need of protective services, to assure that it does not overly restrict individual rights and freedom choice. <MD>

Extend the annual number of days for which an individual may qualify for respite care with concomitant increases in funding. <MD>

Determine the proper agency location for the Client Assistance Program based on examination of whether or not effective advocacy on behalf of the consumer is possible within a service-providing agency and based on other state's experiences and choices in locating the Client Assistance Program. <MD>

Increase funding for all services provided by Department of Human Resources particularly to strengthen prevention efforts. <MD>

Provide funding for volunteer coordinators in the Social Services to Adults program. <MD>

Support passage in Congress of the Medicaid Home and Community Quality Services Act which would allow states to receive some federal financial reimbursement for a broad range of community-based services for individuals with developmental disabilities - including respite care. <MD>

Efforts to protect persons with developmental disabilities and assure their right to be free from abuse must become more proactive. Advocacy staff resources must be expanded to allow: greater emphasis on educational activities with consumers in public and private institutions and community residences designed to help them become strong advocates for their right to be free of abuse and to provide information about available help; and proactive involvement with professionals responsible for care, treatment and services to persons with developmental disabilities designed to prevent instances of abuse, as well as sufficient staff resources to respond promptly to all allegations of abuse. <ME>

A task force should be convened to examine the effectiveness of existing protective services efforts, the nature and scope of violence against persons with disabilities, the response of the legal system particularly as it relates to effective prosecution, the role of human services providers in preventing and reporting abuse, and protection of children and adults in out of home placements. The task should be broadly constituted to include consumers, legal and judicial systems, public safety, human services providers and state agencies. Its action should produce a State Plan for the "Prevention of Abuse of Persons with Disabilities", including recommendations for administrative and legislative action. <ME>

Individual case advocacy services must be made available to families and individuals with developmental disabilities, including assisting families in securing appropriate educational

services their family member with a developmental disability; assisting persons with developmental disabilities in assuring their right to services such as rehabilitation, day programs, financial assistance, residential options or medical care; helping families advocate for their treatment, support or other needs as a family unit; and protecting the rights of children and adults in institutional and other residential care placement. <ME>

Persons with developmental disabilities who experience sexual abuse should be offered such treatment services as are appropriate to their need as a "survivor". Existing treatment resources should receive training in working with persons with developmental disabilities, and the adequacy of available treatment resources should be reviewed to determine additional treatment resource needs. <ME>

Payment for assistive technology under Medicaid should reflect current market standards and be prompt (within 30 days after receipt of equipment). Payment systems should not force providers to subsidize the state through interest payments or unusually low profits. <ME>

The State of Maine should implement recommendations of the Commission on Children in Need of Supervision and Treatment for implementation of a system of family support and services to children and families not presently covered by existing categorical programs. <ME>

Medicaid policy defining eligible assistive technology should not be a definitive list but should be based upon the concept that assistive technology will be provided pursuant to physician order and individual treatment plan. For example, if equipment is necessary to support someone in their own home or to enable them to gain maximum benefit from training programs, it should be eligible for reimbursement. <ME>

Develop state plans for the expanded use of AFDC-FC and Title IV E and other resources to support interdepartmental coordination in prevention treating and caring for victims of child abuse and neglect. <ME>

Establish a state Medicaid Plan for children and families which identifies new or expanded use of Medicaid to fund case management services, therapeutic foster care, group home care, day treatment, residential treatment, and "related services" costs in special education. <ME>

Case management services must be available to all persons with developmental disabilities and their families who want assistance in the planning, coordination and receipt of services. Recommended is expansion of the Medicaid Case Management option proposed for the Bureau of Children with Special Needs. <ME>

The policy of the State of Maine should more strongly support the principle of family and consumer decision making and control over their services plan, via an expansion of

the voucher system. The voucher system piloted by the Bureau of Mental Retardation, should be available to all families and consumers with developmental disabilities. Eligibility should be based on need, not disability or income. <ME>

The State of Maine should place greater emphasis on supporting families and consumers in decision making and direction of their services. In order to be effective decision makers and to be integrally involved in planning their services, families and consumers need responsive and reliable sources of information and support. To accomplish this, the State of Maine should establish a statewide parent and consumer operated information and referral system. <ME>

Full funding and implementation of the Technology-Related Assistance for Individuals with Disabilities Act (P.L.-407). <ME>

Revision of Medicare and Medicaid statutes and regulations to support the provision of assistive technology necessary to support independence, integration and productivity. <ME>

Rehabilitation agencies, the Bureau of Mental Retardation and independent living programs should assure that, whenever appropriate, individual plans include the development of consumer skills in leisure time activities as part of independent living. <ME>

The Office of Community Services of the Department of Economic and Community Development should provide technical assistance, training and consultation to public recreation programs and private agencies seeking to provide services to people with disabilities. The Office should establish a developmental grant program to assist local communities in the development of integrated recreational programs. <ME>

An interdepartmental effort should be undertaken to assess the treatment and other support services needs of people with developmental disabilities in state and county correctional facilities, develop a plan for the coordinated delivery of services and programs to inmates with developmental disabilities, including responsibility for follow-up, and make recommendations for financing the system of services including both new state resources and use of existing state and federal resources (such as Title IVE, AFDC-FC, and Medicaid). <ME>

The Bureau of Maine's elderly, with the assistance of Area Agencies on Aging, should develop a "Memorandum of Understanding" with their state agencies serving persons with developmental disabilities. The "Understanding" should detail how Maine will comply with the Older American's Act Amendments of 1987 for integration of persons with developmental disabilities in programs serving people who are aging. <ME>

The governor should direct, the legislature should fund, and the Michigan Departments of Mental Health, Corrections, and Social Services should establish units with expertise

in offender treatment strategy, developmental disabilities, crime prevention, and public policy to work to prevent criminal activity by people with developmental disabilities, by moving toward a comprehensive remedial system of intervention; and provide technical assistance, training, and consultation to service providing agencies, to insure that offenders receive fair treatment and access to all services to which they are entitled from these organizations. <MI>

The Michigan legislature should fund, and Michigan Rehabilitation Services should implement, expansion of Independent Living Services through community-based Centers for Independent Living, to achieve statewide availability. <MI>

The Michigan legislature should fund, and state agencies should carry out, expansion of services and improved coordination between Michigan Department of Social Services' Home Help and Services for the Physically Disabled programs and Michigan Rehabilitation Services' Personal Care Attendant program, to maximize federal resources, and to expand availability and quality of Personal Assistance Services (PAS) for people who need ongoing supports for community living and for work. <MI>

The Michigan Council for Independent Living, with support and assistance from the Michigan Developmental Disabilities Council, the State Independent Living Council, and other advocacy organizations should convene a statewide coalition on Personal Assistance Services to pursue state legislation and state agency implementation of a comprehensive program of PAS that meets standards of the Independent Living model. The program should include assurance that assessments are objective and allow flexibility for individual needs. Legislation should tie allocations to increases in the cost of living. The program should also maximize federal resources, consumer control, and quality programs throughout Michigan. <MI>

The Department of Social Services, with the help of advocacy groups, should encourage expanded use of Medicaid optional services that are important in community-based care and support for people with disabilities. Examples include occupational therapy, physical therapy, and home help. <MI>

The Michigan legislature should establish program authority and funding for necessary in-home engineering or adaptations (that cannot be provided under existing programs) to promote independence. <MI>

The Department of Social Services (DSS), in setting up its new Children's Services Management Information System, should consult with other agencies and advocacy groups who work with children who have disabilities, to determine the type of data about disabilities needed to assure that children and their families in the DSS system are receiving appropriate services. The system should provide regular analytic reports of trends, with recommended actions, to the Human Services Cabinet. <MI>

The term "case management" will be replaced in the next few years, by terms that focus on individuals and service coordination. <MN>

Individuals and families should be trained and empowered to be their own case managers, relying on case management support when and as required. <MN>

Priority attention should be paid to the development and implementation of new or revised individual plans for people who are currently unserved or underserved, rather than continuing to tolerate their situations of no service or inappropriate service. <MN>

The services of case managers should be made available to anyone in need of support, regardless of type or severity of disability. <MN>

Recognizing the significant role of quality case management services in transforming the system to ensure independence, productivity, and inclusion for all people with disabilities, we believe that the caseloads, training, and mandate of case managers should be brought into line (in policy and practice) with the standards of best practice. <MN>

Social, physical and fiscal access to such support services and programs as Family Subsidy, Semi-Independent Living, Home and Community Based Waiver, and case management should be extended to individuals who are unserved and underserved, including people with physical disabilities, emotional problems, and sensory impairments. <MN>

Policies and practices should be developed to enable and empower individuals and families to purchase the supports and assistive technology required from specialized providers and generic community resources. <MN>

The goals of support to individuals should be seen and mandated as integration, independence, and productivity, but equally important are interdependence, contribution to the social and economic life of the community, participation, friendships, relationships, dignity and respect. <MN>

A voucher system: allocate funds to the individual (directly or indirectly). Charges are made against the individual's account as supports are purchased from agencies or individuals. <MN>

Enable case managers to achieve plan implementation (reduce caseloads): set caseload limits at a level which allows case managers to be more actively involved in not only identifying existing programs, but adapting them to meet the individual's needs, and developing new supports. <MN>

The Council, the State Advisory Council for Comprehensive Psychiatric Services (SACCPS), and other groups should advocate for increased funding for the Divisions of

MR/DD and CPS in order to provide an array of individual and family support services statewide including supported living, supported employment, etc. <MO>

The Divisions of MR/DD and CPS should maintain the integrity of the family by supporting the concept of permanent families for children and restructure programs and resources for children and currently in the system. <MO>

Long term case management for people with developmental disabilities through the Divisions of MR/DD and CPS should be enhanced by more fully implementing the functions of information and referral, service coordination, and advocacy. <MO>

The Autism Resource Center should be expanded to include other disabilities. <MO>

Training for employees of the Divisions of MR/DD and CPS should include methods to enhance individual and family support planning. <MO>

Alternative funding mechanisms for individual and family support services should be pursued by the Divisions of MR/DD and CPS (e.g., vouchers, subsidies, and tax credits.) <MO>

The Council, the SACCPS, and other groups should advocate for the passage of Medicaid Reform (the Chafee bill, S.384) as a mechanism to train families and individuals in the areas of empowerment, advocacy and networking. <MO>

All Mississippi citizens with developmental disabilities should have available a 24-hour hotline for families or consumers in times of crisis. <MS>

As the deinstitutionalization of people with developmental disabilities continues, adequate community support to allow persons with developmental disabilities to function satisfactorily in the community and enjoy a real "quality of life" must be guaranteed. Services for individuals with developmental disabilities should include all supports needed by consumers for a satisfactory transition into homes in the community. <MS>

Home and community-based services, respite care, and day care should be expanded. <MS>

Various settings should be considered as a service base for respite care. <MS>

Mississippi's area agencies on aging should facilitate the coordination of community-based, long-term care services for Mississippi's older individuals with developmental disabilities who reside at home and are at risk of institutionalization because of limitations on their ability to function independently; who are patients in hospitals and are at risk of prolonged institutionalization; or who are patients in long-term care facilities, but who can return to their homes if community-based services are provided to them. <MS>

Mississippi's older individuals with developmental disabilities who are eligible for assistance under the Older Americans Act should be informed of the availability of this assistance through an "outreach" program. <MS>

Funding levels for discretionary programs that stimulate the development of supports, including grants for recreation programs, assistive devices, community support systems in mental health, temporary child care/crisis nurseries, and independent living centers, must be maintained — and expanded where possible. <MS>

The Mississippi Council on Aging should assure coordinated planning, identification, assessment of needs, and service for older individuals with developmental disabilities, with the state agencies with primary responsibility for individuals with disabilities, and develop collaborative programs, where appropriate, to meet then needs of older individuals with disabilities. <MS>

Increased coordination among Mississippi's agencies will become necessary to serve the growing elderly population with severe disabilities. Combined efforts must be made to coordinate services for such individuals. Specific recommendations are to establish programs for cross-training of current providers of services for people who are elderly and for people with mental disabilities; temporary assignment in the other field would allow workers in both fields to be better prepared to serve elderly individuals who also have a mental diagnosis; and to coordinate training programs jointly sponsored, and held in at least two locations in the state. <MS>

Service workers within social service systems such as the Department of Family Services need to be provided structured, systematic cross-training regarding disabilities, services for persons with disabilities, and related issues. Their caseloads should be appropriately adjusted in order to provide adequate assistance to persons with disabilities. <MT>

Recreation and leisure resources need to be developed, adapting existing resources or creating new services. The resources must be integrated and individualized for persons with disabilities and be available at a reasonable cost. <MT>

Adequate case management services and information and referral procedures should be increased, assuring integration of clients into regular services, and providing respect for the client's dignity. <MT>

Funding and availability of providers for respite or attendant care services need to be increased. The assistance available should be more appropriately individualized to suit clients' needs (i.e., individual is behaviorally challenging, medically fragile). <MT>

Funding and assistance for architectural modifications which adapt individuals' living, work, learning, or recreational environments to make them more accessible or functionally useful should be increased. <MT>

Community living assistance or training for persons with disabilities must be increased. <MT>

Funding for adaptive equipment and assistive devices should be readily available so that currently prohibitive costs for the equipment do not constrain individuals to choose to live less than normalized lives despite the availability of technologically advanced devices. <MT>

Physical therapy, occupational therapy, and communication services for children and adults need to be increased and individualized to meet their unique needs. <MT>

Assistance in area of financial management services should be increased. <MT>

Availability of and information about guardianship services should be more readily accessible and comprehensible. <MT>

The concept of companions and friends within advocacy programs needs to be explored and enhanced to better provide assistance for persons with disabilities. <MT>

Protective or legal services individualized to meet the unique needs of persons with disabilities need to be reinforced. <MT>

The costs for appropriate adaptive equipment are exorbitant. A system such as a local, regional, or national "clearinghouse" should be developed for acquiring low-cost equipment or securing the equipment at a reasonable cost through exchanges or resale of equipment no longer needed. <MT>

The Council recommends that the proposed Individual Life Plan (ILP) be accepted and utilized by all service agencies and that it replace all currently used service planning documents (e.g., IFSP, IEP, IWRP, IHP). <NC>

Consumer organizations should work with federal, state and local recreation programs to encourage all persons (with and without disabilities) to participate together in recreational programs. All available resources, including newspapers, public service announcements, consumer newsletters and informal community networks, should be utilized. <NC>

The Council recommends that the Parks and Recreation Division of the Department of Environment, Health and Natural Resources work with consumer organizations and the Council to develop a "self-diagnostic" survey for distribution to all federal, state and local recreational facilities in North Carolina to determine the accessibility of facilities and the degree to which programs provide opportunities for integration of persons with developmental disabilities. <NC>

Each facility/agency should develop a plan by December 31, 1992, to improve accessibility and recreational opportunities for persons with developmental disabilities. The plan should be reviewed on an annual basis. <NC>

One of the many services which might enhance integration is "companion or friend/advocate programs," which provide persons with developmental disabilities opportunities to spend time with non-disabled individuals who are not family members. Such services also provide much needed respite for families and other caregivers. <NC>

The Council recommends that the University of North Carolina System cooperatively address the education concerns by expanding degree programs in these professional areas (interpreters, recreational therapists, cognitive retrainers, speech/language therapists, physical therapists, occupational therapists, and augmentative communication specialists) and finding creative incentives to attract students to these programs. <NC>

The Council recommends that the Division of Vocational Rehabilitation Services work with other state agencies, rehabilitation technology programs (both public and private) and consumer organizations to identify existing assistive technology resources and to identify future needs. <NC>

The Council recommends that the Division of Vocational Rehabilitation Services identify barriers to accessing services in order to specify ways to make adaptive equipment and assistive devices more readily available to the people with developmental disabilities who need them. <NC>

The Council recommends that the Division of Vocational Rehabilitation Services convene an interagency, inter-organizational task force to design a consumer-responsive assistive technology services network which will encourage expansion of existing service delivery programs. <NC>

Because of service similarity, respite care providers such as Easter Seals should be encouraged to also offer attendant care services, at least on a trial basis. Such diversification may be mutually beneficial to both services and could effectuate further reductions to the overall hourly rate for respite care. In order to facilitate such diversification, DHS should consolidate funding for all respite and home health care services administered by the Department into a single budget unit/division. <ND>

A directory should be compiled which identifies the charitable organizations in North Dakota that purchase or otherwise provide adaptive equipment or assistive devices or needy individuals. <ND>

The North Dakota Coalition on Assistive Technology formed in 1988 should be encouraged and supported in its efforts to promote networking and informational exchange among

clients and disabilities case managers. Such activities should focus on minimizing vendor determination of adaptive equipment/assistive device needs of individual clients. <ND>

In cooperation with the Coalition on Assistive Technology, the state Office of Vocational Rehabilitation should pursue proposed plans to establish regional adaptive equipment/assistive device assessment centers throughout North Dakota. Such centers could not only offer needed technical assistance to individuals with disabilities with equipment needs, but would also impose further checks and balances on equipment vendors. <ND>

The feasibility and desirability of creating in North Dakota a state assistance program to supplement, but not replace, the efforts of charitable organizations to furnish adaptive equipment and assistive devices should be explored. <ND>

As a cost-saving measure, the North Dakota Department of Human Services should consider creating and maintaining within its Medical Services Division an equipment procurement unit. This unit should be responsible for minimizing the potential for overcharges and abuse by imposing conventional competitive bidding practices on all vendors of adaptive equipment and assistive devices who wish to conduct business with the state. <ND>

Sufficient funding should be allocated to enable the Developmental Center to complete all adaptive equipment work for institutional residents as soon as possible so that its adaptive equipment capabilities can then focus on addressing needs of community clients. <ND>

If the regional adaptive equipment/assistive device assessment centers being proposed by the state office of Vocational Rehabilitation materialize, the State Center's adaptive equipment unit should assist in developing the capability of those regional centers to furnish adequate services to community clients. <ND>

Attendant care issues including abuse, supervisory problems, and payment to family members should be examined and plans for the resolution of problems developed. <NE>

Issues specific to aging and developmental disabilities should be examined with the goal of coordinating services and insuring integration of elderly persons with developmental disabilities. <NE>

The case management function within the developmental service system should continue to evolve away from the coordination of specialized services towards a focus on assisting people with disabilities to develop and implement personal plans, arranging access to generic services, and building strong ties to communities and community groups. <NH>

Area Agencies should establish working relationships and cooperative agreements with generic community recreation and leisure services, such as health clubs, adult education programs, clubs and community and volunteer organizations to increase the participation of people with developmental disabilities in these programs. <NH>

Expenses for equipment to augment communication for people with serious communication difficulties should be allowable as an expenditure under Medicaid. <NH>

The intake and eligibility process of the Division of Developmental Disabilities is complex and time-consuming. The necessary time for completing the process may prevent the delivery of a particular service when it is most critical. In fact, the duration of the intake process may exceed the time it takes to deliver the service. In these cases, the intake process is a disincentive for seeking services at all. <NJ>

It is recommended that case management services be decentralized and deregionalized to increase access to generic services, garner community resources and facilitate local linkages to meet the needs of persons with developmental disabilities and their families. <NJ>

It is recommended that existing case management systems identify solutions to known and persistent problems within the system, including policies and procedures for determining realistic caseload assignments; clarification of roles and the differentiation and redistribution of certain functions; and the development of "specialized" case managers and supervisors to meet the needs of unique populations. <NJ>

It is recommended that interagency agreements be developed to reduce the duplication of services and maximize the use of resources. <NJ>

It is recommended that independent living centers be funded through the Division of Vocational Rehabilitation Services at a level sufficient to enable the centers to meet all national standards. <NJ>

It is recommended that independent living centers market additional services to other state and county agencies with responsibilities for people with various disabilities. <NJ>

It is recommended that each independent living center that meets national standards be encouraged to engage in strategic planning to develop its unique identity reflecting the distinctive characteristics of its designated catchment area. <NJ>

It is recommended that independent living centers be encouraged to incorporate activities that foster purposeful personal futures planning by anyone interested, especially younger people with disabilities. <NJ>

It is recommended that independent living centers be encouraged and enabled to establish subunits at the county and subcounty levels for the convenience of members and potential members. <NJ>

It is recommended the independent living centers be given technical assistance to pursue funds in the private sector. <NJ>

It is recommended that independent living centers develop a statewide identity that enables centers to participate in policy-making with other statewide organizations of consumers and providers. <NJ>

It is recommended that consideration be given to the establishment of a single unit within the Department of Human Services that would be competent to set policy, identify needed reforms, maintain a job market and arbitrate issues relevant to the provision of personal assistance for persons who need help with the activities of daily living. <NJ>

It is recommended that extraordinary authorization and resources be made available to the Division of Advocacy for the Developmentally Disabled, the Bureau of Guardianship and the Office of the Attorney General to expedite the validation of guardianship status of current clients of the Division of Developmental Disabilities who need but have not received the benefits of the 1985 amendments to Title 30 guardianship provisions. <NJ>

It is recommended that the New Jersey Developmental Disabilities Council, in concert with interested organizations, renew efforts to perfect the laws pertaining to adult protective services. <NJ>

It is recommended that a task force be formed to address issues of guardianship for people with developmental disabilities who lack the capacity for self-direction. <NJ>

It is recommended that the national Probate Code be reviewed, with special references to its provisions for guardianship for persons with mental disabilities of early onset. <NJ>

It is recommended that the pending proposals for state funding of County Offices on Disability be enacted and implemented. <NJ>

It is recommended that interdivisional and interdepartmental "case mediation" capacities within the Department of Human Services be strengthened and invoked effectively to the benefit of clients. <NJ>

It is recommended that the Division of Developmental Disabilities accept responsibility for adults with developmental disabilities who need case management, regardless of whether other services specifically provided by the division are required by the applicant. <NJ>

It is recommended that responsibility for social services, other than protective services, for all adults with disabilities, without regard to severity or age of onset, be reinforced and made more visible within the Department of Human Services. <NJ>

It is recommended that the portion of the law pertaining to personal attendant services which makes ineligible an individual who lives in a family or other household where there is a member "available" as a caregiver be amended to permit a reasonable flexibility and adaptation to individual circumstances. <NJ>

It is recommended that a national program of personal attendant services sustained in part by federal funds and subject to federal standards of quality be developed and enacted. <NJ>

It is recommended that the present interpreter service for the deaf, Division of the Deaf and Hard-of-Hearing, be expanded and funded to permit a more liberal use of interpreters in community group settings and places of public accommodation. <NJ>

It is recommended that the issue of affordability of assistance or devices be addressed by each agency with respect to its clients, using a basic premise that the consumer should not bear the main burden of equalizing his or her opportunities for independence, productivity or integration. <NJ>

It is recommended that an examination be made of present funding streams that support personal aides or the purchases of assistive devices, with special reference to how these streams accommodate the needs of individuals to lead connected lives around-the-clock, and to issues of quality and cost-effectiveness. <NJ>

It is recommended that, upon completion of the study of funding streams, rules that presently and arbitrarily limit assistance to employment-related activities be relaxed, including the mandatory "employment" priority under the federal Developmental Disabilities Assistance and Bill of Rights Act in effect since 1984. <NJ>

Expand funding for community and family based support to include: grants for recreation programs, assistive devices, community support systems in the areas of mental health, temporary child care, respite, and independent living centers. <NM>

Expand the Home and Community Based Waiver Option for persons with developmental disabilities. <NM>

New Mexico should review and support, if acceptable, the National Guardianship Act of 1989 should it be enacted. <NM>

A system of coordinated case management is needed to provide assistance in accessing services, advocacy and monitoring services. <NM>

Continuing linkages of cross-disciplinary coordination, collaboration and planning in all areas of Nevada which will effectively interface with state level efforts to increase technological access should be established. <NV>

Service providers should begin immediate action to fully inform persons with disabilities of their rights and the services available to them. Such action might include broader community and interagency networking, consistent multi-media coverage, development of an informational registry and development of service directories specific to the needs to the needs of varying disability groups. <NV>

Existing and potential consumers should be identified who may benefit from enabling technology services planned and provided in an appropriate culturally sensitive and holistic manner. <NV>

Technology related services should be provided by all major provider which will increase the independence, mainstream integration, competitive work opportunities and life control of people with disabling conditions. <NV>

Consumer knowledge and understanding of assistive technology and their ability to exercise significant control over the barriers which inhibit their access to that technology must be increased. <NV>

A continuing process which will assure cross-disciplinary providers and professionals are knowledgeable about enabling technology and its beneficial application should be developed and implemented. <NV>

Policies, practices, attitudes and funding constraints should be eliminated or ameliorated which negatively impact access to technologically related services and devices. <NV>

Respite care which may be accessed by families of people with developmental and other severe disabilities, of all ages, must be provided in order to keep Nevada families together. <NV>

Recreational activities provided by counties, cities and all other entities as well as recreational locations, (parks, facilities, etc.), should be designed and/or modified to fully accommodate the integration of people with disabilities. Programs and events should provide staff and instructors skilled in adaptive recreation and other qualified assistance as required i.e., interpreters and adaptive equipment as necessary to full participation. <NV>

Adaptive recreational programming should be planned and implemented to effectively include people with sensory and cognitive disabilities and people with mental illness. <NV>

Radio reading and multimedia translation services for people with blindness should be implemented statewide. <NV>

Funding should be substantially increased to allow people with disabilities to purchase the technology they need for independence and integration. <NV>

Attention must be given to the development of support services for individuals who can meet the eligibility criteria for services from OMRDD or OMH but who need help in learning how to live in the community that no other agency provides. Some examples are people with epilepsy, traumatic head injury, spina bifida, and severe learning disabilities, and other neurological impairments. Services to this group of people can prevent them from becoming dependent on public welfare and, ultimately, institutionalized. <NY>

Home based services must continue to be expanded through the evaluation and replication of successful models developed throughout the state. Emphasis must be put on models that are based on equal partnerships with individuals with developmental disabilities and their families. <NY>

A wider range of options should be made available for adults with developmental disabilities to enable them to become contributing members of the community. It is more cost effective to make adaptive equipment or technology available to individuals to enable them to work and communicate with others than it is to maintain them in a costly, segregated setting. <NY>

People with developmental disabilities and their families must have equal access to the supports they need in the community whether they are children or adults, rich or poor, in urban or rural settings. <NY>

The guardianship reform legislation, recently passed, which allows for limited guardianship, should be strongly supported and training and funding should be available to facilitate its enforcement. <OH>

Long term or futures planning should be implemented for all students with developmental disabilities. <OH>

Support must be provided to assist individuals and families in making informed choices. <OH>

Highly individualized and intensive supports must be available to support persons with special needs such as challenging behaviors and chronic medical conditions. To meet the needs of the most difficult to serve persons, it will be necessary to develop community-based back-up services to help in preventing the need for institutionalization. Responsibility for the development of these specialized supports should be shared cooperatively by all appropriate state and local agencies. <OH>

In order to maximize the state's experience and financial investment in the two public information and referral programs now operating, the OASIS Project and the Office of Handicapped Concerns, it is suggested that these two projects be combined under a single agency, and that the data base be built upon the foundation of both. The need for additional information should be assessed and additional data bases added to provide a full service information and referral capability for the state. Putting together the funding sources of both programs and the data resources that are already developed, few new state resources would be needed to have comprehensive information available to persons with disabilities and their families. <OK>

The data gathered firsthand from the 1990 Report activities suggest that one agency should be designated to take on the responsibility of developing and implementing a statewide information and referral system which serves persons with developmental disabilities. This approach would provide a continuum of information services for families that would address the family needs from infancy through adolescence, to adulthood, and finally to individuals with disabilities who are 55 years and older. The system we propose would be computerized with an 800 access number, and be administered in an agency whose primary responsibilities is for programs serving people with disabilities, like the Department of Human Services or the Office of Handicapped Concerns. The system would be characterized by providing public and private resources. <OK>

Create a network of regionalized case managers who would be assigned to families/individuals seeking assistance in coping with the added responsibilities associated with caring for persons with developmental disabilities in accordance with the federal definition. This cohort of case workers would specialize in the support of non-institutionalized Oklahomans. The regions should be created to be identical with DHS Regions or other commonly recognized boundaries. The case managers would be supervised by the Developmental Disabilities Services Division within the Department of Human Services. <OK>

Procedures for temporary medical guardianships should be established or other forms of proxy consent that also protect the rights of individuals. <OR>

Concerted state efforts are needed to coordinate and disseminate information on assistive technology and to provide actual services relevant to both employment and to daily living needs of adults with disabilities. <PA>

A variety of avenues for funding must be energetically pursued to develop a stable and comprehensive avenue through which adaptive devices can be obtained by adults with disabilities in the Commonwealth through a coordinated state effort. <PA>

To make generic recreational services more available to persons with disabilities, funding is needed for the purchase of barrier free recreational equipment and programs sensitive

to the requirements of citizens with disabilities. The employment of persons with disabilities in recreational planning will help increase visibility of these needs. <PA>

Prepare and submit a Home and Community-based Medicaid Waiver for persons with disabilities. <PA>

Recreational activities will be open to all persons, regardless of disability. <RI>

Coordinated case management (with accessible data base) must be provided to facilitate arrangements for support. <SC>

Funding levels for discretionary programs that stimulate the development of supports, including grants for recreational programs, transitional programs, assistive devices, community support systems for people with mental illness, respite care and temporary child care/crisis nurseries must be maintained. <SC>

Establish a service delivery program in conjunction with the Department of Vocational Rehabilitation that will enhance the provision of assistive technology services to people with disabilities in South Carolina. <SC>

Funding options need to be explored for independent living services for persons with severe physical disabilities. Such services as assistive devices, attendant care and transportation (which enhance the quality of life and independence of persons with disabilities) are sorely lacking in the state. Currently there are no state funds available for these services. <SC>

The state should give serious consideration to electing to cover targeted case management services as one means of putting in place a more extensive network of such services. <SD>

It is recommended that South Dakota reassesses its approach to the provision of case management services and consider the establishment of a unitary external case management system on at least a limited basis. <SD>

Assistive technology services and devices should be consistently available throughout all areas of the state. It should be required that consideration be given to the need for assistive technology services and devices during the development of habilitation or support plans for individuals with developmental disabilities. <IN>

Supports to individuals with developmental disabilities that promote their independence, productivity and integration in the community should be a major policy goal in the 1990s. These supports should be based on the following principles: services should be based on consumer choices as much as possible; services should be community-based; and services

should be available to people in all areas, of all ages, and with all types and levels of disability. <TN>

A support system should be developed which is not tied to facilities, and which includes supports which encourage the participation of communities neighbors and informal organizations; and supports which are developed and funded based on the needs of individuals. <TN>

Coordination assistance or case management services should be available throughout life to all individuals with developmental disabilities and their family members. <TN>

Medicaid restrictions on the financing of home and community-based supports should be removed so that these services can be made available to people regardless of the nature of the developmental disability. The availability of supports to individuals with developmental disabilities and their family members should not be limited to "medically necessary" services. <TN>

Physical therapy and exercise programs should be included in medical programs and insurance coverage. <TN>

The Texas Planning Council recommends the Texas legislature increase funding for and expand the array of communication options for people with disabilities in both rural and urban areas of Texas. <TX>

The Texas Planning Council recommends the Texas legislature pass legislation to establish an information and referral (I&R) system across the State which includes all public and private services and which has an 800 number and resources for regional and/or local access. <TX>

The Texas Planning Council recommends the Texas legislature establish an independent case management system to coordinate services and advocate for the range of assistance needed by all people qualifying for case management services, including people with developmental disabilities. <TX>

The Texas Planning Council recommends the Texas Legislature enact legislation which revises the probate code and ensures the development of an array of effective guardianship options and effective alternatives to guardianship so that people with developmental disabilities will have necessary supports for successful community living. <TX>

The General Assembly should require and provide funding to establish and make uniformly available a statewide Personal Assistance Services (PAS) system of consumer-directed, individualized supports necessary to promote the maximum independence and productivity of individuals with developmental disabilities. This system would provide attendant

services to assist in accomplishing activities of daily living; it would include financial/technical assistance to obtain adaptive equipment, communication devices, and mobility aids which maximize individual funding. <VA>

The General Assembly should establish and make uniformly available throughout the state a system of case management services for persons with developmental disabilities that is independent from agencies which directly fund/provide services. Caseload sizes should be limited to 20-40 persons to allow individualized, consumer-directed services. <VA>

Policies and guidelines must be developed by Commissioners, Directors and other leaders to develop unified policies, guidelines and training for case management. A well-trained case manager or service coordinator should be available to families choosing such an option. There should be alternative options available for others needing different degrees of assistance. <VT>

Aggressively pursue federal and state funding for the Assistive Technology Development Grant. Issues around assistive technology can be addressed appropriately only if people with disabilities who will use the technology are made equal participants in the design and implementation of all activities undertaken as part of the grant activities. <VT>

It's not enough to offer services and support...you must have the resources to deliver them when requested. In other words, access to a waiting list does not mean anything to a person who needs help now! Thus, expanding entitlement to individual and family supports, such as through Medicaid Reform efforts under consideration in the 101st Congress, must be accomplished. <WA>

Personal futures planning for all at-risk children should be a simplified, coordinated process. <WA>

Services and supports for at-risk children and their families should be based on individual need. Terminology and funding should be based on need rather than on arbitrary labels. While the existing system is in place, categories should be broadened and include an acknowledgement of social and emotional needs. <WA>

Case management functions for all children's services should be coordinated. <WA>

Investigate a "service voucher" program where the client would receive a set amount of money to pay for personal support and then shop for providers on the "open market". <WA>

Agencies such as the Division of Developmental Disabilities and the Division of Aging and Adult Services should develop networks which will effectively determine where and how people can best be served. <WA>

Effective networks should be developed between Adult Protective Services and other advocacy groups to ensure that people receive timely and appropriate services. <WA>

Additional funding should be provided to Adult Protective Services to serve existing caseloads faster and more efficiently. <WA>

Older persons with disabilities should be able to access the same services as those offered to other senior citizens. <WA>

Each Area Agency on Aging should be required to provide a written plan of accommodation to serve people with developmental disabilities. They should be required to target this population as part of their funding agreement with the Older Americans Act. <WA>

Information regarding protection and advocacy referral should be accessible and centralized. <WA>

The Foster Grandparent Program should be made available to all people with developmental disabilities. The program must be available and accessible to all individuals who request it, not just to those living in institutional settings. <WA>

People with disabilities and their families should be represented in the decision-making process as developed by the Area Agencies on Aging. This would further the goal of integrating people with developmental disabilities into community senior activities. <WA>

Expand the data collection on child abuse and neglect to include the number of children with disabilities and the number of children who become disabled due to abuse or neglect. <WI>

Disseminate information on the process for becoming a certified, community-based personal care provider under Medicaid. <WI>

Change some of the current state developmental disabilities laws to require designated information and referral systems in each county, individual assessments, service planning, and ongoing service coordination, an effective system for reporting unmet needs to the state, long-term state planning for developmental disabilities, and due process opportunities to appeal to the state level when all local remedies are exhausted regarding the denial of basic community services. <WI>

Establish a statewide program to provide intensive long-term parenting supports, when needed, to families headed by parents with developmental disabilities. <WI>

Helping people be present in the community is only the first step. Some people with developmental disabilities will need additional assistance in forming relationships with

other community members. All service providers should be watchful for opportunities to help the people they serve create relationships with nondisabled people who may be their neighbors or co-workers. In addition, programs such as Citizen Advocacy and Community Guides, designed to recruit individual friends/volunteers for people with disabilities, should be encouraged. <WV>

What is needed in West Virginia is a strategy to enhance the autonomy of case managers that is coupled with a strategy for providing an adequate level of resources through multiple service providers. The findings of this report suggest that independent case management alone cannot resolve the serious resource problems that have been identified. <WV>

What is needed is a comprehensive plan for all people who need guardians in West Virginia. Whenever possible, guardians should be family members or others who have a personal interest in the individual. <WV>

The state should take immediate action to maximize the Medicaid options that currently exist for individualized supports. A Medicaid Waiver application should be submitted and implemented, as soon as possible, for the 143 nursing home residents who have been identified as in need of alternate placements. The state should also pursue expansion of the existing Waiver to whatever extent possible. In order to take full advantage of Medicaid Waiver funding, more staff within the Department of Health and Human Resources are needed in this area. <WV>

Guardianship statutes should clearly provide for the protection of individual rights and flexible alternatives such as public guardianship to fully meet the needs of individuals. <WY>

The data collected by all Wyoming agencies should reflect those served who meet the federal definition of developmental disabilities as found in P.L. 100-146. <WY>

Coordination assistance ("case management") must be available to individuals with developmental disabilities and family members to facilitate arrangements for supports and their monitoring. Sufficient funding must be available to permit small enough "caseloads" for effective help with coordination; additional resources must be available for systems-level coordination. Service providers in Wyoming should convene a task force to assess the creation of such a case management system. <WY>

FAMILY SUPPORT: BARRIERS

Multiple States

Child care is expensive and difficult to find for families with children who experience There is increasing demand for child care and pre-school services from the growing numbers of working mothers in all income groups. <IN,LA,MT,UT>

More and more mothers are working. The proportion of working mothers is expected to reach 68 percent in 1990, compared to 30 percent in 1960. Coupled with the large increase in the number of single parents, this indicates a related increase in the need for family supports, also unmatched by increased availability. <LA,MT,UT>

Family supports tend to provide somewhat more flexibility, such as those available through a cash subsidy program. Overall, however, there is little family input in the design and monitoring of family support programs. <MT,UT>

Although the Medicare Catastrophic Coverage Act included some provisions for family supports (80 percent reimbursement for up to 80 hours per year of in-home care for persons who are "chronically dependent"), basic Medicare coverage reimburses only for services that are reasonable and necessary for the diagnosis and treatment of an illness or injury, and excludes coverage of assistance in activities of daily living. <MT,WY>

There is a renewed national interest in support and preservation of "the family", even as major changes in social mores have redefined the family to include many single-parent families and other arrangements as part of the mainstream. Meaningful efforts to help strengthen and support families, however, have not been developed to correspond to the "pro-family" rhetoric. Families with children are the fastest-growing segment of the homeless population. <ID,LA,MT,UT>

Individual States

One of the most often requested services in Alabama is that of family counseling. <AL>

The gap in day care services often places a single bread winner whose child has an acute problem, such as an upper respiratory infection overlaying a developmental disability, in a jeopardized situation...care for the child at home and risk the loss of a job or send the child to school and risk aggravating the status of the child's health. <AL>

The lack of further requests for family support services relates to the paucity of information that individuals have regarding the nature of services that might be available to them or a family member. Once the interviewee understood the nature of the support service, however, it was often requested, even though the initial response was to the contrary. <AL>

Managing the behavior of some family members with developmental disabilities in the home was another issue of concern. A moderate need for behavior modification services was reported. <AL>

Another need reported was that of day care. With over half of the school age population coming from single parent families or from families where both parents work outside the home, it is not surprising that day care is frequently requested service. A family member with a developmental disability places a burden on his/her care provider. The lack of affordable, reliable, and safe day care, with options both in and out of the home, was a factor some parents commented on during the public hearings. <AL>

Overall, the amount spent nationally to support families pales in face of what is spent on out-of-home alternatives. This holds true in Arkansas as well, given comparison of the resources expended to support out-of-home options with amounts allotted to home centered family support. <AR>

Very few community day care facilities are willing or able to meet the needs of young children with developmental delays. <AR>

It appears from talking to many parents throughout this project that much needs to be done to improve lines of communication among parents, and between them and state agencies and providers. Families have the most to gain and lose when they are the victims of misinformation. This is an area where the role of the Council as an independent advocate could be firmly asserted to ensure that families are not dependent solely on providers or state agencies for information about services and their role in shaping them. <AR>

There is a renewed national and state interest in support and preservation of "the family" Major changes in social mores have redefined the family to include many single-parent families as part of the mainstream. Meaningful efforts to help strengthen and support families, however, have not been developed to correspond with this philosophy. <AZ>

The increasing emphasis on consumer and parent empowerment service practices are coming under increasing scrutiny. Families are becoming empowered. Those that have receive family support services now understand that its effectiveness is both programmatic as well as financial. Even so, there remains no solid commitment to the concept of Family Support within the state leadership or the state legislature. <AZ>

There is a perceived need for more family support resources and for more flexibility in empowering families to maintain their children with developmental disabilities at home. While over half the people served by regional centers could benefit from these services, only about 15% of the regional center purchase of service budget is targeted to services. Of even greater concern is the fact that the Department of Developmental Services has projected a 30% growth in the population with developmental disabilities living at home within the next five years, which will exacerbate the need for these services. <CA>

Tube feeding is one prime example of where a parent can teach a support person to feed the child in a few minutes, but unless the individual is a registered nurse it is unlikely that the individual will be reimbursed for the work performed. <CA>

A total of 159,000 exceptional needs children in California have employed mothers, and at least 80,000 of those need child care. Children with disabilities or exceptional needs are under-represented in publicly and privately funded child care programs, and there is a need for specialized training of day care providers to serve children with medical and behavioral problems. It is estimated that state supported child care programs serve less than 1,000 exceptional needs children requiring child care services. <CA>

There is a need to better educate the train parents to access the support services they require. <CA>

There is a lack of family support resources in California and a lack of flexibility in the service system to empower families to make their own choices. <CA>

Difficulties in obtaining MediCal reimbursement approval for durable equipment purchase, inadequate reimbursement for vendors building specialized equipment, lengthy payment periods, and few vendors willing to produce equipment for MediCal recipients all lead to major barriers for children in need of durable equipment. A MediCal vendor may not receive payment for up to two years after delivering the equipment, and then the reimbursement is often below the vendor's cost of producing the equipment. <CA>

There is a lack of culturally appropriate training in management of their disabled children's behavior. Although the strong family orientation of Hispanics provides a basis for developing nurturing and positive parent-child interactions, specific techniques in behavior management would help these parents deal more effectively with special problems encountered in children with disabilities. <CO>

The average time parents with developmental disabilities need services is about three years. In addition, once the parents have learned good parenting skills and other coping skills, there is a need for long-term follow up. The need is most acute in rural areas, where there are no organized programs or support networks. At this time, the Special Education Services Unit at the Department of Education is developing resources to work

more effectively with these parents. However, the school system serves people only to age 21. <CO>

Of the approximately 600 cases between 1982 and 1985 where the clinic acted as guardian ad litem for children, approximately 200 involved families in which the child was adjudicated dependent/neglected and in which there was at least one parent with a developmental disability. It is estimated that nearly half of these families could have benefited from services similar to those provided by the PACT club. Although it is impossible to determine how many of these families could have been prevented from entering the county child protection system, it speaks to a large unmet need for this type of services. <CO>

Parents with developmental disabilities who have children pose many challenges to the service delivery system. Most of these parents have mild developmental disabilities, and need education and support in order to develop their parenting skills. Although most of these parents themselves would not meet the federal definition of developmental disability, because of their inability to parent satisfactorily, their children are at great risk of having developmental delays. In order to effectively meet the needs of these parents, cooperative efforts among the service providers must be enhanced. <CO>

There is a great need for child care for children with disabilities in order for the parents to get some relief from constant care, as well as child care for other children in the family when the child with disabilities is being cared for by the parents. The disintegration of the nuclear family among Hispanics as they move into urban areas contributes to the need for these services. <CO>

Agencies deny respite care when the agency or the family can't provide back-up help. <CT>

Out-of-home respite care "beds" are difficult to find. <CT>

Agencies are experiencing increasing difficulties in providing the required 50% matching funds due to bureaucratic reimbursement policies, unrecoverable fees, and rising salaries of professionals. Since 1983/84, all statistics for the respite care program have increased, including state appropriations, agency match, the number of families reached, hours of respite provided, hours of respite per family and cost per hour of respite care. This latter costs has risen from about \$5.76 per hour to about \$15.26 per hour. <CT>

Agencies discourage families from requesting weekend respite. <CT>

Agencies regard respite care as secondary to everything else they do. <CT>

Families are refusing respite care rather than undergo a fee assessment and they view respite care as an entitlement. Also, some families refuse to pay the assessment. <CT>

Agencies can't provide transportation to their staff for respite care, particularly during off-peak hours. <CT>

Agencies cannot hire the respite care staff they need due to labor shortages. <CT>

Due to Department/provider agency inability to negotiate a contract \$140,000 of Respite Care funds were unspent in 1987-88. At \$15.26 per hour of service, about 9,174 hours of service were lost, or, at an average of 26 hours of respite care per family, about 73 families were not reached. The demand for respite care is expected to rise. <CT>

The respite care program cannot be used to enable a family to work. <CT>

Too often, parents have not been supported in the 24-hour care they give to their sons and daughters in their natural homes. The stability of families and quality of family life have been undermined by public policy. Public policy has cast stability and quality of life in the form of institutions. Without casting blame on parents, the presence of institutions reflects society's devaluation of persons with disabilities. <CT>

Family support services in practically all communities are inadequate and in many cases inappropriate for most families. <CT>

The child day care program has served 200 to 300 extra children per month during FY'88. The rapid growth in the number of participants can be attributed to a modest increase in the program's eligibility levels implemented in February 1987; expansion of the state's economy; and participation of public assistance clients in employment and training programs as a result of welfare reform initiatives. The added expense of these children has eroded the program's carry-over from one fiscal year to the next. Both of these alternatives are costly. <DE>

In addition to specialized educational programs and services, Delaware's children with disabilities and their families may also need special day care, health care services, counseling, respite care, and summer school programs. <DE>

Access to respite care was cited by advocates and providers as a critical concern, especially for those families who live in the rural areas of Florida. <FL>

Day care/respite care programs should be established on Guam. <GU>

There is a need to provide family cash assistance to assist families of the individuals with developmental disabilities. <GU>

In the focus groups conducted by the State Planning Council on Developmental Disabilities in 1989, some family member participants expressed the feelings that professionals and

the "system" don't trust them. They are made to feel irresponsible as though they are demanding unnecessary services. <HI>

Because of the limited funding for family support services in Hawaii, most programs are able to serve only those families from the lower income groups. Families need family support services, particularly respite care, without respect to their income due to the many demands placed on them. Finances are almost always a problem and those families that don't qualify for Medicaid but who don't have large incomes suffer the most. <HI>

Federal and state governments do not allocate sufficient resources to family support programs and often existing programs are not designed in ways that empower families. <HI>

Funds expended on family support services are minimal compared to the need. More mothers are working. Coupled with the large increase in the number of single parents, the need for support services will continue to increase. Funding does not reflect a state commitment to family support services. <HI>

In all the studies and research done on family needs, the need for respite services continues to be placed as the top priority for parents, advocates, and professionals. Presently, however, respite services are minimal. <HI>

Idaho needs to provide specific educational services for parents, siblings, and other family members with useful information on a variety of areas including: developmental expectations, instructional methods, behavior analysis, health maintenance, consumer education, legal rights and other topics related to individual needs. There is a definite lack of skills training for parents and families in Idaho according to the Idaho Focus Group, 1989. There is a need for extended family support groups for siblings of individuals with a developmental disability. <ID>

The residential support system lacks training and educational services for families who want to keep their children at home. Parents need and want skills training to provide the necessary services to their children. Parents need training in the general development skills necessary to deal with a specific disability, behavioral matter, and crisis intervention situations. The Idaho Focus Group believed these skills should be developed in the home setting. <ID>

The Idaho Focus Group noted that families of an individual with a disability who requires complex medical attention also need respite care services to meet the needs of the individual. <ID>

Along with the need for additional day care for children with a developmental disability, the Idaho Focus Group pointed out that Idaho needs trained staff and financial benefits

for day care providers. Financial resources need to be made available for training day care staff in the proper methods of care for children with disabilities. <ID>

Many families with children who have a developmental disability are opting to keep their children at home. Unfortunately, in-home financial assistance services have not kept pace with this trend. There are no federal funds and only \$10,000 given to each region or \$70,000 statewide from the Department of Health and Welfare, Division of Community Rehabilitation to support this program. <ID>

Parents indicate having difficulties when trying to locate services. A statewide, coordinated system of information and referral available for both parents and professionals would enhance access to services. <IN>

The proportion of working mothers is increasing and, coupled with the large increase in single parents, indicates a related increase in the need for family supports. <IN>

Parents of special needs children often require additional education or training in order to improve their awareness of the problem and to help their child at home. This training can also help parents recognize quality agency programs and become more knowledgeable consumers of children's services. Some particular parent populations may need targeting: teen-age mothers, single mothers seeking employment, and low-income families, for instance. <IN>

Professionals need to strengthen their ability to work with parents as partners. Important aspects of professional/parent collaboration include improving communication, involving parents in decision-making, assuring that an interdisciplinary approach to solving problems that includes parents, and program planning that values the parents' role. <IN>

There is a lack of staff training in social-sexual counseling and in providing support for married couples and parents who have developmental disabilities. <KS>

Adequate and affordable respite care is lacking in all Kansas communities. <KS>

Families need a wide range of supports. Supports needed include: ongoing education and training programs (e.g., behavior management, nutrition, early stimulation, child development), peer support groups, crisis intervention, marriage counseling, job training, budget management, assertiveness training, stress management counseling, education concerning their legal rights, and genetic counseling. <KS>

Married couples and parents who have disabilities need long term supports. <KS>

In Louisiana, the budget for the Division of Mental Retardation/Developmental Disabilities' (DMR/DD) In-Home and Family Support Program increased from \$147,000 last fiscal year to \$423,000 for fiscal year 1990. While this is a 200% increase in funding from

the previous fiscal year, it is still totally insufficient to meet the needs of families in Louisiana. <LA>

The In-Home and Family Support Program in Louisiana is underfunded and does not begin to meet the needs of families with individuals with developmental disabilities. <LA>

Eligibility criteria for the Medicaid-funded Kaileigh Mulligan Home-Care Program are restrictive, resulting in a failure to serve many families in need of home-based support. <MA>

Families and caregivers who need specialized kinds of respite care involving medical or behavioral expertise have few places to turn. Despite the well known serious shortage of services for those populations, a Western Mass. resource used by families throughout the state for medical respite has been closed without alternatives on place. <MA>

Michigan has been considered a leader in support for families with a member who has disabilities. Our Family Support program has been model for service delivery systems in several states. However, if we are to maintain this leadership, legislators must continue to provide enough funding for comprehensive, community-based support for families who want to provide an integrated family-centered life for their family member with a disability. <MI>

Funding and program planning have focused on the child with the disability. Funding for supports for the families of these children has not been redirected or expanded to keep pace with needs. <MI>

Parents who themselves have developmental disabilities have special support needs. Very few programs include special focus on the needs of this population. <MI>

Almost none of the supports for families who are caring for people with developmental disabilities are federal entitlements. Services that are completely funded by the state may be more subject to revenue fluctuations than federal or federal-state shared programs. <MI>

Peer support groups run by parents can be very effective in helping families deal with caring for a member who has a disability. However, these groups need support in training and out-reach. Peer support groups are only effective if families know they exist. <MI>

Local capacities and funding for providing respite care need expansion. Communities must look beyond existing funding sources for creative respite care options. <MI>

Current service delivery practices do not usually include advocacy for family needs or identifying gaps in needed services. Case management rarely includes coordinating access to agencies or acting as agents for systems change. <MI>

The time and effort necessary for families to find the information they need adds to the already strenuous demands placed on families by the special needs of their family member with disabilities. <MI>

Other than the Family Support Subsidy, family support services allocations are not usually listed as identifiable are not usually listed as identifiable line items at either the state or local level. They are considered part of a general community mental health funding allocation. As a result, it is difficult to determine how much is spent for family support, or to track changes in spending. Information about where family support services funds are being spent could inform advocates about equity issues for funding across the state. <MI>

Michigan's Family Support Subsidy has provided important symbolic and financial support to families. However, current eligibility requirements exclude families with children with severe physical disabilities who have no mental impairment. <MI>

Primary caretakers of children with disabilities often must forego employment, career advancement, and educational opportunities to remain home and care for their children. <MI>

Many families worry about leaving their children with disabilities in child care, because they are not certain that their children's special needs will be met adequately (i.e., they are concerned about the training of the day care staff). <MI>

Fiscal incentive to state and county authorities is toward the Medical Assistance program and not toward family support services. <MN>

A commitment to permanency planning means supporting families to whatever extent necessary to avoid out-of-home placements, to returning children and youth to their homes as soon as possible, and to never acquiescing to institutionalization. Permanency planning has not been practiced by Missouri's Division of MR/DD. <MO>

Creative ways of funding individual family support services such as vouchers, subsidies and tax credits, are being tried in various states across the country. Missouri needs to continue to address the difficult economic realities of how to finance family support services both in traditional and creative ways. <MO>

Families with children with disabilities continue to need information about disabilities and the fragmented system that provides them with services. Information and referral services are particularly needed by parents in the early childhood years and in the secondary years as children begin to reach the age when they will be leaving the more coordinated, mandated services of special education and move into the more fragmented adult service world. Ways to bridge the information gap between older more experienced families and the younger families just entering the race, demonstrate the need to foster

family support groups, to develop more parent advocacy and training groups such as MPACT, and to expand discrete training initiatives. <MO>

Respite services, although available throughout the state, continue to be a needed service that is underfunded. <MO>

Family support services, although moving in the right direction with the Divisions of MR/DD's and CPS's new emphasis, continue to be needed by many families and individuals throughout the state, especially by those families who have never received any services. <MO>

Access to respite care for persons with developmental disabilities is more restricted than it is for persons who elderly and those with other kinds of disabilities. Respite care for persons with developmental disabilities is generally limited to fifteen hours per month, 180 hours per year, and is generally restricted to persons with a primary or secondary diagnosis of mental retardation, while respite care for others has no such limit and is in fact provided on the basis of individual need. <ND>

Limited availability of trained and competent respite care workers is often cited as a primary reason for respite services not being available in a timely and consistent manner for all persons who are elderly or have a disability who need such services. Lack of adequate funds to support such training contributes to the scarcity of proficient respite care providers. <ND>

Federal Title XIX Medicaid funds cannot be used to support respite care training. <ND>

The \$5.00 to \$8.60 hourly rate for respite care services has become prohibitively expensive for many families and individuals, even for those who are eligible on the basis of income/means testing to have the state assume a share of the costs. As such, many families and individuals who legitimately need respite care choose not to access such services. Besides being a disincentive to access, high hourly rates reduce the overall amount of funding available, which in turn erodes the number of individuals who can be served within a restricted respite care budget. <ND>

Families are the primary caregivers for many persons with developmental disabilities regardless of age. The survey indicates that families feel they provide needed services yet wish supports and services to be available when needed. Families are experiencing pressures and stress from both within. The supports of extended families are less available and single parent families are not uncommon. In many cases both, parents may work outside the home. In these situations, the care of a family member who may need continuous supervision or have high medical needs becomes a major problem. System issues also may adversely impact on the family. Lack of resources in rural areas may encourage families to move to urban ones, which may separate them from family members who could provide support in many ways. Family resources may be too high to qualify for

most support services. The actual lack of support services was a greater concern to most survey respondents. There are simply not enough supports in their communities to assist them when needed. Respite is the most frequently stated family support issue. It consistently shows up as a strong need but is not always available. <NE>

Families reported difficulties in obtaining information and a lack of coordination among service providers. <NH>

A high level of consumer satisfaction was evident with the quality of early intervention and family support services. The major source of dissatisfaction was with the quantity of respite and other family support services available, not the quality. <NH>

Some parents report being told that they must find their own providers of respite care. Respite rules require agencies to first assist a family to develop its own provider contacts and networks, but then assign that responsibility to the respite agency "in the event that the family does not identify a potential respite provider" (He-M 513.04(b)). Some families report never utilizing their respite "quota" because of an inability to recruit providers on their own. <NH>

A back-log of requests for respite so great that families must make any plans months in advance. For example, several families were unable to attend the Council's Community Meeting because, with three to four week's notice, they were unable to obtain respite care for an evening. <NH>

Difficulties in obtaining providers who have the necessary training to meet the special needs of some children; for example, responding to a seizure or changing a catheter. Some families report that they "cannot get qualified people to do respite." <NH>

One of the most critical times for parents to receive information is when they first learn of their child's disability. Parents frequently find that doctors and hospital personnel know very little about disability, that the information they are given is out-of-date, or that each medical specialty focuses on only a part of the person, without a focus on the whole person or the family. <NH>

Lack of access to information about services and programs was a consistent theme at the Council's Community Meetings. One parent explained that "I should have information about services on hand and shouldn't have to call 20 people to get it." <NH>

Of women with infants under 3 in 1986, more than 50 percent held jobs. Seventy percent of all the infants and toddlers in out-of-home care were in unregulated family day care. As many as 250,000 elementary school children in New Jersey are left alone while their parents work. <NJ>

Parents of children with disabilities require child-care services. Since that industry has not kept pace with the concept of mainstreaming, the child-care needs of parents with children with disabilities go unmet. <NJ>

In areas where respite care is available, the number of hours were too limited. In most cases respite care was not provided in the consumers home or a homelike atmosphere which added to family and consumer anxiety. <NM>

Parents voiced concern that families that had placed their children in institutions received a "package" of services when they leave, while families that kept their child at home were forced to seek their own supports from a variety of limited and uncoordinated sources. <NY>

Parents seeking respite in some regions of the state are limited in choices to those agencies serving people with development disabilities. They feel that they could utilize other sources in the community, such as neighbor, relatives and friends, if there were mechanisms to reimburse them. <NY>

An additional problem is that the Family Resource Program of the Ohio Department of MR/DD provides funding for support services in only a limited number of categories. There is also clear evidence that the program is not uniformly administered in counties across the state. <OH>

Parents of children with developmental disabilities in Ohio currently are not entitled to receive support services. In fact, formal support services are a relatively new idea so few resources are allocated and many families go unserved. For example, while most of our community-based services are of benefit to families and even though there have been substantial increases in Family Resource service funds, in 1988 the Ohio Department of MR/DD and the County Boards of MR/DD spent less than 1% of their combined budgets on direct support to families. <OH>

Current delivery of services tend to supplant natural support systems rather than build on the family's natural strengths and supports. <OH>

In 1988 only slightly more than \$4 million in state funds were allocated by the Department to the Family Resource Program to serve all the families in Ohio that were trying to keep their children with disabilities at home. Compare that the budget of one ICF/MR that served only 104 children yet had an annual budget of over \$4.5 million. The point is not that the ICF/MR program was provided too much money - it is simply that more funds were used to serve 104 children in one facility than was allocated for the state's major family resource program which is responsible for providing support services to thousands of families. <OH>

It is unlikely that it is practical for state government to establish a network of respite care services on a state-wide basis. Communities will be required to establish alternative care sites, meeting specific local needs, with local resources. State funds and leadership will be required to initially establish centers with volunteer services at churches, hospitals, nursing homes and other organizations. <OK>

Developmental disabilities cover a broad range of mental, physical and emotional characteristics, occur in various stages of intensity and complexity, and in all age groups. Current organizations of private day care centers are not equipped to assume the responsibilities for children with developmental disabilities. There are few places where adults with disabilities may be placed for short periods of time. In short, organized respite care is not available to Oklahomans due to lack of trained staff, associated cost, and scattered volumes of clients that preclude economical market sizes. <OK>

Family support is not generally available for families raising children with other than retardation disabilities. An additional state supported program is needed for these children and for children with severe emotional disturbance. <PA>

Need for family training for dealing and managing their members with autism. <PR>

Lack of emotional support and respite services for families which include members with a developmental disability. <PR>

Establishing a statewide family support program is a complex programmatic task and one which should involve families in the service planning. <SC>

There is a natural reluctance to expand family support services due to the scarcity of fiscal resources. Advocates of family care argue that all parties would benefit if families were supported. <SC>

Strong parent leadership in South Carolina is needed. If parents were organized into advocacy and support groups they would develop invaluable informal support networks. <SC>

While these gains are hard to measure, policy should reflect a strong commitment to adopt a statewide family support program. <SC>

Concerns were expressed that families are left to their own devices in terms of coping with the demands that a son or daughter with developmental disabilities might pose. The review of current programs in South Dakota failed to turn up any program that might be viewed as a comprehensive, integrated strategy for extending a full range of family support services to a broad-based population. <SD>

Closely related to the concerns about the scope and quality of early childhood programs is the lack of family support services that often play an integral role in assisting a family to maintain its son or daughter with developmental disabilities at home. One individual noted that only very limited respite care services are available and then, in only a few parts of the state. <SD>

Discussions with the parent of a child with developmental disabilities in a family on one of the reservation areas brought to the fore the obstacles faced by Native Americans in obtaining needed services for their sons and daughters with developmental disabilities. It was clear, based on this conversation, that little support was available to the parent, either through the provision of direct services or assistance in obtaining such services. The family faced the prospect of having to leave the reservation to relocate to a city where services might be available. <SD>

Families state they are often unable to find out about or gain access to services because of the bureaucratic maze they must negotiate. They state they are often frustrated, tired and feel hopeless because they cannot get the services they need. <TX>

Families in Texas are unable to find child care for their children with disabilities. Parents generally stated there are no day care centers in their local area which will accept their children, even if parents are willing to pay the additional costs of providing care for their child. <TX>

During informal conversations at the 1990 Report public forums, parents frequently complained about professionals' lack of knowledge about developmental disabilities. One parent stated she did not know her child was born with Down Syndrome until several months later. Her physician had not told her. When she confronted the physician, he stated he had not told her because he did not feel it was necessary and he did not know enough about Down Syndrome to inform her of what services the family would need. <TX>

If family support monies were not funded with straight state funds, Utah would be able to expand its support programs and serve a much wider cross-section of the population. If the number of people served under the waiver were increased greatly, the state could expand the family support services without requiring additional state dollars. Limited resources force the state to make choices about who will be served by Medicaid funding and results in restricting the availability of state assisted programs to a minimum. <UT>

Working mothers of children with disabilities require a unique type of family support services that help with after school child care and summer programs, on a consistent basis. These services are not offered in the generic system because child care providers do not have experience with children with disabilities and will not take them. <UT>

A relatively new area of concern in Utah is a population of infants whose lives have been saved and continue to rely on medical technology. Regardless of outcome, parents and families need intensive support during the technological dependency period. Many will require medically trained persons that are not currently offered by Social Services. Because many of the children will not have a permanent disability, there is a question as to which agency should appropriately provide the service. Regardless of designated responsibility, there are an estimated 2,400 parents and 1,200 families, who have "high tech kids" with virtually no outside assistance for support or respite care. This is another example of a new phenomenon evolving so quickly that the system has not caught up with the problem. <UT>

One of the participants in the Utah focus groups pointed out that she had to pay someone \$4.50 an hour to tend her autistic child while she earned only \$5.00 an hour. She said it seemed futile to work because she could not keep up with the costs incurred by her son's disability. <UT>

One of the most commonly cited forms of needed family support is that of respite care, or temporary supervision of their family members. <VA>

Development of a comprehensive system of Family Support Services is a very frequently identified need. Families of individuals with developmental disabilities (including single parent, adoptive, and foster care families) need to have access to a system of supports which will allow them to remain intact. These supports may include financial assistance, respite care, training and behavior management consultation, in-home adaptation and barrier-free modification, transportation, and adaptive equipment. The specific forms of family support provided should be determined by the family itself. The unavailability of these services has resulted in the out-of-home placement of many individuals whose families were willing for them to remain home, but were unable to provide them with the necessary level of support. <VA>

The need to increase family support services and remove disincentives for families providing in-home supports. <VT>

Traditionally many families have turned to the service system for answers to the risks they face. Yet often they find only a system that lets them down. The ability of service systems to meet the pressures facing families today is limited. <WA>

Adoption support and assistance programs are based on eliminating barriers to placement but...there is a catch 22. Assistance is only available if a couple or an individual asks for help at the time of adoption. However, a true picture of the child's special needs may not be evident at the time. Years later, when the child's more severe need may become apparent, the family is barred from getting the financial help they need. Contracts are needed which are flexible and allow for future recourse. <WA>

Few families who have children with developmental disabilities are able to pick their way unaided through the maze of bureaucracies (also known as "the system"). All too often the bureaucratic "helpers" become gatekeepers and the message parents often hear from these "helpers" is "No!" <WA>

Parents often express frustration with the lack of accessible information. They recommend establishing an information center that will make program information, factual publications and newsletters easier to find. A logical place for parents to receive information would be through their case manager but — as case managers can barely keep up with an overburdened system as it is — information and referral often take a back seat. <WA>

Families often must deal with several case managers acting in behalf of different agencies in order to obtain a comprehensive set of supports. This leads to confusion for families and inadequate or inappropriate services for children. <WA>

Different eligibility requirements and various definitions of the term "developmental disabilities" can create confusion for both staff and families. Sometimes, this reality can increase program flexibility but, in many cases, it has the effect of decreasing accessibility. <WA>

When a family is struggling to meet its basic needs, there is little time, energy or resources left for dealing with other problems. If people find themselves unable to fulfill their own psychological, emotional and financial needs, they may find it difficult to make healthy decisions concerning their children. This is where the community and family support can make the difference. <WA>

Current Family Support Programs are funded at only 45% of the total amount needed to serve all who have indicated a need for Family Support services. <WI>

Waiting lists for the Family Support Program more than doubled between 1986 and 1988. <WI>

Although West Virginia has been successful nearly eliminating the institutionalization of children with developmental disabilities we have been far less effective in supporting children within their natural families. Among the small number of families who were receiving respite care or other types of support, many were dissatisfied with the services they received. Larger numbers of parents reported that they needed, but did not receive, family support services. <WV>

Many community programs, due to insufficient funding, are forced to limit the number of people they serve or the level of service provided. <WV>

Finding appropriate day care is a problem for many families throughout the state. As of 1988, thirty-three counties had no licensed day care for infants and toddlers, and thirteen counties had no licensed day care centers at all. Families who find day care may not be able to afford it. The average cost of child care is \$2,392 per child per year, or one-third of a family's minimum wage income. <WV>

FAMILY SUPPORT: RECOMMENDATIONS

Consumers and advocates should work at the local level to increase the capacity of local child care centers to serve children who experience disabilities. <AK>

The Alaska Department of Community and Regional Affairs currently offers grants for training child care workers in various skills, including with children who experience disabilities. The Department should expand these efforts to include funding of specialized equipment, low interest loans for renovation to child care facilities to improve accessibility, and methods of supplementing the salaries of child care workers who acquire specialized skills for working with children with disabilities. <AK>

The Governor's Council should work with the Division of Medical Assistance and the Division of Mental Health and Developmental Disabilities to develop a family subsidy program to provide financial assistance to families to purchase and maintain needed adaptive equipment, home modifications, and specialized resources. <AK>

Supports to families which include a member who experiences a disability should be designed to meet individual needs and emphasize supports that involve families in the design, implementation and monitoring of family support systems, and that reinforce the primary role of families in providing care and support. <AK>

Family members and other primary caregivers must be given both tangible and intangible supports before they exhaust their resources (e.g., physical, financial, or emotional). Examples of support that must be given in a timely manner are counseling, respite care, cash assistance, architectural modifications, protective and legal, and other resources and services that would allow the family to function. <AL>

Mandate family support for increased general revenue funding in order to meet the documented needs of families on waiting lists for this service. Family support is a proven service option that is consistent with strong Arkansas values of commitment to one's family and should be available for both adults and children. This service should take the form of highly individualized, family-driven support. <AR>

While this cannot be done wholly under Medicaid, Medicaid funding can play a complementary role by funding selected family support services such as TEFRA, EPSDT, case management, transportation and home health care. <AR>

Develop initiatives designed to maintain and enhance family caregiving especially for children with disabilities. <AR>

Create a special DD Planning Council task force to study the relationship between private and public sector supports and prepare a detailed report with recommendations for change to be submitted to the Council for action. For instance, there is a need to examine insurance issues that affect financing of services for persons with disabilities and their families, specific issues include health insurance, life insurance and liability of community respite care providers. <AR>

Establish service goals; then develop funding strategies. For instance, family support is a culturally desirable and economically efficient service option that has been demonstrated to be effective. The fact that some of the basic program may not be able to be financed under Medicaid should not lead to a decision to eliminate family support. This is important since even though the basic program may not be covered under Medicaid, there will be Medicaid-eligible individuals in the program for whom selected services will be reimbursable, thus defraying the overall cost of the service. <AR>

Family support services must be available for families of children 0-5 as well as older children and adults served by DDD. These services are essential to the family in addition to school programs. A plan must be developed to inform the public and the Legislature of the need to continue these services. <AZ>

Training and education should be available for parents to better enable them to understand and access the service system and obtain needed services for their children. <CA>

A voucher system should be piloted which would empower families to purchase their own support services. A greater emphasis must be placed on the use of regional center purchase of service money for in-home and family support needs. <CA>

Advocate the development of a comprehensive system of family support services for families with children with developmental disabilities. <CO>

The Department of Mental Retardation's family support "pilot program" must become an established program within the Department with a substantial increase in funds. In addition, a similar program must be made available, probably through the Department of Human Resources, to families with children who do not have mental retardation. <CT>

Family support must be permitted to be used with Aid to Families with Dependent Children, Day Care, Respite, Medicaid (Title XIX), Essential Services, State Supplement and other public assistance. <CT>

Merge the Department of Human Resources Parent Subsidy Aid Program into the Family Support Grant Program at that Department. Transfer the dollars for the Community Nursing Respite Program from the Department of Health to the Department of Human Resources (the designated lead agency). Increase access to this respite program by using

less stringent provider criteria, as in the model presently used by the Department of Mental Retardation. <CT>

In order to ensure a flexible responsive system of services which is sensitive to family needs and values, the Connecticut Coalition for Families supports an increased allocation of funds for staff development and training in those agencies serving families of children with special needs. Training should include such topics as family systems, empowerment, case coordination, assessing services and funding and reimbursement. <CT>

It may be necessary to abandon the respite care program as it is presently configured, transfer state funds to the Department of Human Resources, and use the state funds for a family support program that gives the funds directly to families to use as they see fit to acquire the in-home or out-of-home support they need from whomever they want. <CT>

Increase the Department of Mental Retardation Family Support Grant Program; increase the Department of Human Resources Family Support Grant Program; and ensure continued financial and administrative support for both programs. <CT>

Any definition of community or habilitation services in Medicaid reform must be broad enough to encompass the array of necessary family supports which must be individualized, family-centered and flexible over time. Medicaid reform must also mandate the waiving of the deeming of parental income for eligibility for family support as it does for institutional services in order to remove another aspect of the "institutional bias" of Medicaid. <CT>

In order to maximize federal dollars for family support, expand the Home and Community Based Model Waiver (Katie Beckett) administered under the Department of Income Maintenance from its present fifty slots, to the allowable two hundred slots. <CT>

Family subsidies must be based on monthly Supplemental Security Income available to adults who have disabilities and live with their families (i.e., \$236 per month) for an annual total grant to families of \$2,832. <CT>

Expand and develop an informal system of supports, including parent to parent supports, dissemination of information to local communities, and development of a public awareness campaign to increase private support for these initiatives. Allocate \$100,000 to the Connecticut Coalition for Families of Persons with Disabilities, Inc., to facilitate the expansion and development of this system. <CT>

Expand the two formal respite programs in Connecticut - one through the Department of Mental Retardation, and the other presently offered through the Department of Health Services. <CT>

Eligibility must be based on a functional definition of disability, thereby tending to focus the program on families with children who have severe and multiple disabilities, but eligibility must not be tied to verification of the prevention of institutionalization or removing someone from an institution. <CT>

Delaware needs to provide additional day care, counseling, health care services, and respite care for children with disabilities and their families. The Department of Public Instruction should look toward the development of specialized summer school programs for children with disabilities. This will provide not only respite for families, but also continuity of educational experiences throughout the year for the child with a disability. <DE>

Establish more day care centers. These centers should be jointly funded by arrangements between business, the state of Delaware, and working parents, and staffed by individuals trained in early childhood development. The centers should be located near business premises to encourage parents to spend time with their children, and thus strengthen the family. Unused school facilities should be considered for use in order to reduce costs. The increased availability of specialized day care for children with developmental disabilities along with highly trained staff will ease day care burdens and provide the important respite these parents require. <DE>

State agencies need to work closely with families to identify the specific assistance needed. Services to families must be specific for each family's needs, and support families in their efforts of self-empowerment. <GA>

Expand respite care. Respite care is a critical need for families and should be available to all families. <GA>

Increase family support services. <GA>

The Council recommendation is to investigate and establish an Adult Day/Respite Care program for the purpose of determining the feasibility and cost associated with these services. <GU>

The Council recommendation is to investigate federal and local funding sources for family cash assistance. <GU>

The State of Hawaii should support and enhance families by assuring that the necessary supports are available to keep families together. The State Planning Council on Developmental Disabilities should make family support services, particularly respite, a high priority and will advocate for additional funds. <HI>

The family support service made available should be determined by the family. <HI>

Protocols should be developed for criteria on family support services. A committee made of at least 75 percent consumers and/or family members should be coordinated by the State Planning Council on Developmental Disabilities. <HI>

The Governor, state legislature and department heads should make a firm commitment, backed by resource allocation, to family support services. <HI>

The Department of Health's Developmental Disabilities Division should expand respite programs and facilities on Oahu, Maui, Kauai, and Hawaii (Hilo and Kona) by December 1990 and establish respite services on Molokai and Lanai. <HI>

Clarify HCB waiver policy to eliminate the possibility of misinterpretation of the sort that, for example, results in current Iowa employee manual information that recommends giving preference to families on the basis of the perceived care-giving skills of family members. <IA>

Life-long family support services for families with a member with developmental disabilities, including severe mental illness, should continue to be supported in state and federal policy and funding. Family support should include, but not be limited to: financial assistance, respite (in-home and out-of-home), training in future planning, information and referral, and other services found to be effective in supporting families who desire these services. Family support services should recognize cultural differences among families. As a beginning, the Council recommends that Articles II and III of the Developmental Disabilities Services Implementation Plan Act (HB 69) should be fully funded and implemented in future years. <IL>

Income tax laws shall be restructured to permit tax credits and write-offs to defray the cost of care for people with a disability, regardless of family income. <IN>

Indiana shall unify its multiple case management systems to provide coordinated, family-centered, and locally available service. <IN>

The Division of Mental Retardation/Developmental Disabilities should quadruple its current In-Home and Family Support Program funds by 1991. <LA>

The Office of Human Services should establish a cash stipend program in addition to the existing In-Home and Family Support Program (reimbursement for purchase program), with limited administrative overhead. <LA>

The Department of Social Services and the Department of Health and Hospitals should coordinate and expand respite services through state and federal funds. In addition, agency respite services should be expanded to include families with children who have severe emotional problems and behavioral disorders. <LA>

The Office of Human Services should provide in-home training and technical assistance to families who have family members with severe disabilities living with them. <LA>

Be wary about imposing sliding fee scales, co-payments, or other charges for vital support services. The Developmental Disabilities Council opposes charging families with a member with a severe disability at home for respite care. <MA>

Support efforts to coordinate with day care to increase opportunities for integration of children with special needs. <MA>

Designate a specific state agency (e.g., the Mass. Department of Mental Retardation or some other agency) as the primary funder of family support services. Those with special health care needs should receive family support services from the Mass. Department of Public Health. <MA>

Establish a statutory entitlement (i.e. legal right) to an array of family support services (e.g. respite care, cash assistance, tax breaks) for all families supporting a member with one or more disabilities. <MA>

Secure a priority for support services to families of children and adolescents with developmental disabilities to prevent out-of-home placements and to foster positive family life. <MD>

Conduct research funded by the Department of Health and Human Services on the long term financial, psychological, and social impact on families of caring for child with complex medical needs in the home, to guide future family support policy. <MD>

Expand availability of day care services for children with disabilities by increasing the incentive of the two dollar/day funding differential for day care providers who serve these children and by mandating that a certain percentage of day care openings be set aside for children with disabilities. <MD>

Expand training for respite caregivers. Explore an approach similar to the "registry" of trained paraprofessionals being piloted through the Office on Aging to enable families to access trained caregivers with minimum bureaucratic red-tape. <MD>

Investigate utilization of Medicaid funds in the adoption subsidy program. <MD>

Institute more uniform policies and language regarding foster care and adoption in the court system and state agencies, enabling the state to qualify for increased federal Title IV-E funds. <MD>

Place highest priority in adoption and foster care services on the timely delivery of services that result in stable living situations. <MD>

Medicaid reimbursement policies should be reviewed to determine to what extent definitions of eligible services and providers can support families in addition to individual children. The Interdepartmental Medicaid Plan for Children and Families should specifically address the degree to which Medicaid priorities can be supportive of families. <ME>

Expanded child care options through the Child Care Investment and Security Act or similar measures with specific references to children with disabilities. <ME>

The availability of child care for children with disabilities should be strengthened. The Office of Child Care Coordination should, in cooperation with the Interdepartmental Coordinating Committee for Pre-School Handicapping Children and the Bureau of Children with Special Needs, review existing publicly funded child care programs. The review should determine barriers to child care for children with special needs and the resources necessary to provide adequate integrated or special child care programs. This analysis should, in recommendations to the governor and legislature, provide for those resources necessary to assure availability of this important family support service. <ME>

The Michigan Department of Mental Health, with legislative support, should expand respite care capacity in the state. Respite should be available to help families caring for family members with developmental disabilities, regardless of age, and with special attention to the broad definition of developmental disabilities. <MI>

Every Community Mental Health Board should maintain capacity to provide emergency respite care in addition to, and without diminishing funding for regular, ongoing, in-home and out-of-home respite care. Every Community Mental Health Board, in future needs assessments and Program Revision Requests (PRRs), should document any need for additional funding for emergency respite services, in addition to regular in-home and out-of-home respite care. <MI>

The Governor should direct the Human Services Cabinet Council, through the Departments of Mental Health, Social Services, Public Health, and Education, to develop initiatives to assure that parents who themselves have developmental disabilities can get the supports they need to function as independently as possible as parents, family members, and citizens of their communities. <MI>

The Michigan Department of Mental Health, with legislative support, should establish a pool of funding that Community Mental Health Boards can use to help provide emergency respite care services beyond their anticipated needs. <MI>

Regional Interagency Coordinating Committees (RICCs) and other advocacy organizations and agencies should encourage and help local groups to build local, consumer-driven coalitions that would develop creative alternatives for providing in-home and out-of-home respite care services. <MI>

The Michigan Department of Public Health, with legislative support, should expand its scope of services and funding to include increased respite care and supportive home care for families with children who have developmental disabilities who are not eligible for mental health programs. Expansion should include appropriate training for respite care providers in meeting the needs of people with physical disabilities. <MI>

The Governor should direct relevant state agencies to expand, refine, and clarify client services management and advocacy policy to recognize the family-centered nature of the service; the family's role as caretaker and nurturer of the person with developmental disabilities; that family members may, and do, sometimes differ from service providers in their perception of which services are needed, and that their preferences, if in the best interests of the child, should be honored; and families' needs for a range of intensities frequency of flexible supports. <MI>

State client services management and advocacy policy also should recognize the need to offer peer support services, life planning, and transition services to families and to involve family members and friends/advocates identified by families, who should be invited and assisted to participate in service planning meetings, and the role of the client services manager as an advocate for the needs of families, recognizing the importance of family involvement in client services management. <MI>

The Human Services Cabinet Council should convene a task force to develop criteria that will expand eligibility for the Family Support Subsidy to families with children who have severe physical disabilities but are not eligible under current law. The task force should also develop estimates of the potential costs and impacts of expanding eligibility. <MI>

Local community mental health agencies, school districts and parent advocacy groups, the Department of Social Services, child Care Coordinating Councils (CCCCs), and Regional Interagency Coordinating committees (RICCs) should work together to develop a plan of action to increase the availability and accessibility of integrated child care, with appropriate supports, for families with children who have developmental disabilities. <MI>

The Michigan Developmental Disabilities Council should fund a third baseline study of family support services. <MI>

The Department of Mental Health and Community Mental Health agencies should collect demographic, budget, and services information about families that identifies specific expenditures for family support services. <MI>

Life-long family support for all families who have a member with developmental disabilities should be made available. Family support should include respite, financial assistance, emergency and shelter care for adult consumers, and other supports found to be effective in assisting families. <MS>

Estate planning and counseling for families wishing to plan for their relatives' futures should be made available. <MS>

Integrated child day care services must be increased, adapted and individualized to meet the needs of children with disabilities. <MT>

Development of family self-help support groups which adequately meet their needs should be encouraged and supported. <MT>

Behavior management assistance or training should be increased, with services adequately staffed with skilled professionals to meet the demand for such assistance. <MT>

Support services for families of children with disabilities, including counseling, group therapy and communication strategies, need to be instituted or expanded. <MT>

Family-focused programs need to be more closely aligned with existing school services. Specific features could include peer or sibling tutoring, respite training for neighbors or friends, summer education and recreation programs. <MT>

The Council recommends that the recommendations of the North Carolina Interagency Coordinating Council as presented in its 1988-1989 report to the Governor, "A New Day for Young Children with Handicaps and Their Families", be implemented. <NC>

Affordable, reliable respite care must be provided for families and other caregivers. The Council recommends that the Department of Human Resources ensure that quality community-based respite care services for persons with developmental disabilities be made available within all 100 counties by June 30, 1993. <NC>

DHS should revise its administrative requirements to remove service hour limitations from respite care enjoyed by persons who are elderly or who have other disabilities. Regardless of disabling condition, DHS administrative rules should uniformly promote equitable provision of respite care services on the basis of individual need. <ND>

DHS administrative requirements should in actual practice acknowledge North Dakota's statutory definition of developmental disability and permit access to respite care services by DD persons other than those with mental retardation. <ND>

DHS should solicit consumer input in revising respite care services as part of its development of the proposed new family support program. <ND>

Providers of respite care services such as Easter Seals should be encouraged to proactively market and provide such services to families and individuals other than those who qualify for state funding support. Such broadening of respite services may decrease the overall

\$8.36 hourly cost of respite care, particularly administrative overhead costs which are included in this hourly rate. <ND>

Should HCFA continue to disallow respite care training costs under Title XIX, state funding options should be explored, and the DD Council should be considered a potential temporary source for such funds. <ND>

The DHS Developmental Disabilities Division's sole source contract with ND Easter Seals for provision of respite care services for DD persons should be opened to competitive bidding upon expiration of the current contract. The DD Division needs to determine if other entities such as county social services, home health agencies, nursing services, hospitals, other care providers, etc. can provide respite services at less cost. <ND>

At a minimum, respite care training should be offered on a periodic basis and should emphasize competency-based testing to assure there is an adequate supply of proficient respite care workers across the state at minimal cost. In order to assure that training competencies are realistic, the training curriculum should be developed jointly by DHS and respite care provider agencies. <ND>

A respite care system must be developed on a statewide basis. Providers should be adequately trained and supported. Funding stipends for families should be made readily available. <NE>

Assessment of family satisfaction with services should be conducted by means of in-home interviews with a sample of families as a regular part of quality assurance monitoring of contracts with Area Agencies. <NH>

Outreach campaigns should be ongoing in each region to inform families about the scope and availability of family support services, through hospitals, pediatricians, day care centers and schools. <NH>

Families rely upon respite services as a supplement to their own local resources. Therefore, in addition to encouraging and assisting families to solicit respite providers from within their natural social networks, a pool of qualified and trained respite providers should be available in each Region sufficient to meet the need for respite services. Respite provider rates should be maintained at a level competitive with similar community services. <NH>

A flexible array of services should be available to the families of children with a developmental disability, including both in-home and out-of-home respite care, family counseling, behavior management and skill development instruction, adaptive equipment assistance, and so forth. Maximum flexibility and control in determining the type, amount and source of support should be afforded to families. New funding mechanisms which maximize family flexibility and control should be explored. <NH>

It is recommended that alternate routes be developed to determine eligibility for state family support services, particularly when single services are requested, including presumptive eligibility, streamlined eligibility, and temporary eligibility. <NJ>

It is recommended that the state ensure flexibility in services provided by contracted agencies. <NJ>

It is recommended that stable and expanded funding sources be developed to continue services that promote independence, productivity and community integration. <NJ>

Services should be equitably available, not dependent upon when an application is submitted or what is needed. The development of new or expanded services should reflect input from case managers and parent/consumer advisory board. <NJ>

It is recommended that working parents have access to high-quality day care, regardless of family circumstances or the disabilities of their children. <NJ>

Extensive professional and public education must be provided not only about the nature of the less well known disabilities but about the role of professionals and other community groups in helping families to get the supports they need to live in and contribute to their community. <NY>

Supports offered to families should be flexible and provide the assistance required for a person with developmental disabilities to make informed choices, including help in determining what supports are required to implement the choices. <NY>

Workers providing in-home family supports should be adequately compensated and receive specialized training to meet the needs of individuals with severe or multiple disabilities. <NY>

Identify and accommodate exemplary approaches for the provision of support services to minority and ethnic families. <OH>

Implement a study to identify strategies to make typical day care services more accessible to children with developmental disabilities. <OH>

Implement more effective strategies for involving private industry in family support issues (i.e., employers assisting employees with day care). <OH>

Provide parents with training, information, and facilitate the development of parent support groups to assist families in learning more about their rights under state and federal laws. <OH>

Implement a publicly funded, fully independent case management system to assist all families of children with developmental disabilities in their dealings with the service system. The primary role of case management should be to support parents in their interactions with the service system, assist them in coordinating services, and in advocating for their children and themselves. <OH>

Increase the funding for the Ohio Department of MR/DD's Family Resource Program. The program should also be revised to broaden the eligibility for services, increase a direct financial subsidy to families with children with developmental disabilities to help them purchase whatever they need to enable their child to live at home, and develop specific guidelines for service coordination which place a clear priority on family control. <OH>

Pass state legislation to make access to family resource services an entitlement for families with children with development disabilities. <OH>

Develop a readily accessible system for providing parents with information about services, referral to services, and how to contact other parents. Such a resource should be parent managed and tied to an independent case management service system. <OH>

Enact legislation to provide financial incentives, training, and ongoing fiscal and service support to families that adopt children with developmental disabilities. Foster families should also receive similar fiscal and program supports. <OH>

Organized respite care is the fundamental cornerstone of a family support system and a strong family support system is a primary recommendation of this report. <OK>

The needs addressed by the Family Assistance Fund may include respite or day care services, purchase of educational apparatus, special transportation needs, home modification, self-help project start-up, one-time cash assistance and other similar services developed by the Family Assistance Fund policy board. It is proposed that this Family Assistance Fund be established as a matching fund with the state of Oklahoma and private vendors/foundations participating at 50% each." (OK)

A separate service area of family support should be established and funded with both current and new programs for families consolidated within it. <OR>

Historic sites and museums should also be made accessible. Barrier free training is available and has been done creatively by the National Trust for Historical Preservation. <PA>

It is proposed that the Department of Social Services shall be responsible for developing and promoting support and respite services for families with a member with developmental disabilities. <PR>

Services will focus on supporting families and will provide alternative families when the birth family is not available. <RI>

If family centered care is to flourish then the design of services should be responsive to families and should seek their input as to when and in what ways they need services. <SC>

Expand policy for providing extended care, day care, and respite programs. <SC>

Tax credits need to be expanded for families who provide care for their severely involved children in the family home. <SC>

Develop and implement a statewide family support policy that will provide supports to families (in the least restrictive environment) enabling them to assist family members with a disability to reach their maximum potential. <SC>

Over the next two years, the state should initiate steps to create a family support program. <SD>

The Texas Planning Council recommends the Texas Legislature create incentives for child care for families of children with developmental disabilities. <TX>

The General Assembly should support the establishment and maintenance of local or regional family support resource centers throughout the state. These would provide centralized information about and referral to local and regional programs and services for persons with developmental disabilities, planning and problem-solving consultations, counseling and specialized training for family members and/or primary caregivers, and respite services. <VA>

The General Assembly should require and provide funding to establish a multifaceted system of Family Support Services (FSS) to be uniformly available throughout the state for all persons with developmental disabilities. This flexible system would respond to changing individualized needs of families; it would include direct support services, stipends/vouchers to purchase or obtain services, and financial/technical resources to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning. <VA>

A family support plan, such as the model proposed by Carl Dunst (1988), addresses the need for case coordination, the individual's strengths and current level of function, family strengths and uniqueness, identified needs, sources of support and resources, a plan of action and methods to evaluate the extent to which needs are being met. A family support plan is an essential and necessary way to encourage interagency cooperation and to allow participation in the process by individuals and their families. <VT>

Eligibility requirements and standards for adoption and adoption support programs should be simplified. <WA>

Crisis intervention and early intervention programs should be adequately funded to prevent out-of-home placement and to identify children at risk of developing disabilities. <WA>

Government should provide leadership in forming public policy as well as individuals and groups to come to a renewed understanding of the meaning of family support. <WA>

Government should support existing, as well as new, organizations to empower families and assist them in accessing resources and acquiring information skills. <WA>

Government should encourage schools to explore ways in which to use their facilities and resources to more effectively support both families and the community. <WA>

Government should encourage businesses to support their workers, especially in the area of medical insurance coverage, child care and parental leave policies. Consideration could also be given to exploring employment opportunities for the children of current employees (this is especially effective for children who have disabilities and find it hard to break into the job market). <WA>

Federal, state, and local governments should work together to develop a process to support families at the community level. <WA>

Redefined processes should help families find a way to receive emotional support and assistance in a crisis; acquire the information and skills necessary to better meet their own and their children's needs; identify specific family needs and then link-up with existing community services, resources and activities; and work with both the formal service system and the community to adapt and redefine existing services to better respond to the changing needs of families. <WA>

Local communities should develop a way to identify the needs of each family and to strengthen and blend formal services with informal assistance. They should work toward developing creative solutions. <WA>

Increase the availability, accessibility and affordability of integrated child care. <WI>

Provide training and/or professional expertise in serving children with severe emotional disabilities. <WI>

Include children with severe emotional disabilities among those eligible for the Family Support Program. <WI>

Increase funding levels for the Family Support Program to at least 75% of total need in all counties by 1992-93 and 100% of total need by 1994-95. <W>

SUPPORTS TO COMMUNITIES: BARRIERS

Multiple States

There is a lack of supports to neighborhoods, individuals, informal organizations and communities to enable them to participate in the support network for people with developmental disabilities. <LA,MT,UT>

Individual States

The goal of support is the creation of a competent community able to include, benefit from and enhance the capacities of citizens with disabilities. Human service specialists within this vision become supporters of community environments, at least as much as supporters of people with disabilities. In a real sense the supported employment movement is attempting to provide the skills, experience and knowledge from which communities have been excluded. <AR>

There is a lack of information and public awareness programs for individuals, organizations and communities to enable them to access and participate in the service system network for people with developmental disabilities. <ID>

An active community-oriented University Affiliated Program (UAP) can strengthen and encourage service providers efforts to furnish programs and supports in ways that enable people with disabilities to direct their own lives. The Developmental Disabilities Institute (DDI) at Wayne State University, Michigan's UAP, is an innovative, community-oriented "UAP without walls." However, DDI receives very little financial support from state agencies, and has no direct funding from the state. <MI>

If community living is to become a reality in Missouri for people with disabilities, efforts will need to be implemented to develop the capacity and desire of local communities to explore how they can benefit and provide needed supports which would enable individuals with disabilities to participate in their community. <MO>

In New Hampshire, most of the state's geographic area has an essentially rural focus and experience. The bulk of the population, however, is concentrated in the southern tier of the state, which turns for its news to Boston and Manchester for both air and print media. As a result, the news which New Hampshire reads, watches and hears has an urban focus. This focus tends to downplay the rural experience and distance readers and viewers from local concerns, which get less coverage in the media. Yet it is at the local, personal level where members of the general public, members of the mass media, and people with disabilities most need to meet, overcome attitudinal barriers, and effect change. <NH>

The imagery and assumptions about people with disabilities in the New Hampshire media is overwhelmingly negative. Most of the public is unaware that the editors select what news is presented and how it is presented to readers and viewers. <NH>

Numerous speakers at the Council's Community Meetings noted that community connections and relationships for people with developmental disabilities do not and can not be expected to occur by themselves. Citizens have been separated from people with developmental disabilities and naturally feel a degree of discomfort. Well-planned strategies are required to help people connect. As one speaker put it, "We can't just say let the community do everything." <NH>

Community education is needed to promote an understanding of the significance of independence, productivity and integration in the lives of people with developmental disabilities. The community need to be build "systems of support" around persons with disabilities rather than "systems of care." Each community needs to provide: personal assistance, peer support, respite, case management, advocacy, financial assistance for assistive devices, supplies, home/auto modifications, home aides, employment supports, counseling, transportation and recreational opportunities. <NM>

Consumers and advocates want to inform legislators, policy makers and the public about successful programs that focus on the capabilities of individuals with developmental disabilities. <NY>

Need to increase community awareness of conditions such as autism and other developmental disabilities. <PR>

This is not to say there is no role for the service system in supporting families. But as the system has taken over the nurturing role of the community, natural supports have been supplanted. <WA>

Parents express a desire for more public awareness around developmental disabilities. Some feel this is the only way true community integration will be successful. Knowledge is essential to acceptance. <WA>

SUPPORTS TO COMMUNITIES: RECOMMENDATIONS

Increase opportunities for community members to develop friendships with persons with disabilities and to provide a helping hand as needed. Seek out ways for each citizen to join in this support of individuals, families and communities. <AR>

More public information and education must be provided to change public attitudes about people with developmental disabilities and their abilities to be productive, independent citizens. Their awareness should be established, early in life so that discriminatory attitudes and prejudices do not develop among our younger population. All media should be influenced. <CA>

A major, overall effort must be made to provide training in the following areas: public education about developmental disabilities, including factual, basic information and attitudes; prenatal care education, including good health and good nutrition during pregnancy; training of people with developmental disabilities which promotes optimal independence and personal development; education of parents, siblings and extended family members regarding basic facts, attitudes, needs and care; training of caretakers and service providers at all levels, both specialized in the developmental services field, as well as generic community service workers (bus drivers, police, etc.); and training of professionals in appropriate fields, such as health, education, religion, justice and law. There are serious shortages of professionals familiar with developmental services in many fields. <CA>

Resources must be made available for the development of appropriate training materials, trainee stipends, public information/education campaigns, training seminars and conferences, and for statewide and local coordination of training and education efforts. <CA>

Connecticut's public human service agencies must take steps to make resources available to enable the building of circles of support and bridges to community associations for people with developmental disabilities. Public agencies must set community building as a goal by creating positions as free from the service system as possible and as free as possible from state job descriptions. Public agencies must make resources available to the private sector to create "bridge-builders." <CT>

Encourage communities to make community resources such as the local recreation department available to all citizens. <GA>

The State Planning Council on Developmental Disabilities should work with the Commission on Persons with Disabilities and the University Affiliated Program to develop and implement an ongoing public awareness campaign. <HI>

The Michigan Developmental Disabilities Council, and consumer and advocacy groups should develop public education and citizen participation strategies to communicate to the general public the basic concept: Every member of society, every citizen of a community, benefits from the community's inclusion and support for participation by people with diverse backgrounds, abilities, and characteristics. But every citizen is demeaned and impoverished when social, physical, and attitudinal barriers exclude, humiliate, and prevent participation by individual members because of handicapping characteristics. <MI>

Minnesotans should come to assume that people with disabilities are people with whom they can develop relationships, obligations and interactions. Minnesotans should come to assume that people with disabilities are members of the community and belong in the places and with the people of the community. <MN>

Unfortunately, persons with disabilities continue to be undervalued. The general public must recognize the strengths of persons with disabilities and become aware of obstacles that may inadvertently exclude these individuals from participating fully in their communities. <NE>

The Council should establish membership and become active in more generic organizations such as the Business and Industry Association, service clubs, the Housing Finance Authority, etc., in order to encourage broader base of community support for persons with developmental disabilities. <NH>

The Council should continue its public education efforts and communicate directly with media professionals regarding the frequency and quality of coverage. Training should be offered to service providers regarding how to communicate positively with the media. <NH>

Greater attention should be paid to the effects of portrayal of people with disabilities by the media and by service provider and advocacy organizations. Training should be offered to members of the mass media on language, imagery and assumptions about people with developmental disabilities, conducted in part by people with disabilities themselves. <NH>

Development of a network of viable citizen advocacy programs should be facilitated through the creation of a statewide coordinator. The primary responsibility of the coordinator should be to work with local community groups to establish organizational capacity and secure funding for programs to match persons with disabilities with citizen volunteers. <NH>

Program models that emphasize one-to-one linkages between individuals with developmental disabilities and others in the community should be expanded. <NY>

In reaching the general public statewide, the normal vehicles of mass communication such as public service announcements, community programs, speakers' bureaus and news stories are a traditional approach. The most effective approach will be to involve the leaders of the state and the local community in the overall plan for developing awareness about developmental disabilities. One goal is to establish a Community Council for Developmental Disabilities in each of the 77 counties. Each Community Council would be composed of a 5-6 team member team, chaired by a person with developmental disabilities, and composed of an elected or appointed county/city official, at least one other member with developmental disabilities or family member, a business community representative and a school superintendent. The mission of this group would be to provide information and public education on issues related to developmental disabilities. The activities may include providing community supports to assist individuals with developmental disabilities who are being placed in that community, addressing zoning issues related to disability and distributing disability awareness information. <OK>

The attitudes and behavior of the residents of Rhode Island will support integration of persons with developmental disabilities into the complete life of the community, including housing, work, recreation, transportation, education, and family life. <RI>

Government should encourage involvement of schools, community organizations and churches in actively supporting and responding to the needs of local families. <WA>

Government should encourage and reward local governments, communities, businesses, schools and other organizations for their efforts in supporting families. <WA>

In response to families' needs in the context of community, government should encourage public policy which supports local government and community organizations to become more involved in providing mutual support among families. <WA>

Local government should be responsible for fostering an environment that encourages the community to coalesce around the needs of families. Policies and services of other government bodies should support these goals. Families should have a major influence in how both the process and the services are developed. <WA>

Educate communities about the capacities and contributions of people with disabilities. <WA>

Concerted efforts need to be made to involve the broader community in supporting people with developmental disabilities to become active, participating members. One method of encouraging this involvement is through participation in a variety of integrated community activities. <WV>

EDUCATION: BARRIERS

Multiple States

The 3-21 age range for service eligibility stated in federal law and regulation is not being implemented across all states and territories. Only approximately 42% of the states provided services for eligible students in the 3-21 age range as of school year 1986-1987. <IN,MI,MT,WY>

State discretion excludes many children with disabilities from special education and related services. <IN,MT,WY>

State submission to the U.S. Department of Education of some important data is voluntary. Because related services data are not required by the U.S. Department of Education, data on definitions and utilization for individual states are available only at the state level. <MI,MT>

Americans with disabilities have far less education, as a group, than do Americans without disabilities. 40% of all people with disabilities did not finish high school. This proportion is nearly three times higher than in the non-disabled population, where only 15% of adults have less than a high school education. <AL,ID,IN,MI,MT,TN,WY>

Not all states provide education and related services to the entire range of eligible children. <MT,MT,WY>

As of the 1986-1987 school year, only 21 states provided special education and related services across the full 3-21 age range defined in P.L. 94-142. <MI,MT>

Many students with disabilities are not receiving the support they need to be placed in integrated settings because states tend to interpret federally-defined "related services" so literally that if a service needed is not included in the "letter of the law," it is not provided. <IN,MI,MT,NM,UT,WY>

Available special education data are problematic, and much needed information is unavailable. Attempting to determine the number of individuals with developmental disabilities included in education statistics is very difficult. Thus, issues such as placement of children with the most severe disabilities are difficult to determine and analyze. <LA,MT,WY>

Obtaining necessary related services and environmental supports is often extremely difficult. Services are often provided according to what is available in the local districts, rather than according to which services are actually needed. <ID,IN,LA,MI,UT,WY>

Nationally, the drop-out percentages for many of the handicapping condition categories which are most likely to include those with developmental disabilities are significant. For example, those with other health impairments comprised 30.86% of the total percentage of students 16 years and older who exited the educational system by dropping out during the 1985-1986 school year, those with mental impairments comprised 24%, and those with multiple impairments comprised 17.69%. <ID,MT,TN,WY>

26.29% of the students in special education dropped out in the 1985-1986 school year, 10% higher than even the highest regular education drop-out estimate, and the percentages for the handicapping conditions associated with developmental disabilities account for over half of this total percentage. <ID,MT,TN,WY>

Most students with severe disabilities continue to be segregated from other students in public schools and states continue to rely far too heavily on separate "state schools" and educational settings in hospitals and other segregated institutions. <IN,TN,WY>

While the number of children with disabilities served under The Education of the Handicapped Act State Grant Program (EHA-B) and Chapter 1 Handicapped Programs of the Education and Consolidation Improvement Act - State Operated Programs (ECIA/SOP) has seen a 19.2% increase during the past 11 school years, many of these students are not receiving educational services in integrated settings with all other children. During the 1985-1986 school year, only 26.24% of the students received the majority of their educational services in the regular classroom. <MT,TN>

Nationally, a small number of handicapping condition categories account for a high percentage of students in fully integrated regular class settings. More segregation may exist for other handicapping condition categories, such as mental retardation, multiple handicaps, and deafness and blindness, but obtaining information statistics is very difficult. Thus, issues such as placement of children with the most severe disabilities are difficult to determine and analyze. <LA,MT,WY>

It is very difficult to determine the number of individuals with developmental disabilities included among the special education statistics. <MI,MT>

Several factors contribute to the problematic nature of current special education data. First, while federal language exists with reference to the definitions of each of the handicapping condition categories, states exercise a significant amount of discretion in defining the "state level contents" of these categories. Thus, the ability to evenly compare data across handicapping condition categories, for example, is greatly hindered. <MT,WY>

Funding authorizations for the Handicapped Infants and Toddlers program and the Preschool program were based on federal estimates of the number of children to be served

under these two programs. Both estimates are considered far too low. <HI,MI,MT,UT,WY>

While a new entitlement for infants and toddlers has been authorized by the Handicapped Infants and Toddlers Program, Part H of the amendments to the Education of the Handicapped Act of 1986, there are disincentives to implementation. <IN,LA,MT,UT,WY>

Federal funding contributions for P.L. 94-142 fall far below the statutory maximums. The initial commitment of the federal government was to reimburse the state governments and local districts for 40% of the national average per pupil expenditure (NAPPE) by 1982. Instead, the total actual appropriation for P.L. 94-142 as a percentage of the NAPPE in relation to the number of children being served has never exceeded 12% during the late 1970s. It reached a low of 7% in the early 1980s. <CA,FL,ID,IN,MT,NM,UT,WV,WI,WY>

Funding for special education programs is woefully inadequate. <IN,LA,MT,UT,WY>

Despite the importance of parental involvement, many parents are not attending IEP conferences or becoming involved in the educational planning process. <ID,IN,MT,WY>

Students are "falling through the cracks" because adequate mechanisms do not exist to follow and to link them to the transitional services they need. <IN,MT,TN,WY>

Head Start is currently serving only approximately one out of every six of the eligible low-income preschool children. <IN,LA,MT,WY>

There is a serious shortage of qualified special education and related services professionals. <CA,IN,LA,MT,UT,WY>

Projections of both student and professional demographic data indicate that over the coming years the personnel shortages will reach crisis proportion and seriously impede the ability to provide students. <MT,UT,WY>

While the Head Start Act requires that no less than 10% of the total number of enrollment opportunities in Head Start programs in each state be available for children with disabilities, there is no responsibility within the state for overseeing this requirement. <IN,MI,MT,UT,WY>

Individual States

Nationally, the drop-out percentages for many of the handicapping condition categories which are most likely to include those with developmental disabilities are significant. For Under P.L. 99-457, educational services for children under the age of three will become an entitlement. It is unclear how these services will be funded and how the services will be extended to currently unserved and underserved areas of the state. <AK>

Many young people who experience disabilities graduate or finish school unprepared to enter the world of work. Many have insufficient or no vocational education services as part of the IEP. <AK>

Parents interviewed as part of the survey were the most dissatisfied with educational services if their child was in a regular class in a regular school. Only 32.5% indicated that they were satisfied with this setting, most commonly because it was not suited to the individual needs of their child. The main reason for this was that necessary training and support was not available to the classroom teachers. <AK>

There is a shortage of certified special education teachers in rural areas, with the shortage of specialists (physical, occupational and speech therapists) even more critical. Children in rural and remote areas receive specialized services less often than children living in urban areas. <AK>

Most students with severe disabilities continue to be segregated from other students in public schools. They are denied opportunities to participate in age-appropriate, integrated learning environments with non-disabled peers. There is significant research evidence that educating students with special needs in the regular classroom is more beneficial than using segregated environments provided that specific and intensive services are provided as needed. <AK>

Assessment tools and measures are biased and inappropriate for children who are bilingual. There is currently no method of determining the child's language proficiency prior to assessment. <AK>

Special education teachers in rural areas are often responsible for serving all students with disabilities and gifted/talented students, regardless of the student's age, exceptionality, or intensity of program. These teachers are rarely trained in more than one area. <AK>

All districts count special education students in regular school enrollments and receive regular education foundation support for them. Special education funds are generated in addition to those regular foundation funds and are to be used to provide the special education services with students with disabilities require. Many districts do not spend all these funds to benefit special education students while some provide significant local funds in addition to foundation funding for this purpose. <AK>

Research and parent input verify that many children in special education programs lose skills gained during the school year over the summer without summer programs. <AK>

The quality of preschool programs varies greatly around the state. Some districts offer only minimal programs while others have a variety of settings, including regular half-day programs. The services a preschool child receives are often dependent on where the child

lives rather than what he needs. There are virtually no pre-school services available to children with emotional disabilities. <AK>

Another educational need expressed in both the public hearings and discrimination hearings was the need for transitional programming. Transitional programming for many groups was limited and those same services to people with deaf/blindness were non-existent, particularly from high school to adult living. <AL>

A number of people indicated that educational services may not be fully operational, either in quantity or quality. For example, a number of parents in the Mobile area expressed high levels of satisfaction. Many of these parents were new recipients of educational services and were, thus, very pleased to receive any type of service. Yet when questioned, few of these parents understood the nature of Individualized Education Plans (IEPs), the extent of physical therapy services their child needed or was receiving (hours per day, days per week, etc.). <AL>

In data provided in the 1987-88 Statistical Report of the Alabama Department of Education, the Birmingham school district had one physical therapist employed as of December of 1987 to serve a total of 5,198 handicapped children (ages 3 - 21). This illustrates a critical issue related to recruitment, basic and specialization training, and retention of support personnel. Many school districts report similar problems in identifying support personnel (PTs, OTs) to serve their exceptional students. <AL>

A count of the teachers and support personnel in Alabama was developed. Using a conservative teacher/pupil ratio for just the preschool population would yield one teacher for every 59 preschool children. Worse, only one teacher in six is certified in the field of Early Childhood Education for the Handicapped (ECEH). Clearly, the need for teachers and support personnel to serve the spectrum of public school eligible children and youth (3-21 years of age) in Alabama is staggering. <AL>

Data taken from the Discrimination Hearings indicated a very strong need for educational services. <AL>

Generally, persons with disabilities have far less education than those who do not have disabilities (Harris Poll, 1986). This impacts on their ability to work since most unemployed persons with disabilities did not finish high school. <AL>

Despite the family focus of P.L. 99-457, parents and other family members are grossly under represented on national and state level policy making bodies. <AR>

Nationally the majority of both principals and regular educators have not had adequate training in special education, and many are not very confident in making decisions concerning children with disabilities. <AR>

Nationally, only a small proportion (less than 40%) of parents of children with disabilities are knowledgeable about their rights. Slightly more than half report that they had to "work hard" to get the educational supports their children needed. <AR>

Many students with disabilities nationally continue to receive their special education programs in separate, "handicapped only" settings. Fewer students labeled "learning disabled" and "mentally retarded" are being educated in regular classes, and a small percent of students labeled "mentally retarded" or "emotionally disturbed" are more likely to receive public education in residential facilities or at home. <AR>

Parent participation falls far short of unanimous (in fact, below 50%), with even less participation among poor families. <AR>

A substantial number of educators (38 of regular classroom teachers and 30% of district directors of special education) report nationally that there are handicapped students who are either not identified as handicapped or who are not receiving services. <AR>

For a majority of handicapped students aged 17 or over nationally, transition plans designed to assist them in moving from school to work have not been made part of the IEP. Less than half of these students have received counseling concerning employment or further educational plans. Only 11% of parents and 15% of educators say that the schools do an excellent job in preparing students for jobs after high school. <AR>

The Council, through the Protection and Advocacy System, has identified difficulties in providing persons with developmental disabilities a free and appropriate public education, especially in the rural areas of the state. The Arizona Department of Education is still in the process of resolving problems associated with full implementation of P.L. 94-142. <AZ>

Summer courses to enable teachers to meet certification requirements and to enhance training in specific disability categories in areas such as early childhood education, deaf education, etc., are very limited in Arizona. <AZ>

In a recent national study, Arizona ranked 38th in funding per student. This ranking indicates that Arizona's funding for "typical" students is far below the national average; and correspondingly, that funding for "special education" students in Arizona is also below 37 other states. <AZ>

One issue has to do with the establishment of state requirements for certification of early childhood educators. Agencies and local school districts need to work together to continue to provide the best possible programs and at the same time maximize resources from P.L.99-457, so all children can be served. Currently the DDD has approximately 200 on waiting list for children's services. <AZ>

Agencies, school districts and parents have concerns as to how the transition of educational services for pre-school children ages 3-5 from DDD to the Arizona Department of Education (ADE) is to be implemented. The Arizona Legislature needs to provide funds for adequate services for all children ages 3-5. There need to be assurances in place that the minimum of 6 hours per week is not allocated independently of the child's needs. Funding needs to continue for family support services, such as respite care, which are provided for through the Division of Developmental Disabilities, and which are not covered by education. <AZ>

Recent statistics from the Protection and Advocacy (P&A) system, Arizona Center for Law, indicate that Arizona, as well as other states, is still resolving problems related to full implementation of P.L.94-142 (The Education for all Handicapped Act). <AZ>

The Department of Health, Division of Behavioral Health Services sometimes finds it necessary to place children with serious mental disturbance in residential settings to treat their mental and emotional problems. These children are not eligible for a special education voucher; the question of who is responsible for paying for the special education needs of these children has not yet been resolved. <AZ>

As of June 1989, the Arizona Department of Education reported that there are 2,728 students in the special education system who are aged 18-21. The majority of these students are in need of transitional employment services. Local school districts statewide could be receiving increased services to students through RSA if they were to match RSA funding on a four to one basis (four RSA dollars for every dollar the schools make available for work preparation services). School districts are not currently making use of this potential resource. <AZ>

The Arizona Legislature has not authorized or appropriated state funding for school districts to provide extended school year programs. Arizona Special Education has used discretionary federal funding to provide this service in the past, however, these discretionary funds are encumbered for 1990-91 for other programs. A joint legislative committee has been studying this issue. <AZ>

Arizona law does not require vocational training for students with disabilities. Some funding is available through the Carl Perkins Act and some local school districts have comprehensive vocational programs and transition services available. However, the majority of special education students graduate with no jobs or training to enter the world of work. <AZ>

Persons with developmental disabilities are guaranteed the right to fair compensation for labor according to ARS 36-551. These standards have not always been enforced in community training programs for special education students in Arizona. These programs are sometimes discontinued when students need to be paid for training. <AZ>

There is a shortage of trained specialists who provide related services with the school setting. This includes occupational and physical therapists, for whom the pay is not competitive with the private sector, as well as other types of technicians and therapists. <CA>

There is a need for better transition planning at key points in the service system for individuals ages 0-22. <CA>

Federal law stipulates that states must develop interagency agreements among agencies which provide support services for special education participants. In addition, California law moves some of the responsibility for providing related services to generic agencies and programs, such as California Children Services and the Departments of Mental Health, Social Services and Rehabilitation. This fragmentation has led to many gaps in services and disputes over eligibility and responsibility for service provision. <CA>

California is experiencing a teacher shortage. This is even more crucial to the provision of special education services, which requires additional skill and training. During the past five years 27% of the individuals pursuing a special education credential have dropped out upon entrance. Forty-two percent have not completed the program. Seventy-five to ninety percent of those who do complete the program, do so while teaching with an emergency credential. There is a lack of quality among those who do pursue this career, except in special cases where the individual is personally dedicated. There are also a large number of teachers whose special credential requirements have been waived. <CA>

Special education is not meeting the federal mandate of providing services in the least restrictive environment. According to information provided by the Organization of Area Boards, there are approximately 400 segregated special schools in California, and 4,000+ children with severe disabilities who have little or no contact with their age appropriate peers without handicaps. For thousands of children in special day classes on regular school campuses there is little or no participation in learning and non-academic activities with children without disabilities. Children with disabilities are bused on segregated school buses, sometimes several miles from home, and taught in segregated classrooms. Therefore, the concept of "least restrictive environment" is not truly being upheld in this state. <CA>

When mandated services are not provided, there is a due process mechanism available to parents in order to obtain a satisfactory resolution to the issue. However, this process is usually intimidating to parents, and is frequently not used due to lack of individual advocacy services. <CA>

Shortfalls in the special education budget are leading to overloaded classes and depletion of local funding sources. It is relevant to this budget issue that California, as with most other states, only receives about 10% of its special education funding from the federal government. <CA>

A uniform data collection system for special education is needed which portrays students, the services they receive and their outcomes by disability definitions utilized at the federal/state level. This information is essential to developing accurate assessments and investing public dollars where they will be most effective. <CA>

According to the California Department of Education, reasons for a lack of integrated school sites include a severe shortage in funds to improve school facilities and make them accessible; the lack of teachers and specialists to provide services at multiple school sites; and the less progressive, more protective attitudes of school administrators, teachers and parents regarding integration. <CA>

The processes which lead to appropriate assessment, placement and services for individuals in special education must be scrutinized. <CA>

Although the school system has made great improvements in educating children with autism, appropriate educational services are not available statewide. <CO>

Lack of awareness and education, especially of students and teachers. Students with epilepsy are ridiculed, and their peers and teachers don't have enough accurate information about epilepsy to deal with seizures in the classroom. <CO>

There are still a few schools where kids with disabilities attend separate schools and/or classes. <CO>

There is great concern about the high school drop-out rate of Blacks in Denver, including special education programs. <CO>

Problems are encountered in integrating children with special health care needs into the school system, with a lack of qualified medical personnel in many schools to handle their special health care needs. Typically, school nurses and health programs are among the first affected when budget cuts are made. <CO>

Although many schools are nominally integrated, the children with disabilities are integrated only in the sense that they occupy the same environment as other kids. There is little effort to help them form friendships and actively participate to the fullest extent possible with typical kids. <CO>

Public Law 94-142 was cited by the Center on Deafness staff as having some negative impact on people with hearing impairments. The concept of least restrictive environment has lead to thinking in terms of a continuum of care for those with hearing impairments, with the perception that specialized residential schools such as the Colorado School for the Deaf and Blind are considered "bottom rung" programs; i.e., only people with exceptionally severe problems attend these schools. Parents feel that they are pressured

in accepting a particular option selected by professionals as the only one that is appropriate for their child, with little consideration of family preference. <CO>

Schools seldom provide appropriate vocational training to prepare students with developmental disabilities to be employed. <CT>

Most parents and educators recognize that nothing is more important to a child's development as a student than quality early education. Unfortunately, children from low-income families generally, and many Black children particularly, are not able to attend preschool without financial help. According to the U.S. Department of Commerce, less than 38 percent of four year olds and 17 percent of three year olds in families with annual incomes under \$10,000 were enrolled in such programs in 1986. <DC>

The need for a strong and viable special education program for children with developmental disabilities is greater today than ever, but the funds to fulfill that need are both nationally and locally inadequate. <DC>

Housing residents with disabilities over the age of 25 are much less well-educated than their non-disabled counterparts. More than half of the persons with disabilities have not completed high school compared with less than one-third of the non-disabled. <DC>

Too many of Delaware's children are "at risk" of not completing their education because of the following factors which contribute to academic failure: low family income; poor nutrition; pregnancy; and children who have been retained one or more grades are more likely to drop out. These "at risk" children face a bleak future, because if they have not completed their education; they will be forced to face the challenges of adult life unskilled, and only marginally literate. <DE>

Most students with severe disabilities (including students with severe physical disabilities and no mental impairment) lack opportunities to participate in a chronologically age-appropriate, integrated learning environment with non-disabled peers. The former are the students who need the most practice learning appropriate social behavior and modeling with non-disabled peers. <DE>

According to a 1988 Delaware Task Force on Children at Risk, a recent study by a Boston organization reports that Delaware schools "suspend" a higher percentage of students than almost any other state. The report also indicates that Delaware's percentage of students with serious emotional or learning disabilities ranks second highest in the nation. <DE>

A 1987 survey of teachers conducted by the Carnegie Foundation nationwide indicated that Delaware teachers felt some of the school problems perceived included: 91 percent reported abuse or neglected children, 76 percent cited poor health, and 73 percent said undernourishment. <DE>

Transition services provided for Florida's exceptional students indicated that only 25 of the 67 local school districts had a comprehensive transition process in place for their students. <FL>

Services aimed at assisting young people with developmental disabilities to make a successful transition from public to the community and the world of work are uneven in availability and quality. <FL>

Currently the number of preschool children with developmental disabilities is grossly underestimated and poorly defined. <GA>

The spirit and intent of Education of All Handicapped Children Act needs to be enforced in Georgia. Real community integration needs to occur. <GA>

Extended school year programs are needed. <GU>

Post-secondary education opportunities are needed by individuals with disabilities desiring further education. <GU>

Consumers expressed dissatisfaction with the special day school program their children attended. <GU>

To improve related services, the Department of Education identified the following needs: 1) additional mental health personnel, in-service training for all personnel, and the need to revise and/or enforce the Mental Health Division of the Department of Health and Department of Education agreement to provide psychological services; 2) additional occupational therapist/physical therapist personnel; and 3) additional nursing personnel and guidelines and procedures for dealing with communicable disease possibilities. <HI>

Sixty-five percent of special education teachers identified classload size as "often or always" hindering their abilities to provide effective services to their students. Sixty percent of special education students receive services on a daily basis in settings where the staffing ratio exceeds 15-1. <HI>

The Department of Education identified the following needs: facility renovations and additional trained personnel to provide instruction and educational services; 2) additional trained personnel to provide adaptive physical education services and training to special education teachers and students; and 3) additional personnel for coordinating transition planning, to conduct formal vocational assessment, to assist in transitioning activities, and to expand supportive employment opportunities. <HI>

There is a serious shortage of qualified special education (20 percent of special education teachers are not certified in special education) and related services professionals. The high turnover and the scarcity of special services personnel have contributed to delays in

evaluation time lines and a reduction in the quality of services provided special education students. <HI>

There are several factors contributing to the lack of adequate personnel, among which is the nationwide shortage of nurses, physical therapists and occupational therapists; the high cost of living in Hawaii; and the need for a professional school for physical therapist. Nurses, physical therapist and occupational therapists receive higher salaries working in the private sector in Hawaii or on the Mainland. And, as an occupation, teachers have traditionally been poorly paid. The particular skills and attitudes needed to be a special education teacher are not adequately compensated. <HI>

The lack of resources for both financial and personnel-related services has led to a situation that often pits parents against Department of Education personnel. <HI>

An issue raised both in the focus groups and public forums was the need for ongoing education classes for adult persons with disabilities. There is a real lack of imaginative, creative classes or daily skills building classes which can be taken by adults. <HI>

In focus groups conducted in 1989 in Hawaii, many parents expressed frustration and/or dismay at the IEP process. For some, they experienced the IEP meeting as confrontational, with the parent "fighting" for services; others feel powerless and accept what the teacher and counselor are saying as appropriate and available for their child. Several parents felt that the Department of Education has a "let them sue" attitude. <HI>

The Department of Education in their 1989 report to the federal Office of Special Education Programs, indicated that there is a need for additional personnel to conduct formal vocational assessment; to assist in transitioning activities with students, parents and agencies; and to expand supportive employment opportunities. Transition plans should be developed early, focus on functional knowledge and skills, and services should be coordinated with other agencies. <HI>

The Hawaii State Department of Education has made extensive efforts to provide an education for special education students which gives them the skills required to live independent and productive lives in the community. Unfortunately, this does not occur consistently throughout the system. Each district is given discretion on the implementation curriculum used in special education classrooms. <HI>

The preschool program suffers from the same problems found in the special education program serving older children with disabilities; there is a shortage of special education teachers and facilities are extremely limited. The schools are crowded, with teachers sharing classrooms, and the numbers of children being certified in this age group for special education continues to grow as a result of the greater awareness about the value of early intervention. <HI>

The Head Start program in Hawaii has difficulty in finding facilities in which to operate the programs. Lack of facilities has been identified as the major barrier to expanding the Head Start program. <HI>

There appear to be several areas where children with special needs can potentially "fall between the cracks" in Hawaii's school system. Children ages 0-3 receiving early intervention services from the Department of Health may not qualify for certification as "learning impaired" at age three, yet many still need services. The Department of Health, Developmental Disabilities Division's infant development program served 292 children in 1987-88. The Department of Education shows only 123 three-year old enrolled in preschool special education classes the following year. There are no data to show if they become eligible for certification at a larger age. <HI>

Although some use of Head Start for mainstreaming occurs when there is a Head Start class on Department of Education school grounds, it is very seldom that Department of Education provides special education and/or related services to children with handicapping conditions in non-school based programs. This mitigates against the fullest integration of this age group. <HI>

Hawaii needs a data system which has the capacity for tracking all developmentally delayed and at-risk infants and toddlers to determine needs and services. <HI>

In Hawaii, the situation is similar to the national picture: 1) there is a lack of resources for identification, diagnosis, treatment and rehabilitation of infants and toddlers at risk; 2) preschool opportunities are too limited and restrictive for infants and toddlers exiting early intervention programs; and 3) there is a need to develop an integrated service system for young children at risk, including Head Start, public preschools and day care. <HI>

It appears that the transition from elementary and intermediate and from intermediate to high school, there is a trend to decertify some special education students, especially those with learning disabilities. There is no data to show how all these decertified students perform. However, the drop out rate for special education students in Hawaii mirrors the national trend — ten percent higher than even the highest regular education drop out rate. <HI>

Existing eligibility criteria for special education students has often presented barriers to a child accessing needed services. Although the labeling of children as "handicapped" should be done cautiously and judiciously, there is concern that the state Department of Education's procedures and criteria are not addressing children who have special learning needs. <HI>

What is also unacceptable are the regular schools with "special" classrooms where the special education students hardly ever are seen by or see "regular" students. In a school on the island of Hawaii, for example, the special education classroom for all age special

education students is geographically located with the "little children." The older special education student never mingles with students his/her own age. <HI>

Many public schools in Hawaii are not accessible for children in wheelchairs, e.g., all special education students with physical disabilities go to Waiakea High School in Hilo because Hilo High School is not accessible. The lack of accessibility often forces children out of their own communities and away from their friends. <HI>

Special education students are often spending large portions of their time getting to and from school. One should not expect small communities to have every available resource, but the extreme exists in some of the rural areas of Hawaii. <HI>

The lack of special education resources has led to a situation that often pits parents against administration as parents struggle to get the necessary services, and administrators struggle with lack of funds and trained personnel. Lack of resources affect the Hawaii State Department of Education's capabilities to achieve the purposes and goals of P.L. 94-142 and P.L. 89-313. <HI>

For special education, persons living in rural areas may have to accept having their child spend hours on the bus to travel to a distant school to get services. <IA>

While the analysis of special education program policy led to generally positive results, there is the potential for improvement in policy support for the outcome of independence. Policy is found to inhibit independence when considerations other than student need are primary factors in determining who provides what service and where. Special education-program policy permits the final decisions about special education services to be made by the Director of Special Education of the Area Education Agency. Support for independence is also limited because the policy does not provide clear consumer/family choice in how much service is provided. <IA>

Serious concern arises with policy that permits as much as a six-year age span between students in some special education classroom settings. Furthermore, integration is not promoted by policy that allows or requires some students to receive special education services in segregated settings. <IA>

In contrast to the policy analysis, in which special education policy appears to be supportive of productivity, survey respondents give special education low ratings in this area. Consumer and surrogate concerns focus on deficiencies in the areas of vocational training, basic life skills training, and programs that help students make a successful transition from school to work. <IA>

Among respondents who are receiving services from special education, more than 80% report some dissatisfaction with the special education program. Satisfaction levels varied greatly from person to person; for example, some report being very satisfied with the

quality of the teachers while others complain about the lack of qualified personnel. Other participants note that often the determination of services is based upon funding issues that may arise at any level of the educational system, rather than upon the needs of the student. Less than half of the respondents report that they have enough choices in this program. The common response is that the only choice is whether or not to use the services, not in selecting the level or types of services, or the location of services. <IA>

Respondents report little program support for integration. Criticisms center upon segregated classes, large age disparity in the classroom, and problems with students being bussed to non-neighborhood schools. A strong relationship is seen between where the respondent lives and his or her level of satisfaction with special education services, with many more negative comments coming from the residents of small towns and rural areas. <IA>

Extensive commentary was offered at the public forums on special education issues. Since the policy ratings for the special education program are so high, it is of particular interest that the amount and intensity of critical comment about this program was likewise quite high. To a large extent, these concerns echo those brought up in the consumer survey. By far the most common complaints have to do with "independence," especially as it relates to the degree of input and choice that parents and students have in developing appropriate programs. It is clear that parent participation in programming decisions is not as prevalent as the policy would allow. <IA>

The issue of integration is a major concern for parents, with most being in favor of more integration, which some have found opposed by school or area education agency policy. <IA>

Other areas of concern are a lack of qualified personnel in rural areas of the state, particularly of therapists such as occupational and physical therapists; transportation issues; and the low expectations that some professionals have for children with disabilities. Although many positive comments about teachers and about some programs and outcomes were made at the forums, there is a powerful sense that parents are having to fight very hard to get the services for their children that are promised in special education policy. <IA>

P.L. 94-142 intended that the development of a child's Individualized Education Program (IEP) involve parents. However, statistics suggest that fewer than half actually attended their child's IEP meeting. Parents should be provided with formal training so they can understand their rights and the laws concerning the placement of their children in the "least restrictive environment". <ID>

Parent-professional relationships are too often strained and difficult, and parents and professionals frequently view one another as adversaries rather than partners. Less than 1% of parents of students with disabilities have actually been involved in litigation at the

state level. This may be due to the perception that they would not have an equal chance against the school system, or it may be because many parents do not know their rights. <ID>

The budget rationale for Idaho's State Operated Schools for the Severely Handicapped is to serve "...students too severely handicapped to be served effectively by local public schools, ..." The rationale for State Operated Schools is more an economic and efficiency consideration than one of effectiveness. <ID>

Although "least restrictive environment" is referenced in Idaho Department of Education rules and regulations, the Department does not have a formal policy favoring the integration of students with disabilities. <ID>

In testimony before the National Council on Disability (1989), concern was expressed that parents are not actively involved in the transition of their son or daughter from school to adult life, despite the critical role parents play in the development of appropriate education programs. <ID>

The Idaho Transition Project within the Idaho Department of Education has raised the visibility of the need for transition planning, developed a model for local implementation of these efforts, and laid the foundation for a statewide initiative. Unfortunately, the project is time-limited and efforts to continue its focus will be left to local discretion. Although certain local transition programs are in place which utilize best practice principles, no statewide mandate exists for transition services for Idaho's students. <ID>

According to a recent national Harris poll (Harris and Associates, 1989), a majority of students with disabilities age 17 and over did not have transition plans as part of their Individualized Education Program. <ID>

Transitional services are not available or accessible to many Idaho students with disabilities. Currently coordination between vocational rehabilitation, school districts and other agencies that could assist in the transitioning process is minimal in many cases. <ID>

An alarming number of special education students are dropping out school. <ID>

Many parents do not know their rights and the rights of their children, or if they do, do not understand how to advocate for those rights. They are often intimidated or frustrated by the educational system. <ID>

In Idaho, 23% of students with a disability who were 16 years and older dropped out during the 1987-1988 school year, and 82% of these students were those with a specific learning disability. <ID>

Many students with severe disabilities continue to be segregated from other students in Idaho's educational settings. <ID>

Due process under the umbrella of P.L. 94-142 is heavily weighted on behalf of the school system because of the families' lack of information, energy, time and resources, as well as the intimidation they may feel in "taking on" the education and related services professionals. The Idaho Focus Group believes this is a major reason why school districts knowingly discriminate against students with developmental disabilities and continue to engage in segregation practices. <ID>

State and local discretion excludes many children with disabilities from special education and related services. <ID>

School districts often do not notify parents about their right to an independent evaluation at public expense. <ID>

According to witnesses who testified before the National Council on Disability, parents in low-income communities who must focus their energies on basic survival, may find it very difficult to provide the extra attention needed by a child with a disability and may not have the luxury of time to advocate for better services from the school. <ID>

Some parents believe they have two service options: full service in a segregated setting, or few, if any, services in a general classroom setting. <ID>

A 1989 Harris survey, "A Report Card on Special Education", states that while regular education teachers have an average of three to four students with disabilities in class for at least part of the day, only 40% have had training in special education. The Idaho Focus Group noted that teachers should have formal training in both the "regular" and "special education" system. They believe all educators should have the same level of skill. <ID>

Reports on school reform have not, for the most part, addressed issues of quality education for student with disabilities for two reasons: special education is viewed nationally (and in Idaho) as a sperate system with its own organizational, educational and teaching practices and is thus disconnected from the regular education reform movement; and giving attention to the needs of students with disabilities may appear to run counter to the increased emphasis on higher academic performance standards. <ID>

Funding for special education programs has not been appropriately monitored, fosters segregation, and is woefully inadequate. <ID>

Idaho's submission of some important data to the U.S. Department of Education is voluntary. For example, data on related services for the 1987-88 school year was not required, although Idaho did provide it. Because related services data are not required by the U.S. Department of Education, data on definitions and utilization for individual states are available only at the state level. <ID>

Sexual identity and appropriate sexual behaviors for students with disabilities are areas that should be covered in the educational setting. Almost 89% of those surveyed in the Needs Survey believed sex education should be part of the special education curriculum for teenage students. <ID>

Social skills training for students with developmental disabilities should be a key element of the special education curriculum. More than 89% of the respondents to the Needs Survey felt special education programs should expand social skills training. <ID>

According to a 1989 Harris poll, 38% of classroom teachers surveyed reported that there are students with disabilities who either have not been identified or are not receiving services. <ID>

There is a serious shortage of qualified special education personnel and related services professionals. The problem is linked to high turnover and recruitment difficulties. Idaho projections of both student and professional demographic data indicate that over the coming years these shortages will seriously impede the ability to provide students with disabilities the special education and related services they are guaranteed under federal law. <ID>

In a 1988 study, R.C. West found that, in Idaho, the turnover rate for special education elementary teachers was 66% higher than for regular education teachers. <ID>

Although 935 special education teachers were employed in Idaho during the 1987-1988 school year, 19 more were needed. Additionally, while 662 teachers aides were employed for that school year, 57 more were needed. These numbers are low, however, because they represent the local school districts' pragmatic requests rather than a true indication of actual need. <ID>

Idaho lacks enough money to fund educational support services mandated by federal laws. These service include speech therapy, physical therapy, and occupational therapy. <ID>

The Idaho Focus Group felt parents and employers should be incorporated into transition planning models. Educating parents and employers on the issues and choices involved in the process is critical to a worker's success. <ID>

People with a developmental disability should be trained and transitioned into work at the level that immediately meets their needs and should not be forced to work their way through a "readiness continuum." Transition services for Idahoans with developmental disabilities lack consistent planning between primary programs. Students and workers are locked into the "readiness trap" or on waiting lists. <ID>

Many graduates exiting public schools are not adequately prepared for employment, and are unable to access resources that enhance their participation in community life. <ID>

In Illinois, over 58,000 children with disabilities are taught in segregated settings. One out of four students with any type of disability is not spending any time in regular classes in public schools. <IL>

The Council finds that, in Illinois, despite P.L. 94-142, many Illinois children are not receiving an integrated education in the least restrictive environment. Most adults with developmental disabilities are not given the chance to receive any continuing education. <IL>

The enrollment statistics at the Blind and Deaf Schools provide evidence of a trend toward educating in less restrictive environments. Both average daily attendance and number of residents as a percent of enrollments have declined over the years. Due to lower numbers of solely blind deaf students and the trend to educate in less restrictive environments, the Blind and Deaf Schools are admitting more children with multiple disabilities each year. As local school systems expand their special education programs, they will require technical expertise for testing, evaluation, and program and curriculum development. In short, the role of the special residential facility must be reconsidered. <IN>

Providers report that it is difficult to find qualified personnel for early childhood positions, and enough of them. They are concerned that quality services may not be available unless the pool of well-trained caregivers is increased and that there is funding to provide adequate wages to attract qualified, competent staff. They are concerned about where the money will come from and when it will become available. <IN>

Silvercrest (a state school for children with multiple disabilities) is located in the southernmost part of Indiana near Louisville. The distance from the northern half of the state presents considerable transportation problems both for the parents of the children and their local public school districts. <IN>

It is not unusual to find that the geographic market served by state institutions is inversely proportional to the distance from facilities. This seems to be the case for the State Schools for the Deaf and Blind. For school year 1986-87, 39 percent of the enrollment for the School for the Blind and 28 percent of the Deaf School came from Marion County (Indianapolis). Yet Marion County has 14 percent of the state's population. When counties contiguous to Marion are included, the proportion enrolled was 52 percent and 40 percent for the Blind and Deaf Schools respectively - although Marion and contiguous counties comprise about 21 percent of the state's population. In short, although these schools are available to all residents, they are not accessible to populations outside the greater Indianapolis area. <IN>

Few students with disabilities are participating in post-high school education programs. <IN>

Adequate, appropriate, and consistent services are not always available throughout the state. Program content, quality, funding, and delivery vary from area to area, and often from county to county, resulting in many children not able to receive appropriate or adequate services. Especially difficult is funding adequate services in the rural areas and small towns of Indiana. <IN>

Indiana mandates the provision of special education and related services to children within the 6-18 age range. In this respect, Indiana compares unfavorably with her neighboring states. <IN>

Parents and providers are concerned about the quality of services currently available and their effectiveness. They look for comprehensiveness in services, so that their varied needs can be met. Agency-based programs alone are often inadequate to meet the needs of many children and families. Parents want to be able to use generic community services, or they may have special medical or home-bound needs. Many sought increased integration of services into community-based settings. <IN>

The requirement that children with disabilities be educated within the least restrictive environment should shift numbers down the continuum of services from more restrictive to less environments. Since state residential schools are considered more restrictive than most other environments, there should be less demand for the traditional services provided by them. <IN>

Many eligible children do not receive services right away. Many are placed on agency waiting lists for months before they can receive services. This causes much frustration among parents and providers who know the importance of early intervention. Other children receive only limited or infrequent services (e.g., therapy sessions only once a week), when their needs require more. <IN>

Parents of children with disabilities other than mental retardation have difficulty finding services for their children in Indiana. They cite needs for services and options that consider disabilities and conditions such as visual and hearing impairments, emotional impairments, chronic illness, multiple-disabilities, and physical disabilities. Children from low income and/or minority families also need special consideration. <IN>

Parents and providers are aware that funding for programs has not been and may not be adequate to meet the needs of young children. Some current programs are only partially funded, hampering their effectiveness. Participants especially cited assessment and therapies as services that will need more funding. <IN>

Screening processes used to identify children for early intervention services need to be expanded and improved. Currently, many children are not recognized as needing intervention until three or four years of age; by this time, many developmental opportunities have been missed. Further, current assessment tools are not sensitive

enough to detect delays in very young children. In particular, many at-risk children do not receive services because their needs are not as obvious. <IN>

Because of the nature of early intervention and the multiple needs of children, services must be provided across a variety of agencies and funding streams. The early intervention and public school programs will need to coordinate. At the professional level, interdisciplinary teaming and interagency coordination could be enhanced with improved communication among various professionals. Both parents and professionals expressed concern for assuring continuity of programs and services at critical transition times — at age three, when entering preschool programs, and when the child enters kindergarten. A critical feature of an early intervention system will be effective case management services. <IN>

Current professional training needs to be supplemented with information about young children with special needs and with skills for working with and understanding families. Indiana has few professionals certified in both early childhood and special needs children. Caregivers (teachers, therapists, day-care workers) will need to be prepared [in] language, motor skills, social skills, working with parents, etc. Physicians will need to be, made more aware of the benefits of early intervention. In addition, an ongoing staff development program is needed for those already in the field. <IN>

House Bill 1231 on Transition to Adult Services from Special Education status mandates the Division of Rehabilitation Services to determine if an individual with a disability in high school can benefit from ongoing adult services, after completing his high school education program. This bill, a revision of P.L. 28, called for the evaluation to be provided during the student's freshman year rather than during his senior year of school or effectively three years prior to completion of high school. The Division of Rehabilitation Services was to establish a Task Force to develop plans, policies and methods for transition to supported employment services. The degree to which compliance with the requirements have been met is not clear, however. A recent survey of 45 Special Education District Directors suggests, however, that the requirements will not be met for the 1989-90 school year. Only a third of those responding said that a representative from Vocational Rehabilitation was fully involved in the implementation of HB 1231. Only 27 percent said they would be able to implement plans fully by January 1, 1990, with vocational rehabilitation to comply with the additional three years prior to completion requirements to give materials and obtain written permission to transmit information. <IN>

Special educators, support service professionals, and appropriate summer programs are lacking in some local education agencies. <KS>

Adequate referral, early identification, and early intervention services are lacking in many communities. <KS>

Efforts to promote full integration of students with developmental disabilities with peers should be strengthened and functional, community-based curricula should be implemented in all school districts. <KS>

Appropriate services for students with dual diagnosis are lacking while services for students with emotional and behavior disorders are not of uniform quality among districts. <KS>

Personnel and funding to develop post-school transition plans are lacking. <KS>

Vocational training is lacking in some districts while in others it is not available until the later school years. <KS>

More support for establishing meaningful family-education system partnerships is needed. <KS>

There are indications that early intervention and effective education can reduce the limitations of disability in later life. As the number of people with disabilities increases in the population, failure of education to help all persons with developmental disabilities to achieve their potential will cost Kentucky much more in future years. <KY>

Children with developmental disabilities have the right to quality education, but many areas of the Commonwealth lack appropriately trained personnel to meet the special needs of children with various types of developmental disabilities. This has resulted in overcrowded special education classrooms, wide age ranges (sometimes 14 years or more), and inappropriate grouping of children with diverse disabilities are needs. <KY>

The greatest dissatisfaction expressed in the study was with educational services. The major dissatisfaction with that services were inappropriate to the needs of the individual student. Regular classes with resource rooms is an option seldom experienced in Kentucky, unlike the United States as a whole. <KY>

Dissatisfaction with education was an overwhelming outcry from those participating in this study. Therefore we recommend that education for persons with developmental disabilities both in and out of school settings be specifically addressed by the Commonwealth so that education is equal to that received by those with disability and is appropriate for the individual's needs, regardless of location of residence or disabling condition. Further, we recommend that the interests of persons with no developmental disabilities be directly represented on the Special Task Force on Educational Reform. <KY>

Representatives of the deaf community have expressed concern about the application of the Least Restrictive Environment to students who are deaf, because in most instances adequate support for effective communication and learning are not provided in regular schools and classes. <LA>

Nationally the ability to evenly compare data across handicapping condition categories is greatly hindered. There are some variations between the Federal definitions of handicapping conditions and Louisiana's. For example, Louisiana lists "autism" as a separate handicapping condition but reports it as "other health impaired" for federal reporting purposes. Additionally, "mentally handicapping" is used instead of the federal category of "mentally retarded." <LA>

In Louisiana, 34.6% of special education students over sixteen years of age dropped out of school during the 1985-86 school year. This is compared with a national average of 26%. When examined by disability group, 40% of individuals with emotional disturbances, 30% of "other health impaired" individuals, and 25% of the students labeled "learning disabled" dropped out of school. Louisiana does have a number of drop-out prevention programs currently under way. However, while special education staff have input into their planning and implementation, there are no programs which are specifically aimed at special education students. <LA>

Educating children with developmental disabilities in "regular" schools with their non-handicapped peers is essential to achieving independence as adults. Both federal and state legislation have laid the groundwork for achieving this goal. However, like many other states, most children with developmental disabilities and their families in Louisiana have yet to realize this goal. <LA>

Students are "falling through the cracks" because adequate mechanisms do not exist to follow and to link them to the transitional services they need. This was evident in the Public Forums which were held as part of Louisiana's Consumer Satisfaction Survey, where the lack of transitional planning for students exiting the school system was identified as a critical need. <LA>

Individualized transitional planning for students with severe disabilities exiting school systems exists only in a few pilot programs. School systems lack community-based transition programs. Moreover, few adult service providers offer supported employment or follow-along services for exiting students. <LA>

Getting special needs children to finish school is another critical issue. Studies show that the drop-out rate is increasing, especially as drop-out prevention programs in the state are being cut. <MA>

The federal state aid formula has rewarded school systems for isolating students in segregated settings. The "60/40%" law, which reimburses towns for 502.6 (residential) placements, can make it "cheaper" for a town to choose this option since the state reimburses 60% of the cost; in addition, another state agency often shares the cost. <MA>

Local education budgets are often determined by the town, and any cost savings revert to the town's general fund rather than being reassigned to educational services. <MA>

The segregation of children with special needs in educational services in Massachusetts has increased from the 1970s into the 1980s, contrary to the intent of Chapter 766 and of the Education of All Handicapped Children Act (P.L. 94-142). Disincentives of the system, as well as lack of alternatives, have encouraged families and towns to place children out of their communities and to keep them out. <MA>

Private schools (Chapter 766-approved) have become an industry, and have their own voice; their interests are served if their "slots" are filled. <MA>

Divergent experiences and expectations of the educational system on the part of parents have led to wide spread mistrust between state and local educational staff and between parents and professionals, resulting in poorer dialogue and coordination around the needs of particular children. <MA>

There has been a lack of planning for the entry of young adults into the adult service system when they "age-out" of eligibility for Chapter 766 at age 22: there is no entitlement to "adult" services as there had been under Chapter 766, and the families of these young adults need supports and preparation for this new life stage. <MA>

There has been a polarization between regular education and special education, creating a barrier to the integration of children and special needs. <MA>

There is a backlash in reaction to the high costs of special education, and a feeling that children without special needs are not well served. <MA>

On the one hand, children who are members of racial or ethnic minority groups are disproportionately placed into special needs classrooms due to language or other difficulties. On the other hand, minority students often cannot access services they need because of a lack of bilingual personnel to conduct assessments and provide special programming. For instance, there are only six Asian psychologists nation-wide who can evaluate these children in their native language. There are no Asian bilingual special education teachers in the state, so that most special education programs rely on special education teachers working in tandem with bilingual/bicultural teacher aides who may or may not have knowledge of special education issues. <MA>

The transitioning initiative needs greater emphasis: it is currently a "paper exercise." Agencies who need to be involved with the student later should begin their involvement earlier, before the student reaches age 14 to make a commitment to transitional students. <MD>

The Michigan Department of Education does not collect adequate outcome information on students with severe impairments exiting special education. Most school districts do not collect this information either. This makes it difficult to evaluate how educational methods and settings affect students' adult lives. <MI>

People with disabilities have lower educational levels than the general population, and much of their education takes place in segregated settings, where all the other students also have disabilities. <MI>

Adults with disabilities (at the CRI Forums and elsewhere) report significant barriers to obtaining further education. <MI>

The number of two-career families and single-parent families is growing. This means increasing demand for child care and preschool services. The availability of early education and preschool programs that include children with disabilities is limited, despite evidence that such programs provide substantial benefits for these children. <MI>

Michigan's Mandatory Special Education Act (1971) has never been fully funded nor increased to substitute for the lack of promised federal increases. Michigan's contribution to over all funding for special education services has declined steadily throughout the 1980s. <MI>

Federal spending for educational programs for students with disabilities has not kept pace with inflation or increased as promised since 1980. Federal funding contributions to Michigan for P.L. 94-142 (Education of the Handicapped Act) have fallen far below the statutory maximum. <MI>

Special Education Services has sought to provide leadership in improving outcomes of independence, productivity, and integration in the community for students. They have limited leverage because the legislature appropriates federal funds for Special Education directly to schools through the State Aid Act, rather than through the Department of Education Appropriation Act. <MI>

Many parents testified in the Family Support Hearings that they feel intimidated, isolated, powerless, and confused when attempting to obtain appropriate services, including educational services, for their children. <MI>

Parental involvement in the Individualized Education Plan (IEP) process is crucial to planning services that focus on community integration, independence, and productivity for the student. Despite the importance of their involvement, many parents do not attend IEP Committees for their children or become involved in the educational process. It is even rarer for students themselves, even those who are legally adult, to attend their own IEP Committees. <MI>

Too many young adults, especially those with severe cognitive disabilities, complete special education without the skills they need to live and work in the adult world. <MI>

Students with the most severe disabilities are usually the ones who most need practice to learn appropriate social behavior. However, these students (including those who have no

mental impairment) rarely have opportunities to participate in regular classrooms with other students their own age who do not have disabilities. <MI>

Too many students with disabilities receive their education in segregated, center-based programs, rather than in regular classes with students who do not have disabilities. <MI>

Students who receive most or all of their education isolated from people their own age who do not have disabilities do not learn the skills needed to participate in integrated communities. <MI>

Too many people with disabilities complete special education programs without the skills they need to work and make a living. <MI>

Education data for different topic areas are not consistently available for the same school year. Thus, the ability to supplement data of different focus areas is hindered. <MT>

The Head Start Act requires that no less than 10 percent of the total Head Start enrollment in each state be available for children with disabilities and that services be provided to meet their needs. More than 35,000 eligible children are not served by Head Start programs. In addition, many of those who are served receive only one-half day sessions. <NJ>

Students in the greatest need of services are concentrated in poorer school districts. The increasing numbers of children at risk of developmental delays threatens to overwhelm school districts with little resources. <NJ>

New Jersey's system of early intervention and pre-school for children with developmental disabilities almost entirely segregates children from non-disabled peers. From the onset, children with disabilities are receiving special services in special settings, frequently with a "pull-out" model for therapy. This sets the stage for an entire educational experience that is out of the mainstream. <NJ>

In many programs, funds for providing transportation for children and their families and for an early intervention program for children under 3 are insufficient. <NJ>

Many young children and their families are not receiving the programs and services they need to develop to their full potential. <NJ>

Current available state funding for serving infants and toddlers with developmental disabilities is inadequate. <NJ>

New Jersey's current eligibility criteria for state or federally funded early intervention programs are more stringent than those which will be required under P.L. 99-457 Part H. Current state criteria request that a child be delayed in two or more developmental areas

or have a known disorder, while the federal definition changes the requirement to one or more developmental areas and allows states to consider providing services for children who are "at risk" of delay. <NJ>

There exists a need to increase parental expectations of the potential for people with developmental disabilities to be educated and employed in integrated community-based settings. <MO>

Education services for individuals with developmental disabilities, especially mental retardation, are still primarily provided in segregated environments away from age peers and the activities they participate in. Consequently, the separation between those with disabilities and those without continues to be perpetuated, and students with disabilities are offered limited opportunities to learn needed skills in natural situations. <MO>

In many instances individual education plan (IEP) goals and least restrictive environment (LRE) placement for students with developmental disabilities are based on available programs and services, rather than on the educational and integrational needs of a particular student. <MO>

School districts and service agencies designed to assist with development of employment opportunities, such as Vocational Rehabilitation and JTPA, coordinate at minimal levels, thus minimizing the potential for successful transition. <MO>

Inadequate funding for support services limits the transitional opportunities for young people with severe disabilities. <MO>

There is a lack of needed information on what happens to students once they leave the educational system. <MO>

The drop out rate of students with developmental disabilities is at a critical level. <MO>

Although some school districts in Missouri have implemented more functional, life skill oriented curricula, such as the Life Centered and Career Education curricula, in many instances, out-dated attitudes and beliefs continue to be reflected in existing curricula and outcome expectations for young people with developmental disabilities. <MO>

Students with developmental disabilities find little or no supports to assist them with transitioning to viable employment opportunities in the community — in part due to the lack of opportunity in the community and in part due to a lack of available transition services. <MO>

Educational services systems should be designed around individual needs. The focus should be on preparing individuals for life, giving them the functional knowledge and skills to actively take part in it. <MS>

Montana has a total of 546 public school districts, but only 774 schools, so it is not surprising that one-school school districts are the vast majority. There are 114 one-room schools and 158 schools with less than three teachers. Of the latter, 95 have one teacher only and the other 63 have only another teacher or aide. With the school population of 152,207 spread out over an enormous geographical area, 86 percent of the school districts are considered rural. With schools of that size, teacher preparation, knowledge of curriculum and instruction, and a supportive network of colleagues becomes imperative for the provision of appropriate educational experiences to all students, particularly students with disabilities. <MT>

Limitations exist in the state definition for children eligible for the Part H Education of the Handicapped Act grant intervention program for infants and toddlers aged birth through three years. The definition needs to be broadened and access ensured to a greater array of early intervention services identified as needed. <MT>

Swelling the ranks of the unemployed with disabilities are youths recently transitioned from high school programs into the competitive workplace without marketable skills. Since 1979, more than 2.5 million youths with disabilities have graduated from the public school system in our country. Of that number, only 23% are competitively employed or in post-secondary training. <MT>

The demand for personnel trained to serve the 14,745 students with special needs in Montana is dramatic. The Office of Public Instruction reports that a current shortage of 55 teachers with cross-categorical preparation exists and that at least ten school districts in Montana are unable to hire a certified special educator. In addition, 25 special educators in Montana are teaching with partial (emergency) certification due to the extreme need. <MT>

The need for special education personnel in Montana must be seen in terms of quality as well as quantity. As more students receive educational services in regular classes, special educators work in collaboration with regular educators to plan, implement, and evaluate programs. Because Montana is a rural state, persons serving students with disabilities often function in various capacities. Competencies such as collaborative consultation skills, pre-referral intervention strategies, knowledge of various generic instructional approaches, knowledge of computer-assisted instruction, instructional area skills (e.g., expertise in reading or math), and classroom organization skills to accommodate diversity are among those needed for successful educational service delivery. <MT>

Concern was expressed regarding the condition of public school busses and the inability of school bus drivers to respond to the special needs of children with developmental disabilities. <NC>

Parents frequently reported lengthy bus rides, sometimes in excess of two hours, to and from school. <NC>

Availability of qualified special education teachers, particularly with expertise in severe/profound disabilities, transitional services, vocational services, behavioral/emotional services, services for persons with autism, cognitive retraining, augmentative communication, American Sign Language, preschool education and deaf/blind services, has been identified as a major concern from both the consumer and the agency perspectives. <NC>

Concerns were expressed at the public hearings and in the consumer survey that reflected a perception that children were being placed in inappropriately restrictive learning environments. The "least restrictive environment" standard is clearly mandated in P.L. 94-142 but is being inconsistently enforced in North Carolina. <NC>

Federal commitment under the original Title XVI, Part B of the Education of the Handicapped Act, P.L. 91-230 (1969), to achieve a 40% reimbursement rate for special education services has never been realized. <NC>

Schools are required to notify parents of their rights under P.L. 94-142 with regard to the education of their children with developmental disabilities. Some consumers presented testimony that not all schools comply with this requirements. <NC>

Although some federal and state funds can be used for transition services, only small amounts have been specifically budgeted for this purpose. Transition services are encouraged, but not required, as part of the special education program for school age children with developmental disabilities. <NC>

The need to transition students with severe disabilities is also an issue, as they currently are transitioned primarily to sheltered workshop settings and segregated group homes. <NE>

Interagency and intra-agency agreements are needed to coordinate services and funding sources to plan the student's smooth transition from school and adult life. Students are now faced with waiting lists and ineligibility for adult services from community based programs until age 21. Thus, services such as residential placement and training to effectively learn to live independently do not begin until after school training has ended. There is also a need to continue to look at how these functional/life skill issues are met within the school curricula. <NE>

Individual Education Programs (IEPs) are problems in some areas. Often they are completed prior to meeting with the parent and presented as a document for signature rather than this meeting being part of the plan's development. School districts are reluctant to identify needed services on the IEP if they are not available or costly. There is a perception that such a written statement could provide the foundation for a due process hearing although the federal law is unclear on this. As a result parental input is critical in assuring that the needs of the child are kept in focus. The very nature of IEPs

contain the risk that they may become standardized documents with children with this diagnosis getting this plan. It is only with active participation of the family that the child's individualized needs can be consistently addressed. <NE>

Transition planning currently is not effectively occurring statewide, as some districts do not feel this is the role of their special education teachers. <NE>

P.L. 99-457 has served to open up discussion on a variety of issues relative to preschool education. Although Nebraska has provided services to infants, toddlers, and preschool children since 1978, it has been the sole responsibility of the Department of Education and the focus has been on the child. With P.L. 99-457, an Interagency Council has been appointed to examine the issues of coordinating services and implementation of Individualized Family Service Plans (IFSPs). When the needs of the entire family are to be addressed then the need for interagency cooperation, including resource sharing, becomes essential. The Department of Education faces the challenge of convincing other agencies that they have responsibilities in these areas. One of the difficulties is the differences in eligibility for different programs. Educational services are provided based solely on diagnosis. If a child meets the eligibility criteria for a particular disability, the full array of services are available. However, other agencies may have criteria other than this. Income eligibility is a common one. Obviously, this can present a problem when a family is determined to need a particular service but is not financially eligible for it. This potential conflict between the provision of services that are an entitlement and those that are not is also evident in discussions surrounding IFSPs. Currently, since educational services are mandated from date of diagnosis, the IEPs written for this young population include the full protection of entitlement, due process, etc. The IFSP process has been proposed as more inclusive than the IEP with needs that are not entitlements. The issue becomes one of whether these services if written into an IFSP are then mandatory and families have the right of due process if they are not made available. As Nebraska begins to develop and implement this process these issues will need to be resolved. <NE>

Special education students who are taught in segregated classroom are often not given the opportunity to participate in classes or events that may be appropriate, such as assemblies, choir or physical education. Many factors contribute toward this situation. With the focus on special educators being trained with "special" skills, regular educators are reluctant to accept children with disabilities into their classrooms as they feel they "haven't been trained" so are uncomfortable with the situation. Some children would require accommodations to participate in certain activities and schools may be unsure how to make these or unwilling to take the extra time to work obstacles out. Regardless, it has become apparent that just having a special education classroom located in a neighborhood school does not guarantee integration of the students. Special efforts must be made by teachers and administrators to insure genuine interaction among all students. <NE>

Currently in Nebraska, special education students may remain in school until their 21st birthday, but at that date, regardless of the time within the school calendar, the student graduates. The school districts/ESUs are to coordinate and implement the many faces of transition: vocational training, job site practicums based on aptitudes and interest, functional independent living skills and other individualistic areas of need and that are identified in the student's transition plan in their IEP. Often the needed services cannot be accessed until after the student's 21st birthday. Meetings between the school and service providers are now beginning to address how to use traditional post-school services prior to age 21, to adequately prepare students for adult life. <NE>

Transition planning is mandated in Rule 51 of the Nebraska Department of Education Regulations. The rule suggests that transition planning begin at age 16 to facilitate whatever training the student will need to use their skills to hold a job, use community resources and live as independently as possible. Currently, there is a great deal of difference in how the transition planning is interpreted and implemented by school districts. <NE>

There are currently 862 school districts in Nebraska with 60% of them serving fewer than 100 students. Each has a school board that operates somewhat autonomously. This great number of school districts allows for a lack of consistency in eligibility and services provided. State level efforts have attempted to standardize the eligibility criteria. These discrepancies tend to occur at the milder ends of disabilities as far as eligibility is concerned. Most children with developmental disabilities would have no difficulty being found eligible. However, the services available could vary widely. <NE>

Despite a national trend in recent years towards regular school and regular classroom placement for children with disabilities, the percentage of students assigned to self-contained classes in New Hampshire has remained the same over the past several years. The Office of Special Education and Rehabilitative Services ranks New Hampshire 35th among states in their integration of students with disabilities. Differences in reporting procedures may account for some of these statistics. <NH>

Many parents have experienced difficulty in obtaining an integrated education for their children. As one parent put it, "schools have learned to use that word 'appropriate' as a weapon" to deny opportunities. Thus, in some instances language intended to assist consumers has been experienced as a doubled edged sword. <NH>

For many children, involvement in school extends beyond formal instruction. Students participate in clubs, teams, school plays, special events like the school prom, and other social activities. Schools vary widely in their openness to make the necessary accommodations so that students with severe disabilities can participate in this aspect of school life. One school district responded to repeated parent requests for their children to be allowed to participate in the school sports program by establishing a gym class for students with disabilities only. <NH>

Along with the growth of special education as a distinct discipline has been a widening separation between "special" and "regular" education. Such a separation cannot be healthy. One educator voiced a concern that "regular teachers have gotten the message that they can't teach special kids." <NH>

Parents object to the practice of bringing a pre-developed final IEP document to a meeting for their signature. Some say that services offered may be dictated more by professional and organizational convenience than the individual needs of the student. As one parent put it, "What is available is what is put on the IEP." And the meeting itself can be a "very intimidating experience" for parents, who may be mystified by professional jargon or fearful of a loss of services if they do not agree with what is offered. <NH>

The Education for All Handicapped Children Act envisioned that parents participate in the planning of individualized educational services for their children, and this vision is embodied in state rules requiring parental participation in the development of individualized educational programs (IEPs). But parents report that their participation in the development of educational plans is very limited. <NH>

Wide variation in the quality of vocational preparation can be found across school districts. Nationally, the most promising programs are community-based and offer individualized curricula. In many New Hampshire districts, "STEP" (Special Training for Employment Program) training (offered through vocational education) is not currently community-based or geared to the learning needs of students with severe disabilities. Some districts experience difficulty in finding staff experienced in job coaching or community skills training. <NH>

Coordination difficulties occur between schools and adult service agencies regarding the transition of students from schools to developmental Service Area Agencies. In a study conducted by the Institute of Disability 89% of SAUs reported that communication occurs with their corresponding Area Agency. However, the number of students expected to require Area Agency assistance reported by SAUs was far larger than the number expected to require Area Agency assistance reported by the corresponding agencies. This indicates that transition planning and inter-agency coordination may be lacking for graduating students or that school districts and Area Agencies have different perceptions of service needs and roles. It should be noted that Area Agencies are not mandated to provide services as an entitlement. <NH>

Adult education is provided to citizens in New Hampshire both through the state system of vocational technical colleges and through the continuing education programs of local schools. In several states, post-secondary curricula have been adapted to meet the needs of students with developmental disabilities. Consumers in New Hampshire infrequently participate in generic adult educational opportunities. This may be due to a lack of support, a lack of information, or a lack of transportation. <NH>

New Jersey has the highest percentage in the nation of women infected with the HIV virus, and ranks second in the number of pediatric AIDS cases. The majority of families with HIV-infected children are overburdened by poverty, drug abuse, illness, inadequate education and limited access to health care. Approximately 240 infants are born with the HIV virus in New Jersey each year. Current estimates suggest that between 60 and 90 percent of asymptomatic children with HIV infection have subclinical symptoms that may interfere with their ability to learn. Preschool and school programs for these children already exist, but eligible children sometimes have difficulty accessing the programs. <NJ>

Decisions, with input from physicians, regarding the need for the provision of home bound instruction are not consistently applied across local school districts. <NJ>

State regulations require a medical examination to determine a child's eligibility for special education, but there is no mandate that physicians directly participate in the decisions and deliberations of child study teams. The result may be inappropriate decisions about services and therapies, medically inadvisable elements in Individualized Education Plans, and poor management of medical conditions associated with a developmental disability in the school. <NJ>

Curricula should be comprehensive and provide a continuum of option and services to meet the needs, abilities and interests of all special education students. Instructional programs should be derived from regular curricula, ensure equal educational opportunities within the least restrictive environment, coordinate various program components and help ease transitions. <NJ>

While hospitals served more than 4,000 children and adolescents for head injury in 1985, a very small percentage received needed services to benefit from education. <NJ>

New federal regulations accompanying P.L. 99-457, Part H, allow flexibility in defining services within funded early intervention programs. Current New Jersey criteria tends to prevent a funded early intervention program or parent to freely choose from an array of funded services. For example, in order to be "counted" for funding, a child must receive a basic program session in addition to therapy or a service to the family. Such restrictions may force agencies to fit a child to available services, rather than individualize programs to meet the child's or family's needs. <NJ>

For 3- to 5-year old, related services are provided to help a child benefit from education programs. Parents who choose not to send their preschooler with a developmental disability to a segregated preschool-handicapped program may have no access to district-provided related services. <NJ>

Many therapists are trained within a strong medical model that works against the cross-disciplinary, integrated therapy model, which may be most effective for some children. <NJ>

There is a critical shortage of related-service personnel, particularly occupational and physical therapists. <NJ>

Approximately 1200 students are classified as "eligible for day training," which means automatic placement in a segregated facility. <NJ>

Some state regulations discourage integration of regular classrooms. In many cases, it is cheaper for school districts to send a child to a special services school district. This is a disincentive for integration. <NJ>

New Jersey is one of the five states that did not take advantage of new provisions under ECIA, which encourages movement of children from state-operated facilities to local school districts. <NJ>

Most students with severe disabilities continue to be segregated from other students in public schools. New Jersey continues to rely heavily on separate, "handicapped only" schools. <NJ>

School districts may offer a program within the district, or contract with another local district, special services school district or regional day school. Districts have not paid attention to the need for integrating children with disabilities with non-disabled children. As a result, preschoolers with disabilities are served in self-contained classrooms in large, segregated facilities. These children become deprived of many opportunities for positive, age-appropriate interaction with non-disabled peers. <NJ>

The classification and labeling of students by disability is arbitrary and may stigmatize the individual. The classification process is currently an important element in monitoring how well local districts and programs are serving the needs of particular types of students. It provides consistent criteria by which parents, the Department of Education and the federal government can judge the performance of program providers. There are problems, however, inherent in the unnecessary labeling of students. The Plan to Revise Special Education in New Jersey seeks to improve the situation by increasing the capacity of regular education to serve pupils with learning problems, without having to unnecessarily label them as disabled. <NJ>

Boards of Education are under no obligation to provide services not covered by the state's special education administration code. <NJ>

Most classification procedures are unreliable and invalid. The same student may be classified by one child study team and not by another. <NJ>

The federal government requires states to report special education data according to disability, while using labels to allocate and evaluate funds. This system tends to rule out the regular classroom as a possible setting for many students. <NJ>

The expertise and time of specialists tends to be used entirely on assessment and classification, instead of direct education services. An important goal of the state Plan to Revise is to increase the role of the child study team to provide services to pupils and teachers in special education. <NJ>

Students may experience lower self-esteem by being labeled; peers may treat them differently and teachers and parents may have lower expectations. Labels are particularly harmful to minority children, whose cultures and lifestyles make accurate assessment difficult. <NJ>

Classification and subsequent removal from a classroom often leads to programs that may not improve the student's learning opportunities. <NJ>

The typical special education curriculum, especially for students with severe disabilities, does not stress socially validated, functional life skills that include stated outcomes for successful participation in society. <NJ>

It is difficult to predict which agencies should be involved with the transitional process. It is equally difficult to garner agency interest and encourage interaction among different agencies. <NJ>

Secondary special education frequently does not incorporate outcomes for students and prepare them for successful adult life. <NJ>

Programs for students with severe disabilities should emphasize preparation for adult life in the least restrictive environment. <NJ>

The transition from school to adulthood and community life is not receiving careful thought and consideration in many secondary special education programs. <NJ>

Federal and state regulations emphasize the parent's right to be involved in decisions regarding their child's programs and stipulate access to due process in cases of dispute. In reality, however, parents are often confused and uninformed about their rights. <NJ>

Current New Jersey certification requirements have no mandate for special education training. <NJ>

There is not widespread support among teachers and administrators for integrating students with developmental disabilities into regular classrooms. <NJ>

Special education teachers have very little contact with regular education teachers on pre-service and in-service levels. <NJ>

There is a lack of comprehensive transition services in New Jersey for young adults with developmental disabilities who are graduating from special education. Consequently, these individuals leave school ill-prepared for employment. <NJ>

There is a serious shortage of qualified special education and related service professionals. Projections of both student and professional demographic data indicate that over the coming years services guaranteed under federal law. <NM>

Accessibility continues to be a problem in New Mexico schools. Many school buildings are old and were built before accessibility regulations were written. While most buildings are accessible, many students with developmental disabilities cannot fully participate in the programs offered by the schools. <NM>

Hispanics, Native Americans and African Americans are placed in special education programs and other restrictive settings disproportionate to their representation in the population. <NM>

Providing an appropriate education to students with low incidence disabilities (i.e., deafness, blindness) presents special challenges to rural states like New Mexico with numerous small school districts. State schools are providing outreach and assistance to small school districts. Several small school districts have joined to share staff and resources in regional cooperatives. <NM>

The educational potential of a student with a developmental disability, for example, might be substantially increased through the provision of specific computerized technology. In theory, that equipment could become a component of the student's Individualized Education Plan as prescribed by P.L. 94-142. In practice, if a school district's funds are limited, the need for this technology may not be "formally" recognized if and until an outside resource can be identified. The same student, if he or she has a severe disability, would again in theory be eligible to receive the equipment under the Independent Living Rehabilitation Services of .PL. 93-112, the Rehabilitation Act. Local policy, funding constraints or disagreement over whose "responsibility" it is to provide the service could prevent inclusion of this need in the Independent Living Service Plan and thereby disallow the service. <NV>

Inadequate qualified personnel and specialized resources for programming, equipment and educational materials for students with visual impairments or severe disabilities was the number one concern of both conference and survey participants. <NV>

Participants attributed much of the problem to failure of educational and rehabilitation personnel and community providers to effectively communicate with one another. There

is general belief that improved coordination among these entities, even without additional funding, would substantially increase meaningful implementation of individual education and transitional plans. <NV>

Lack of teachers and administrators who have been trained in the specifics of disability and in the technology and specialized curricula available for use in teaching students with severe disability. <NV>

Lack of funding for technology specialized curricula and appropriate vocational training. <NV>

Lack of timely, coordinated transitional planning for students with severe disabilities exiting the school system by aging, graduating or dropping out. <NV>

Parents whose children are coming out of an integrated education system are not ready to be told that the only programs choices available are sheltered workshops and day treatment centers. Their vision of the capabilities of their visions for their children's future are different from that of a previous generation. <NY>

Parents stated it was a waste of the state's monies to provide integrated educational services to the child and then abandon the child after the school years, by not offering appropriate choices for adult services. <NY>

While the large majority of students with disabilities are served in regular classrooms in public school, most students with severe disabilities are still served in self-contained classrooms in public schools or separate facilities designated as serving only students with disabilities. <OH>

County Boards of MR/DD operate a segregated school system, primarily for students with mental retardation. The County Boards provided educational services last year for approximately 11,000 children, at both the preschool and school age level. <OH>
Many County Board schools offer transportation, recreation, case management, and other auxiliary services to students and their families from the early years throughout adulthood. These services are not usually available to the same degree in the public schools. <OH>

For too many parents, agreeing to a "mainstreamed" education for their children in a public school can mean that their children will not receive the support services they need in areas such as occupational therapy, physical therapy, and speech/language services. <OH>

Accepting school placement in the segregated County Board system virtually eliminates the possibility of daily contact with students without disabilities, which both experience of daily contact with students without disabilities, which both experience and educational

research have proven significantly facilitates the development of social and functional community skills. <OH>

Students with more specialized needs, such as challenging behaviors or chronic medical conditions, present a major challenge in both in public school and County Board settings, where there are usually not enough classroom aides and teaching and support staff are not trained to meet these challenges. <OH>

The "debate" over public schools versus County Board schools reflects not so much a rejection of integration as a value but a genuine concern on the part of many parents and professionals over how the transition of services can be made, while at the same time ensuring quality in public school settings. <OH>

Ongoing educational opportunities are not available for adults with disabilities in most communities. <OH>

Although Ohio law mandates vocational education or continuing education to students upon request, there remains no assurance that graduates will be employed or in continuing education within six months of their graduation. <OH>

The problem with teaching children with disabilities in regular public schools is not the lack of money... it's that related services get spread so thin. <OH>

The attitude of school administrators, teachers, and other parents concerning "mainstreaming" is oftentimes unsupportive. This is especially acute pertaining to students with severe disabilities who require special aids. <OK>

The lack of professionals to provide specialized services to students with developmental disabilities such as physical, speech and occupational therapy. <OK>

The lack of special education teachers who teach children with autism, visual impairments, and other special disability categories. <OK>

Assistive technology equipment in the classroom to provide children with developmental disabilities equal opportunities to learn and to be mainstreamed into a regular classroom. <OK>

The lack of extra assistance by the school system in providing after school tutoring and summer programs for special education students. Of the 64,000+ students receiving special education services in 1987-88, only 369 received services in summer programs specifically designed for students with handicaps. <OK>

Training for parents to enable them to participate in the process of developing an individual education plan (IEP). <OK>

Oklahoma educational reform and funding is the primary public policy issue in Oklahoma. Twice it has caused special sessions of the legislature to discuss a tax increase to improve the quality of education offered to Oklahoma's children. Not once has the issue of improving the future of children with disabilities been raised by the media nor by members of the state legislature, when discussing this public policy debate. This absence of mention is perhaps the basis of the most serious barrier to improving education opportunities for children with developmental disabilities. This population does not have an advocate in the state representing education for children with handicaps. Special education issues are not being articulated on the floor of the legislature, in school board meeting rooms, in superintendents' meetings, or in parent-teachers organizations' agendas. <OK>

Professionals are not trained in special education for an unserved population of people with autism. There is a distinct lack of service providers in the areas of therapy, (speech/physical/occupational), especially in special education programs. This is particularly acute in rural areas. <OK>

The area of greatest concern expressed by parents, students, and teachers in the secondary public education system was the lack of preparation for the special education students to exit the system when they finished public high school by the age of 21. The result of not having transitional services available to individuals with developmental disabilities and their families is that there are many young people who are left with few viable options after leaving school and who have no preparation to access those systems outside of education. This problem is even more acute in the rural areas of our state where there are fewer opportunities for employment and day programs. <OK>

Rehabilitation Services of the Department of Human Services now makes available to the school district a counselor who is to contact every special education student at the age of 16 to determine what vocational needs they may have. This relationship, if successful, should assist the student to make a reasonable transition into community life, whether it be further education or employment in the community. However, this relationship between Rehabilitation Services and Education is once again a fragmented approach toward developing a transitional plan. <OK>

Other critical aspects of the special education system have received less speedy action. Of note here include insufficient responses to the call for a functionally based curriculum and for enhanced efforts to provide transition supports to students as they go from special education to employment and community living. Citizens with disabilities and advocates also note that little is generally being done to achieve mainstreaming of children with disabilities. <PA>

Other identified problems are the lack of sufficient coordination in the transition of special education students into community employment. Greater efforts besides the

Developmental Disabilities Council pilot are needed by the state to explore and initiate the conversion of sheltered workshops into supported employment models. <PA>

Schools and universities have many physical barriers, with no ramps or adapted restroom facilities. <PR>

Very few persons had heard of vocational educational and even fewer had participated. <RI>

Head Start in Rhode Island has a lower percentage of children with a disability than the national percentage and the percentage of the other New England states. <RI>

Most persons with cognitive impairments and with physical or sensory impairments received their education in special schools or in special classrooms. <RI>

Few transition from "school to adult life" programs are in effect in the public schools. <SC>

Vocational education is not readily available to all special education students. <SC>

Technical colleges need to take an active role in post secondary education of persons with disabilities. <SC>

Parent training regarding the laws protecting their children's rights is lacking. <SC>

Specialized supports do not follow the student into the integrated classroom. <SC>

Providing the least restrictive environment is an undermanaged component of the IEP. <SC>

Some districts say they do not have the resources to serve the students who require the most supports and that the students are better served in the Regional Centers. <SC>

Decisions on the least restrictive environment for students with disabilities are often made subjectively and procedures vary from district to district. Local school boards have the last authority. <SC>

The drop-out rate for students in special education is high and climbing. <SC>

A state plan for transition from school to adult life must be presented, adopted and implemented if students are to be prepared to enter the community with realistic expectations of fulfillment and productivity. This plan should include services for all students within special education (who have an IEP) and any other students with disabilities who may not be in special education but who may wish to have transition planning assistance. <SC>

At present there is no provision within the IEP for transition planning. <SC>

Students are "falling through the cracks" because of the mechanisms missing to link them to the adult services they will need following school. <SC>

Vocational education programs are not consistently available to all special education students. <SC>

IEPs often are missing parent signatures. Attendance of parents in planning sessions is crucial. Parent involvement needs to be encouraged. <SC>

Summer programming for students with disabilities is a critical issue. <SC>

Students should have more input in the IEP planning process. <SC>

Strong special education coordinators make home visits and outreach efforts, inducing parent participation; many districts lack this initiative. <SC>

One of the major concerns expressed throughout the preparation of the 1990 Report was the need for transitional services. Transitional services are those which facilitate change for persons with developmental disabilities from the school setting, to the community, to the workplace. Lack of proper transitional planning and the limited availability of supported employment programs leave many individuals with few options after exiting the special education setting. Little planning is done to prepare these persons with the skills and resources necessary for success in the community. <SC>

The initial work by the Department of Education and Cultural Affairs to implement the provisions of the Part H provisions of the federal Education of the Handicapped Act indicates that South Dakota is only now considering potential strategies for providing services to infants and toddlers with developmental delays or at risk of such delays. <SD>

One clear problem that emerged during interviews is that responsibility for early childhood services is so diffuse in South Dakota that parents are often confused about what steps to take to access needed services. In response to that problem, several state agencies are now collaborating on a pilot program to use case management services as a means of improving access to needed services. <SD>

It was also noted that the quality and consistency of preschool services varies substantially across the state. While state officials felt confident that the state was doing a good job of identifying youngsters with disabilities for enrollment in preschool programs, they expressed concerns about the effectiveness of programs in particular areas. <SD>

In South Dakota, there is a particularly firm partitioning of responsibilities between the special education and adult services systems. While this compartmentalization of service delivery, based on age, heightens accountability, several individuals commented that it also had unfortunate side effects. One such result is the lack of effective strategies for transitioning of youth with developmental disabilities from one service system to another. One individual commented that young people are "dumped into Social Services." <SD>

Transition planning appears to be inconsistent from one locality to another in South Dakota. <SD>

Funding at both the federal and state level for mandated programs is inadequate, so that education and related services are not available for all individuals with disabilities of all ages in all areas of the Tennessee. Funding to Tennessee under the Education of the Handicapped Act State Grant Program Act increased only 15.6 percent between 1980 and 1986. The number of persons served in Tennessee under this program declined by 2.8 percent between 1977 and 1987. <TN>

In Tennessee, 56.3 percent of students with handicaps who were 16 years and older dropped out of school during the 1985-1986 school year, a rate which is twice the national rate, and more than double the 24.7 percent dropout rate for all students in Tennessee. <TN>

Over 1,100 adults with mental retardation are currently on waiting lists in Tennessee for community mental retardation training programs. Many students with mental retardation or other developmental disabilities who leave public schools do not find an appropriate continuing source of training and support. <TN>

There is not an adequate number of trained educational and related services personnel to staff service programs. One measure of this in Tennessee is the extent to which teachers participate in the career ladder program, which provides financial incentives for improved competence in teaching. The career ladder program payments constitute almost 18 percent of the total salaries of regular teachers in institutional programs, but only 5 percent of total salaries in programs for the education of students with handicaps. <TN>

Obtaining necessary related services and environmental supports is often extremely difficult. Services are often provided according to what is available in the local districts, rather than according to which services are actually needed. <TN>

Parents of children with disabilities across the state are concerned about what will happen to their children when they graduate and are no longer entitled to receive education services from local schools. They are worried that special education programs will not prepare their children to work and live independently as adults. Parents whose children are out of school regret that their children did not gain functional work and community living skills during the years spent in public education. <TX>

Although the Texas Education Agency (TEA) does not have any statistics on the adult outcomes of students existing special education programs, it has been estimated that from 65-85% of all students with disabilities graduate without jobs. <TX>

The Council supports the new state special education initiatives in transition planning but believes the new requirements are complex and cumbersome and may not achieve the desired results. The major areas of concern are: (1) starting at age 16 is too late, transition planning needs to start earlier to identify students at risk of dropping out before, not after, they drop out; (2) a separate ITP will create additional paperwork and may require additional meetings; and (3) a separate complaint process may create confusion and not be effective for families or school personnel. <TX>

Both state and federal monitoring reports indicate that the vast majority of children with disabilities are still being educated in separate classrooms, buildings, facilities and nonresidential school districts. In actual implementation of the law, the trend is to exclude rather than include children with disabilities into regular classrooms with their nondisabled peers. <TX>

In Texas, many school districts state their role in interpreting and implementing "least restrictive environment to the maximum extent possible" is confusing. <TX>

In more recent years and due to part to litigation and efforts made by the Office of Special Education and Rehabilitative Services (OSERS), the trend has been to interpret the continuum of services to favor integration. However, school districts continue to experience difficulty in interpreting the intent of the law, and with an estimated 1,100 school districts in Texas, it is difficult for the Texas Education Agency (TEA) to closely monitor local district practices. <TX>

The way special education programs are funded in Texas rewards school districts for segregating students who have special needs. Extra dollars are generated for students in special education who are placed in segregated instructional arrangements. Even though Senate Bill 1019 provides some new incentives for school districts to move children with disabilities into more integrated school settings, the funding weights are still skewed toward segregated instructional arrangements and do not provide enough incentive for school districts fully implement the concept of least restrictive environment. <TX>

Another barrier to least restrictive environment is the scarcity of resources needed to implement these provisions. Many school districts tend to interpret "related services" so literally that if a service is not explicitly listed in regulations, it is not provided. Also, services are often provided according to what is readily available in the local district, rather than according to which services are actually needed. As a result, obtaining necessary related services and environmental supports is often extremely difficult. <TX>

Children with developmental disabilities (DD), if identified, receive services from birth to three years of age from the Department of Health. At age three, they become Public Education's responsibility and may continue to receive services from Public Education until age 22. At age 22, the Division of Services to the Handicapped (DSH) is legislatively authorized to begin day service. However, if the child with DD graduates from high school (or receives a Certificate of Completion at age 18), Public Education's responsibility is ended and DSH may not provide day service until the person is 22. Theoretically, the person receiving a high school diploma or a Certificate of Completion, as most do at the age of 18, is trained sufficiently to be able to be employed. In reality, this is not the case for many. Therefore, there is a hiatus in service of three to four years during which the person with DD loses skills gained during the Public education period. <UT>

A frequent complaint of parents in Utah is that they do not feel that they are welcome in IEP meetings. Some comment that they are not told of the meeting time and place; others are told that they really shouldn't be there; others are invited and simply do not respond at all to the invitation. <UT>

Diagnostic and assessment services are the most prevalent related services. Parents express considerable frustration about costly assessments that are not backed up with timely and even essential interventive services. <UT>

Even though Utah offers all twelve of the related services defined by federal definition, local educational agencies (LEAs) share personnel who deliver selected services. This is a particular disadvantage to rural communities who neither have the local resource people to utilize nor are able to access professionals from urban areas. <UT>

Funding for special education has long been a point of contention in the legislative appropriations process. Special education must compete with all education funding in a state with the second highest child population per capita in the nation. Unfortunately, state legislators have not recognized the investment potential in providing quality special education programs to students with disabilities. <UT>

There are some educational programs in place which could serve students with disabilities that are not accessible due to inflexible policies or simple complexities like scheduling transportation. One example is the Technical Center in Salt Lake City, a traditional vocational education program that could be used by students with disabilities in the Salt Lake City District, but they simply can't get a ride to the site. <UT>

The primary concern here is the extraordinarily large numbers of special education students who have a right to a free and appropriate education through the age of 21, but who are no longer in the system. The drop-out issue is clearly a problem for both regular and special education. The loss of special education students, the primary concern of this study, is creating an inordinate transition problem due to gaps in service provision. <UT>

Students are "falling through the cracks" because adequate mechanisms do not exist to follow and to link them to the transitional services they need. Transition services for young people under age 22 are non-existent. Once the school drops them, these students have a certificate of completion that is worthless to their future and they have no access to services. <UT>

Transition for those age 22 and over is not well-established yet and many are on waiting lists inordinate amounts of time, especially if their parents were not advised to get their child on a waiting list at age 20. Certain towns report that increasing numbers of students with disabilities who do not stay in school until their 22nd birthday are dropping out of the mainstream altogether and are becoming our most unfortunate street people. And those who remain in parental homes lose their skills and their hope for any kind of productive life. <UT>

Though a large percentage indicated a need for additional education or vocational training, a dominant theme was that these are too expensive to obtain. <VA>

Lack of consensus regarding federal and state standards for special education and insufficient/inadequate mechanisms for monitoring compliance, including least restrictive environment (LRE) placement, Individualized Education Plan (IEP) development and implementation, and adequacy of physical plants. <VA>

Providing students who have developmental disabilities with a comprehensive and effective educational experience must begin with an adequate supply of properly trained and appropriately endorsed teachers who are experienced in their profession. Currently, students of special education are frequently provided with instructors who have not received adequate training, are not appropriately endorsed to provide instruction, or have limited classroom experience. <VA>

Students with developmental disabilities are exiting schools (e.g., aging-out) without the skills or experience necessary to maximize their current or future independence, productivity, and integration into community life. <VA>

The majority of students with developmental disabilities are regularly denied access to, and experience with, age-appropriate peers who are not people with disabilities. <VA>

Not all persons with disabilities are taking advantage of the opportunity to obtain driver training while eligible for the school-based program. Many of these people realize the need for driving skills as young adults in the community at a time (beyond age 18) when it is much more difficult to obtain and pay for these services. <VT>

All students under 18 years of age in Vermont's schools, including those with disabilities, have the opportunity to take driver education at no cost to them; however, there is a lack of driver's education opportunities in the state for people with developmental disabilities

- particularly for people with physical disabilities - who may be over 18 years of age. Opportunities for functional assessment are limited and very few private driver education trainers are equipped to, trained for, and/or interested in providing services for people with disabilities. <VT>

Transition planning for the move from school to work settings and from the educational service system to the adult service system along with job training and work experiences are seldom available early enough (e.g., by 14 years of age). Consequently, students do not have the time to acquire the skills and knowledge necessary for success in the workplace. <VT>

The need for continued pressure to enhance education through P.L. 94-142, Education for All Handicapped Children Act of 1975, and P.L. 99-457, Education of the Handicapped Amendments of 1986. <VT>

Educational costs continue to rise and there are insufficient funds to appropriately educate all special education students. <WA>

When you offer flexibility to local communities, you often end up with inconsistencies between jurisdictions and geographical areas. It can truly be a matter of chance that children receive the early intervention services they need. Many parents feel frustrated at having to "shop around" for early childhood services. Frustration also comes up when parents move to another city or county in the state and seek services similar to what their child had been receiving. <WA>

Feedback from parents and advocates involved in early childhood education issues calls for more trained caseworkers, child care providers, teachers, therapists and doctors to provide for the growing need. Professionals who deal with early intervention services are not well informed when it comes to the unique abilities of children with disabilities. <WA>

People who work in the field of early childhood education are dedicated and hardworking but there aren't enough of them to provide needed services. There are some very real reasons for this — the first being low pay. Increasing training opportunities would also be a way to attract more qualified people. <WA>

Work is not yet completed on the development of a comprehensive early intervention program. Recommendations need to be implemented and coordinated. A focus also needs to be placed on the needs of children ages three to six years of age. <WA>

Teachers and other educational personnel are not provided with sufficient training and support to help them teach all students effectively. <WA>

Starting in elementary school, address occupational awareness, life choices and social skills in each student's Individual Family Service Plan. <WA>

Special education graduates should be prepared to continue their education or to enter the work world after high school. Studies show, however, that only a small percentage of special education students are finding long-term employment. <WA>

The Washington State Interagency Transition Report (October 1988) attempted to answer the question "What happens to special education students after they graduate?" Their findings (based on 1984-1986 special education graduates) reveal that 47% of special education students are unemployed, compared to 24% of regular education students; 5% enter supported or sheltered employment; 20% earn at least \$3.35 an hour; the rest earn less; 30% neither work or go to school; 16% go to college or vocational school, compared to 50% of regular education students; and 80% of students with mental retardation or physical disabilities live with their parents. <WA>

In a 1988 survey of special education teachers, parents and administrators from the Division of Developmental Disabilities and the Division of Vocational Rehabilitation, the areas of greatest need were identified as vocational training opportunities that include a wide array of options; more training and assistance for vocational and regular education teachers in working with special education students; community-based instruction that includes on-the-job experience; programs that facilitate social integration; and social and interpersonal objectives addressed in transition planning. <WA>

Some school districts cannot fulfill the legal mandate to notify and assess all students who may qualify for vocational training for programs because they simply don't have the money to do it. <WA>

Some special education directors do not know about the legal requirement for vocational training assessment and notification. There are few professional evaluators and — when they are available — hiring them is very expensive. This creates a staffing problem for small districts. <WA>

Training for transition to employment is often insufficient in terms of supporting students, teachers, and employers. In addition, there are many excellent projects addressing these issues but many are not duplicated or extended because of insufficient funding or lack of awareness. <WA>

The Adult Basic Education (ABE) system is not well prepared to deal with special needs students. The basic goal of the program is to help adults achieve literacy but waiting lists are long and the program is underfunded. <WA>

School and programs providing adult education services do not have the resources to work with students to assess individual interests and abilities. Quite often, these training programs have no prior knowledge of the special assistance a student may require. This again points to the importance of an individual plan staying with a person beyond the age of 18. <WA>

It is particularly a problem that we have to label people (or put them in a category) in order for them to receive education and related services. On the other hand, no one wants to lose sight of the advantages gained by mandated services. We must find a middle ground. <WA>

Special education students are faced with a number of problems when they attend public school. Programs aren't always sensitive to an individual's unique needs. Issues around accommodation and physical access with respect for cultural, ethnic and geographic differences must be respected. <WA>

School administrators say the need for guidance, counseling, vocational evaluation, training and transition services is paramount to decreasing the drop-out rate of special education students. <WA>

The two federal funding programs making a free and appropriate public education for all children a legal right and responsibility go a long way toward their goal, particularly when their funding is combined with state and local funds. Nonetheless, students with special needs still experience fewer educational options than their peers and drop out of high school at a significantly higher rate. <WA>

Even with current laws and well-intentioned philosophies, students with disabilities still do not have as many educational opportunities as do their nondisabled peers. <WA>

Different school districts offer different programs that may or may not meet a child's needs. Accessibility of programs may differ greatly from city to city and from state to state. <WA>

Different programs and different government agencies use various definitions of developmental disability and handicapped to determine eligibility for educational services. In many cases, confusing or restrictive eligibility criteria may deny children access to the very help they need. In addition, the curriculum offerings may not be practical or realistic nor are all services offered in all areas. <WA>

Schools are faced with personnel inadequately trained to effectively work with people with disabilities. Teachers also need trained aides and parent volunteers for classroom assistance as well as money for equipment and supplies. <WA>

The extent of classroom integration varies by school district. <WA>

It goes without saying that funding of special education programs must be stable for long-term success. More funding is also needed to train students to deal with the real world after high school. <WA>

There are some barriers to providing a good education in truly integrated settings. Insufficient funding for personnel and materials is one road block. Some students (having experienced it all their lives) are more comfortable and adjust better in segregated settings — in fact — some families say they prefer it. The biggest barrier is often educating other children to accept and support someone who is different than they are. <WA>

Transitional employment services in Wisconsin are not available in all Wisconsin schools. There are no clear mandates at either the federal or state level. Also, there are no clear guidelines on what transitional employment services should encompass, which students should receive the services, and when in the student's education these services should begin. <WI>

Most students with moderate/severe mental retardation were still receiving the majority of their education in separate classrooms (in Wisconsin, 73.6% of the placement of these students was in separate classrooms). Of the students with disabilities placed in regular education, only .17% were individuals with moderate/severe mental retardation. <WI>

Because of state-by-state differences in the way data are reported to the U.S. Department of Education, it is not possible to make accurate state-by-state comparisons. <WI>

The percentage of funding at the state level has decreased annually since the 1986-87 school year. For example, despite the fact that state statutes define the level of state program aid to be 63% of the amount expended by the county, agency and school district during the preceding year for certain reimbursable costs, the total categorical aid paid in 1988-89 on 1987-88 exceptional education needs program costs was at a 57.72% level. <WI>

Wisconsin has made significant strides in increasing general student awareness of students with disabilities through the student awareness contest conducted in regular education classrooms. This has been a major cooperative effort of the Department of Public Instruction and the Wisconsin Council on Developmental Disabilities. Despite these efforts, more needs to be done in the area of awareness. <WI>

The data collected at both the federal and state level is based on a definition that has a limited focus (i.e. a focus only on a school to work transition). <WI>

There is currently no established system for informing parents who have children existing the school system of the services available through the adult services system. <WI>

While there is overwhelming evidence of the benefits of providing early childhood services to those children "at risk", as well as those who are actually experiencing delays the estimated cost of \$15 million to implement P.L. 99-457 is prohibitive unless there is greater federal participation in funding early intervention. <WV>

Both survey data and anecdotal reports from consumers and families confirm that there is a severe shortage of vocational opportunities for adults with developmental disabilities. The lack of sufficient vocational services constitutes the biggest barrier to successful transition planning from public schools to the adult service system. <WV>

Children from age three until age 21 are served in Wyoming but not entirely through an education mandate. Education agencies in Wyoming, by state law, are allowed to serve children when they turn five and enter kindergarten until the date of their 21st birthday. Children from age three through age five may be served through regional child development centers operated through the Division of Community Programs. <WY>

Of particular concern in Wyoming is the shortage of certified or licensed related service providers such as physical therapists, occupational therapists, speech pathologists and others. <WY>

Wyoming is unique in this approach to special education services to three to five-year-old children since the Division of Community Programs is the provider but the State Department of Education, under federal law, receives the federal funds and is responsible for assuring that all provisions of EHA are met. While this approach makes use of the existing service delivery system for preschool children, the level of funding available to the service providers raises concern about the ability of this system to provide free and appropriate services to preschool children with developmental disabilities. <WY>

In Wyoming most students are educated in the public school setting, however, schools rely heavily on resource and self-contained classrooms where students are, in effect, segregated. For many students the only integration opportunities offered are lunch, art class or physical education with their peers. <WY>

When young adults turn 21 and become ineligible for services provided by the school districts, the existing adult community programs in Wyoming lack the capacity to handle the flow of individuals with developmental disabilities from the school system. Another critical point is encountered when individuals with developmental disabilities lose their existing family support structures because of aging parents and siblings. <WY>

EDUCATION: RECOMMENDATIONS

Multiple States

The 0-21 age range for service eligibility should be implemented across all states and territories. Eliminating the opportunity for states to exercise discretion with regard to the age range will help to ensure that more individuals with developmental disabilities receive early intervention, pre-school, as well as vocational services. <LA,MT>

A plan should be developed for better federal level data collection. Federal requirements should help insure that all data that is presently collected continues to be so, that other areas of data collection are added as needed, that comparable information is readily available for the same school year, and that data are made comparable by mandating consistency across the use of various definitions. <ID,MT,TN,UT,WY>

The least restrictive environment (LRE) (most enabling) concept must be scrupulously adhered to. The individual should not have to change before he or she can take part in the most integrated setting, but rather there should be more emphasis on changing the related services so that he or she can take part in this setting. Federal language should help clarify that "whatever it takes" are the services that should be delivered. <ID,MT,TN,UT,WY>

The use of segregated school facilities should be eliminated. <LA,MT,WY>

Mandatory collection and reporting of appropriate data may help to ensure that more individuals receive transition services. <LA,MT,UT,WY>

Plans for transition should be developed and implemented at the local levels. <LA,MT,TN,UT,WY>

Federal policy should help ensure that each local education agency (LEA) has an on-going drop-out prevention program which specifically addresses the needs of the special education population. <ID,LA,MT,UT>

Educational service systems should be designed around individual needs. The focus should be on preparing individuals for life, giving them the functional knowledge and skills to actively take part in it. Functional curriculums should be developed and adopted by local education agencies. <ID,LA,MT,TN,WY>

Adequate federal funds should be available in order to support and enhance state and local contributions. Federal contributions should move quickly towards the originally promised 40% reimbursement rate. <ID,LA,MS,MT,NM,UT,WV,WY>

Individual States

The state Department of Education should require and enforce that local district accounting systems charge actual special education expenditures to special education accounts so that advocates can work at the local district level to insure funds are spent where needed. <AK>

The Alaska Legislature should fully fund Infant Learning Programs. State legislatures should be urged to adopt the program as an entitlement program and provide sufficient funds to eliminate all waiting lists. <AK>

The Division of Mental Health and Developmental Disabilities, the Division of Vocational Rehabilitation and the Department of Education should form a group to plan for the residential support and employment needs of young people graduating from or finishing high school. The work of this group should also include developing new funding mechanisms and methods of simplifying the movement from one system to another. <AK>

The Department of Education should ensure that all Alaskan school districts provide meaningful summer programs for special education students who need such services to maintain gains made during the school year. . <AK>

The Special Education staff and Bilingual staff at the Department of Education should develop a means of assessing students for language proficiency. The Department of Education should provide technical support to school districts in developing culturally and language appropriate screening and evaluation methods. <AK>

The Alaska Board of Education should require that all districts develop a plan for full inclusion of students who experience disabilities, including providing all special education programs in integrated school settings; a community-based, functional curriculum that prepares students for full community participation; and encouragement of regular collaboration between regular and special education staff and programs within school districts. <AK>

Funding should be increased to reduce teacher/pupil ratios and provide training and support to regular and special education teachers who serve multiple grade levels and a wide range of exceptionalities. <AK>

Pre-vocational planning and educational services for eligible students enrolled in special education should begin no later than when the student is twelve years old and be community based. <AK>

The state should support the development of in state training programs for physical, occupational and speech therapists or alternative out of state programs that offer

incentives for people to become therapists and return to Alaska. At the same time, the state should create mechanisms to train, legitimize and support paraprofessionals in providing specialized services in rural and remote areas. <AK>

Planning for the transition from school to work should involve the parents and the private sector and should become a part of the IEP by the time the student is fourteen years old. Transition planning in rural areas must be compatible with the subsistence lifestyle and/or cultural differences of the area. <AK>

The Alaska State Program for the Deaf in Anchorage provides educational services to school-age children who experience deafness. Children from rural areas of the state must leave their home communities and live with foster families in Anchorage if they are to attend the school. <AK>

The state Department of Education should provide technical support to schools developing screening and evaluation methods and preschool services for children with emotional disabilities. <AK>

Parent education and support groups should be encouraged and financially supported by the Alaska Department of Education and by each school district and the state Department of Education and recognized as allowable special education expenditure under related services. <AK>

The Department of Education should work with rural school districts, the State Program for the Deaf, the Special Education Services Agency and parents to develop educational and support options for children who experience deafness. <AK>

All educational programs must be strengthened and appropriately funded, including prevention; educational programs for students ages birth to 22 years; pre-vocational/transitional programs; vocational education; leisure/recreational programs; pre-service, continuing education, and specialization for professionals in the fields of health, education, and social sciences; programs for primary caregivers, including family members, and direct care workers; and educational programs for public policy makers. <AL>

Place continued emphasis on the mandate to provide age-appropriate educational services in the least restrictive environment from the child's initial entrance into the system, including children with the most severe disabilities. Parents, with the assistance of the Council and the Protection and Advocacy Agency, must take an active role as monitors and advocates to ensure that the mandate of PL 94-142 is actualized throughout the state for all children and disabilities. Where mainstreaming is in place, adequate supports must be provided to ensure success. <AR>

The responsibilities of DDD, RSA, and ADE need to be clarified with regard to persons with developmental disabilities, aged 16-22 (both for students and for those who have left school). <AZ>

Efforts must be made to identify, develop and implement appropriate, cost effective models of staffing, personnel training and certification, and administration of preschool programs in Arizona in accordance with federal law. <AZ>

The 10% set-aside to fund vocational services for students with disabilities under the Carl Perkins Act should be continued. <AZ>

There needs to be increased cooperation between Special Education and regular Vocational Education programs. <AZ>

Vocational programs in Special Education should be expanded to serve more students in Special Education. <AZ>

In implementing the principle of least restrictive environment, policies should assure that special education students have the same opportunities as other students. (For example, they should transfer from elementary to high school at the end of the school year, and not on their birthday, etc.) <AZ>

The Arizona Department of Education needs to propose and advocate for, and the Legislature needs to support legislation making preschool education services available in all school districts for children aged 3 to 5. <AZ>

Adequate funding and other strategies need to be developed to increase the availability of related services statewide. <AZ>

There should be more accountability and coordination provided for local school districts from the Arizona Department of Education to ensure consistency and enforcement of P.L. 94-142. <AZ>

The Arizona Department of Education needs to propose, and the Legislature needs to support funding of the extended school year for students to assure that they will continue to benefit from their educational program and will not regress significantly during school breaks. <AZ>

Cooperative efforts should be promoted between the Arizona School for the Deaf and Blind (ASDB), DDD, ADE and local school districts to enable ASDB to support and fund local educational agencies (LEAs) in the provision of appropriate services for individuals with sensory impairments in neighborhood schools within a specified time period if parents request that options. <AZ>

Additional pilot projects modeled after the interagency agreement between RSA and the Pima County School District should be established to enable the state RSA to place students in jobs while they are in high school to ensure a smooth school to work transition. <AZ>

Efforts should be made to determine what barriers exist for having local school districts match federal vocational rehabilitation funds (e.g. difficulty of districts coming up with matching funds, local autonomy, resistance to the state RSA providing services directly to students, etc.) and strategies must be developed to maximize cooperation between RSA and local school districts in the development of work preparation programs. <AZ>

Parents should be informed regarding the potential for increasing resources through the state RSA to improve the transition of their children from school to work. Parents should also be encouraged to promote cooperation between their local school district and the state RSA. <AZ>

The Arizona Department of Education should assist school districts to develop and implement plans to increase parent involvement in team building with the school. <AZ>

Early involvement with the Rehabilitation Services Administration (RSA), the DDD and other relevant vocational training programs in school-to-work transition planning needs to be actively promoted. <AZ>

The DDD should work cooperatively with school districts to facilitate the transfer of educational services for children aged 3 to 5 to assure the safety of the children, and that standards and policies on certification are appropriate. All education funding budgeted by DDD for children aged 3 to 5 by DDD should be transferred to the Arizona Department of Education. <AZ>

"Least restrictive environment" must be enforced. There must be real integration in school settings. This requires a change in attitudes as well as an increase in resources for physical plant development. The special education system must break away from providing traditional services in traditional settings. <CA>

The commitment and prestige of teaching special education must be revived through improved salaries and changes in public attitude. This should be a more appealing career choice and not just a job for the "most dedicated". <CA>

The IEP process must be examined and its implementation monitored more closely. Parents must be trained and encouraged to be more intensely involved in planning and advocating for their children's rights and service needs, and utilize due process provisions more effectively. <CA>

Interagency coordination must be improved to enhance the provision of "related" services to special education. There must leadership in the creation of collaboration efforts among key agencies on this issue. <CA>

Both state and federal commitments to special education must be examined. The budget shortfall must be eliminated so that public education is provided to individuals who are entitled to it. <CA>

A state budget commitment must be made to establish a more comprehensive early intervention services system in California for infants and children age 0-5 years, taking advantage of available federal funding to supplement these services. <CA>

Advocate a state mandate for public school services for three and four-year-olds with handicapping conditions. <CO>

DRS's efforts as "lead agency" for the transition of children with disabilities from education to work is thwarted by the lack of state policy supporting integration into public schools and the Connecticut Department of Education's failure to provide adequate funding. <CT>

More attention is needed in the areas of integration, the implementation of a functional curriculum and transition services from school and adult life. Funding authority and categorical aids that serve as disincentives to integration in regular schools and classes need to be changed. The policy of "least restrictive environment" calls for the presence and participation of students with developmental disabilities with other students. Isolating either group denies opportunities to learn from one another, to observe role models and to cultivate a broader range of social relationships and attachments. <CT>

DRS should use its "inside" relationship with the State Department of Education to advocate for changes in policy to assure the content, style, people, objectives and places of education are age appropriate and individualized, and that interactions with nondisabled peers, and others, is essential. DRS cannot be expected to integrate a child with a disability into the world of work when the child has not be integrated into his or her classroom in the neighborhood public school. DRS must point out how Connecticut's "special education" policy contributes to the unemployment of people with disabilities. <CT>

Increase the provision of vocational education services to children with disabilities in the 14-22 age range. It is far simpler and more cost efficient to provide vocational training in the schools than trying to do so after years of opportunity have been lost. <CT>

There is a need to improve and to expand the community outreach program to bring about a greater awareness of the special education program for children with developmental

disabilities and to reach those who are eligible for the program but are not being served by it. <DC>

Given the universe of the problem, increased federal and local funding is vital for the special education program. Both parents and educators agree on this. Inadequate funding hampers the efforts of the state education agency to provide well-trained and qualified teachers and specialized instruction for the student. <DC>

A greater effort must be made to achieve the integration of students with developmental disabilities into the regular classroom. Such placements allow the student to enjoy more interaction with the non-handicapped and is far more beneficial to them than segregated environments. <DC>

The Council's Transitional Plan for fiscal year 1990-1991 should be recast to accomplish the state goals, objectives and activities within a more compressed time frame. <DC>

A pilot program utilizing professionally trained and fully certified school social workers trained in addressing "at risk" problems should be established. These professionals could perform crucial linkage functions between schools and agencies, as well as address family and culturally related problems. <DE>

Delaware needs to improve the integration of social services and school programs. A program should be initiated to improve the linkage of state social services with schools. Some possibilities are services that counsel on delinquency, teen pregnancy, child abuse, and persons with learning disabilities. The state and the United Way of Delaware should be asked to implement recommended programs. <DE>

The Department of Public Instruction should continue the long-range planning of the Least Restrictive Environment (LRE) Initiative under P.L. 94-142, The Education for All Handicapped Children Act. This initiative, if implemented effectively, can reduce the educational and social isolation of students with disabilities. <DE>

Delaware needs to help protect the children of young parents from being "at risk." Curriculum for teen parents should have information on child development and "How to Parent," in addition to academics. <DE>

Actively pursue adequate federal funding of educating for handicapped students to obtain the originally promised 40% reimbursement rate through EHA-B, P.L. 94-142. <FL>

Increase efforts to ensure that young people with developmental disabilities receive appropriate guidance, counseling, vocational and career education, and transition planning and support services necessary to assist them in planning for, choosing, and obtaining post-secondary school education, training and work options. <FL>

Proactively address the need for improved communication and collaboration between educators, providers of related services, and parents and aim for effective partnerships. Empower parents to exercise informal choices regarding the education of their child. Focus on what the student with developmental disabilities needs and how those needs can be met through creative action which expand the current limit is of an individual agency. <FL>

Continue to expand the availability and quality of transition services for young people with developmental disabilities who are leaving Florida's public schools. Ensure that transition plans address the major life areas of living, learning, working and playing. <FL>

Require all local school districts to conduct periodic studies of the state of exceptional students after their exit from public schools. Ensure that young people with developmental disabilities are adequately represented in these studies. <FL>

Aggressively implement public awareness activities and training for providers which illustrate the right to education in integrated settings, and the specific models for successful education in the least restrictive environment. Emphasize that planning for the individual should begin with the regular, integrated classroom and only move to more restrictive placement when supported by evidence that such a placement is required to provide an appropriate education for the student. The supports which would be required to educate the young person in each setting and the rationale for why this option would be harmful to the person or his/her other classmates should be determined and documented along with any rationale for why this setting is not the appropriate placement. <FL>

Identify at risk preschool children. <GA>

Recognize exemplary teachers. Teachers and peers who make community integration work should be recognized. <GA>

Promote teacher retention. Research should be conducted to understand why good teachers and therapists stay on job. <GA>

Promote training that will promote community integration with scholarships to parents, students, teachers, special education coordinators, principals, or superintendents. <GA>

Expand educational opportunities. <GA>

Ensure access to all educational environments, free from architectural and attitudinal barriers. <GA>

Summer school programs for students with developmental disabilities should be increased and enhanced. <GA>

Curricula should be examined to ensure that functional components are included and that they are appropriate and aid in assisting individuals to function as independently as possible. <GA>

Investigate the need to increase extended school year programs for students with disabilities. <GU>

The Council recommendation is to review existing post-secondary education opportunities available through Guam Community College, University of Guam and other private vendors to determine the extent of accessibility and availability of programs to meet the needs of individuals with disabilities. <GU>

An evaluation of the existing segregated day school programs for children with disabilities should be conducted to assess the feasibility of integrating eligible students within regular school campus. <GU>

The Department of Education should provide incentives for districts and principals to use a team teaching model for including special education students in "regular" classes. <HI>

The Department of Education should take the following measures to decrease special education staff and special services personnel turnover: assure student/teacher ratio appropriate for learning; convert temporary positions to permanent; and establish incentives for special shortage categories. The Hawaii state legislature should allocate adequate funds to allow the Department of Education to take the above measures. The State Planning Council on Developmental Disabilities should advocate for this funding in support of the Department of Education request. <HI>

The Department of Education should develop programs and foster a climate which promotes acceptance and understanding among all students about disabilities. <HI>

The State Planning Council on Developmental Disabilities should monitor the state of Hawaii "A+" after school program to insure that children with disabilities meeting the program eligibility criteria are included in the program. <HI>

The Hawaii state legislature should mandate and provide funding for the Department of Education to provide adaptive physical education. <HI>

The State Planning Council on Developmental Disabilities should be made responsible for the follow up monitoring of federal Offices for Civil Rights and Office of Special Education and Rehabilitation Services reports. <HI>

The Department of Education should develop and implement a system for an outcome evaluation of the special education program. <HI>

The Community College system and the Department of Education should provide adult education programs designed specifically for persons with developmental disabilities. <HI>

The Department of Education should make the necessary accommodations for all disabilities in formatting the Hawaii State Test for Essential Competencies (HSTEC). This is the test given to students which determines whether or not they can receive a diploma. The present format discriminates against some students with disabilities who cannot read fast enough or are hearing impaired. The HSTEC test should be adapted to enable all students equal opportunity to pass and receive a diploma. <HI>

The Department of Education should take a pro-active posture in informing parents of their child's education and related services rights. The Department of Education should develop orientation classes for parents. The Protection and Advocacy Agency of Hawaii should make educational rights a high priority area. <HI>

The Department of Education should expand its educational program for special education students to give them functional knowledge and skills to live independent and productive lives. <HI>

The Department of Education should develop procedures to insure that the Chapter 36 deadlines for identification and assessment are adhered to by all personnel in all districts. If additional resources are required, the Department of Education should ask the Hawaii state legislature to allocate sufficient funds for this critical program. <HI>

The Department of Education should expand its efforts to assure all students are identified early and provided with appropriate education and related services. <HI>

The Department of Education should commission a longitudinal study to determine if children leaving the early intervention programs are appropriately identified. <HI>

The State Planning Council on Developmental Disabilities supports the Department of Education's effort to refocus eligibility criteria in a noncategorical manner and recommends that the Department of Education seek further community input before finalizing the criteria for eligibility. <HI>

The Department of Education should develop a plan by 1991 for elimination of all segregated special education school facilities. The plan should include a timeline for making all schools accessible, with students placed in their home community according to their individual needs. <HI>

The Department of Education should scrupulously adhere to the concept of "least restrictive environment" (most enabling). They should request the legislature to expand resources to provide appropriate services to special education students, particularly those

with unique needs such as children with learning disabilities/attention deficiencies, with mild mental retardation, with hearing impairment and with technological needs. <HI>

The Hawaii state legislature should increase special education funds to insure that special education services are being provided in the least restrictive environment with adequate resources to provide the necessary related services. <HI>

Congress should act to insure that federal funds are increased to states until they meet the originally promised 40 percent level in support of P.L. 94-142. <HI>

The Department of Education should expand its related services to include any and all services which assist a child with a disability to benefit from special education. <HI>

All school districts need to be provided instructional training regarding employment alternatives for implementation of pre-vocational and vocational training, and career awareness, beginning at the eighth grade level. <ID>

A strong partnership between case managers and parents of infants and toddlers with disabilities must be encouraged to assist parents in becoming effective case managers for their children, especially as their children, transition on to pre-school services where case management is no longer required. <ID>

Statewide training opportunities for job coaches and work coordinators in the school system who work with individuals with a developmental disability, in order to increase skills, need to be identified and implemented. <ID>

There needs to be increased monitoring of Vocational Education Title II A funds in local school districts. <ID>

Idaho education should focus more on vocational training and less on academic curriculum when appropriate. <ID>

School financing methods favoring segregation should be replaced with restructured mechanisms which reward regular education placements, including adequate supports, and encourage the collaboration of regular and special education. <ID>

Transition plans should be initiated by school personnel and be developed and implemented at the local level by a multi-disciplinary team, including students and their parents. These plans should be required for all special education students, at least by the middle school years, and the goals coordinated with those in the IEP. <ID>

While federal language could help clarify the related services that should be delivered, Idaho should implement the LRE/"most enabling" concept regardless. <ID>

The birth-21 age range for service eligibility should be implemented across Idaho. Eliminating the opportunity for Idaho to exercise discretion on the age range will help to ensure that more individuals with developmental disabilities receive early intervention, pre-school, and vocational services, for full life development as soon as possible. <ID>

The use of segregated school facility models should be eliminated. <ID>

Personnel preparation and training efforts, both pre-service and in-service, should expand to regular education teachers, paraprofessionals and related services providers with a revised role for the special educator as consultant and co-teacher. <ID>

Since parental involvement is critical to the success of a child's development and educational experience, the professional community must encourage and support that involvement in order to create a system that is "user friendly" and that recognizes the importance of the family. Concurrently, parents must pursue that involvement by aggressively advocating on behalf of their children for the service to which they are entitled. <ID>

Special education funding must follow the student, regardless of placement, and financial changes supportive of mainstreaming should not be regarded as an effort to dilute or lessen funding for special education programs. <ID>

Funding for education programs for gifted and talented students should be regarded separately from special education funding for children with disabilities. <ID>

A statewide task force of parents and consumers should be commissioned to review federal and state special education funding to determine if they result in disincentives to integration and to make recommendations to the Governor and the General Assembly. <IL>

State and local school district policies should be changed so that students, regardless of the severity of their disabilities, have the opportunity, in regular, neighborhood schools, to attend classes with and to participate in school activities with students who are not disabled. <IL>

Indiana shall mandate early intervention and special education services to all children and youth with disabilities from birth to age 21 in the least restrictive environments. <IN>

Indiana shall institute a system of in-service training and technical assistance for general education professionals designed to increase their ability to serve special education students in mainstream environments and shall require the inclusion of course work on disabilities for all education students and professionals. <IN>

Indiana shall have an effective monitoring system for all public agencies providing special education and early intervention (which shall include technical assistance and a continuum of sanctions). <IN>

Indiana shall provide any needed support (e.g., interpreters, readers, attendants, adaptive equipment, assistive learning devices) for students attending preschool, elementary, secondary, vocational, and post-secondary education programs. <IN>

Indiana shall give first priority to the integration of all students with disabilities in neighborhood schools, unless it is clearly demonstrated that the needs of a particular student cannot be met in that setting. <IN>

Indiana shall provide all services (OT, PT, related services, etc.) on the basis of individual student need and in the least restrictive environment. <IN>

Students with disabilities exiting school programs shall be prepared for higher education, vocational school, or integrated community employment. <IN>

Indiana shall ensure planning and procedures for a smooth transition from preschool to public school and from public school to adult life for students with disabilities. <IN>

Indiana shall develop university and vocational training programs and/or reciprocal agreements with other states to assure that an adequate number of certified/licensed personnel are available to meet every intervention and special education program needs (e.g., teachers of students who are blind, preschool teachers.) <IN>

Indiana shall ensure that there are effective transition programs from school to work for students in special education. <IN>

Indiana shall allocate the necessary funds to provide early intervention and special education programs and related services to all children with disabilities or at risk of disabilities. <IN>

Special education allocations should be increased to 40 percent as originally promised, and states should be required to serve children from birth through twenty-one. <IN>

Indiana shall mandate that integrated educational services be provided for all people with disabilities from birth to age 22 in their neighborhoods and with their peers. <IN>

Indiana shall foster positive peer interaction and social development through such programs as peer-tutoring, awareness curriculum, and participation in extra-curricular clubs and activities. <IN>

Indiana shall encourage the development and adoption of general curriculum materials and textbooks which depict people with disabilities as contributing members of society. <IN>

Indiana shall expand the development and implementation of a comprehensive system of training based on needs assessments of parents, students, educators and other interested advocates. <IN>

Consumers with disabilities or parents of children with disabilities shall be required on all recommending and governing bodies related to special ed services, giving equal representation to all people with disabilities, including those with deafness. <IN>

MRU (contractor) recommends that the Kansas Association of Rehabilitation Facilities (KARF) support the reporting of enrollment data by school district AND by county so that county and regional trends can be monitored in the future. The state special education staff indicate that beginning in December 1989, the enrollment data will be reported by school district and county. <KS>

MRI (contractor) recommends that the state establish a monitoring system to track students with developmental disabilities and their entrance into the service delivery system after they exit the school system. <KS>

The State Department of Education should monitor and enforce standards in the Education of Handicapped Children Act law and R.S. 17:1941 et seq. for Least Restrictive Environment in local educational agencies. <LA>

The State Department of Education should continue to provide training and technical assistance on Least Restrictive Environment. In addition, the Developmental Disabilities Council's Child Development Task Force should collaborate with the State Department of Education in identifying video tapes on school integration and develop a mechanism for statewide dissemination to schools. <LA>

The State Department of Education should include out-of-state educators and parents to speak on successful integration in their states at the department's annual Super Conference. The State Department of Education should also focus on least restrictive environment in their regional parent workshops. <LA>

The Developmental Disabilities Council, the Advocacy Center for the Elderly and Disabled and other advocacy agencies should recommend that the Board of Elementary and Secondary Education direct the State Department of Education and local educational agencies to make integration of students with disabilities into regular schools and programs a priority and to allocate resources accordingly. <LA>

The Comprehensive System of Personnel Development should develop recommendations on competencies needed by regular, special education and other educational personnel to

teach children with special educational needs, recommend the allocation of resources to develop a training system for these competencies, and monitor the implementation of the system. <LA>

The Developmental Disabilities Council, Louisiana Rehabilitation Services, and the Office of Human Services should negotiate with representatives of the State Department of Education to develop long-range incentives, policies, and procedures for improving school curriculums and to remove those barriers that prevent local education authorities from developing and implementing functional community-based curriculums. <LA>

The DD Council's Supported Employment Education Project should closely coordinate its training activities with the Project PROMPT (Parents Reaching Out for Model Parent Training), the Individualized Education Program, and other parent training programs to insure the maximum use of training resources to inform parents of their rights and responsibilities with regard to special education and transition services. <LA>

The State Department of Education should continue to jointly fund transition service demonstration projects with the DD Council and other agencies such as the Louisiana Rehabilitation Service and provide incentives for local education agencies to develop community-based instruction, vocational training, and comprehensive transition plans and services that target students as early as possible in their school careers. <LA>

Eliminate Chapter 766 funding disincentives which cause communities to place children in out-of-home care. <MA>

Schools should coordinate with other agencies and local resources. Every school system should have a person assigned to be responsible for resource development and networking. <MA>

Disability awareness should be a standard part of the public school curriculum and required training for all school personnel. We suggest a statewide disability awareness week in the schools. Training should go beyond physical integration issues to address inclusion of people with disabilities in community life as valued and involved community members. School systems should provide adult role models for students with disabilities by hiring more qualified individuals with disabilities. <MA>

Monitor colleges and other educational institutions, including post-graduate and professional programs, to make sure they provide services for students with special needs, including those with learning disabilities. <MA>

Prepare at a much earlier age (by junior high school grades) for the coming adult lives of students: e.g., making decisions, living independently, choosing careers, raising families, getting jobs, drug education, sexuality, and HIV/AIDS prevention. <MA>

The State Department of Education needs to promote a "functional curriculum" to increase students' functional knowledge and skills to enable them to participate in the adult world after graduation. <MA>

The Mass. Department of Education and local education authorities should redouble their efforts to locate more bilingual professionals who can assess and teach children of non-English speaking cultural and linguistic groups, to reflect the local community. Special sensitivity is needed towards minority children, especially those with special needs. Outreach to parents and more translated materials are needed, as well as classroom materials and settings where minority children can be comfortable. <MA>

Promote and encourage adult and continuing education offerings in the community for people with disabilities among with their neighbors. <MA>

Offer early intervention and other early childhood learning opportunities programs to every child who can benefit from them. Continue with plans to make early intervention services an entitlement in compliance with EHA Part H, P.L. 99-457 (for children birth-3); include all children at established biological and environmental risk; support and fund preschool services for three and four-year-olds, through Chapter 188, the Education Reform Act, as well as Head Start. <MA>

Promote integration of children with appropriate supports in local schools (school buildings, day care) as opposed to placements in segregated settings. Special attention must be given to the needs of children with special medical conditions. To do this, all schools must be made truly architecturally accessible, more school personnel with disabilities must be hired, and present funding mechanisms which discourage integration must be replaced with incentives to local schools. <MA>

Recognize and provide alternative services for those who may need special segregated programs, since these may be effective for some children. <MA>

Support ongoing local efforts at coordination, within particular schools around particular children; with other agencies around particular children and their needs (besides "educational") or on program development; support cooperative efforts around transition of very young children into preschool/education services, and encourage involvement of other agencies in Individual Transition Plan formulation well before a child will exit the Chapter 766 system to adult services to plan for and document future needs. <MA>

Uphold the Massachusetts legal standard that education plans and programs should afford the "maximum feasible benefit" to the student. Massachusetts standards commendably exceed the federal standard of "appropriate and adequate." <MA>

Continue to support involvement of parents or other family members, such as support to parent advisory councils and through dissemination of special education material to families prior to school registration. <MA>

Support efforts of the Department of Education and of the Department of Public Health to coordinate their "child-find" efforts to identify children with special needs. <MA>

Encourage the State Department of Education and local school systems to be more flexible within the parameters of Chapter 766: identify family needs, create additional program prototypes, and use strong incentives to make sure children receive services that provide maximum feasible benefits. <MA>

Develop alternative community-based services and more creative ways of using funds so school systems will not have to rely on segregated/residential programs for children. <MA>

Educational institutions from pre-school through post-graduate programs should teach all students about the needs and rights of persons with disabilities throughout their curricula. Certification requirements for professional licenses should require expertise in disability issues. <MA>

Publicize the cooperative transitioning initiative of the Developmental Disabilities Administration, the Division of Vocational Rehabilitation, and the local school systems. In particular inform parents of adolescents of the importance and availability of transitioning planning and preparation for their children. <MD>

Merge special education and general education administratively in order to promote true integration of students with and without disabilities and the recognition that many students will need support services in order to succeed. Implement team teaching in general classrooms to support successful performance by all students. <MD>

Establish an initiative by the state Department of Education to demonstrate ways that highly intensive educational services and supports can be provided in integrated settings even though federal requirements for a continuum of services have led many educators and parents to believe that separate educational programs exclusively provide the most intensive education for students with disabilities. <MD>

Change the current funding formula in which the state pays all costs in excess of 300% of the local education authority's cost of educating the average student which encourages out-of-state placements. Explore and test on a pilot basis incentives to prevent these placements and to return students home. <MD>

Develop within the State Department of Education an equivalency formula which would encourage integration by reducing class size for those teachers who have students with significant disabilities in their classes. <MD>

Provide sensitivity training as a component of the curriculum for students without disabilities as integration of students with disabilities becomes more prevalent in Maryland. <MD>

Encourage these students from birth through age 13 who are deaf to remain with their families and to be educated based on their unique needs, by offering cooperative education by individual local education agencies in conjunction with the Maryland School for the Deaf. This cooperative effort should begin by piloting several satellite sites around the state. Students with and without hearing impairments would attend the same classroom using a team teacher approach with the School for the Deaf retaining responsibility for educating students with hearing impairments and for supervising their teachers. Other students in these integrated class rooms should be taught American Sign Language; interpreters should be present to enable communication when teachers who sign are not present in these classrooms. <MD>

Determine the course of secondary education for students age 13 and above who are deaf on the basis of each student's desire and ability. <MD>

Develop the campus facilities of the Maryland School for the Deaf at Frederick and Columbia for use in hi-tech secondary and post-secondary integrated high schools and/or junior colleges serving all students once satellite classes are sufficient in number to educate primary students who are deaf. Maryland is uniquely situated for such an eventuality since the nearest technical school for students who are deaf is in Rochester, New York. Offer a high quality program of study to attract students. Require knowledge of sign language as a prerequisite for hearing students to attend. <MD>

Expand on the development of sign language and interpreter education in the state. <MD>

Provide foster parents with official standing in the process of developing Individual Educational Plans. <MD>

Assure that the Admission, Review, Dismissal and Individual Education Plan meetings work sessions during which the strengths, abilities and needs of students are explored as required by law. Prohibit practices in which Individual Educational Plans are prepared in advance of meetings and presented to the parent(s) for approval and signature. <MD>

Establish on the part of the State Department of Education a leadership role in assuring the integrity of the Admission, Review, Dismissal and the Individual Educational Planning

processes. Provide parents with a written description of these processes and their legal rights prior to a meeting. <MD>

Assure that the social needs of students who are deaf are provided for while they are receiving education services for local education agencies, due to the unique nature of social needs stemming from the low incidence of deafness. <MD>

Devise within the Maryland State Department of Education a system that regularly evaluates the life situations of both drop outs and graduates. Disseminate this information widely for use in influencing any needed changes in the curriculum. <MD>

Coordinate the efforts of Special Education, Vocational-Technical Education and Vocational Rehabilitation to encourage and enable students with significant disabilities to avail themselves of integrated vocational educational opportunities. <MD>

Retain the "set aside" provisions of the Perkins Act, a federal law under which the vocational technical program operates. In part it provides "set asides" to support involvement of students with handicaps in regular vocational programs. Reauthorization of the Perkins Act in the U.S. Congress threatens to remove these set asides. <MD>

In partnership with LEA's and appropriate professional groups, the state Department of Education should collate existing reports, studies and other state and national information on the status of and need for a better system of supports for special education professionals. <ME>

The State of Maine should continue efforts to develop its pre-school services network for the identification and treatment of children with handicapping conditions, 0 to 5 years of age. The pre-school system should assure inclusion and service delivery to the 0 to 2 age group as it is required to do for the 3 to 5 age group and remove disincentives for identification and services to "environmentally at risk" children to the 0 to 5 age group. <ME>

In its "Comprehensive Plan of Personnel Development," the state Department of Education should recognize the crisis of insufficient appropriately training professionals to meet the needs of local education agencies across the state. <ME>

Promising new initiatives begun under the education reform movement, such as "Restructuring the Schools", that offer the promise of school environments more conducive to the integration of students with developmental disabilities should receive a higher priority for funding. In particular, the Department must more clearly recognize the crisis facing Maine schools in attracting training and retaining professionals involved in the education of students with developmental disabilities. <ME>

The Department of Educational and Cultural Services should strongly reflect, in all appropriate policy statements, plans and reports its mission to assure appropriate educational programs for students with developmental disabilities, in the least restrictive environment. <ME>

The Bureau of Vocational and Adult Education should assure the availability of appropriate adult education opportunities to persons with developmental disabilities. Specific efforts to address the needs of persons who have aged out, graduated or otherwise left the public schools and who did not benefit from transition services should be undertaken. Such efforts should be coordinated with adult service providers in order to maximize available resources and develop a coordinated local community approach to the provision of adult educational opportunities for persons with developmental disabilities. <ME>

The Bureau of Vocational Education should expand efforts already underway to assure vocational training opportunities for all students with handicapping conditions. Allocation of additional resources to existing inter and intra departmental efforts should further enhance the provision of transition services, the availability of appropriate, integrated vocational education opportunities and services and technical assistance in support of local vocational education programs. <ME>

The Division of Special Education should provide guidelines for the inclusion of extra curricular activities in individual education plans. The Division should assist in the development of curriculum for the preparation of students with developmental disabilities in the use of recreational/leisure time activities as another aspect of independent living. The Division should encourage innovative efforts, particularly in collaboration with public recreation agencies, through discretionary grants. <ME>

The U.S. Department of Education should strengthen leadership through major demonstration efforts, incentives, and specific funding initiatives in general education programs. Efforts should be focused on developing and demonstrating models of inclusive education designed to meet the needs of students with disabilities and those without disabilities. <MI>

The Department of Education, Special Education Services, and the Michigan State Board of Education should encourage schools to plan innovative uses for existing physical plants of segregated facilities, and actively discourage new physical plant construction of school buildings segregated by impairment category. <MI>

The Michigan State Board of Education should develop and adopt a mission statement for Special Education Services that emphasizes principles of inclusion and integration. They should require all local and intermediate school districts to include in their districts plans; policies, procedures, and strategies for providing support to all special education programs in integrated, age-appropriate school settings; and strategies for eliminating use of all

segregated school buildings for students with disabilities, including those with severe disabilities. <MI>

The Department of Education and Special Education Services should develop and carry out expanded training and technical assistance for administrative and instructional staff of intermediate and local education agencies. <MI>

The Michigan Developmental Disabilities Council with Regional Interagency Coordinating Committees (RICCs) and other advocacy organizations, and with the consultation of the Department of Education, Special Education Services, should develop community support for integrated learning environments. <MI>

The Michigan Department of Education, Special Education Services and Michigan Rehabilitation Services, with statewide advocacy groups, should educate parents and guardians about what to expect in an Individualized Education Plan (IEP). <MI>

To prepare students with disabilities for independent and productive living, the Governor should direct the Human Services Cabinet, through the Department of Education, Mental Health, Social Services, and Public Health, to develop an interagency agreement, strategies for carrying it out, and a funding mechanism to require a transition plan for each special education student from age sixteen to twenty-six; jointly determine which agency will take lead responsibility for general services coordination (Client Service Management), monitor implementation of the service plan during transition from special education to adult life, and assure that one agency does not stop coordination until another has picked it up; maintain joint program responsibility, as appropriate, for meeting the services needs of adults with disabilities; and resolve any disputes that may arise on a local or state level about agencies' specific responsibilities toward adults with disabilities. <MI>

All certification should include information about the principles of normalization; functional curriculum and community-based instruction; and methods for teaching decision making, self-advocacy, and citizenship. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations should support the Recommendations of the Board of Education's Blue Ribbon Task Force regarding post-secondary, technical, graduate, and professional education for people with disabilities (e.g., revolving scholarships for graduate education.) <MI>

Michigan Head Start grantees should promote enrollment of children with more severe disabilities. They should increase their outreach efforts to families who meet the federal income level criteria and have children with more severe handicapping conditions. <MI>

The Michigan Developmental Disabilities Council, with the Michigan Department of Education, Special Education Services, should develop and carry out a cooperative plan

for dissemination of student outcome information developed from the Michigan Developmental Disabilities Council's transition projects and other demonstration projects. <MI>

The Michigan Department of Education, Special Education Service, with help from the Michigan Developmental Disabilities Council and other advocacy organizations, should continue to support and fund existing pilots of model integrated programs, and increase the number of such projects annually. <MI>

Schools should carry out educational and in-service program for all teachers and administrators, and for parents and students, to support and enable integrating special education students into regular education settings, including training on disability issues, conducted by people with disabilities; and training in behavior management and other special needs of students with disabilities. <MI>

Michigan Protection and Advocacy Service should continue to strengthen and expand its Parent Network Program, to increase the number of knowledgeable advocates who can help parents in IEP Committee meetings. <MI>

The Michigan Department of Education, Special Education Services, with legislative support, should clarify and modify accounting practices and other barriers to the use of Special Education funds in integrated settings. <MI>

The Michigan Legislature, should enact legislation to forbid construction or establishment of new schools that are segregated according to disability; and mandate that school districts adopt an affirmative action approach to increasing the number of students with disabilities in regular classrooms with needed supports, including integrated transportation and other school activities. <MI>

State Legislation should require all general education teachers to have core special education competencies. <MI>

State agencies and advocacy organizations should encourage universities to include barrier free and total accessibility design in architect education, building construction, interior design, real estate, and other relevant programs. <MI>

The U.S. Department of Education, with the states, should develop means to improve the utility of information gathered by states for tracking improvements for students served by Special Education. <MI>

The Michigan Department of Education, Special Education Services, should continue and intensify its efforts to develop state level collection and analysis of information about outcomes for students exiting special education. This should include specific information

about the independence, productivity, and integration in the community achieved by students with severe disabilities who have exited special education. <MI>

The President should request, and Congress appropriate, increased funds for Special Education programs. Appropriations should include planned increases phased to raise the federal contribution to the amount initially committed (40% of national average per pupil cost). Increased appropriations should target expanded integration and independence in real community environments, with regular students, in ways that will improve and diversify the educational experiences of all students. <MI>

The Michigan legislature should enable the Michigan Department of Education, Special Education Services, to provide state level leadership in improving outcomes of independence, productivity and integration in the community for students by appropriating federal Special Education funds through the Department of Education Appropriations Act, rather than directly to schools through the State Aid Act; reversing the declining trend in the state contribution to Special Education funding; and including financial incentives that will accelerate planned change toward integrated, age-appropriate education for all special education students, with needed ongoing supports, and end segregated educational settings for students with disabilities. <MI>

The Michigan Department of Education and the Early Intervention Council should assess the Department's outreach efforts to families with children who have disabilities. <MI>

High schools, community colleges, and universities, as part of their plans to integrate schools should include in their Family Life Education Programs information about the needs of families with members who have disabilities. <MI>

The Michigan Board of Education and the Department of Education, Special Education Services, should work with colleges and universities with teacher certification programs to enhance educators' ability to improve students' skills and outcomes. All programs approved for teacher certification should include information about the principles of normalization. Programs should require classes in functional curriculum and community-based instruction. They also should emphasize methods for teaching decision making, self-advocacy, and citizenship. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations should support the Recommendations of the Board of Education's blue Ribbon Task force about identifying additional funding sources for post-secondary education for people with disabilities (e.g., a revolving loan fund for graduate education. <MI>

We must develop and implement comprehensive inclusive learning for persons with disabilities, that underscores a fundamental commitment to: transforming the services which are in place for children and young people (birth to age 21) to make them available, accessible, and supportive to all children and young people, regardless of type or severity

of disability; ensuring that children and young people receive a quality education and the opportunity to develop relationships and a sense of belonging with other children; welcoming all children into typical classrooms of their neighborhood schools; establishing curriculum and integration strategies that prepare students with disabilities to live, learn, work, play and participate in the adult world; and developing staff training and support for administrative teaching personnel to ensure that typical teachers receive the knowledge and support necessary to include all children in their classrooms. <MN>

We must determine how to support a child in typical settings and make those settings socially and physically accessible to all children. The question is not if a child can be supported, but which measures will be required to ensure that the child is supported. Such a commitment means a policy of "most environment" rather than "least restrictive." <MN>

Lifelong learning is important for all people, and such options as vocational technical, community college, and university classes should be available for persons with developmental disabilities. <MN>

The State Board of Education should require that a full range of placement options for children with severe disabilities be developed by education agencies. <MO>

The State Board of Education should develop and implement training programs for parents and professionals regarding the benefits for integrated options for children with disabilities. <MO>

The State Board of Education should call for a programmatic review of all segregated educational facilities. <MO>

The Department of Elementary and Secondary Education should fully implement P.L. 99-457. This would require legislation mandating public schools to provide services for handicapped children three and four years of age. This would also include full implementation of Part H which recommends a comprehensive set of service for infants and toddlers. <MO>

The Department of Elementary and Secondary Education should require local education agencies to provide school-to-work transitional planning and services beginning at age 14 in cooperation with DMH, the Division of VR and other community agencies. <MO>

Individual education plans and educational placements in the least restrictive environment should be based on individual need rather than service availability. <MO>

The use of functional life skills curricula should be implemented consistently in local education agencies' special education classes. <MO>

Financial incentives should be targeted for local school districts providing integrated placement options for children with severe disabilities. <MO>

There should be developed a sensible and responsible solution to the preparation of personnel so that, in future years, every individual with a developmental disability who needs service by a highly specialized professional will, in fact, receive the services no matter where he or she resides in Mississippi. <MS>

Mississippi's schools should formulate a formal, written plan that specifies how a student will be trained and placed in a permanent job upon graduation. This transition team should specify who is responsible for each goal/objective of this plan and a time-line for completion of each goal/objective of the plan. This plan should be part of both the Individual Education Plan (IEP) and the Individual Written Rehabilitation Plan (IWRP). Creative programs whose goals and procedures are oriented toward easing the school-to-work transition for its pupils/clients with disabilities must involve both special education and rehabilitation personnel. <MS>

Mississippi's schools should train students with disabilities in communication, self-care, mobility, and recreation skills. They should teach all of these skills within the context of job training whenever possible. By the teens the IEP should address specific vocational training in a variety of potential jobs related to realistic employment options in the local labor market. <MS>

Local school systems should employ additional personnel (e.g., psychologists, guidance counselors, physical therapists, speech pathologists, occupational therapists, audiologists, etc.) who are appropriately trained to provide "related services" needed by children and youth with developmental disabilities. <MS>

The State Department of Education should establish policies and regulations to ensure that all children and youth with developmental disabilities are educated, to the extent possible, with non-disabled peers and within their home communities. <MS>

Mississippi's institutions of higher education should expand and initiate new programs of appropriate education and pre-service training for teachers and related personnel to become qualified/certified to provide special education and related services needed by children and youth with developmental disabilities. <MS>

State policy should help ensure that each local school district has an on-going drop-out prevention program which specifically addresses the needs of the special education population. <MS>

Functional curriculums should be developed and adopted by the State Department of Education, such as the work study special education-vocational rehabilitation program available in Mississippi in the 1970s. <MS>

Transition services should be mandated for all special education students. Students leaving school should have self-advocacy problem-solving, and community life and employment skills. Independent living skills and training such as those activities that decrease an individual's dependence upon other people (e.g., grooming, cooking, and home management skills) as well as activities that allow the individual to use generic community services (e.g., mobility and shopping skills) must be expanded and must serve a more diverse population. <MS>

Greater emphasis should be stressed in continuing educational activities to increase and update the competencies of current personnel and to fit existing personnel into a rapidly changing service area (for example, to better serve people with multiple disabilities). <MS>

Emergency permits or provisional certificates that allow individuals to teach who do not meet the minimum requirements for teachers of students with developmental disabilities (severe disabilities, multiple disabilities, etc.) should be allowed to be renewed only twice, and then only if the individual holding the provisional certificate has attended yearly workshops per year sponsored by the State Department of Education and has successfully completed six semester hours in one of his or her deficient areas each year. <MS>

It is recommended that Mississippi meet its human resource needs, in part, by providing grants-in-aid annually (or loans in case the recipient elects not to fulfill the terms of the grant-in-aid) to individuals desiring careers in the education of children and adolescents with developmental disabilities. Financial incentives should be provided at both the federal and state levels to encourage college students, upon graduating, to work in service programs with persons with developmental disabilities. <MS>

Plans for transitional services should be developed and implemented at the local levels. Mandatory collection and reporting of appropriate data may help to ensure more individuals receive such services. <MS>

Provision of early intervention and preschool services for children with disabilities must be expanded and individualized to appropriately meet children's needs. <MT>

Refinement is needed in the comprehensive and coordinated child find program to insure that infants and toddlers with disabilities in the birth through 2 age group are identified early and referred to appropriate service providers. Efforts should also include coordinated transition plans for 0 - 2 children's movement from development disabilities services to preschool programs for 3- 5 year preschool programs. <MT>

Opportunities for children with disabilities to participate in summer school programs must be expanded through increased funding for such activities. <MT>

Special classes in regular schools need to be qualitatively improved providing services more appropriately individualized, suited to the needs of children with disabilities. <MT>

There is a need in Montana for a formal system of transition services to insure that students graduating from special education programs can receive adult services within their local communities. <MT>

The system of higher education in Montana and its human service system need to establish a mechanism for improved communication and goal-setting regarding training needs for teachers and direct-service providers. Specific training for those regular classroom teachers participating in mainstreaming programs needs improvement. <MT>

Adult education for persons with disabilities who require continued instruction in academics should be established. <MT>

Preschool aged children with disabilities should be mandated to receive public school services. Beginning in September 1990 such children in Montana will be entitled to a free and appropriate public education. <MT>

There is a strong need to address employment programs and training opportunities for people with learning disabilities as they transition from high school into the work world. Under the current system it is difficult to obtain services for these individuals after they leave school. The educational program for students with learning disabilities typically focuses on academic assistance with very little emphasis on supported employment and preparation for the world of work. As a consequence, many of our students with learning disabilities are not employed after high school. <MT>

The Council recommends that school bus drivers receive a minimum of one hour of training each school year with regard to special needs of children with developmental disabilities by the beginning of FY 1991-1992. <NC>

The Council recommends that the Department of Public Instruction's recommended maximum travel time of 50 minutes each way be established in policy and enforced no later than the beginning of FY 1992-1993. <NC>

The Council recommends development of incentives to attract more young people into the special education field with sub-specialty emphasis in the areas needed. Incentives might include tuition reduction (with federal or state subsidy to schools), loan deferment and/or reduced interest rates, and improved salaries in the special education teaching field. <NC>

Incentives should be offered to colleges and universities to improve existing special education programs, particularly in the area of developmental disabilities services, and to create special education degree programs where none currently exist. <NC>

The Council recommends that educational policies and programs for persons with cognitively impairing developmental disabilities be formulated with the goal of assuring year-round learning opportunities and options for continuing education beyond the public schools. <NC>

The Council recommends that federal contributions be steadily increased with the goal of reaching the originally promised 40% reimbursement rate by FY 1993. The Council on Developmental Disabilities will work with national and state consumer organizations to follow up on this recommendation. <NC>

The Council recommends that school guidance counselors or social workers be required to read and explain to parents and/or caregivers of children with developmental disabilities their rights under P.L. 94-142 upon referral for special education services. At the time of enrollment, parents should also receive a written copy of these rights in layman's language, separate from any other materials they receive." <NC>

The Council recommends that a well-defined, non-subjective test of "least restrictive environment" be developed; that each local education agency in North Carolina be required to apply this test to every student with developmental disabilities, and be prepared to defend placement of each such student; that the Department of Public Instruction develop an audit procedure to ensure statewide compliance. <NC>

Smaller school systems, or school systems in designated poverty counties, may encounter financial barriers in complying with the least restrictive environment rule. Therefore the Council also recommends that a special fund be established within the DPI annual operating budget, to be used as necessary to ensure school system compliance with the least restrictive environment mandate. <NC>

The Council recommends that federal and state education policies make specific provisions for transition services as a required element in all special education programs. Specific characteristics of such services should be stipulated by the Department of Public Instruction and should include early introduction of transition planning, no later than middle school, for each student with a developmental disability. <NC>

The General Assembly pass a bill guaranteeing that the state will provide necessary educational and support services to all children from birth to five years of age who have or are at risk for handicapping conditions. <NC>

The Council recommends that the State, through the intensive efforts of the Department of Human Resources and the Department of Public Instruction, establish mainstreamed preschool educational programs in a variety of models in all counties by July 1, 1994. <NC>

The Council recommends that the University of North Carolina System determine the support service manpower needs (such as speech and language services, physical therapy, occupational therapy, recreation therapy) resulting from implementation of P.L. 99-457 and develop and begin implementation of a plan for meeting those manpower needs by July 1, 1991, including inducements to attract students to the programs which provide degrees in areas of need and incentives for students to work in rural areas after graduation. The Council recommends that the General Assembly provide adequate funding to provide these additional educational and support services. <NC>

Educational service system should be designed around individual needs. Increased family participation in the development of each student's Individual Education Plan must be assured. <NE>

Schools must actively promote integration of special education students in classroom settings and extra-curricular and social settings. <NE>

Planning for the transition of all special education students into adult life should be mandatory. A position should be created within the Department of Education to coordinate transition activities in the State. <NE>

Models for developing Individual Family Service Plans (IFSPs) must be implemented for the 0-3 population with the philosophy of family inclusion in the process being carried over as the child ages. <NE>

The roles and responsibilities of schools and adult service agencies to effectively transition students into employment opportunities must be clarified. <NE>

Steps should be taken to insure full participation by students and families in the IEP planning process, including (a) insuring that plans brought to IEP meetings are subject to change, (b) documentation of plan modifications based on student and family input, and (c) the conduct of a statewide study of family satisfaction with participation in educational planning and current best practices to enhance participation. <NH>

Staff training and Comprehensive System of Personnel Development activities should continue to disseminate best educational practices among schools. The provision of funding for "release time" for teachers to visit exemplary programs should become a major focus of professional development and should be adopted by local schools. <NH>

School districts and the State Department of Education should continue to work towards modifying the role of special educator to that of a specialist in including students with special needs into regular educational and community environments through the use of dual certification and the incorporation of innovative practices such as team teaching and the use of teacher consultants. <NH>

The State Bureau of Special Education should adopt a clear plan with numerical goals for the reduction of placements in separate schools and separate classes for students with severe educational disabilities. Training and technical assistance in the inclusion of students with disabilities in regular classes and activities should be an ongoing activity for districts receiving Catastrophic Aid through revisions in education law. <NH>

School districts should continue to work to ensure that an appropriate educational program in a student's home school (the school he or she would attend if not educationally disabled) is available to all students. <NH>

Our second primary recommendation is that parents who would like to see their child with a disability attend a local public school have that option freely available to them with no barriers. Some parents whose children are classified with disabilities that are not traditionally mainstreamed find it difficult to successfully negotiate an unresponsive system. <NJ>

Our focus is to stop removing students with disabilities from the mainstream at very young ages. All children under 5 should receive needed services in natural settings with many opportunities for interaction with their nondisabled peers. We must stress and help parents to see the benefits of keeping children within their natural environments. Then, when children with disabilities turn 5, perhaps parents will be more likely to insist that they continue to receive their special education and related services alongside the non-disabled children from their neighborhoods. <NJ>

It is recommended that New Jersey's segregated special services school districts and regional day schools be frozen at current levels. It is further recommended that a long-range plan be developed to keep students in neighborhood schools. <NJ>

Special services required by pupils in order to benefit from an education program must be provided, whether or not such services are included in the description of a particular program, and cannot be limited to what is available. <NJ>

Since the current pilot projects of the state Plan to Revise waive the involvement of many students with severe disabilities and those who attend out-of-district programs, all students should participate in a controlled, highly evaluative study before conclusions are reached regarding the plan's effectiveness. <NJ>

Parents whose children are no longer classified should maintain access to due process. <NJ>

It is recommended that alternative federal and state methods of data collection, funding and monitoring be designed to replace stigmatizing labels and restrictions on placement options. <NJ>

It is recommended that education be designed to meet individual needs. It is further recommended that focus be on preparing individuals for adult life in the community. <NJ>

An extended school year should be included as a service for students with severe disabilities in order to prevent significant regression of skills or behavior. <NJ>

It is recommended that secondary education include heavy concentration on employment opportunities, leisure skills, functional life skills and appropriate social behaviors. Vocational programs should be community-based and flexible with opportunities for students to sample various employment options, work part-time while still in school and graduate with a job in hand. <NJ>

It is recommended the integration and natural settings become immediate priorities in serving children under age 5. It is further recommended that a plan be developed to set reasonable time lines for integrating all children enrolled in early intervention and preschool programs. Program funding should be contingent upon the provision of services in an integrated setting. <NJ>

It is recommended that the State Interagency Coordinating Council for Early Intervention continue its efforts to amend the state's criteria for early intervention eligibility to a developmental delay in one or more areas. <NJ>

It is recommended that federal funding for Head Start be increased to allow programs to serve more children for a full day and enhance the special education and related services that are provided to children with developmental disabilities. <NJ>

It is recommended that students, regardless of the severity of their disabilities, have access to a full range of learning environments, including regular classrooms. The Division of Special Education should immediately undertake the revision of current codes, regulations and funding formulas to eliminate barriers to integration. <NJ>

It is recommended that a position of "integration specialist" be created in each region of the state to assist parents, local school districts, administrators and teachers to integrate students with developmental disabilities into regular classrooms. <NJ>

It is recommended that the Department of Education undertake a plan to remove the school district incentive for sending students to special services school districts. Districts willing to educate students in their own community should not be fiscally penalized. <NJ>

It is recommended that the classification "day training eligible," which automatically leads to segregated placement, be abolished from state code. <NJ>

It is recommended that a comprehensive state program for early childhood regular and special education be developed, involving the Departments of Human Services, Education, Health and Community Affairs. The program should include a process to coordinate the early childhood education efforts of Head Start, community-based services and public schools. <NJ>

It is recommended that transition planning for post-school years begin when a student is 14 years old. Further study should explore the need for cooperation and coordination among the Division of Vocational Rehabilitation Services, the Division of Developmental Disabilities and the Department of Education. <NJ>

It is recommended that children with HIV infection be assured access to education programs. Early intervention programs should accept HIV-infected children and establish less-restrictive school attendance criteria. <NJ>

It is recommended that the Department of Education ensure that local school districts provide parents, especially those who are multi-linguistic and culturally diverse, with a statement of procedural safeguards. <NJ>

It is recommended that a medical expert participate in child study team deliberations to ensure that all pertinent medical information is considered. <NJ>

It is recommended that the Department of Education, in conjunction with local school districts, parents and the medical community, undertake a study to determine the educational needs of medically fragile and chronically ill children, and recommend policies for incorporating such children into public schools. <NJ>

It is recommended that training on the interpretation of code and funding formulas be immediately provided to school district personnel to demonstrate the existing availability of integrated service options. <NJ>

It is recommended that the Department of Higher Education, in conjunction with the Departments of Education, Health and Human Services, assess the need for trained professionals and take appropriate action to increase the available pool of needed professionals. <NJ>

It is recommended that training on the aspects of supported integration be available for parents and educators, and that this training become a component of pre-service programs for all education personnel. <NJ>

It is recommended that adequate federal funds be available to support and enhance state and local contributions for education programs. <NJ>

It is recommended that regular education curricula include creative and age-appropriate opportunities to learn about and discuss disability issues. <NJ>

While New Jerseyans with disabilities are participating at all post-secondary education levels, serious problems of physical and programmatic access continue to exist. <NJ>

It is recommended that adequate strategies dealing with the transition of special education students into the workforce be implemented, including: a mandate that transition planning and services be part of a student's Individualized Educational Plan; the integration of students with developmental disabilities into regular classrooms within their local school district; the development of community-based vocational training in local schools; on-going training for school personnel regarding strategies and practices for integrating students with developmental disabilities into their local school district; and the establishment of local interagency councils that promote planning and coordination of services. <NJ>

The 0-21 age range for service eligibility should be implemented across all states. <NM>

New Mexico should develop an ongoing dropout prevention program which specifically addresses the needs of the special education population. <NM>

New Mexico should institute transition planning as a mandatory part of the Individual Education Plan. <NM>

Functional curriculums should be developed and adopted by all school districts and local education agencies. <NM>

New Mexico should implement educational services to children with disabilities ages 0-21. <NM>

Community-based instruction should be available to students with disabilities in the junior and senior year of high school. <NV>

Administrative staff should receive training which insures that they view special education transitioning efforts as a solution rather than another bureaucracy to administer. <NV>

In-service training should be provided for educators in the development of transition goals and the necessity of including a variety of basic living requirements. <NV>

Delineated areas should be included in all individual transition plans (ITPs) in which the subjects of guardianship, transportation, health care and financial concerns are addressed. If they are not appropriate to be considered for a given ITP, the section should be marked NA. <NV>

Once specific services related to student transition needs have been identified, students should physically go through the process of accessing them. <NV>

Written agreements should be developed with community Independent Living service providers. Resource teachers with skills in independent living should be identified to provide in-service training to their peers. <NV>

Community resources and job opportunities after graduation should be considered in planning instruction and on-sight training. <NV>

Self-advocacy programs should be established to assist students with disabilities in developing appropriate academic, vocational and social choices in a post-secondary setting and to obtain the services (school based and community) needed to effectively pursue them. <NV>

A statewide policy should be implemented to insure that individual transition plan meetings will include, as appropriate, the student, parents or guardians, teachers, vocational consultants or other resource professionals, a rehabilitation counselor and an advocate. Vocational training programs at all levels should be based on and targeted toward demand occupations and should include opportunities for instruction on the spectrum of jobs available and the importance of career planning. <NV>

Individual Transition Plans (ITPs) should be written for every student with disabilities age 14 and above, a component of which must specify how the student will be vocationally and socially prepared and who is responsible for the timely completion of each individualized goal. <NV>

Advocates should lobby for vocational education resources to develop a consistently applied vocational assessment process for special education students. <NV>

Independent living skills training should be extended beyond the superficial household/daily living chores to such issues as taxes, checking, housing modification, socialization, etc. <NV>

A formal evaluation should be conducted of the impact increased academic levels have had on decreasing the occupational opportunities available to students with disabilities. <NV>

Programs should provide focus on recreation/social options and practice, include community-based activities and provide extensive, specialized life-skills training for students with disabilities beginning at the elementary school level. <NV>

A data management system should be implemented which consistently addresses student participation in terms of levels of service, types of services currently received by

students, service impact, recommendations for future services, and how academic and/or vocational strengths, needs, and weaknesses are perceived by the students themselves. <NV>

Student learning outcomes in all areas should be established which are measurable and which specify specific competencies. Written guidelines should be provided for compensatory strategies to use with specific functional limitations. <NV>

Students and parents should be consistently informed, after all diagnostic tests have been administered, of the exact nature of the disability and how those factors will impact learning. Students need to know their areas of strength, the areas in which they may have more difficulty, and how they learn (auditory, visual, haptic). Parents need to be educated regarding what learning disabilities are and what they are not. <NV>

Parent and students should be actively involved in the IEP/ITP process from primary school on. <NV>

Collaboration between special education and vocational teachers (with parents and students) should be implemented in developing and selecting options in curricular planning. Procedures for such collaboration should specifically state how minority youth with disabilities will be incorporated into this process. <NV>

Continuity of services should be insured during vacations and summer to avoid regression. <NV>

Vocational instruction should begin at the elementary level and continue throughout the special education student's educational process. <NV>

Vocational instruction should be mandated for all students with disabilities at least five years prior to graduation with a career component included in all IEPs. <NV>

Student interests and ability levels should be considered in individualizing vocational instruction. <NV>

Participation of special education students in occupational education centers and/or classes should be formally monitored in order to develop methodology for increasing participation by these students. <NV>

Course work should be provided in occupational education and transition planning to all special education teachers and vice versa. <NV>

Dual certification should be provided for special education and vocational teachers. <NV>

School and community based vocational alternatives should be identified and described in each county. <NV>

Formal guidelines should be established to assure true and meaningful equal access of special education students to vocational education. <NV>

Comprehensive information on adult services should be provided to all school leavers, independent of the reason for exiting school, which includes referral procedures and eligibility criteria. <NV>

Incentives should be provided to teachers to seek out assistance from community and interagency resources and all faculty should be sensitized to the needs of students with disabilities and methodologies to meet those needs. <NV>

In-service training should be instituted in changing and/or coping with the negative attitudes of professional staff toward mainstreaming and integration. <NV>

Teachers should be provided with regular in-service training relative to labor market trends and the capabilities and needs of students with disabilities and school districts should be encouraged to identify consultants available to teachers for adapting instruction. <NV>

A course in mainstreaming and adaptation of instruction should be included within the prerequisites for basic education licensing. <NV>

Parent education should be provided dealing with the exact nature and resulting dysfunction of learning and other disabilities which may be mistaken for being "stupid." <NV>

In-service training should be provided in accessing the variety of community agency support services to parents of students with disabilities. <NV>

Cooperative learning strategies should be implemented to improve social/interpersonal skills of students with disabilities within groups of non-disabled peers. <NV>

Ability and interest permitting, every student should be afforded the opportunity to take introductory and advanced course work in all areas of their choice. Training sites should be retrofitted (if necessary) to enable the student to fully utilize the equipment available. <NV>

A representative of the DD office of Protection and Advocacy should participate in all placement decisions of district multi-disciplinary evaluation teams regarding special education students. Controversial placements should be reviewed annually. <NV>

Extensive assessments of aptitudes, abilities and appropriate technology should be provided when placing students with disabilities within the available curricular options and students should participate in determining and reviewing their IEP and transition programs. <NV>

Immediate attention should be given to identifying supports, assistive technology and developmental aids which are needed and may be utilized by teachers in developing the full functional and cognitive potential of preschool and elementary students with very severe disabilities. Needs of teachers and students on self-contained campuses should be formally studied and plans developed for addressing equipment, space staffing, service integration and assistive technology needs of those schools. <NV>

Integration of students with disabilities, including those with severe and profound disabilities should be a priority of all Nevada schools. Nevada should solicit information from other states regarding integrated school systems such as those in Connecticut (e.g., Middletown District) for feasibility of implementation within our state. <NV>

The Department of Education should mandate that IEPs be monitored to insure that they reflect all services needed by the student to benefit equally from his or her education process regardless of the district's ability to pay for such services. <NV>

Carl Perkins funds should be utilized and monitored to insure that developmentally and other students with severe disabilities receive meaningful vocational training and preparation prior to leaving the school system. <NV>

Continuing assessments of beneficial applications of technology should be mandated as a requirement of the IEP process. <NV>

Continuous monitoring of students with disabilities who are mainstreamed should be mandated to insure they are truly integrated into vocational, recreational and other mainstream curricula and receive the supports and transitional services they need for eventual community integration. <NV>

The U.S. Department of Education should mandate that vocational planning and training should be included as a component of the IEP at the elementary level and continued throughout the educational process. <NV>

Integration of students with disabilities, including those with severe disabilities, should be established as a priority of the U.S. Department of Education. <NV>

Schools should develop written plans for providing supportive services and information/training to families of children with disabilities. <OH>

The requirement that all families be informed about their right to a public school placement for their children should be closely monitored and vigorously enforced. <OH>

Formal guidelines for transition from early intervention to preschool and from preschool to school-age programs should be developed. <OH>

Students with developmental disabilities should have access to vocational training and experience early in their school career, beginning, in many cases, in elementary school. <OH>

Relevant state and local education departments and agencies should explore the development of model programs which allow the systematic integration of children with disabilities into regular education settings with non-disabled peers; serve students in cross-categorical or non-categorical settings based on their specific educational needs through the use of educational strategy teams at the building level; and develop teaching teams comprised of regular and special education personnel who would share resources (e.g., space, materials), design, coordinate, and deliver instructional programs to students with disabilities. Based on the results of these initiatives, revisions should be recommended to Ohio's Rules for the Education of Handicapped Children. <OH>

"Supplemental service teachers" should be made available to all regular class teachers who have students with disabilities in their classrooms. <OH>

Learning plans for each student in special education should be developed by a building level team. <OH>

All teachers with students with disabilities in their classrooms should have the assistance of classroom aides, as appropriate. School health nurse services should be mandated in all schools. <OH>

Opportunities of lifelong learning and/or retraining should be increased and expanded. <OH>

Relevant state and local agencies should work together to develop a common data-base that will allow for the comparison of educational data across different systems. <OH>

All schools should be required to provide documentation within the IEP that every child in special education participates with students of the same age who are non-disabled on at least a daily basis. <OH>

Change state funding and administration of special education services, especially as it relates to educational support and related services, to facilitate movement toward education in integrated, public school settings. The rules governing unit funding should be changed so that educational support services can be provided based on the needs of

individual students rather than being tied to particular settings. Family input should play an important role in the development of these new rules. <OH>

All graduates of teacher training programs, administrators, and members of school boards should be able to demonstrate appropriate knowledge in a) individualizing instruction in small or large groups, b) consulting and collaborating with parents, educators, and community personnel in the delivery of educational services to children with disabilities, c) providing appropriate educational services which reflect a sound base of knowledge in human growth and development, learning, and curriculum, and d) use of technologies supports such as mobility aids, computers, and alternative communication devices. <OH>

All schools should require documentation of in-service training or continuing education for renewal of all licensed/certified personnel in the areas of a) individualizing instruction in small or large group settings and b) consultation with parents, educators, and others community agencies. <OH>

Parents should be provided with support, such as training, information, and support groups, related to their rights under P.L. 94-142 and its amendments - especially the right to a public school placement for their son or daughter. <OH>

A formal process for school districts to follow in developing a written plan for providing information, training, and supportive services to families of children with disabilities should be implemented. <OH>

Implementation of all the education personnel and family training recommendations should be supported through legislation, rule development, certification and other appropriate mechanisms. <OH>

All schools should encourage earlier exploration of the employment interests and abilities of students with disabilities and assure that needed training and work experience is included in the IEP. <OH>

Schools should develop career apprenticeship programs for students with disabilities. <OH>

Schools should work to assure that all students with disabilities are employable prior to graduation. <OH>

State and local level departments and agencies should support and initiate new projects which would educate the public, teachers, support staff, administrators, and school board members about disability issues related to the school, the community, and the workplace. <OH>

Develop advocacy organizations on the local level. These groups may organize in the local school district and come together on a statewide level to pursue goals to better improve the education of children with developmental disabilities and to improve the participation of parents at the local schools. (OK)

Make parent training resources available which enable them to understand and meaningfully participate in the development of the Individual Education Plan for his/her child. (OK)

Support and advocate for reallocation of current public funds and increased spending if necessary, for special education which addresses assistive technology in the classroom, establishment of ongoing summer programs, and after school tutoring programs. These efforts support mainstreaming of students with handicaps in the regular classroom. (OK)

The education system must assume leadership in providing transition programs for the 16-17 year old special education student. School counselors must be knowledgeable concerning the available options and communicate them to the student and parents. (OK)

Individual Education Programs (IEPs) should contain transitional services such as supported employment programs and access to vo-tech education. The fundamental responsibility of the public school system is to prepare all students to move into the larger community whether it be additional education/training or employment. Therefore students in special education programs should not be denied this component of public education. (OK)

The state Department of Education should review and strengthen the current policies and procedures concerning the preparation of the transitional components of the IEP. (OK)

Monies available through the Carl Perkins Act for vocational education can be creatively used to sponsor employment opportunities for persons with disabilities. <PA>

It is proposed that the Department of Public Instruction shall be responsible for ensuring architectural accessibility in schools serving students with disabilities. <PR>

It is proposed that the Puerto Rico Department of Health shall be the lead agency for the coordination of services for the infants and toddlers population (birth to age two, inclusive) with disabilities or developmental disabilities. <PR>

It is proposed that the University of Puerto Rico shall be responsible for ensuring architectural accessibility on all its educational facilities. <PR>

It is proposed that the Puerto Rico Department of Public Instruction, the Puerto Rico Department of Social Services Vocational Rehabilitation Program and the Department of Labor shall coordinate the transition services to all vocational and employment programs. <PR>

All schools will be integrated: there will be no special classrooms. <RI>

A state plan for transition (from school to adult life) must be adopted which will promote the opportunity for persons with developmental disabilities to be more independent, productive and integrated into the community. <SC>

A component to focus on the drop out rate of special education students should be included in Senate Bill S.321, Target 2000. <SC>

Expansion of the system is necessary if the adult services are to be available to the students when they exit school. <SC>

A dedicated system of tracking students for a period of five years should be implemented. Only by follow up studies will we know what our "report card" looks like as we proceed to make systems change in the process of educating our young people who have disabilities. <SC>

Congress must finalize the EHA Reauthorization Bill with the inclusion of the \$25 million transition initiative requiring the Department of Education to award one-time five year grants to help states improve their transition services. <SC>

There should be a weighted system for the number of federal dollars funded per student under The Education of all Handicapped Children Act giving the larger weight to students with the most severe disabilities. Such a system could facilitate funding enabling the local education agencies to serve the students with the most severe disabilities and providing the necessary supports in the least restrictive environment. <SC>

School curriculum should include a course on human disability that would be taught to students who are nondisabled. Knowledge and understanding can remove barriers of fear and misconception. This outcome could go a long way toward true integration. <SC>

Higher education must incorporate training programs for teachers and other professionals which will educate these providers to the needs of students with disabilities. <SC>

Students with disabilities should be recipients of training in functional skills performed in real community settings. <SC>

Drop-out rates will likely increase in special education with the implementation of the competency exam. This increase intensifies the odds that students will need more programs and services for years to come as they are picked up by adult service provider. Each school district should consider implementing a program which would educate students with disabilities (at risk of dropping-out) about the benefits of transition services with a special focus on their futures. This encouragement could have a positive effect on drop-out rates. <SC>

Vocational education must be offered to all special education students. Voc-ed programs and vocational assessments are essential if successful transitioning of students from school to the community is to take place. <SC>

Develop a model service delivery system in the state that will provide necessary services and appropriate education and intervention activities for infants and children ages 0-5 (and their families) who have disabilities and/or developmental delays. <SC>

It is recommended that the state education agency's efforts in the area of early childhood services be substantially stepped up and broadened to include a systematic assessment of the steps South Dakota should take to put into place an effective, comprehensive network of such services. <SD>

Efforts to enhance supported employment services must give high priority attention to the special education system. Effective transition strategies must emphasize integrated employment while youth with disabilities are in school and assure that each individual has the necessary supports to maintain employment after he or she enters the adult service delivery system. <SD>

Tennessee should develop an aggressive in-service and pre-service training program for individuals who provide educational and related services to students with developmental disabilities. <TN>

Educational programs should be designed to meet the vocational needs of all students, and should be implemented from kindergarten through twelfth grade. Education programs should form a continuum of developmental learning experiences designed to facilitate a smooth transition from school to work and/or further career opportunities for all. <TN>

Tennessee should have a full continuum of education and related services available consistently throughout all areas of the state, including early intervention programs for infants. <TN>

Educational programs in Tennessee should be provided in integrated settings. The least restrictive environment (LRE) concept should be scrupulously adhered to. <TN>

A transition plan should be developed for each student by age 16. <TN>

Independent living, job training, and/or college preparation should clearly be the focus of the secondary school curriculum for the individual with developmental disabilities. <TN>

The Texas Planning Council recommends the State Board of Education establish rules for monitoring and enforcement of state transition planning requirements of local education agencies which will ensure that students in special education receive the services they need to get jobs and live on their own as adults; and the Texas Legislature require that

agencies establish rules for monitoring and enforcement of state transition planning requirements. <TX>

The Texas Planning Council recommends the Texas Congressional Delegation seek to amend the Education of All Handicapped Children Act (P.L. 94-142 as amended) to require school-to-adult transition planning as part of the Individualized Education Plan to assist families and individuals in gaining access to the system of adult services. The Council believes there must be a national transition policy as part of the Education of All Handicapped Children Act for transition planning to be implemented effectively in Texas. <TX>

The Texas Planning Council recommends the Texas Legislature direct the State Board of Education to continue to revise the funding weights for special education to provide financial incentives for integration so that students will be taught in the environments where they will live, work and play in the community. <TX>

There must be parent training that helps parents feel empowered at the IEP meeting. Educators must reach out to parents to attend meetings and include them in the development of objectives. <UT>

Extended school year programs should be implemented throughout the state. <UT>

Related services and expertise must be offered in the neighborhood school and in rural areas. Professionals with these skills must find ways to implement specific technologies in the regular and special education classrooms by consulting and/or training regular and special education teachers. <UT>

The use of segregated school facilities should be phased out and the use of the neighborhood school should be phased in accordingly. <UT>

The neighborhood school concept must mean less inactivity and more inclusion in "normal activities." <UT>

The State Office of Education must enforce least restrictive environment compliance. <UT>

Administrators must assertively prepare programs that get teachers beyond their fears, their prejudices, and their feelings of being overburdened by empowering them to do an effective job. <UT>

The State Office of Education must enforce its new regulations for children with behavior disorders. <UT>

Transportation access strategies for all ages at state and district levels must be rethought. Coordination of transportation services must be reassessed and new more creative solutions must be considered. <UT>

Transitional programs that help young people identify and retain their skills before exiting school are needed before students fall into the gap of no services prior to adult opportunities. <UT>

Special educators must examine the kinds of skills that students will need to function in employment and the community. They must develop strategies to help students gain and maintain these skills as part of their special education. <UT>

The 0-21 age range for service eligibility should be implemented across Utah. Students who will suffer serious gaps of service due to "early" graduation should be encouraged to remain in the school system until the maximum age for educational services is attained, rather than be "nudged-out". <UT>

It is important that students with disabilities be age appropriate at graduation so they may experience commencement with the same people they have been in school with. After graduation, some kind of accommodation must be made that will provide them with a vocational setting for either preparatory purposes or actual placement that will continue with normal job development. Because education is mandated by federal law to provide educational services for people with disabilities to the age of 21, the cost of this transition phase will fall totally on education and then be assumed by the appropriate adult service agency at the age of 22. <UT>

Functional curricula should be developed and adopted by local educational agencies. <UT>

The educational system should become viably involved in the "birth to death" plan for services that will provide individuals with developmental disabilities with early intervention, pre-school, public education, vocational, and adult services without gaps of time that cause irreparable regression of learning and expensive duplication of training for recoupment of that learning. <UT>

Interagency coordination and flexible funding is necessary to ensure smooth transition planning and services. <UT>

In Utah, data collection that compares the costs of services when there is not continuous transition between high school and adult services with costs that include transition services into the adult years is necessary to demonstrate the cost effectiveness of transition service provision. <UT>

The Virginia Department of Education should strengthen its policies and procedures for the certification/re-certification of teachers, administrators, and other educational personnel to address the appropriate preparation of both "special education and related services" personnel and "regular education" personnel to work effectively with children and youth with developmental disabilities. Local Education Authorities should aggressively work to recruit and employ qualified personnel with disabilities. <VA>

The Virginia Department of Education should establish, monitor, and enforce favorable caseload standards to assure that the needs of children and youth with developmental disabilities are met with appropriate special education and related services. <VA>

The Virginia Department of Education should increase its efforts to assure the employment of sufficient numbers of appropriately trained/ certified special education teachers and related services personnel by local school divisions. Local school systems should employ additional personnel (e.g. psychologists, social workers, guidance counselors, physical therapists, speech pathologists, occupational therapists, audiologists, interpreters, etc.) and other providers of related services. <VA>

The Virginia Department of Education should provide technical assistance necessary to assure that educational standards and regulations are appropriately implemented. Particular areas needing attention are academic and functional curricula, assistive technology, vocational training, and leisure skills training. These areas should be directly reflected in Individual Education Plans for children and youth with developmental disabilities. <VA>

The Virginia Department of Education should aggressively monitor and follow through with implementation of corrective action plans with Local Education Authorities to insure uniform compliance with the intent and requirements of P.L. 94-142. <VA>

The Virginia Department of Education should enforce implementation of "Standards of Quality" for the delivery of special education and related services by Local Education Authorities. Persons with developmental disabilities, parents and other family members, and disability advocacy organizations should have active participation through public comment opportunities and the legislative process in future revisions of these "Standards of Quality". <VA>

The Virginia Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of appropriate education and pre-service training for teachers and related personnel to become qualified/certified to provide special education and related services needed by children and youth with developmental disabilities. <VA>

The General Assembly should establish funding specifically to promote a comprehensive, coordinated system of services for children ages 0-2 years with developmental delay or

those with a diagnosed condition or subject to environmental factors which have a high probability of resulting in delay. This should promote the collaborative efforts of community agencies, including school divisions, to comply with Public Law 99-457, Part H in the provision of early intervention and transition services for infants and toddlers. <VA>

The Virginia Department of Education should establish specific certification categories for teachers qualified to teach children and youth with autism, children and youth with traumatic brain injury, and children and youth who are multi-disabled. Teacher preparation programs in these areas must be established. <VA>

The General Assembly should require and provide funding for a formal statewide transition effort to promote collaborative activities between school divisions and community service agencies to provide for transition planning and delivery of transition services for youth with developmental disabilities who are exiting school and entering adult community life. <VA>

The Virginia Department of Education should implement policies and regulations to insure that all children and youth with developmental disabilities are educated to the maximum extent possible and appropriate with non-disabled peers and within their home communities. A full range of appropriate placement options should be available. <VA>

Local Education Authorities and community agencies should work collaboratively using "Virginia's Plan of Coordinated Transitional Services for Youth and Young Adults with Disabilities" to educate students with developmental disabilities, family members, employers, and the public concerning the employment potential of individuals with developmental disabilities. <VA>

The State Department of Education should increase efforts to communicate to every family/caregiver and student with a disability the fact that driver training is available in their school and is required to obtain a learning permit for those under 18 years of age. At the same time, the Department should work cooperatively with Vocational Rehabilitation and private providers to address the need for assessment and driver education services for people with disabilities who are over 18 years of age. Incentives should be identified and provided to those who become trained and equipped to provide these services to people with disabilities. <VT>

All aspects of employment training and support must take on more of an orientation toward the development of a career path through employment. This concept requires leadership from the Institutions of Higher Education, the Department of Education, the Department of Employment and Training, and other agencies to train staff in career development planning. <VT>

The State Department of Education and Local Education Agencies should place priority on education of all children with disabilities, including those presenting the most intensive educational challenges, in their local, neighborhood school. <VT>

Adjust vocational educational programs so that they could more appropriately serve students and adults with severe disabilities. <VT>

The Department of Education should require local education agencies to develop transition plans for all students with disabilities when they turn age 14. This initiative will insure that a longer period of time is devoted to learning appropriate job skills and that the students are exposed to the potential employment programs available to them upon graduation. <VT>

Use more specific terminology for what is often referred to as "social skills." Words such as personal responsibility, occupational awareness, career readiness, employability skills, and work ethics are examples. <WA>

Conduct outreach for hard-to-access populations. <WA>

Early childhood intervention programs should be related to each family in a holistic manner utilizing a family-centered approach. The family should be involved in the planning and implementation of program services. Parents and professionals should be partners. <WA>

Investigate ways to address cultural diversity in our society as it applies to early intervention and family participation. <WA>

All community providers of early intervention and early childhood services need to work together to create appropriate, integrated assistance in the least restrictive setting possible. <WA>

All levels of government should standardize and coordinate requirements, definitions and services for preschool programs. <WA>

Integrate and coordinate early intervention and early childhood services with family support programs. <WA>

Early childhood intervention services should be included in our commitment to provide a universal basic education for all children. <WA>

Early childhood intervention services should be available to all children and families who need them as an entitlement. They need to be offered statewide and in a comprehensive, coordinated, multi-disciplinary, fashion. The services must be family centered and community based. <WA>

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Early childhood intervention services should be available to all children and families who need them as an entitlement. They need to be offered statewide and in a comprehensive, coordinated, multi-disciplinary, fashion. The services must be family centered and community based. <WA>

Early intervention services should be available to all children who have, or who are at risk of, developing disabilities. These services should be available regardless of income, current family status or place of residence. The state should make a commitment to a minimum level of service for all children throughout the state. <WA>

Allocate sufficient resources to properly train early intervention personnel. Services and facilities must also be funded. Dollars are needed to educate the public about the value of early intervention. <WA>

Pass appropriate state legislation to implement the goals of the Birth to Six Project. <WA>

Plan, coordinate and fund early intervention services for children three to six years of age. <WA>

Vocational education should be more community based, not just limited to school settings. Increase cooperative efforts between schools and businesses. <WA>

Coordinate all programs for special education student in the 18 to 21 year range, including those offered by school districts, community colleges, vocational technical institutes, the Department of Vocational Rehabilitation, and private employers. An effective training and a coordinated transition plan from high schools to higher education or appropriate employment should be in place by age 14. <WA>

The adult education system should be viewed as an extension of public school basic education — it continues until the student is prepared to live or work in the community. <WA>

Simplify the vocational assessment process. <WA>

Enforce the federal requirement for vocational assessment and notification as outlined in the Carl Perkins Act. <WA>

Every child in special education should receive an appropriate vocational assessment in elementary school with periodic assessments. <WA>

Appoint a case manager, teacher or job placement coach to assist in developing transition plans on an individualized basis for each student. Fund this process. <WA>

Increase vocational education and training opportunities for both special education and regular students. Integrate special education with vocational and regular education. <WA>

Maintain the principle of the least restrictive appropriate educational setting for each individual student. <WA>

All educational personnel need to have some exposure to, and knowledge of, special education students. Teachers who have special education students in their regular classrooms should receive intensive, appropriate training. <WA>

Provide more support to teachers and parents. <WA>

Develop relevant, practical special education curricula. <WA>

Simplify eligibility criteria and standardize definitions at all levels of government. <WA>

Education programs must be individually designed and less categorical. Social, psychological, cultural and ethnic issues need to be addressed. <WA>

A student's vocational assessment information should be included in his or her future service plan. This would then transition with the student to adult services and employment. <WA>

Develop curriculum and objectives for people with developmental disabilities within the structure of the basic adult education system. Encourage citizen involvement in that process. <WA>

Provide funding and entitlements to adult education services. <WA>

Promote the concept of having funding resources and transition plan follow a student into the adult education. <WA>

Adult academic education services should be coordinated with adult vocational education. <WA>

Fund additional training support for all teachers, not just those in special education. Teacher training to work with special needs students should start in college and continue throughout their career. <WA>

In terms of allocated funds, the definition of institutionalization should be broadened to read "at risk of institutionalization" in order for more people to access adult education services. This would enable community based programs to access some of the federal money earmarked for educational services provided in institutional settings. <WA>

Fund the Washington State Transition Plan which calls for combined federal funding and coordinated services between state and federal as well as private industry and nonprofit programs. An emphasis should be placed on teacher training. <WA>

Support the expansion of successful transition and integration programs. These programs should be available in school districts across the state. <WA>

Provide funding to support students with developmental disabilities who graduate and move on to the work world. This would mean reprioritizing the student groups we currently serve. This funding should also be used to support a long-range plan that promotes successful job placement, job retention and advancement opportunities. <WA> Community colleges and vocational technical institutes need to help further training opportunities for students with disabilities. <WA>

Offer training and assistance to students to ensure smooth transition from school to work. <WA>

Develop curriculum that is practical, relevant and based on long-term employment and educational goals. <WA>

Continue planning, followed by implementation of P.L. 99-457, the early Intervention Birth to Three Program. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to receive a free public education appropriate to their individual needs, with access to the same schools which other children in their neighborhood attend, and the access to education throughout adulthood. <WI>

Conduct ongoing monitoring of state education funding levels to ensure the maintenance of adequate funding. <WI>

Continue to assess current state funding procedures and levels to determine if they are meeting the needs of all exceptional education students. <WI>

Ensure that exceptional education programs are funded, at a minimum, at the 63% statutory level. <WI>

Fund exceptional education programs at the 40% reimbursement rate outlined in federal statutes. <WI>

Strengthen federal legislation for the development and implementation of transition services. <WI>

Develop and implement state legislation that supports the recommendations on transition of the cooperative effort of the Wisconsin Council on Developmental Disabilities and the Department of Public Instruction. <WI>

Conduct studies (with statewide, regional, and district analyses) to determine why certain students with exceptional education needs are educated primarily in separate educational environments (e.g., separate classrooms, separate buildings) rather than in regular educational environments (e.g., regular classrooms), and develop recommendations to maximize the number and participation of students with disabilities in regular education environments, facilitate the availability of adequate and appropriate funding for the supports necessary to successfully educate students with disabilities in regular education environments, and facilitate the closing of separate educational environments whenever appropriate. <WI>

Encourage student awareness efforts be made a part of every school district's curriculum. <WI>

Make federal data collection more consistent across each state by developing a common taxonomy for federal reporting purposes. <WI>

Establish a system to inform all parents/guardians of exceptional educational needs students at least 2 years prior to their child's termination of education, of the agency(ies) responsible for adult services, of the service of the DVR and the 51/HSD systems, of the possible waiting lists, and of the assessment process for competitive and other employment options. Develop new legislation for the establishment of this process. <WI>

Because separate schools rarely qualify as the least restrictive setting for students with handicaps, long range plans need to be developed to reduce or eliminate this form of segregated education. <WV>

The principle of least restrictive environment must be strictly implemented and enforced in all school districts. <WV>

Educational services should be designed around individual needs, with emphasis on functional knowledge and skills. <WV>

The IEP process should be used as a collaborative process for the student, his/her family and teachers to design an individualized program that addresses current and future goals. <WV>

The entire education system in Wyoming from districts and the Department of Education through the University of Wyoming must develop a plan to solve the shortages of special education teachers and related service providers such as physical therapists in Wyoming schools. <WY>

Directors/coordinators of special education should be required to have a background in special education as well as the administrative qualifications currently required.

Substitute teachers working directly with special education students should also have some special education training. <WY>

Wyoming should require that each Local Education Agency (LEA) has an on-going drop-out prevention program which specifically addresses the needs of the special education population. <WY>

Through three programs and two state agencies, Wyoming provides services birth to 21. The state must ensure smooth transitions between the programs and agencies as well as adequate funding to service all eligible children, especially preschool children, in accordance with EHA. The state must also ensure that more individuals with developmental disabilities receive the vocational services they need. <WY>

Wyoming students who receive special education should receive the assistance they need in the regular classroom. <WY>

WORK: BARRIERS

Multiple States

The multiple agencies and programs concerned with employment policy and programs are a formidable barrier to the implementation of an employment initiative for people with developmental disabilities. <IN,MT,UT>

The result of the current situation is fragmented policy and an inability to address the several interlocking and interacting issues that must be simultaneously addressed. These issues include: training, placement, individual worker supports, employer and employee incentives, family and provider resistance, benefits, employment discrimination, income subsidies, etc. <IN,MT,WY>

One of the difficulties in securing a mandate to providing ongoing supports is the lack of single state or federal program or agency focused on the employment of people with developmental disabilities. <IN,MT,UT>

The governmental service system (both state and local) currently lacks the resources and mandate to provide ongoing employment supports to people with developmental disabilities. <IN,MT,UT,WY>

At a state and local level it is likely that there is a relationship between the overall health of an area's economy and its ability to employ and sustain people with developmental disabilities. High unemployment will probably mean fewer job opportunities for people with developmental disabilities. <MT,NJ>

Employers are willing to hire workers with disabilities, but there are some barriers to be overcome. <IN,MT,NJ,UT>

People with developmental disabilities want to work but are not working. <CA,IN,MT,NJ,TN,UT,WY>

Important segments of the disabilities community do not accept the basic promise that people with developmental disabilities can engage in productive activities and, more specifically, that people with developmental disabilities can be employed in the conventional sense of the term. These segments include families of people with developmental disabilities, service providers, agency heads, and political leaders. <LA,MT,UT,WY>

Sheltered workshops are no better. People often work for pennies a day, segregated from workers without disabilities, with no hope for a better future. Other individuals work in similarly unintegrated subsidized settings in which economic productivity is not a major concern. While some people with developmental disabilities are in programs that provide

competitive or supported employment, too many individuals are being deprived because of these established patterns. <HI,MT,UT>

Many vocational services and supports available to people with developmental disabilities do not have an explicit goal of "real jobs for real pay". <HI,IN,MT,UT>

Programs are poorly planned and targeted. <IN,TN,WY>

Employment Security agencies are the score keepers for employment, but they do not include people with disabilities. Consequently, this systemic fragmentation results in a lack of reliable and valid information about employment of people with severe disabilities. <MT,UT,WY>

Employment Security agencies, while providing unemployment compensation and job services, have little experience in serving people with developmental disabilities. They have no mandate to work with employers to develop supports or services for people with developmental disabilities. <MT,TN,UT,WY>

JTPA is not set up to provide the job accommodations and long-term supports often needed by people with developmental disabilities. <IN,MI,MT,UT,WY>

The Jobs Partnership and Training Act lacks a focus on or commitment to people with severe disabilities. <IN,LA,MT,TN,UT>

Structurally, vocational rehabilitation (VR) services are poorly suited to providing the ongoing supports required by many people with developmental disabilities since VR services are time limited. <IN,MT,UT,WY>

Federal employment programs are not organized to facilitate employment of people with severe disabilities into the new industries and job forms that have emerged in the recent past. <MT,WY>

Programs are poorly organized and fragmented. <IN,MT,WY>

Reducing the number of people in sheltered employment is threatening to providers of the sheltered employment and day program. It also challenges other employment services such as Vocational Rehabilitation, Jobs Training Partnership Act, and Employment Security to begin to seriously serve a population that in the past they have not. Without strong federal and state leadership or strong consumer demands, it is unlikely that these fledgling efforts can be maintained. <IN,LA,MT,UT>

The economic and organizational power of these programs poses a serious problem for people with developmental disabilities who wish to be independent of this industry which in turn is dependent upon these very same individuals for its survival. To move people into the competitive job market represents a major potential loss in revenue for the providers of day service. <MT,NJ,WY>

Most government efforts seriously miss the mark. <MT,NJ,WY>

People living in institutions and sheltered communities do not have access to the labor market. State institutions and residential communities tend to be geographically isolated from economic centers. <HI,IN,MT,UT>

Individual States

People who experience a disability due to injury or illness while employed by the state are not provided adequate opportunities for re-employment by the state. <AK>

People with disabilities often only have access to entry level positions with little opportunities for career advancement. <AK>

Transportation and attendant services are not consistently available when needed by people with disabilities seeking or attempting to maintain employment. <AK>

People who experience severe physical disabilities or behavior problems often remain in sheltered workshops rather than finding placements in community based work settings. <AK>

Barriers to employment often cited include prejudicial attitudes towards people who experience disabilities and their abilities; under-education and lack of marketable skills; lack of accessible or affordable transportation; lack of needed equipment or devices to help them work or communicate; and fear of loss of key benefits, such as government health insurance. BUT, in a Harris Poll, only 18% of the Americans with disabilities interviewed who were not working or working part-time, said that fear of loss of benefits is an important reason why they are not working full-time. <AK>

It appears that there are limitations to supported work options in Alabama, even though both the Developmental Disabilities Act and Vocational Rehabilitation mandates required that supported work be offered to individuals with developmental disabilities. Groups for which these options are particularly limited include those people who with deaf/blindness, with severe physical involvement, and/or emotional disturbance. <AL>

Comments by family members of people with moderate to severe levels of mental retardation and by those who had severe mental illnesses (e.g., paranoid schizophrenia) report a critical lack of day training and/or sheltered workshop programs. When those

services are available, they are typically limited to large urban areas. Residents in rural areas have testified to the long distances family members must travel to obtain those vital training services. The scenario worsens for that segment of the population who have low incidence diagnoses (e.g., deaf/blind, multi-handicaps). <AL>

A commitment must be made to consumers and family members that some type of "safety net" or continuous, guaranteed access to some type of services will be available. At meetings with parents, consumers and board members of community programs representatives of both Rehabilitation Services and Developmental Disabilities Services said that Arkansas consumers in supported employment who lost their jobs would "sit at home" until another job could be located. In a state in which unemployment is 28% in some areas such a statement is extremely frightening. <AR>

At the core of the critique of the segregated vocational center is the demonstration that the model is ineffective. Bellamy's studies have been the most influential in this regard, showing that it will take a person identified as "severely disabled" 58 years to be defined as "work-ready" within that system. "Readiness" models simply do not get people "ready" (Bellamy et'al., 1984). The incontestable effectiveness of Wehman's model underscores this failure. Jobs are not just theoretically possible; jobs are attainable now. Within public policy, therefore, segregated training centers are increasingly viewed not only as a failed experiment but more significantly as a disabling barrier to employment for the more than 100,000 people currently in that system. <AR>

Arkansas is currently at an impasse on long term funding between the Division of Rehabilitation Services, which administers a federally funded supported employment grant, and the Division of Developmental Disabilities Services (DDS) which ostensibly will provide long term funding. The Division of Rehabilitation Services Supported Employment Counselors have notified communities interested in adding supported employment services to the options available to persons with disabilities that no new programs will be started until DDS develops a satisfactory strategy provide long term supports. To date, no long term employment support has been implemented by DDS. Without this cooperative effort, supported employment will ultimately not succeed for individuals who may need continued support. <AR>

The model is simple but implementation can be challenging, primarily because supported employment is so different from what professionals usually do. <AR>

In order to fully utilize RSA resources to successfully serve persons with developmental disabilities, other agencies in the service system (e.g. the DDD and local school districts) or the private sector need to guarantee they will provide extended support services such as job coaches after RSA provides transitional and employment services. <AZ>

The potential resources that could be available through the RSA to provide vocational rehabilitation services to persons with developmental disabilities are not being fully used.

State funds are not available to match, however, private providers are able to apply for federal dollars using private matching funds. <AZ>

Each service delivery area of JTPA determines its own target population; the state's JTPA administration does not have a say in it. The state Council may set broad parameters and provide some incentives to serve people with developmental disabilities, but the key decisions are made at the local level. <AZ>

Increased employer awareness of the abilities of this population as a dependable and stable workforce is needed, along with more widespread information regarding employer incentives for hiring these individuals. <CA>

Day programs for adults with developmental disabilities are not providing real opportunities for those individuals to achieve true integration, independence and productivity. <CA>

The issue of quality assurance in the provision of employment and day activities services has been raised on a frequent basis. There is a need to develop better standards upon which to monitor the effectiveness of programs at all levels, from day programs through supported employment. <CA>

Providers of day and work programs in traditional, sheltered settings are frequently unaware or unaccepting of the integrated work philosophy. Moving people into the competitive job market represents a potential loss in revenue for providers of day and sheltered work services, and causes them to look at new ways of doing business which will not be center-based, and which require the development of support services which are sometimes difficult to obtain. <CA>

For day programs, 31,000 people spend their days in segregated DDS funded day programs without the opportunity to work and interact in the community. Many people are frustrated at these rights violations, with little hope that things will change in the near future. <CA>

At the local level there is a need for consistent individualized program planning, including case management, assessment, placement, transition services and follow-along services. This requires communication and networking among a variety of local agencies, including regional centers, rehabilitation field offices, school districts and local employers. In some areas of the state, there is a strong collaboration. In others, there is very little. <CA>

The adult day program system follows a continuum model in which it is assumed that participants will progress from more to less restrictive programming, eventually leading to full community integration. However, practical experience has shown that the model does not yield the expected results. Many individuals in day programs do not progress to the least restrictive end of the continuum, nor are people necessarily prepared by the

programming provided to tailored to individual needs, but rather, are provided most intensively in the most restrictive programs thereby promoting the most restrictive placements for people with the most severe disabilities. <CA>

Consistent, uniform application of statewide policy is needed, in addition to coordination with federal policy where applicable. There are two primary examples of this issue: 1) the "20 hour/week minimum requirement" under federal law for individuals engaged in supported employment, which precludes many with more severe disabilities from obtaining supported employment services; 2) the lack of availability for continuation funding for supported employment for those who do not meet the state definition of developmental disability. <CA>

Comprehensive employment options are needed for individuals at all levels of the service system. CALTASH comments regarding the effectiveness of employment services for California citizens with severe disabilities summarize this issue as follows: "... there is a need at the regional and local level to obtain comprehensive training and develop employment services for persons who present the most significant challenges to providers. It is highly unlikely that 95% of adult regional center clients have chosen to be unemployed." <CA>

For individuals meeting the state definition of developmental disability, the Individual Program Plan (IPP) must address the stress the concepts of integrated work and self-advocacy. <CA>

A vast majority of adults are participating in day programs with no work components. This population primarily consists of individuals with more severe developmental disabilities and lower skill levels. There is a segment of this group which is borderline in terms of ability to perform work tasks and who should be given the opportunity to work in the community, even if it is for a few hours a week. At this time, there is no formal program nor a rates system in California which supports this option. A policy (Integrated Work and Community Services) was developed in 1987 by the Department of Developmental Services to address this issue. However related program concepts have yet to be piloted on an official basis. <CA>

Attitudes and expectations of the general public need to be improved with regard to the abilities of people with developmental disabilities to lead productive lives. <CA>

There is a lack of coordination among all levels of the service system which causes barriers to eligibility, access and effectiveness of services provided. <CA>

California lacks a coordinated statewide system of data collection and evaluation for employment related services. <CA>

There are not enough integrated work opportunities for people with developmental disabilities. <CA>

Improvements are needed in employment "quality" for people with developmental disabilities. A majority of the people with developmental disabilities who work are in entry level jobs. Most earn minimum wage or slightly above, and may not hold jobs at levels where they qualify for fringe benefits. In addition, there is little attention paid for career

planning, opportunities for upward mobility, or transition planning from one job to another. <CA>

Support services which enhance the individual's ability to be employed must be available, accessible and better coordinated. These include coordination with residential care providers so that hours worked and free time do not interfere with group home staffing patterns; coordination of transportation services and/or public transportation to and from work; and provision of other supports such as self-advocacy training, opportunities for socialization and recreation, and appropriate technological devices to assist in job performance. <CA>

There is a lack of trained staff to provide supports for individuals becoming employed. <CA>

Job discrimination, including termination of employment following seizures in the work place and reluctance of employers to hire people with epilepsy because they fear increased liability and general poor performance on the job. <CO>

Supported employment for people with the developmental disabilities that is funded by Colorado Rehabilitation Services has so far concentrated on those with mental retardation. Because there is no agency such as the Division for Developmental Disabilities to access funding and develop programs on their behalf, people with other developmental disabilities who may be eligible for and could benefit from supported employment services have not been included in new initiatives such as supported employment to the extent of those with mental retardation. <CO>

Transition from school to work for people served by independent living centers - there is a need for more intensive services and long-term follow-up. Provisions of services at this stage would lessen the need for services and prevent unemployment later on. <CO>

The Division of Developmental Disabilities and Division of Rehabilitation Services have an interagency agreement to serve the Division for Developmental Disabilities' consumers through supported employment programs funded by the Division of Rehabilitation Services. However, since people who do not have mental retardation are served by the Division for Developmental Disabilities, they do not have access to similar services which would help their long-term employment potential. <CO>

Many people with disabilities literally cannot afford to work because they earn so little working that they cannot live on their wages, yet cannot receive needed financial supports if they do work. The recent changes to Social Security [section 1619 (a) and (b)] may help, but many people with disabilities still face problems in trying to live decently, let alone support a family and enjoy life. The consumer survey also showed that 40% of the respondents who were working earned less than \$12 a week. <CO>

Transition services for young adults leaving high school was cited as one of the most critical needs. Sheltered workshops are not a viable option for students with cerebral palsy, yet supported employment programs are not available in sufficient numbers to meet their needs. <CO>

In addition to attitudinal and access barriers to employment, lack of development and implementation of an affirmative action program to ensure jobs within state agencies for persons with disabilities has been a barrier. People with disabilities have not achieved protected class status, and state government affirmative action guidelines which specifically targeted people with disabilities were not in place until recently. <CO>

Places of employment may be physically inaccessible, so if accommodations are not made, a person with a physical handicap is unable to access that opportunity. Some employers still do not realize that accommodations often can be made with little expense and without high tech solutions. <CO>

One of the most persistent problems in employment of persons with disabilities has been that if they obtain an entry or low level position, they are not promoted even though they are capable of doing a higher level job. <CO>

The extra staffing needed to assist people in the workplace with basic tasks such as feeding and toileting makes it difficult to place people with severe disabilities who are employable. <CO>

Many advocates and people with disabilities believe that some employers still use the issue of potential expense to hide their prejudices and fear of people with disabilities. These attitudes are slowly changing, but still persist in spite of concentrated public awareness campaigns, affirmative action programs, and similar efforts over many years. <CO>

Although supported or competitive employment is a goal for most persons served, if a person needs a personal care attendant, all of the person's earned income may be used in providing for personal care needs, leaving little for other needs. Appropriate use of PASS to maintain SSI has been effective for some employed persons but for others, there is little incentive to work if all the money earned goes to purchasing basic services. <CO>

In virtually every community in the state, a crisis exists in the capacity of service providers to provide post-school services to adults with developmental disabilities. <CT>

Major disincentives to supported work exist on the federal and state levels. <CT>

Among people with disabilities who work, severe underemployment exists in terms of hours worked. <CT>

The vocational rehabilitation program has never been able to serve people with severe and multiple disabilities, even with a federal mandate to do so. The people labeled "severely disabled" by the program are people with mild and moderate disabilities by most other program standards. The program's inability to support people with severe and multiple disabilities, its focus on short-term support, "job readiness" and reliance on sheltered workshops gave birth to the supported employment movement on a national and state level, and the present controversy in Connecticut on the effectiveness of the program. <CT>

The change in both policy and practice from segregated work sites to more dispersed employment in integrated settings requires skills and values training for the Division of Rehabilitation Services and Board of Education and Services for the Blind, service organizations and staff, a different approach to monitoring, and support to the parents and guardians of people with developmental disabilities. <CT>

DRS's inservice training and staff development is very weak. Reliance upon the Regional Rehabilitation Continuing Education Center (RCEP) at Assumption College is sentencing new staff not only to very poor training but a focus on the traditional rehabilitation system. <CT>

The State Board of Education and Services for the Blind considers Home Industries, Work Activity and Sheltered Centers "employment placements." People likely to be characterized as developmentally disabled are found in these places, although it is also likely people with mild and moderate disabilities are locked in these places. Work does not occur in these settings. In 1986-87, the Home Industries Program served people who were older and had multiple disabilities by providing "therapeutic" work activity and training. These people were paid an average of \$364 per year. Work Activities served 30 people with multiple disabilities and they were paid an average of \$2,368 per year. The Production Program, the closest to supported work, served 17 people who were paid an average of \$5,059 per year. It is interesting to note the Board's trend is to increase the number of people in Home Industries and Work Activities but to decrease the average amount they get paid to \$337 and \$1,114 respectively. People in Sheltered Centers would remain the same but earn more (\$3,750). The Production Program would decrease to 15 people but they would earn an average of \$6,000. <CT>

Funding regulations are often inconsistent with the more individualized approach. For instance, significant resources are spent on evaluating people for employment potential and continuum of sheltered workshops to prepare people for job readiness. <CT>

To make supported employment a permanent and integrated part of policy and practice, it must be included in state statute and funds must be allocated. To date, operational guidelines for supported employment have been determined by the terms and conditions of the federal OSERS grant. <CT>

There are very diverse employment opportunities in the District and the surrounding suburbs for the enterprising, well educated person. The opportunities for the uneducated individual are sorely limited. It has been in the service industries where these individuals have been more likely to find employment. The service industry offers low paying, high turnover jobs to a segment of the population, both with and without disabilities, that tends to be poor, inexperienced and, in the case of the District, predominantly Black. According to a study conducted by the U.S. Department of Labor, there are few jobs a person with a disability cannot perform if the physical barriers are removed. For a significant number of the District residents, however, the barriers to higher quality vocational education and training programs must be addressed. <DC>

Participation in DMR's Day Habilitation Program would increase if more funding was available. <DE>

A low unemployment rate recommends working more with individuals with severe disabilities since persons with non-severe disabilities will find employment more rapidly. Serving persons with severe disabilities is more costly and fewer individuals will be rehabilitated; in addition, new services will need to be developed. <DE>

The typical workweek is a median of 30 hours/week. The median pretax pay reported for the last week is \$8 overall (but much lower among females than males and among blacks than whites). <DE>

In the Coalition project conducted by four state agencies (DMR, DVR, DADAMH, DPI) and the Developmental Disabilities Planning Council through DCA/OHS, the following systemic barriers to supported employment for persons with a dual diagnosis were identified: the program's inability to create a living environment for the client which is consistent with the freedom on the job versus the environment where the clients were living; residential staff did not always inform the employment specialists about the barriers to a client's inability to report to work; lack of training in supported employment (SE) for Delaware State Hospital and group home staff; lack of a system generation of referrals; lack of strong guidance by the Coalition in the course of the contract; state agencies did not consistently meet their responsibilities to provide referrals to the contractor; and "pressure" on VR counselors to "rubber stamp" a client as "eligible" because another division has already approved the client. <DE>

Clients with mental retardation and mental illness are provided long-term follow-up through state agencies. There is, however, no agency or funding for long term follow-up

or those individuals with physical disabilities. In order for these individuals to be able to access services, a follow-up service needs to be developed. <DE>

Advocates and providers reported that the content of some adult day training programs is in need of revision. Examples of specific needed revisions included provision of sexuality training, and programs for older consumers which provide age-appropriate activities, i.e., retirement-like activities. <FL>

Consumer complaint data indicated that problems exist in the availability of vocational training, job coaches and supported employment placements. <FL>

Additional employment opportunities for persons with developmental disabilities are needed. Supported employment has proven to be effective with people who have developmental disabilities and needs to be expanded to a larger group of individuals. <GA>

Continued technological support and job modification are needed. <GA>

There is a need to increase the accessibility to work-sites and other public buildings for individuals with disabilities on Guam." <GU>

There is a need to improve and expand supported employment program and also provide appropriate vocational training to include job coaches to individuals with developmental disabilities who are in need of such services. <GU>

Employers are willing to hire workers with disabilities, but there are some barriers to be overcome. There needs to be a concerted effort to reach employers and assist them in developing programs to hire people with disabilities. <HI>

Supported employment programs lack adequate fiscal resources and vocational rehabilitation services are not structurally suited to adequately provide the ongoing supports required by many people with developmental disabilities because their services are time limited. <HI>

While some people with developmental disabilities are in programs that provide competitive or supported employment, too many are being deprived of real opportunity because of these established patterns. <HI>

JTPA lacks a focus on people with disabilities because unlike its predecessor, the Comprehensive Employment and Training Act (CETA), JTPA does not consider a person eligible because his/her disability constitutes a barrier to employment. Income eligibility criteria must be satisfied in order to receive services. <HI>

JTPA is not set up to provide the job accommodations and long-term supports needed by people with severe developmental disabilities. <HI>

Eligibility determination for vocational rehabilitation services may require three to six months, during which time the individual receives no services. There is no initiation of services for an individual on the basis of an interim determination of eligibility. <HI>

Applications of persons applying for SSI/SSDI benefits are reviewed by the Disability Determination Branch of the Division of Vocational Rehabilitation. It is there that the initial eligibility for SSI/SSDI is made. The person is then referred to Vocational Rehabilitation for eligibility determination for rehabilitation services. There is no guarantee that an individual eligible for SSI/SSDI will be eligible for vocational rehabilitation services because of the "work capacity" means used for eligibility. <HI>

All of the community adult service programs have waiting lists. The Department of Health's Developmental Disabilities Division identified the severe/profound population and aged population as the groups most in need of programs. There are no programs for people with developmental disabilities who are not intellectually impaired. <HI>

Productivity is not explicitly cited as a program goal. None of the areas examined is rated as inhibiting this outcome, but four of the five relevant questions lead to assessments that indicate HCB waiver policy does not actively promote productivity. Particular areas of concern include the limited scope and extent of services supported of those that are potentially available through this program. <IA>

The ratings of vocational rehabilitation policy support for independence are generally positive. The major concern identified is ambiguous policy language that allows exclusion of a client from service eligibility on the basis of a lack of "potential to benefit" from the program. In other words, this policy allows the program to serve a select few. The policy likewise does not promote consumer choice in what services the consumer will use and when these services will be made available. <IA>

Among the one-third who do not feel the program encourages productivity, the major issues are the minimal level and type of vocational skills training offered. <IA>

While the policy analysis ratings overall for vocational rehabilitation are relatively positive, 80% of the survey respondents are dissatisfied with some aspect of the program. Comments focus on the lack of variety and choice in programs, the long wait to get into the program, the lack of adequate wages, and the unexpected elimination of programs. <IA>

Some comments suggest that vocational rehabilitation services should be playing a more progressive role in promoting vocational concepts such as supported employment. Particularly in rural areas and smaller towns, there are individuals who are not being

reached by more progressive vocational programs. As one parent notes, "My son is figuring out how to get some job experience, hoping that he, too, could be involved in real work by having a job coach. This is an option that should be available to him, even though he is more than mildly retarded. I was disheartened to hear the comment (that his disabilities are) 'too hardcore'. This only works with the cream of the crop. <IA>

There were relatively few comments about vocational rehabilitation services at the public forums. Comments made at the forums support the policy analysis, which points up ambiguity in eligibility criteria and a lack of client control over the type of service made available. <IA>

Though many consumers who use vocational rehabilitation services report they were assigned to a program with little or no choice about the training they would receive or the job they would work at, nearly 60% report that this program provides adequate support for independence. <IA>

It has been documented that there is little incentive for moving people into the competitive job market because it represents a major loss in revenue for the providers of day services. According to Braddock, there were 287,697 people with developmental disabilities in day/work programs. With the per client cost for supported employment initiative at \$4,473, the projected total cost is \$1.2 billion. Vocational service providers have a multi-billion dollar industry to protect. <ID>

There is a serious lack of real work in Idaho's extended sheltered employment facilities. In work activities and extended sheltered employment (work services), the individual should be doing real work at least 70% of the time and should receive commensurate wages. <ID>

Reducing the number of people in sheltered employment is threatening to providers of the sheltered employment and day programs. It also challenges other employment services such as Vocational Rehabilitation, Jobs Training Partnership Act, and Social Security, to begin seriously serving a population that in the past they have not served. <ID>

In sheltered workshops, people often work for a few dollars a day, segregated from workers without disabilities, with no hope for a better future. <ID>

Sheltered workshops have created a monopoly in Idaho by successfully lobbying the Legislature to allow only workshops who are members of the Idaho Association of Rehabilitation Industries (IARI) as eligible to receive tax dollars to assist Idahoans in long term work services. The IARI consistently opposes any attempt to allow non-IARI members into the marketplace and to conduct business. <ID>

Workshops are only located in 10 counties. Many counties in small rural areas remain unserved or underserved. <ID>

Idaho's sheltered workshops are widely viewed as "readiness traps" in the employment services delivery system. The slow transition of workers with disabilities to community supported employment is seen as a barrier to integration, productivity and independence. <ID>

"Where in 1970, about \$24 billion was spent on persons with disabilities, \$122 billion was similarly spent in 1982, a 400 percent increase in only 12 years" (Vachon, 1987). The economic power of these programs poses a serious problem for people with developmental disabilities who wish to be independent of this industry which is dependent upon them for its survival. <ID>

Idahoans with a disability must not be precluded from meaningful, gainful employment simply because they have a disability. Unemployment and underemployment is one of the biggest problems for people with disabilities. <ID>

Productivity consists of income producing work measured through employment status and job advancement, however, work opportunities for workers in Idaho are categorized by "slots" in segregated work settings through contracts with the regional Adult and Child Development Centers. The number of working hours available to Idaho workers with developmental disabilities are severely limited by program models and entitlement program disincentives. <ID>

Issues identified during the public forums as barriers to employment consist of having to provide twenty-four hour advance notice, para-transit providers providing limited hours of service, only covering certain routes (not outlying areas), and the transit system not running on weekends or evenings. Wheelchair accessibility was also noted to be a barrier to employment. <ID>

The unemployment and underemployment of Idahoans with a disability remains high. Scores of Idahoans living in group homes or family homes have no jobs. Waiting lists for access to the only publicly financed employment system exist statewide. Idahoans with a disability remain a totally separate working class. <ID>

All Idahoans want to work. This state's people hold tightly to the independence, productivity and self-sufficiency ethic. Yet, Idahoans with a disability lag far behind in the opportunity to exert their independence and boast about their hard toil because Idaho does not have a clear vision of all Idahoans employed in meaningful, gainful employment. <ID>

Vocational rehabilitation is an important source of funding for employment training related services. Once a person is rehabilitated and placed on a job, however, the case is closed and there is minimal, if any, follow up. <ID>

Idahoans without a disability have prided themselves on the hard bedrock mining, rigorous logging, long-day farming chores, and most recently, skillful high technology vocations they pursue. The vast majority of conversation in any circle involves, at some point, a discussion of where you work. For Idahoans with a disability, this conversation has been one-sided. Idaho's vision is blurred with a closed system of workshop providers; closed with wages far less than minimum wage; closed with non-productive, non-integrated, non-meaningful dead-end jobs. <ID>

Prevocational skills training was the number one employment concern of those responding to the Council's Needs Assessment Survey. The services included transitional employment services, job seeking/holding skills and job orientation. <ID>

The Idaho Focus Group suggested that rules and regulations for Idaho's Division of Vocational Rehabilitation programs are inconsistently interpreted around the state. <ID>

Nationally, only about 12% of JTPA program participants are classified as "handicapped". JTPA is not set up to provide the job accommodations and long-term supports often needed by people with developmental disabilities. <ID>

Idaho's rural communities lack access to employment training and community supported employment opportunities for people with development disabilities. Idaho's rural population lacks access to outreach services. <ID>

Idaho needs to develop and maintain a comprehensive, coordinated statewide transit network which will meet the basic work related transportation needs of Idahoans with a developmental disability. <ID>

In Illinois, the average person with a developmental disability, including severe mental illness, makes \$54/week. Placement in a Supported Employment program results in an increase of income of 65-200%. <IL>

The Council finds that, in Illinois, the average person with a developmental disability makes \$54/week. Receiving such a low wage has a direct impact on the ability of consumers to pay for accommodations, food, clothing, and other necessities, to participate in leisure activities, to travel, and to pay taxes. <IL>

The greatest obstacle to full implementation of supported employment nationally is long-term funding. The problem is a function of (a) the degree of commitment a state shows in the budgetary process by specifying the use of long-term funds; (b) the potential divisiveness this problem causes between disabilities; and (c) the lack of clear policies mandating cooperative agreements between rehabilitation service funds and long-term funds before a case is accepted. <IN>

While Indiana represents about 2.2 percent of the U.S. population, it serves about 9.4 percent of all adults in sheltered employment settings. There is no evidence that Indiana has adopted a strategy to provide incentives for the future in supported employment through the conversion of existing day programs or mandating the reallocation of existing program slots to supported or competitive employment. Encouragement comes principally through the perception that supported employment funds are new monies and so represent an avenue of more rapid growth of community agencies. The number of persons served in sheltered employment and adult day care continues to grow. <IN>

Social Service Block Grant funds (SSBG) used by the Department of Medical Health are restricted to day services and sheltered employment and do not provide fiscal support for supported employment. It should be added that the Department of Mental Health has requested the State Budget Agency to approve the use of day service monies for supported employment; however, this request has been denied. <IN>

There is a continued need for quality technical assistance and staff development in this rapid growth service. Staff are being asked to perform in areas of skilled behavioral training, training clients directly in businesses and modifying work schedules in ways that require extensive and ongoing staff development. The long-range growth of supported employment is contingent upon additional funds being expended for a large number of qualified personnel. <IN>

Even within DMH's definition of developmental disability, it is unclear whether those with severe disabilities are being adequately served. When measured by intellectual functioning, for example, for individuals in Indiana's supported employment programs with diagnostic data, 14 percent had no intellectual impairment and only 1.5 percent had severe intellectual impairment; when measured in terms of adaptive level, only 3.6 percent had severe or profound impairment and 14 percent had no adaptive impairment at all. In comparison with the other states, it appears that Indiana serves proportionately fewer persons who with severe or profound mental retardation, and a proportionately greater proportion who with borderline mental retardation. <IN>

Despite coordination agreements between DMH and DHS/OVR and the adoption by both agencies of the federal definition of clients eligible under supported employment, there are built-in barriers to accessibility because of differing definitions of what counts as a severe disability. Because DMH is bound to a restrictive definition governing persons with developmental disabilities, many persons with other severe physical disabilities have not received the needed follow-along and other supportive services. <IN>

Providers continue to disagree about the best model of supported employment - e.g., whether individual placement is the ideal or whether enclaves are acceptable - and whether all individuals can be expected to work 20 hours per week. There is disagreement among state staff whether all individuals can be expected to work 20 hours per week. Some agencies have been refused supported employment funding because this condition

could not be met. Since federal dollars drive the Indiana system, it lacks the flexibility to employ people at less than 20 hours using the supported employment approach. <IN>

According to the legislation, supported employment is for persons with severe handicaps who, due to the severity of their disability, have been unable to get and consistently hold a job. There are a number of problems in getting this group served. First, it costs more to train, place and retain people with severe disabilities than people with mild disabilities. Second, more research is required on how to improve behavioral and rehabilitation engineering technologies. Providers require retraining on how to work effectively with those persons who have the most severe disabilities. <IN>

Indiana presently lacks any standards to monitor and determine the quality of supported employment programs in the state. <IN>

The manning tables of the principal state agencies do not reflect the priority of supported and competitive employment. Rapid turnover in positions and the absence of employment specialists at the Department of Human Services and Department of Mental Health suggest that these agencies have not put employment initiatives at the head of the service agenda. <IN>

Uneven implementation of supported employment is often the result of state agencies failing to share resources and providing inconsistent goals and plans. <IN>

There is no management information system for supported employment in the state which integrates the efforts of the two principal agencies. And DHS/OVR has no information system for tracking supported employment data (RSA-911). <IN>

Availability of work centers, training and activity centers is not evenly distributed across Kansas. <KS>

Vocational programs for people with challenging behaviors and multiple disabilities are needed. <KS>

Many people could work in supported or competitive settings if funding and jobs were available. There is a lack of long-term funding for supported employment. <KS>

State VR policies stress case closures, thereby serving people with less severe disabilities in favor of those with more severe disabilities. These and other policies (e.g., rigid 20 hour/week minimum for supported employment) should be reviewed. <KS>

Formal coordination mechanisms (e.g., unified approach to employers) are lacking among the various job placement and rehabilitation agencies. <KS>

Over 525 people are on waiting lists for vocational services. <KS>

There was strong expressed need among consumers for vocational training and employment services which are not currently being met. Only 6 percent of the household and 16 percent of the institutional sample were working full or part time, yet only one-third or less of the household and institutional samples were reported unable to work at all. Many may not be working because of the orientation of vocational rehabilitation services to training, placing and closing a case within a short period of time. <KY>

Many people with mental retardation are employed in marginal jobs with no fringe benefits. Equally important is the fact that among working-age people with mental retardation, 20.3 percent are uninsured when they are employed full time, while 30.1 percent are uninsured when employed part-time compared to only 8.6 percent who are uninsured when they are not employed. <LA>

Over the past five years Louisiana has led the nation in unemployment, with some parishes having a rate of over 20%. At a state and local level it is likely that there is a relationship between the overall health of an area's economy and its ability to employ and sustain people with developmental disabilities. <LA>

According to the Report on Supported Employment Activities in Louisiana, persons with severe physical disabilities and disabilities other than mental retardation are greatly underserved in supported employment services. Only 8% or 44 individuals had a disability other than mental retardation in 1988. Recently, however, this number has increased by 40%-50% as a result of the DD Council and Louisiana Rehabilitation Services funding three new programs that serve people with autism, severe physical disabilities, and severe mental illness. <LA>

Major barriers reported by service providers in developing or implementing supported employment programs included: finding and developing jobs; retaining jobs; funding for programs to hire additional staff; parental concerns related to employment and loss of Social Security income and health benefits; a lack of public or special transportation; and a lack of ongoing staff training and technical assistance. Other problems cited were limited interagency collaboration and service coordination; inadequate support activities for non-work hours (many return to workshop); and the lack of information management and quality assurance procedures. <LA>

Persons with severe mental illness need more intensive training and support than are currently provided in transitional employment programs, traditional day programs, or residential programs to create and stabilize competitive job opportunities. <LA>

The governmental service system (both state and local) currently lacks the resources and mandates to provide ongoing employment supports to people with developmental disabilities. <LA>

The limited use of JTPA funds to provide employment services for people with disabilities is due in part to local vocational providers not pursuing this funding source. <LA>

Approximately 300-310 people with disabilities were working part-time in the community in 1989 as a result of the State Use Program. The major drawback of the program is that these contracts (because of the low bids involved and the expenses associated with operating crews) do not provide the resources to typically include persons with severe developmental disabilities. Another problem is that Mobile Work Crews, due to the after hours nature of janitorial work, and the fact that the crews by and large are composed exclusively of persons with disabilities and a paid supervisor, do not afford crew members many opportunities for social or physical integration or interaction with nondisabled persons. <LA>

Most (52.2%) of the individuals identified in supported employment placements were in mobile work crews that offer limited opportunities for contact with co-workers without disabilities. <LA>

Approximately 2,000 people with disabilities in Louisiana are in segregated workshops or work activity programs. As of March-May 1988, 543 individuals were reported as working in supported employment placements but 565 people are also on waiting lists. <LA>

Supported employment service providers, especially non-workshop programs and programs serving persons with severe mental illness, are experiencing difficulties in developing ongoing support services for persons whose initial job development and training has been funded by Louisiana Rehabilitation Services. <LA>

One of the challenges of the 1990s is to carve out those jobs that through accommodations and other supports can be successfully accomplished by people with severe disabilities. <LA>

The nation spends 65 billion dollars on supporting persons with disabilities who are unemployed. 95% of that 65 billion dollars goes to pay for social security benefits and medical costs. If more persons with disabilities were working, these costs could be reduced substantially, corporate and personal taxes would be reduced, and these persons would be taxpayers. For every 995 persons with disabilities employed in 1986 there was a savings of \$1,000,000 per year in social security payments. <MA>

People capable, with supports, of doing "real work" who remain unemployed in (non vocational, medical model) day habilitation programs. <MA>

The national unemployment rate for persons with disabilities is estimated at 66%; among the persons with disabilities who are unemployed, 78% want to work, and would work if were accessible to them. No other demographic group under 65 years of age has such high unemployment figures. <MA>

The Council should investigate the extent to which the Developmental Disabilities Administration's 85% Supported Employment expansion formula has restricted opportunities for persons with severe or profound handicaps. <MD>

Although many work, their employment is part-time, minimum wage, seasonal, or in sheltered workshops. These marginal positions do not provide promotions or any benefits, such as health insurance and paid leave. <MD>

People with disabilities who do work generally work fewer hours than people who do not have disabilities. Part-time work usually does not provide employee benefits, such as health insurance. <MI>

Many people with disabilities do not work at all, do not work full time, or cannot earn a living wage. Most of them could work if given a chance and appropriate supports. <MI>

Too many people with severe disabilities who want to work are unable to find or keep jobs, or to establish and maintain businesses. <MI>

People with disabilities have such a high rate of unemployment and underemployment that they are a significant proportion of adults living in poverty. Yet generic jobs programs, including job training and job-oriented education programs, which are intended to address poverty and unemployment, rarely consider the needs of handicappers. Most of them fail to provide services to proportionate numbers of this population. <MI>

Expertise in the areas of job accommodation and barrier free design is scattered and difficult for employers. <MI>

Society in general, and people with disabilities themselves, too often have limited expectations about the ability of people with severe disabilities to achieve independence and self-sufficiency. This attitude restricts their ability to get jobs. <MI>

People with severe disabilities encounter discrimination in the job market. Women, minorities, and older people who have disabilities endure additional discrimination. Laws mandating equal employment for people with disabilities do not cover all employers. Existing laws have failed to have a major impact. <MI>

Most employers think only of entry-level positions for people with disabilities, and they tend to leave them there. Handicappers often begin in entry-level positions with little opportunity for career advancement, and never earn as much in wages as people without disabilities. <MI>

The greatest gap in existing employment services for handicappers is the lack of resources to serve people with severe physical disabilities who do not have mental retardation. No agency has designated responsibility for this population. <MI>

Transportation and personal assistance services are not consistently available when needed by handicappers seeking or trying to maintain employment. <MI>

Many people with disabilities see vocational rehabilitation services as not being useful, or as not being available to people with severe disabilities. In a Harris Poll of people with disabilities, most respondents who have gone through vocational rehabilitation said that it provided little or no help to them in finding a job. <MI>

Michigan has often lost opportunities to capture federal funds that were available for rehabilitation services because of lack of matching funds or problems in the state appropriation process. <MI>

Advocates reports that people with severe physical disabilities have difficulty getting the employment services they need, in part because assessments of employability traditionally focus on the person's "deficits," rather than assessing the environment. <MI>

Too many supported workers in Michigan work fewer hours than they could or would like to. People report that this happens for a variety of reasons. These include shortage of jobs; convenience of service providers, including residential service providers; and fear of losing benefits. <MI>

Supported employment as it now operates does not offer significant employment options for people whose disabilities are physical only. Michigan Rehabilitation Services counselors have stated that they do not place people with physical disabilities into supported employment, because funding is not available for ongoing support. People with physical disabilities who meet the Michigan Mental Health Code definition of developmental disabilities often have difficulty getting Community Mental Health programs to provide the support they need. People who do not meet the state definition of developmental disabilities have few potential sources for ongoing support. <MI>

For people with the most severe disabilities, sheltered workshops and work activity centers have been almost the only job options available. <MI>

Programs that focus on independence, such as supported employment, often have inadequate resources. Traditional services have focused on care and maintenance, without providing support for independence, productivity, and community integration. <MI>

Many existing employment programs have significant financial investments in physical plants. If clients move to community work sites, these programs may be left with expensive buildings and equipment no longer needed, and perhaps not yet paid for. These existing investments reinforce maintenance of the status quo. <MI>

Issues around funding for supported employment remain unresolved. Employment service providers are unsure about how to fund ongoing support for people who need supports for

employment beyond those funded by Michigan Rehabilitation Services, especially for those not eligible for mental health services. <MI>

Fiscal systems and limited resources constrain the services available to handicappers. Agencies often want (or need?) to retain clients for whom funding is available, or for whom successful outcomes seem most likely. In addition, agencies sometimes arrange for less costly services than those that would best meet the client's needs. <MI>

Self-employment or establishing a small business can offer individualized employment options for many people with severe disabilities. However, risks to new businesses are high and few supports are available to a handicapper who would like to start a business. <MI>

There continues to be a need for training of professionals in the employment field to expand their understanding, expectation and competence in a number of key areas related to supported and competitive employment of individuals who are severely disabled. Some of these areas include how to assess employment abilities and interests; how to assess work environments for a person/environment match, as well as needed adaptations; and how to develop new job opportunities in the community. <MO>

The federal definition of developmental disabilities requires an individual to have substantial functional limitations in three or more areas of life activity; whereas the definition for "severely handicapped" utilized by the Division of Vocational Rehabilitation only requires a person to be functionally limited in one area of life and work activity. While this would certainly make most people with a developmental disability eligible for consideration of Vocational Rehabilitation services, it does raise concern about how many individuals meeting the federal definition of developmental disabilities might be deemed as too severely disabled to be rehabilitated through Vocational Rehabilitation services. <MO>

Existing partnerships and creative uses of vocational funding resources from such sources as Vocational Rehabilitation, JTPA, Vocational Education, Special Education, SB40 County Boards, and the Division of MR/DD are limited and informal across the state. <MO>

No particular federal or state program is singularly responsible for addressing the employment needs of people with developmental disabilities. <MO>

There exists a need to expand community-based employment opportunities for people with disabilities. <MO>

A large portion of those who are underemployed are individuals currently employed in segregated sheltered workshop facilities. <MO>

Upward mobility and even lateral mobility of individuals placed in various existing vocational services continues to be very limited. <MO>

With new understandings of the ability of people with severe functional limitations to be employed in supported and competitive work situations and with the economic reality of limited vocational resources, Missouri will be challenged to determine the amount of commitment it will place on existing vocational and pre-vocational day services versus expanding into new employment arenas. In other words, Missouri will need to address the issue of whether or not to promote services (tax use) or employment (tax pay). <MO>

There exists a need for the training of individuals with disabilities in skills related to functioning within a work environment, particularly in the area of social competence. <MO>

Sheltered workshop operators in Missouri will continue to experience a tension between trying to balance the fiscal and operational needs of their facilities and the employment potential of their most productive workers. <MO>

Information on vocational services to and the employment situation of people with developmental disabilities is difficult to isolate. <MO>

There exists a need to expand support services, such as transportation, that are critical to maintaining persons in supported and competitive work settings. <MO>

Limited access to competitive jobs means that people with developmental disabilities have limited access to job related benefits, particularly health benefits. <MO>

Limited access to jobs that pay a living wage continues to force people with disabilities to rely on income maintenance programs such as SSI and SSDI for their basic survival needs. <MO>

Many individuals with developmental disabilities in Missouri continue to be unemployed or underemployed and underpaid. <MO>

The lack of employment opportunities with fringe benefits limits the availability of private health insurance for people with developmental disabilities. <MO>

Sheltered employment programs in Montana have been successful. However, demand for supported employment services exceeds current capacity. Long-term funding for follow-along services is especially in short supply. <MT>

The United States has failed to develop a coherent policy for employment of people with disabilities who will become a more important part of the labor force as we enter the 21st century. <MT>

Some consumers indicated that the employment services they needed were not available; others said that available services did not meet their special needs. Review of the vocational rehabilitation agency analysis generated some concern about eligibility criteria. <NC>

People with developmental disabilities expressed both shame and frustration over the relatively low wages they receive. <NC>

Themes that emerged from consumer comments concerning supported employment indicate few job options, dissatisfaction with vocational opportunities in sheltered workshop settings and a strong desire and capability to work in integrated employment situations. <NC>

The Office of Special Education and Rehabilitation Services (OSERS) within the U.S. Department of Education requires that clients participating in federally funded supported employment services work a minimum of 20 hours per week on the job. This requirement creates a disincentive for employers who desire to employ persons with developmental disabilities for jobs requiring less than 20 hours per week. In addition, the multiple job placements that generally result from the 20-hour requirement often present logistical problems for job coach staff which are difficult to overcome. <ND>

Under North Dakota's Medicaid waiver, use of federal Title XIX funds for supported employment services is restricted to DD clients who at one time resided in Intermediate Care Facilities for the Mentally Retarded (ICF/MR). This federal requirement precludes many mentally retarded and other individuals with developmental disabilities who are not past ICF/MR residents from receiving needed supported employment services, since state funding available for supported employment is not sufficient enough to serve all of these individuals. <ND>

Under North Dakota's Medicaid waiver, use of Title XIX funds for work activity is not allowed, yet use of Title XIX funds for supported employment activities is allowed. An apparent overlap between work activity and supported employment, coupled with the absence of a clear definition of what constitutes work activity often results in disallowed costs, which precipitates fiscal management problems at the state level, as well as the community provider level. In addition, such a discrepancy can also disrupt continuity of services to clients. <ND>

Due to North Dakota's economic conditions, persons with developmental disabilities who want to work often find employment opportunities confined to entry-level, part time, minimum wage jobs in the service sector. Such lack of job variety and employment choices available is not conducive to job satisfaction and long term employment. <ND>

Employment is not an option for some persons with developmental disabilities. These persons should have an equal right to appropriate day activities in settings that respect their dignity and value as human beings. <NE>

Current mental retardation programs should begin basing their employment services on business principles. Staff from these agencies are typically from the human service fields with limited experience in marketing and advertising techniques. With their traditional focus on the person with mental retardation, it may require a change in thinking to see the employer as the client in job placement situations. Some employers have seen their employment of persons with developmental disabilities or awarding of contracts to workshops as "charity work". This attitude may make it difficult to them to recognize the real employability of persons with mental retardation and decrease wages and benefits. <NE>

Vocational rehabilitation services under the Division of Rehabilitation Services need to be fully funded so that supported employment opportunities for persons with severe developmental disabilities may be expanded. Currently, the agency is reluctant to include this option in their basic grant as they feel they have inadequate resources to serve clients. The Division should actively work with other agencies to resolve the current dilemma in the state regarding employment and training options for persons with severe developmental disabilities. <NE>

Our survey results substantiated this lack of employment for persons with developmental disabilities. Six percent of the adults sampled had full-time competitive jobs. <NE>

HCB waiver recipients who obtain jobs and earn an income are required to pay most of their salary towards the cost of care. Increases in productivity are not matched by increases in spending power. <NH>

Most non-remunerative day habilitation services are reimbursable, whereas most supported employment services are not reimbursable. While total day habilitation costs are far higher than supported employment costs, the state share is lower in some cases. This creates a financial incentive for retaining people in nonproductive activity. <NH>

Many of the regulations governing public benefits programs have the effect of punishing those who attempt to become productive and independent. Particularly problematic is the "payment towards cost of care" provision applicable to those receiving services under the Medicaid waiver problem. This provision requires that income earned by an individual in excess of an amount needed for room and board and a small personal allowance be paid to the agency providing services. Waiver-eligible individuals cannot increase their disposable income no matter how much they earn. One administrator summed up the view of many who spoke on this issue at the Council's Community Meetings that this "puts people in a situation that none of us would tolerate, in terms of dollars in our pocket for hours worked." <NH>

The need to maintain benefits, especially Medicaid coverage, forces many consumers to stay out of the labor market altogether or to lower their productivity or their work hours. One woman's story dramatically illustrates this problem. This woman found that getting a raise at her job resulted in a loss of Medicaid, a benefit she could not do without. Her only alternative was to quit her job and stay unemployed long enough to re-qualify for Medicaid, then look for lower-paying work. <NH>

Most of the wide disparity between the rate of unemployment among people with developmental disabilities and the general population is attributable to the unavailability of appropriate employment services. For every 10 people receiving employment support, four others are on a waiting list of services. The number of new individuals with developmental disabilities scheduled to receive employment services this year is far below the number with developmental disabilities who will graduate from school. The total number of recipients of vocational services has remained virtually unchanged over the past two years, despite rapid population growth. <NH>

Supported employment is intended as a cooperative enterprise, with the state Vocational Rehabilitation agency sponsored initial job placement, training, and adjustment services up to a maximum of 18 months. Assurance of extended support under Community Developmental Services funding is expected to be provided at the start of the process by means of a letter of long-term support, and the transition itself is expected to occur when initial adjustment is complete, in accordance with a cooperative agreement between the two agencies. However, resource limitations have created a situation in which jobs tend to be selected which require less training and are less challenging. Group "enclaves" are utilized extensively because quicker initial placement and adjustment can be achieved. Currently, continued sponsorship is examined every three months to allow for the possibility of management review. It is possible that some service providers may interpret these reviews as a limitation on services. <NH>

Consumers and families who reported difficulties obtaining vocational services at the Council's Community Meetings were asked about their experiences and current status with the Division of Vocational Rehabilitation. Invariably, these individuals reported being unaware of the current status of their application or service program, whether they had a counselor, whether a plan was in effect, and so forth. Although this was not an unbiased sample and some lack of awareness can be attributed to factors such as forgetfulness, it is likely that a legitimate problem exists in the conveyance of timely and clear information. <NH>

Individuals with developmental disabilities are considered severely disabled within the vocational rehabilitation system and individuals with severe disabilities are required to be selected to receive services before any other groups. Yet nearly half of all adults with developmental disabilities have had no experience with the vocational rehabilitation system. In large part, this reflects unresolved problems in the coordination of supported employment services. <NH>

It is estimated that in Fiscal Year 1990, between 75 and 100 new job placements will occur without expansion of existing support services. The end result will be a longer wait for placement and more individuals placed in more costly day programs. <NJ>

Handicapped Assistance Loans are extremely restricted by the federal government's definition of barriers to business ventures by people with disabilities. The business must be in a field that the person was not trained for prior to becoming disabled. The Small Business Administration will guarantee up to \$350,000 of an HAL, but it guarantees up to \$750,000 of its other loans for qualified, non-disabled individuals. <NJ>

New Jersey's rate of including people with disabilities in the Job Training Partnership Act is slow, compared to other states. One reason may be New Jersey's definition of "disability," which includes people categorized as "socially maladjusted," defined by "a consistent inability to conform to the standards for behavior established by the school. Such behavior is seriously disruptive to the education of the individuals or other individuals..." Many youths in New Jersey's ghettos could fit this definition and consequently be identified as a "handicapped" recipient of JTPA services. The need for services for youths who experience dysfunctional behaviors in school is unquestionable but should be tracked in a separate category. <NJ>

While there is strong sentiment within the Division of Developmental Disabilities and among service providers to convert adult training programs into supported employment models, the lack of necessary training and technical assistance are major obstacles. <NJ>

With the current labor shortage in New Jersey, supported employment specialists can locate more jobs than they can fill. In many cases, the result is a kind of selectivity in which only higher paying jobs with benefit packages are considered. A major problem is that there are only 40 job coaches in the entire state who must share the responsibility of providing on-going support to 514 competitively employed individuals with developmental disabilities. <NJ>

Income limits of the JTPA negatively impact on a state like New Jersey, which has a high cost of living and a high per capita income. Low-income New Jerseyans in need of job training may in fact have incomes that would be considered marginally above the subsistence level in other states. <NJ>

Providers of services to people with disabilities currently have limited participation on Private Industry Councils. Access for people with disabilities to JTPA services could be enhanced by increased sensitivity of local PICs. <NJ>

Even when rehabilitated, many Social Security beneficiaries lack the earning potential to make employment an attractive alternative to benefits. Changes in the benefits structure could return more people to work. <NJ>

Competitive employment transportation — the problems associated with providing transportation for individuals with individual destinations — is an issue that must be examined. <NJ>

Some parents of people with developmental disabilities express concern about the risk of losing benefits, especially medical care, and are ambivalent about their sons or daughters working." <NM>

Despite the success of the Work Incentive (1619) Program in encouraging SSI recipients with disabilities to move into employment, there is no similar program for people with disabilities who receive SSDI, although legislation has been introduced in the 101st Congress to address the issue. <NM>

Because employers are not made aware of the true potential and abilities of people with disabilities, they fail to give them equal consideration in the hiring process. <NV>

Lack of consistent, informative communication with employers. <NV>

Lack of education and rehabilitation counselor knowledge of 1) handicapping conditions and resultant limitations and residual abilities and 2) experience in the "real world of work" which may result in their inability to properly assess the skills of their clients. <NV>

Lack of professionals who are trained in job development and placement of persons with severe disabilities. <NV>

Lack of appropriate job modification or accommodation and availability of post employment intervention. <NV>

Lack of opportunity for homebound or sheltered employment for persons with severe physical disabilities. <NV>

There is a need for day programs that are designed to meet the specialized needs of individuals who are dually diagnosed and blind. Because of the special combination of their problems, other agencies have not felt qualified to do this job. <NY>

Unserved or underserved populations include people who are eligible for services but whose disability requires a more intensive level of specialized care. For example, a person with autism who does not fit into workshop programs because the repetitive work is monotonous and leads to behavior problems. <NY>

People with severe disabilities and multiple handicaps reported they are often excluded from opportunities for meaningful work or kept in "continuum of care" models for inappropriate lengths of time. Others felt they were "stuck" in unchallenging jobs with no choices or opportunities for change. <NY>

The average salary for a job coach is \$14,000 per year. At this salary, agencies are unable to find individuals who are qualified to work with people with more severe handicaps. <NY>

Most adults with developmental disabilities who are employed work in segregated settings such as sheltered workshops. For example, more than 20,000 Ohioans with developmental disabilities (most with mental retardation) currently work in sheltered workshops operated by County Boards of MR/DD and other private agencies. The national study also showed that for adults in vocational service programs 74% worked in sheltered settings, 7% were in transitional/training programs, 5% were in supported work and 14% were competitively employed. <OH>

Many people with developmental disabilities are "trapped" between systems - a County Board of MR/DD may deny services to people who do not have mental retardation while the local Rehabilitation Services Commission representative may also deny the person's eligibility for services because they are judged to be too "disabled" to benefit from services. <OH>

Most adults with developmental disabilities are unemployed. Nationally, approximately 64% of people with disabilities are unemployed; the figure for adults with developmental disabilities is estimated to be even higher. A national study conducted in 1984-85 showed that of adults who work, approximately 32% work only part-time. Even those persons designated as working full time worked only an average of approximately 31 hours/week. <OH>

A lack of integrated alternatives and the limitations on long-term support services still severely limit the vocational choices for thousands of Ohioans with developmental disabilities. <OH>

There are many persons with developmental disabilities who are underemployed and unemployed due to some of the following factors: traditional attitudes of employers that people with disabilities cannot be gainfully employed, or considered for positions not normally held by people with disabilities; lack of training available to persons who require special aids and modifications in the workplace; barriers caused by unavailable transportation and cost of personal attendants to accompany people with disabilities on the job; and lack of job information available to persons with disabilities and referral services to assist them in contacting potential employers." <OK>

Supported employment and community integrated employment programs are available for persons with developmental disabilities to access after leaving school. Sheltered workshop placement is also a possibility for students leaving the public school system. However, these programs are available only to those receiving services through the developmental disabilities service system or to those persons with mental retardation. Therefore, there

is a large service gap in the state at this time for persons with physical disabilities after they leave school. <OK>

Little attention has been paid to providing employment supports for persons with physical or sensory disabilities, e.g., adaptive devices and equipment, job accommodation and transportation. <PA>

Lack of pre-vocational, vocational and supported employment programs for people with physical and mental disabilities. <PR>

In the limited vocational programs available, the consumer must accept what is available and not necessarily what he/she likes or may be able to do. <PR>

The percentage of the consumers being served by Vocational Rehabilitation who have a severe disability is lower than the national percentage and the participation rate in the Work Incentives Program (SSI), though higher than the national rate, is lower than the rest of the New England states. <RI>

Transportation to and from work is a major barrier for persons with disabilities. <SC>

Adult services providing job coach and follow along supports have waiting lists of considerable length. <SC>

Parent training is needed to promote awareness of supported employment. <SC>

Employment programs are needed in the community based service system for people with chronic mental illness. <SC>

Persons with spinal cord injuries and other persons with severe physical disabilities have certain employment needs not being addressed by the system. <SC>

Access to some supports is tied to proving an inability to work while access to other supports requires being able to prove reasonable expectation of employability - "Catch 22." <SC>

Employers have a tendency to discriminate against persons with epilepsy and persons with sensory impairments. <SC>

Performance standards the Congress has attached to mandates of programs serving persons with disabilities appear to be self defeating. The standards an agency must meet frequently require the emphasis to be on quantity served and not quality of service. <SC>

Once linked to adult services, long waiting lists are the norm. <SC>

Supported employment was a major concern of many consumers and their families. It was felt that much could be done to encourage employers to hire people with developmental disabilities, to provide accessibility to the workplace, and to furnish the necessary supports to assist individuals in maintaining a job. <SC>

Persons with developmental disabilities who rely upon van services frequently arrive late for work and have long waits for pick-up after work. Job coaches (trainers) who are on the job with employees who have developmental disabilities cite transportation as one of the biggest obstacles to "job success." <SC>

For their part, ODDMH officials expressed doubts that current funding mechanisms promote placement of persons in more integrated employment settings. Adjustment training center directors questioned whether state funding is structured to sustain broad-based efforts to improve supported employment opportunities for persons with developmental disabilities. <SD>

Efforts in the state to promote the participation of persons with developmental disabilities in community integrated employment appear to be relatively weak in comparison to the proactive strategies adopted by other states. <SD>

The state has not defined nor implemented a comprehensive strategy designed to secure integrated employment opportunities for persons with developmental disabilities. <SD>

In Tennessee the advent of Title VI-C funding for supported employment through the Division of Rehabilitation Services has been an incentive to get individuals out of sheltered workshops and into training for supported employment. The community agencies in Tennessee are aware, however, of the impact which increasing the number of individuals in supported employment will have on sheltered workshops. Currently, only approximately 25 to 55 day programs for adults with mental retardation offer supported employment services. <TN>

Some programs do not place sufficient emphasis on assuring that persons with developmental disabilities are employed in the least restrictive work environment appropriate in their needs. <TN>

The Jobs Partnership and Training Act does not include a specific focus on or commitment to people with severe disabilities, and does not include long-term supports often needed by persons with developmental disabilities. <TN>

In Tennessee, the Division of Rehabilitation Services does not fund the ongoing support needed by the individuals in the Title VI-C (supported employment) program training. Ongoing support is provided in many cases by the Division of Mental Retardation for Title VI-C program participants with mental retardation. However, individuals with developmental disabilities other than mental retardation generally have no source of

ongoing support in Tennessee and, therefore, have not been able to participate in the Title VI-C program or other support employment programs. <TN>

Some programs are not organized to allow persons with developmental disabilities to take advantage of work opportunities. <TN>

The reporting requirements for vocational rehabilitation services do not incorporate incentives for placement of clients in integrated work settings. <TN>

For individuals with developmental disabilities other than mental retardation who are over the age of 22 years, there is no responsible state agency for providing ongoing training and support. <TN>

The Council's experience in demonstration grant projects indicates that many individuals with developmental disabilities, even those with severe and profound functional limitations, are capable of working in integrated community work settings. This experience differs dramatically from the overriding programmatic direction of most programs in the state which continue to promote primarily segregated, sheltered programs with little or no expectation that participants will transition into integrated, competitive settings. <TX>

The Council determined that funds for existing services are not adequate to meet the current demand for services. Additionally, no agency is currently designated to be responsible for long-term vocational and employment services needs of individuals with disabilities with the exception of those with mental retardation and mental illness. This gap results in significant numbers of individuals who do not have access to any services once leaving special education programs. <TX>

Little coordination occurs between programs operated within the MHMR system and vocational rehabilitation programs at a state or local level to assure continuity of services. Many individuals in MHMR programs are in fact employable, but rarely are vocational rehabilitation funds coordinated to provide the program enhancements necessary for that placement to occur. For individuals with mental illness or mental retardation who are placed in employment but who need continued support, it is unclear whether TRC's ERS program or MHMR program should provide that support. <TX>

Day activity programs, work activity centers and sheltered workshops were initiated to provide a continuum of services for adults with developmental disabilities. The precept was that an individual could enter a day activity program, work activity center or sheltered workshop and after demonstrating a certain competence or "readiness" could move to the next step in the continuum. Statistics show that the actual reality of what happens to individuals once they enter this "continuum" is unfortunately not consistent with the original intent. Instead of moving through the continuum, people end up spending

years and sometimes their adult life in their initial placement without ever having the opportunity for integrated work in the community. <TX>

Most adults with severe developmental disabilities have in the past been relegated to segregated day programs or sheltered work programs because service providers did not have the technology to teach them to be successful in real jobs. Supported employment has demonstrated that these individuals have far greater capabilities than once believed and that even people with the most challenging disabilities can work in integrated jobs in the community with the appropriate supports. <TX>

Medicaid Home and Community-Based (HCB) does not allow day treatment programs to offer prevocational or supported employment services to non-institutional people. Because of the heavy federal match, the state tends to provide prevocational and supported employment services to Medicaid eligible people who have resided in an institution. This bias tends to provide services to the "already served" and deny services to equally needy people from the community that have remained in the family home. <UT>

The statistical information regarding "26 closures" has been an effective means of gaining congressional support for VR services. However, the outcome of such a policy appears to be building a barrier to the potential employment of individuals with more severe handicaps. <UT>

In Utah, people with disabilities may qualify for Medicaid if they are willing to spend down to the SSI income level. This creates barriers to employment in three ways: first, people are not inclined to give up certain income for something less stable; second, the wages of most entry level jobs do not provide that much more than the guaranteed income; and third, most entry level jobs or part-time jobs do not have substantive health benefits. <UT>

Health insurance is one of the major barriers to employment for people with disabilities. Employers are often disinclined to hire people with disabilities if they think that their insurance premiums will rise. <UT>

One of the major barriers to employment for people with disabilities in the state of Utah is the lack of transportation. <UT>

The most common problem expressed by people with physical disabilities in the Focus Groups as a barrier to employment was architectural barriers. One young woman had a job in a factory, but the only way she could get to work was to wheel up a very steep ramp in the back of the factory designed for freight delivery. <UT>

Providers have reported that accommodating the administration and paperwork of people receiving pre-vocational services has cost them approximately 5% of their budget in

additional expenses. These kinds of outcomes result from a large bureaucratic system trying to limit the numbers of people served. <UT>

The unavailability of work is a major barrier to increasing productivity and quality of life for many persons with developmental disabilities. <UT>

Currently, service delivery systems in Virginia are fragmented and inadequate to support employment of persons with developmental disabilities. These inadequacies are most pronounced with regard to funding levels, long-term supports, optional ancillary resources, and opportunities to access rehabilitation technology. <VA>

Results from a variety of recent studies conducted within the Commonwealth clearly indicate that persons with developmental disabilities experience chronic and severe underemployment and unemployment. <VA>

A major barrier to the realization of full productive employment of persons with developmental disabilities is the lack of awareness and expectations among professionals, parents, employers, and persons with developmental disabilities themselves, regarding the employment capacity and availability of these individuals. <VA>

Group members also identified insufficient funding of ongoing employment supports, inadequate resources particularly with regard to personnel and staff development, and limited availability of quality rehabilitation technology services as major issues limiting the full productive employment of persons with developmental disabilities. <VA>

Empowerment of consumers with developmental disabilities to have options and make choices regarding employment. In spite of the gains that the Commonwealth has made in recent years to expand the availability of employment services for persons with developmental disabilities, there still exists limited diversity in the options available to persons. As a result, most Virginians with developmental disabilities have very little choice in the employment services they receive. <VA>

The Harris survey has shown that nearly two-thirds of all Americans with disabilities between the ages of 16 and 64 are unemployed while only 25% of the people with disabilities are employed full-time (Harris 1986). In Vermont, that percentage drops to 14% employed full-time for adults with developmental disabilities (Developmental Disabilities Council, 1989). And yet, it is known that people with disabilities are dedicated and capable employees (Guy, et. al., 1989; Palmer, J., 1989) and they want to work. In fact, according to the Harris study, 82% of people with disabilities would give up their disability related benefits in exchange for a full-time job. <VT>

People with disabilities are discouraged from working because many available jobs lack adequate medical benefits and only pay minimum wages. <VT>

A person who is blind and receiving Social Security Disability Insurance may earn an income of \$740 per month without affecting benefits. However, a disabled person receiving Supplemental Security Income can lose their benefits if they earn more than \$300 a month! In the early 1980's the Social Security Act implemented the so-called Section 1619 a and b program designed to protect cash and medical benefits for SSI recipients who are working. In the beginning, few people took advantage of this program for fear that it would expire at the end of the three year trial period and they would be left without medical benefits. Since the Section 1619 provisions became permanent on July 1, 1987, the number of SSI recipients who earned income sufficient to qualify them for the benefits and protection of this program has increased a dramatic 40% nationally. Yet, only a small percent (approximately 1.57% of people aged 18-64 receiving SSI) of those eligible are actually participating in this program. <VT>

Many positions currently being assumed by people with disabilities are entry-level. We are concerned that these positions may be "slotted" for people with disabilities with little opportunity for advancement in wages or position. We must give consideration to career planning for people with severe disabilities and not be satisfied with simply placing a person in a job. People will leave or lose jobs; we should move beyond simple measures of job retention to a consideration of a person's work life as it unfolds over time. Raises, benefits, promotions, and jobs that better build and reflect individual interests and choices need consideration. As the career perspective develops, many present policies must be modified. <VT>

While Vocational Rehabilitation classifies some clients as "severely" disabled, their definition of "severely" is very broad and includes many people who would not be classified as developmentally disabled. Thus while 63% of the Vocational Rehabilitation cases nationally were classified as "severe" and 62% of those cases were listed as successfully rehabilitated, there is no way to tell how many of those served were actually people with developmental disabilities. Based on our knowledge of the Vocational Rehabilitation system and the needs of people with developmental disabilities, we suspect that only a small percentage of people with developmental disabilities are finding employment through the Vocational Rehabilitation program. <VT>

Vocational rehabilitation, which assists people with disabilities with job training, placement, and support services, is not designed to adequately meet the employment needs of most people with developmental disabilities. Federally established program eligibility guidelines require that before Vocational Rehabilitation can accept a person as a client, they must determine that the provision of services over a relatively short period of time will allow that person to assume a productive position either in the work force or at home. <VT>

Supports such as career counseling, job training, placement, as well as follow along supports, and transportation are frequently inadequate, non-existent, or too time-limited. <VT>

Less than half of the Vermonters with developmental disabilities who are working chose their own jobs and yet, of those working who responded to the survey, 75% said they were at least somewhat satisfied with their job. This was another surprising statistic considering the lack of input they had in selecting their jobs. Maybe the service system is doing a great job at matching people with jobs, or maybe people with disabilities are just happy to have any job! <VT>

Not only must employers change their perspective on employees with disabilities, but people with disabilities and their family members and care-givers must expand their career decisions. The Survey of Vermonters with Disabilities had some rather disturbing results concerning how people with disabilities perceive the job market and their ability to be part of the workforce. <VT>

Although more and more employers are hiring people with disabilities, many employers still harbor concerns or "myths" about people with disabilities which may be limiting employment opportunities. There are myths about the ability of workers with disabilities to "fit-in" with the rest of the workforce, their need for costly accessibility modifications, increases in insurance rates, and absenteeism due to illness. <VT>

Information about the most recent adaptive devices and technological advances is limited for people with disabilities and employers in Vermont. Vermonters with disabilities and their prospective employers are currently at a disadvantage because of a general lack of knowledge about assistive devices and the limited availability of rehabilitation engineering. Technology which can enhance productivity and job satisfaction for both workers and employers is constantly evolving, but access is a problem. <VT>

Improved access to reliable, accessible and affordable transportation would reduce a major barrier to employment in all areas of the state, and would benefit many Vermonters with moderate and low incomes, not only those with disabilities. <VT>

Many job sites and work spaces are physically inaccessible to people with mobility disabilities, thus limiting their range of employment opportunities. <VT>

The legal concessions of Sections 503 and 504, however, fell far short of their intended goal. In a poll taken by Lou Harris and Associates in 1988, some 25% of working age people said they believe they had encountered discrimination because of their disability. A full 61% reported that job accommodations were not made available in the work place. In the same poll, 47% of those ranging in age 16 to 64 said public misconception about disability is a major barrier to employment. <WA>

People with disabilities are often relegated to permanently "practicing" employment skills. They're constantly "getting ready" for the real thing. Many people are also stuck in segregated work programs where they earn little or no money. Face it, earning four or five dollars a day doesn't do much for your self esteem. <WA>

Many times, employment options are limited by federal Supported Employment program regulations. In order to qualify for program benefits, an employee must work a minimum of 20 hours per week. This program lacks flexibility. Regulations also discourage job sharing which could enable more people to accept positions. <WA>

Many states are just beginning to implement supported employment initiatives. Although Washington has been very successful in this area, this very critical problem needs to be addressed. Currently the Federal Supported Employment Program funds individual services for a maximum of six to 18 months. It does not provide for long-term employment support.

To make matters worse, federal program policy states that a person cannot receive benefits under this program until a source of long-term support is identified. This creates much confusion and hardship for persons eager to enter the job market. Finding that element is critical yet difficult, and results in people on waiting lists. <WA>

In Washington, JTPA is seen as a critical source of funding which is also used to enhance other funding sources. However, it does not provide job accommodations and long-term supports under JTPA. Individual supports are only available for a three-month period. In addition, agencies receiving funds must make an effort to share their expertise as well as coordinate jointly-funded projects. <WA>

Statistically, more people are receiving employment supports at an overall lower program cost, yet what these figures don't show is that people with more severe disabilities often go unserved. <WA>

Approximately two-thirds of all working age Americans who have a disability are unemployed. Only one in four works full-time; another ten percent work part-time. No other demographic group under the age of 65 has such a large proportion of their population unemployed. <WA>

As our society shifts into a more service-based system, many jobs requiring less skill and more enthusiasm will become available to persons with disabilities. The challenge, however, will not be just to provide jobs...but to open up the entire market to persons who bring a wide array of physical and mental capacities. In other words, not all persons with developmental disabilities will be happy or challenged working at McDonald's Restaurants. On the other hand, some people may not be able to perform traditional or nontraditional jobs and they must be encouraged to contribute to society in their own particular way without being judged as somehow "less valued." <WA>

As large numbers of "baby-boomers" entered the labor force in the 1970s, persons with the greatest barriers to employment (young people with ethnic minorities or young people with disabilities) suffered the most in terms of the job market. <WA>

Employers say people with developmental disabilities make dependable and productive employees when they receive adequate and appropriate employment support services. Unfortunately, funding to help develop these skills is very limited. Sixty-six percent of the employers questioned in a 1987 Harris Poll also said that -- in their experience — people with disabilities lacked proper education and training. <WA>

Washington has a variety of ways to support people in retaining long-term employment. Mobile crews, enclaves, job placement and entrepreneur opportunities are some of the options available in addition to competitive employment. However, a stable source of funding for these supplementary programs is missing. Employment programs struggle to provide quality services in spite of reimbursement rates which quite often do not meet basic costs. Long waiting lists and job retention problems are the result. <WA>

In 1986, Harris and Associates found that 66% of all Americans with disabilities between the ages of 16 and 64 are not working. This is compared to a national unemployment rate of 5%. <WA>

Managers of businesses say they need public and employer education as well as realistic funds to provide training in order to successfully integrate people with disabilities into the work place. When supervisors and co-workers receive appropriate support, their confidence in dealing with special population employees soars. Co-workers can also be successfully trained to work with a new employee in a buddy or mentor relationship. <WA>

There is no data or information available on the number of people considered to be "underemployed". This type of information or data would have significant implications for program planning and development in terms of statewide planning and for individual planning. This refers not only to people who are not working enough hours per day but also people who are working in positions for which they are overqualified and underpaid relative to their qualifications. <WI>

In 1987, Wisconsin ranked 45th nationally in the numbers of people with severe disabilities rehabilitated, according to data collected by the Rehabilitation Services Administration. <WI>

As of October 1988, 44 Wisconsin counties were developing or expanding supported employment programs as a result of a 5-year Division of Vocational Rehabilitation grant. The grant, which was introduced in Wisconsin in 1986, expires in 1991. The future of the program and its staff at this time has not been determined. <WI>

According to data collected by the Wisconsin Council on Developmental Disabilities, there were 856 people on waiting lists in 1989 for supported employment services for the 51/community services systems. <WI>

Both the Division of Vocational Rehabilitation and the 51/community services system provide employment services. For example, supported employment services can be obtained through both systems with differences in the way each is defining supported employment. <WI>

The services provided by the DVR are generally time-limited. The responsibility for continuing services begun by the DVR is generally given to the 51/community services system in each county. Because counties are only required to provide services within the limits of available funds, many counties have lengthy waiting lists. (In 1988, 37 of 72 counties had waiting lists for work-related services.) As a result, many people are without services while they are placed on waiting lists (often for several years). <WI>

There is currently no way of knowing how many people are not aware of the services of the DVR and the 51/HSD community services system. It can only be assumed that there may be a large number of parents or individuals who are not aware of the services of these two systems. <WI>

There are sometimes significant discrepancies between data reported to the Rehabilitation Services Administration and data used specifically in Wisconsin. <WI>

Under federal regulations, the Division of Rehabilitation Services can fund supported employment services for individuals for no longer than eighteen months. <WV>

Of the nearly 2,500 people with developmental disabilities who currently attend vocational or day programs in West Virginia, over eighty percent are served in segregated settings. <WV>

The largest investment of public funds for vocational and day programs is currently invested in the option which is least consistent with the goals of independence, productivity and integration. In terms of both the cost per person and the total dollars spent, day programs are the most expensive alternative. In addition, day programs produce no goods or services and provide no income to its participants. Its high utilization is due mainly to the availability of Medicaid as a funding source, rather than consumer needs and preferences. <WV>

Major obstacles and disincentives presently exist for supported employment, the program that has the greatest potential to promote independence, productivity and integration. The disincentives to serve people with more severe disabilities are particularly great. Division of Rehabilitation Services funding is not only time-limited, but is also restricted to those individuals for whom there is reasonable expectation of obtaining and retaining employment with a minimum amount of ongoing support. Medicaid, on the other hand, is available to persons with even the most severe disabilities but may not be used to fund supported employment (with the exception of the Medicaid Waiver Program). As a result, only a small percentage of people with need of supported employment are being served

at the present time. A needs survey conducted in 1987 identified 4,238 people with disabilities in West Virginia who could benefit from supported employment. <WV>

One of the largest obstacles to employment opportunities for people with developmental disabilities, especially those people with severe disabilities, is the reliance on health-oriented financing for work-oriented services. Because vocational rehabilitation funding is time-limited, people with needs for ongoing support must rely on other systems, particularly Medicaid, for their services. These programs focus on habilitation more than on employment, thereby substantially reducing the chances for people to obtain paid work in regular jobs. <WV>

Fundamental changes are needed in our priorities and funding mechanisms for employment-related services for people with developmental disabilities. Federal funding and policy changes are needed that allow and encourage ongoing vocational supports for people in integrated, community settings. In particular, the federal Rehabilitation Services Administration should provide supported employment funding that is not time-limited for people with severe and life-long disabilities. <WV>

Another barrier to integrated employment is lack of knowledge and possible misconceptions about supported employment. <WV>

Placement status and the age of onset of the disability are good examples of the difficulty with data collection. While much of the needed information is collected in client files, it may or may not be part of the overall information assimilated into reports at the state level or the federal level. In fiscal year 1987 Wyoming vocational rehabilitation programs reported that 882 severe cases were handled during the year. There is no way of determining which of those individuals served in the severe category were people with developmental disabilities and which had disabilities of other kinds. <WY>

Developing expanded employment opportunities and reducing the number of people in sheltered employment is challenging to providers of the sheltered employment and day programs. It also challenges other employment services such as Vocational Rehabilitation, Job Training Partnership Act, and Employment Security to serve persons with developmental disabilities. The challenge is to shift the policy and economic emphasis on sheltered settings toward expansion of supported and competitive work alternatives. <WY>

WORK: RECOMMENDATIONS

Multiple States

State agencies should require vocational service providers (including state operated programs and facilities) to report wages, hours worked, types of employment, and types of businesses employing individuals with developmental disabilities. Monthly, or at least annual reports, should be published that compare service providers, types of vocational programs, and regions of a state. <ID,MT,TN,WY>

The Department of Labor should require that all state employment security agencies report (as they do with veterans, women, and racial minorities) the number and percentages of people with developmental disabilities served and profile this population as other are. <ID,MS,MT,SC,WY>

The Jobs Training and Partnership Act administration should require JTPA state service providers to indicate consistently those individuals who have developmental disabilities. <ID,MT,SC,WY>

There must be the authority to collect data on employment and labor force participation by people with disabilities. These data should be reported along with current labor statistics by functional and diagnostic characteristics of the disability. <MT,WY>

All programs for employing and training people with disabilities should have a single federal locus of authority. <MT,WY>

The Rehabilitation Services Administration should provide additional supported employment funding that is not time limited for people with severe and life-long disabilities (e.g., developmental disabilities). These funds may not be commingled with any other VR accounts at the state or federal levels. <ID,LA,MI,MS,MT,WY>

The rehabilitation services administration should require all state VR agencies to indicate those individuals with developmental disabilities in its statistics. <ID,MS,MT,SC,WY>

Developmental Disabilities Councils, advocacy groups, and others with an interest in a full-employment agenda for people with developmental disabilities can take their cause directly to the employers of this country. <ID,MT,WY>

Individual States

The state and federal government should provide funding of the ongoing support needed for individuals who require those supports to maintain gainful employment in the private sector. <AK>

The Alaska Division of Medical Assistance should expand the availability of personal care attendant services to people who experience disabilities who need this support to work and should encourage incentives to employers. <AK>

People need options in the public sector. Positions within the Alaska state government personnel system should be opened to support employment placements and state employment should provide means for advancement for employees who experience disabilities. <AK>

All individuals should be provided the opportunity for career advancement based on their skills and abilities and without regard to disabilities. The Governor's Council should increase public awareness activities about the abilities and employability of people with disabilities. <AK>

Alaska statutes that provide for the rehire of employees who were terminated because of illness or injury on the job should be fully implemented by the executive branch of state government. <AK>

The Social Security Administration should develop policies to deal with income earned from supported employment. <AK>

All components of vocational services such as pre-vocational, sheltered, and supported employment must be strengthened. The responsibility for programs for people who will be in non-competitive employment must be assigned. <AL>

Expand supported work opportunities through the development of service options statewide and adequate long term funding support by coordination of the efforts of Rehabilitation Services and DDS. Maintain the flexibility of services by keeping a "safety net" allowing people to return to the work center. <AR>

Agencies involved in the implementation of services need to determine the extent to which funding job training/placement programs for persons with developmental disabilities could be redirected to maximize the effectiveness of state dollars, increase use of federal funds, and reduce duplication of services. <AZ>

The Department of Economic Security needs to propose and advocate for the Legislature needs to support sufficient funding to provide services which ensure long term employment support for all adults who desire and could benefit from them. <AZ>

More work opportunities for persons with developmental disabilities need to be developed in Arizona's communities. There needs to be a continuation and further development of cost effective public/private partnerships with corporations, with an emphasis on increasing the private sector's responsibility for providing long term support. <AZ>

There needs to be an increase in interagency planning and sharing of funds through the continuation/development of interagency agreements; a process of continuous monitoring and assessment to support a continuum of employment opportunities, including job development services for competitive employment; determine who can benefit from employment-related training programs, that appropriate referrals are made, and that there is close coordination among referral agencies with DD or other appropriate agencies providing prevocational services, e.g. rehabilitation instructional services, work activity, etc; and provide necessary long term support services for community living after training and post employment services have been provided. <AZ>

There must be comprehensive training and incentives for completion of training for individuals who provide employment related support services. This includes, but is not limited to, job coaches and supervisors. <CA>

Long-range projects identified by the OSERS initiative should be completed including establishment of model programs for adult day services and transition, development of a uniform process for data collection and analysis, strengthening local agency networks, improving employer/consumer relations, and providing statewide training on employment concepts and awareness. <CA>

Day activities for adults with developmental disabilities should be geared to providing real independence, productivity and integration. They should not follow a "caretaker" program concept, but should instead provide the supports, training and opportunities for integration within the community that will lead to the goals of independence, productivity and integration. <CA>

Support services for individuals in supported employment placements should include follow-along assessments to ensure job mobility, promotional opportunities, and advanced training/retraining as required. There is a need to explore different types of jobs for people with developmental disabilities. New opportunities need to be created through further analysis of the labor market, including opportunities to work within the developmental services system itself. <CA>

More attention must be focused on employment goals as part of the case management process. Employment should be a pivotal factor in assessing the service needs of adult consumers. This should take into account residential placement and transportation needs. <CA>

Flexibility and comprehensive service planning are key factors. <CA>

There are currently administrative/legal barriers at the state level to piloting model programs in which more than one state agency might co-fund and take joint responsibility for administering services. This is especially true in the areas of transition programs and adult services with integrated employment options. <CA>

People with developmental disabilities must be empowered to assess their own skills and job interests and advocate for themselves within the work place. <CA>

It is necessary to generate employer/private sector interest in creating job opportunities. Concurrently, the program focus must be changed for a majority of people with developmental disabilities who do not have opportunities at this time related to real work. This includes continuing to promote the concept of "integrated work and community services" in adult day programs, providing for flexibility and creativity within employment day program services, and establishing a systemic commitment to employment as an ultimate goal for adults with developmental disabilities. <CA>

Public information and education must be provided in order to promote the concept that people with developmental disabilities are capable of working and being productive citizens, are dependable, and desire to work. It is also necessary to promote local training and development programs which would include this potential work force. <CA>

Collaboration and coordination among the many agencies (local, state and federal) which provide employment-related services to individuals with developmental disabilities must continue beyond the end of the OSERS supported employment grant period. <CA>

Put into place affirmative action policies focusing on hiring of people with disabilities into higher level positions as well as opportunities for promotion of those currently employed. <CO>

Expansion of supported employment to all sub-populations, as well as general increase in numbers served. This should include redirection of funds from sheltered environments. <CO>

DRS should abandon the Assumption College RCEP and focus all state and federal resources on designing and implementing a Connecticut-based training program using the Connecticut University Affiliated Program (CUAP) and the Institute for Human Resource Development (IHRD). This training should be focused on rehabilitation engineering, supported training, positive futures planning and encouraging creative thinking on the part of counselors. National Rehabilitation Services Administration (RSA) priorities should be taken with a grain of salt. <CT>

Any reform in the traditional rehabilitation process will, by default, have an impact on people caught up in the mental health system. Department of Mental Retardation resources, however, must continue to be directed to creating supported employment and other integrated employment opportunities. <CT>

The time is long overdue for the Division of Rehabilitation Services (DRS) to recognize objectives. For people with severe and multiple disabilities, this means DRS needs to presume their disabilities affect employment potential and presume rehabilitation

engineering can be applied to support people in getting a job. The specific rehabilitation service or device needs to be made available in direct consultation with, and at the direction of, the person with a disability. Where DRS does not have the device or expertise on hand, or cannot purchase it from other expertise in the state in a timely manner, the person with a disability should be given a voucher to acquire the device or service they need. <CT>

Institutions, including Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and skilled nursing facilities, are disincentives to employment. Health Care Finance Administration (HCFA) policies require residents of long-term care facilities to return their earnings to their residences. As a result, individuals with disabilities who are now working as a result of the supported employment initiatives must return their earnings to their residences less a \$40 per month personal allowance. This provides no incentive for work and no ability for rehabilitation organizations to work with employees on developing the concept of economic self-sufficiency. <CT>

State agencies should consider making funds available to allow employees with disabilities to pay for their own health insurance coverage until they are eligible for the employer's plan. <CT>

The Division of Rehabilitation Services should aggressively advocate for long-term support for independent living services. More resources should be freed-up by viewing enclaves and crews as elements of the traditional sheltered center model and moving those resources to support integrated and supported employment. <CT>

Abandon the concept of a continuum of specialized places and moving people as they are "ready." Instead, offer support for employment. <CT>

Consider expanding the availability of supported employment by redirecting the use of existing program authorities and budgets, as well as mandating increased research and development efforts to test its cost-effectiveness for persons with severe disabilities other than people with mental retardation. <CT>

Most of these sheltered, work activity and home industry "employment" practices should be abolished. People who are blind and visually impaired should be supported in real jobs, for real wages in real places to work. <CT>

Abandon the system of "evaluating" the person in terms of a list of generalized work skills to determine if they are "ready" for work. Instead, determine what kind of locally available work the person is interested in doing in a community and develop the job so the person can do it. <CT>

The Department of Human Resources must use its "interagency management" council to explore policy issues to (1) establish supported employment in state statutes, (2) create

resources ensuring the full participation of all adults with severe disabilities in the work force, including grants directly to individuals to create their own job developers and job coaches, and (3) study insurance barriers and disincentives. <CT>

Abandon the use of sheltered settings to move people from one stage of preparation to the next in a sequence as the person becomes "ready." Instead, teach the skills people need for a particular job in the community job setting itself. <CT>

The employment policy statement for the Government of the District of Columbia should be recast to include the establishment of procedures for specifically identifying, locating, training and placing persons with developmental disabilities in general and persons with severe life-long disabilities in particular. <DC>

The Council should develop with the Department of Employment Services (DOES) procedures for identifying individuals with developmental disabilities. The DOES automated data system should be reprogrammed to isolate specific developmentally disabling conditions. <DC>

A full time staff person should be assigned to work exclusively with the Council task force on employment. <DC>

The Council should obtain from the Department of Employment Services (DOES) a commitment to set aside 20 percent of training and employment placement slots. The Council should develop procedures, in collaboration with RSA and DOES, for increasing the number of individuals with developmental disabilities trained and placed in jobs particularly suited for their skills and abilities. <DC>

The Council should take the lead role in the development of training and job placement opportunities which would positively impact upon individuals with developmental disabilities and their families living below the poverty level(s). <DC>

A system of supported employment (SE) for persons with mental illness/mental retardation needs to be established so as to remove barriers identified in the 1989 SE Coalition Project; needed are an effective referral process, established residence in the community for the client and SE training for residential staff as well as for staff of interfacing agencies. Sixty percent of the 1989 DD Consumer Survey respondents report that they need SE, but do not receive it. <DE>

Refine and maintain cooperative agreements with public and private agencies to ensure that gaps in employment services do not occur when public agencies have limitations in program scope, and to ensure cost effectiveness by sharing of services responsibilities without duplication. <DE>

Continue the supported employment initiative in its development. Over the next few years, this concept will require close cooperation between public agencies in order to provide ongoing support to individuals with severe disabilities engaged in competitive employment. <DE>

DHSS/DADAMH should describe the specific employment needs of the population which they are serving and recommend services. <DE>

Develop a long-term follow-up service for those supported employment clients who have physical disabilities. <DE>

Provide additional funding for job coaches to maintain program consistency and to reduce turnover of job coaches in supported employment programs. <DE>

Continue to develop and expand participation in one centralized database to gather and evaluate data on supported employment. This will enable comprehensive planning. <DE>

Provide training in supported employment for staff in group homes and institutions. <DE>

Parents and consumers who attended the public hearings recommended the expansion of supported employment and other specialized opportunities for persons with developmental disabilities. Public hearing participants further recommended study of the high turnover rate of job coaches and participants alike and new methods to reduce turnover; and salary increases for job coaches and others involved in the training and placement of persons with disabilities in jobs. Decreasing staff turnover will help to improve the retention of program participants. <DE>

Provide qualified staff and other resources needed to ensure that all individuals with developmental disabilities who are able to work and who wish to do so are employed in jobs which have value to them. <FL>

Conduct public awareness activities and training which emphasizes the ability of individuals to be successfully employed in integrated settings and the impact of employment on their quality of life. <FL>

Encourage and help individuals with developmental disabilities to choose the type of work which they do and the settings in which the work is performed. <FL>

Provide job training in real life settings, rather than in traditional vocational or day training program settings, to ensure that individuals with developmental disabilities have maximum opportunities to demonstrate the knowledge, skills and attitudes required for successfully obtaining and maintaining employment. <FL>

Conduct a pilot project that will enable a small number of people with severe disabilities to work. Invite current and potential employers to participate in the design. <GA>

Create job models with employers since large numbers of individuals with disabilities are not employed.either full or part time. These models should include work incentives for potential employees with developmental disabilities; for employers, tax benefits and awareness and understanding of abilities and capabilities of employees with disabilities should be stressed. <GA>

A campaign aimed at educating both employers and individuals needs to be launched to focus on the benefits of employment. <GA>

Conduct "reflection teams" so that people with disabilities, families, and staff can learn more about what goes into successful job development, job match, job coaching, and ongoing support. A reflection team is a group of 6 to 8 people who visit job sites, interview the employee, employer, co-workers, and support staff. <GA>

Explore the benefits of contracting for private sector job development and job placement services versus traditional public sector service delivery. <GA>

Sponsor a letter-writing campaign to Congress asking that Medicare guidelines be reformed so that people can work and still have public health insurance. <GA>

Develop more adult day services that relate to training and meaningful work options for individuals. <GA>

Transfer the ownership of the "problem" of unemployment from the disability service system to employers by offering mini-grants to community groups such as the Chamber of Commerce or the Private Industry Council to conduct job fairs and workshops on the employment of people with disabilities. <GA>

Every effort should be made to examine job requirements to eliminate artificial barriers, especially in the public sector. <GA>

Increase employment opportunities. <GA>

The Council recommendation is to seek and increase funding for supported employment to attract well qualified job coaches and to provide relevant vocational training services suitable to individuals with developmental disabilities. <GU>

The Commission on Persons with Disabilities should develop a consumer advocacy group to increase empowerment and provide support and address equal employment opportunities. <HI>

The State Planning Council on Developmental Disabilities should coordinate with other state agencies and community groups with an interest in a full employment agenda for people with developmental disabilities to take their cause directly to the employers of the state of Hawaii to assist them to develop employer-sponsored initiatives. <HI>

The Division of Vocational Rehabilitation should, in cooperation with the University Affiliated Program, implement a study to determine the employment and training needs for people with developmental disabilities. <HI>

The Rehabilitation Services Administration, the Jobs Training and Partnership Act Administration, and the Department of Labor should require all programs and/or services to indicate the number and percentage of people with developmental disabilities served in their respective programs. <HI>

The State Planning Council on Developmental Disabilities, the Commission on Persons with Disabilities and the Division of Vocational Rehabilitation should develop a public awareness campaign on the employability of persons with developmental disabilities. <HI>

The Division of Vocational Rehabilitation should actively pursue supported employment program funds. <HI>

Congress should amend the Rehabilitation Act to add a title expressly authorizing supported employment programs for persons with severe disabilities who can be competitively employed with the assistance of such a program. The program should eliminate the requirement that all participants work 20 hours per week. <HI>

The Hawaii state legislature should create more employer incentives to hire persons with disabilities; for example, paying for workman's compensation insurance. <HI>

The Department of Labor and Industrial Relations and Department of Human Services' Division of Vocational Rehabilitation and Services for the Blind should develop and implement a plan to achieve the same rate of employment and labor force participation for people with developmental disabilities between the ages of 18 and 64 as the general population. <HI>

The State Planning Council on Developmental Disabilities, in cooperation with the Commission on Persons with Disabilities, should form a task force to develop innovative approaches to employment which address appropriate pay and job placement for persons with developmental disabilities. The task force will consist of consumers, employers and service providers. <HI>

People who know about the needs of people with disabilities should be represented on the Private Industry Councils. <HI>

Congress should amend the Rehabilitation Act to base eligibility for rehabilitation services on disability rather than on work capacity. <HI>

The consumer survey, the focus groups, and a survey of parents by the Department of Health's Developmental Disabilities Division, indicate strong need for more adult day programs. There is a waiting list throughout the state for participation in day programs. In some rural areas of the state, such as Kona, Hawaii, there are not sufficient types of services. <HI>

The Department of Health's Developmental Disabilities Division should ensure that day program activities are coordinated with the care home provider and/or family through training, education and monitoring. <HI>

The state legislature should allocate sufficient funds to develop quality day programs dispersed throughout the community. <HI>

Enhance program effectiveness by establishing, through policy and procedure, more consumer control over choosing the services he or she will use, particularly in the areas of vocational training and job placement. <IA>

Eliminate eligibility policy based upon the ambiguous criteria of a client's inferred "potential to benefit" from vocational rehabilitation services. <IA>

Analyze why such a disparity exists between the positive evaluation of vocational rehabilitation policy and the lack of consumer satisfaction with the program. <IA>

Idaho must establish a policy of vigorously enforcing employment discrimination laws when violations occur against people with developmental disabilities. The Idaho Focus Group suggested the creation of a "segregation complaint procedure" which will give people the tools to enforce individual rights and remove the barriers. <ID>

We need to provide the necessary supports to individuals with disabilities who lack access to employment services in rural communities. <ID>

There must be authority to collect data on employment and labor force participation by people with disabilities. These data should be reported along with current labor statistics by functional and diagnostic characteristics of the disability. <ID>

There needs to be greater awareness for the need and availability of strategies about employment and vocational options for families of children with developmental disabilities in Idaho. <ID>

Idaho needs to develop a mechanism to allow individuals in supported employment work sites the freedom and necessary supports to change jobs. <ID>

All programs for employing and training people with disabilities should have a central focus. <ID>

A coherent policy on the employment of people with disabilities using individual supports in a job and location of their choice should be developed for Idaho. Such a policy should have a particular emphasis on those people with severe life-long disabilities. Both federal and state policy development efforts must be cautious of the vested interests of the traditional programs and the public and private professionals who are responsible for them. <ID>

Idaho policy should focus on individual supports for a person in as integrated a setting as possible. Segregated employment placements must be the last option. <ID>

Idaho should eliminate the policy that supports a monopoly on CSE employment funds by special interest groups. Any provider who is qualified should be able to enter the market place as such. <ID>

Technological breakthroughs and the minimal costs of adaptive equipment for workers with disabilities should be shown to Idaho employers. The person with severe disabilities is less likely to receive independent employment support alternatives. This suggests that the notion of "continuum" should be discarded. Emphasis on adaptive equipment and social skills in the work place is necessary. <ID>

Job coach training commensurate with higher salary levels are important factors for achieving successful community supported employment programs in Idaho. Both would help in the recruitment of attractive candidates for job coaching positions. It would also assist to encourage professionals to enter this field, and allow more providers to emphasize community supported employment. <ID>

Funds for federal and state programs should be expanded or redirected to increase options for integrated employment (including supported, transitional or competitive employment) for people with developmental disabilities, including severe mental illness, so that they are able to earn a wage which will assist them to live more independently. <IL>

Indiana shall promote the integration of people with disabilities into the workforce through targeted employer education awareness activities, including information about incentives for hiring people with disabilities. <IN>

Indiana shall develop a Medicaid waiver that includes supported employment programs and amend the Medicaid plan to include all SSI recipients. <IN>

Indiana shall expand the state definition of developmental disabilities to include all people with severe disabilities for the purpose of providing supported employment. <IN>

Indiana shall provide adequate funds for programs and incentives that result in competitive employment. <IN>

Indiana shall provide financial support for the initial training and ongoing staff development of job coaches, personal attendants, and employment specialists. <IN>

Indiana shall ensure that all adults with disabilities have the training and the opportunity to increase their independence and productivity through community employment. <IN>

Indiana shall ensure accessibility in employment environments, including assistive devices, jobsite modifications and necessary individual supports and services (e.g., attendant care, specialized training, etc.) <IN>

Indiana shall place greater emphasis on community integration opportunities (e.g., social and living supports) for people working in competitive employment. <IN>

Indiana shall develop interagency data management system to determine the outcomes, benefits and costs of supported and sheltered employment. <IN>

Indiana shall adopt a more flexible approach to allow resources that have been used for traditional segregated work and day services to be used for integrated work services such as supported employment. <IN>

Indiana shall name a lead agency with authority to coordinate the interagency activities related to supported employment. <IN>

Indiana shall promote employment and employment programs with income that provides for the highest level of independence. <IN>

Indiana shall incorporate strategies that lead to hiring people with disabilities as part of its economic development strategies. <IN>

Employment and training programs and data collection should be coordinated with the goal of achieving a level of participation in employment for people with disabilities that is the same as the general population. <IN>

Indiana shall provide incentives to accelerate the expansion of competitive and supported employment options for people with disabilities and the necessary supports to enable them to choose, maintain, and advance in their jobs. <IN>

Indiana shall provide people with disabilities who desire to be self-employed with any necessary technical assistance, personal assistance, job development skills, and training programs. <IN>

Indiana shall ensure that adults with disabilities who are not employed have opportunities for valid and enriching life pursuits and life enrichment with outlets for creative expression in mainstream environments. <IN>

Additional new funding is needed to expand programs for supported employment. Securing more vocational placement opportunities with private industry could also help alleviate the waiting period for those desiring avocational placement. <KS>

The Interagency Council on Supported Employment should form a subcommittee on marketing to plan and develop a statewide campaign to inform employers on the benefits of hiring persons with disabilities. <LA>

On the federal level the U.S. Department of Labor, the Rehabilitation Services Administration, the Administration on Developmental Disabilities, and the Social Security Administration should hold top level policy meetings to develop long-range incentives and strategies to expand supported employment services for persons with severe disabilities. <LA>

The Council's Supported Employment Education Project should continue to target parents and employer associations for supported employment information, using employer associations for supported employment programs as a mechanism to access employer groups. <LA>

The Interagency Supported Employment Council should be the vehicle to increase interagency cooperation and coordination on supported employment and transition issues (e.g., eligibility, follow-along, job development and training). <LA>

The State Developmental Disabilities Council should continue to sponsor the Supported Employment Training and Technical Assistance Network and work with the Network's Advisory Council and state agencies to expand local training and technical assistance resources to assist supported employment service providers statewide. <LA>

The Interagency Council on Supported Employment with assistance from the DD Council and state agencies should sponsor two or three local councils, made up of service providers, parents, state agency representatives, employers, and JTPA representatives, to facilitate service collaboration and coordination and problem-solving on employment issues. <LA>

The Interagency Council on Supported Employment should be encouraged by the DD Council and other advocates to develop an Interagency Plan that promotes the expansion of supported employment services statewide to target rural areas and unserved and underserved populations with severe developmental disabilities (e.g., persons with autism, cerebral palsy, deaf/blindness, head injuries, chronic mental illness, and dual diagnosis or multihandicapping conditions). <LA>

Develop and fund programs to correct the shortage of well-trained staff to operate employment and employment-related programs. Address recruitment, qualifications and duties, salary and other remunerations, pay equity, training, high turnover rates and retention. <MA>

Devote resources and develop programs for special populations or problems; e.g., the working person with a progressive, sporadic, or "invisible" disability; immigrants and refugees; minorities faced with "double-discrimination"; teens needing career guidance; persons transitioning in or out of the workforce; persons capable of home-based or part-time work, etc. <MA>

Support "supported" employment! This involves declaring a state commitment, converting workshops and other restrictive programs, training providers and employers, evaluating programs, doing outreach, ensuring an array of worker-support services, and the like. <MA>

Designate and empower a high-placed agency, office or commission to further develop and oversee a statewide policy and practice for state-assisted work-related programs, and to link with the private sector to promote employment options. <MA>

Implement State Executive Order 246 (accessibility and affirmative action for persons with disabilities), with attention to more hiring by state government, changes in the civil service system (e.g., temporary appointments, special lists of applicants with disabilities), training regarding reasonable accommodations, monitoring of cities and towns, etc. <MA>

Implement a state policy whereby 5% of state contracts are set aside for businesses owned by persons with disabilities, similar to the Small Business, Women and Minority Owned Business State Set Aside Programs. <MA>

Expand technical assistance to business and corporations to help them internally develop job supports for employees with developmental disabilities while reducing the necessity for external service interventions. <MD>

Promote continuing development of supported employment by involving providers, employers, consumers and policymakers in designing incentives to increase conversion of traditional center based programs and to expand support options for persons with the most severe disabilities. <MD>

Transfer funds which are presently administered through the Developmental Disabilities Administration's Individual Support Services program for persons who do not meet the definition of developmental disability to the Division of Vocational Rehabilitation's Independent Living Services program. This change would provide more state funds which are accessible through the relatively simple processes surrounding delivery and independent

living services and a single point of independent living support services access for persons who do not have a developmental disability. <MD>

Expand grant funding by Division of Vocational Rehabilitation to local private non-profit agencies to provide both vocational and independent living rehabilitation services and thereby encourage not only the development of flexible, effective, long-term support systems necessary for persons with developmental disabilities (as opposed to the purchase of service method), but also consumers' integration within their home communities. <MD>

Assure full utilization of Division of Vocational Rehabilitation services by assigning counselors for persons who are deaf to work with a lower than average number of clients. <MD>

Continue within the Division of Vocational Rehabilitation to place a high priority on supported employment, and to streamline access of and delivery to these services. <MD>

Assure education of consumers and families to facilitate cooperation and participation leading to more successful Division of Vocational Rehabilitation interventions. Increase consumer education especially for new programs like the Governor's Transitioning Initiative. <MD>

The Governor should support the work of the Commission on Supported Employment by continuing to support implementation of its recommendations. Of particular importance is the Commission's focus on a public/private partnership. This policy focus is critical to the success of supported employment through its planned allocation of public resources in support of private community initiatives and the commitment of the business community. <ME>

The State of Maine should adopt an aggressive affirmative action plan to seek qualified persons with disabilities to fill state positions. In addition, state government should set an example for business and industry in the development of supported employment opportunities in state government. <ME>

Advocate for extension of the recent OBRA inclusion of "Day Habilitation Services" under Medicaid. <ME>

The Michigan Department of Education should submit appropriation requests and the Legislature should approve state funding for programs not funded or underfunded by the federal Rehabilitation Act, including handicapper small business initiatives; independent living (as a supplement to Rehabilitation Act Title VII) for center expansion and program development; and personal assistance services. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations should work with the Michigan congressional delegation to expand the rehabilitation provisions

of the Rehabilitation and Social Security Acts; expand funding for a more comprehensive rehabilitation program; and assure enactment of Medicaid reform legislation that would enable provision of many of the supports people with severe disabilities need in order to work. <MI>

Michigan Rehabilitation Services should expand staff training in: provision of services to new or underserved populations; use of rehabilitation engineering and job accommodation technologies; sensitive collaboration in rehabilitation planning with people receiving rehabilitation services; follow-along and follow-up services during placement; and appropriate vocational assessment procedures for people with severe disabilities. <MI>

Michigan Rehabilitation Services (MRS), in coordination with other agencies, should establish a goal to reduce the proportion of applicants who are rejected and significantly improve employment retention rate, in order better to meet the needs of people with disabilities and to increase revenues from the Social Security Trust Fund. <MI>

Michigan Rehabilitation Services and the Michigan Department of Mental Health should support the recommendations of the State Board of Education Blue Ribbon Task Force on Rehabilitation, but emphasize the need for activities to increase supported employment options beyond the recommendations of the Task Force Report. <MI>

Expand resources to increase the number of people with severe disabilities moving from segregated day programs to supported employment by 1,000 people per year; increase the number of hours they work; and assure that supported employment is available as the first option for people on waiting lists and those leaving school. <MI>

The Michigan Department of Commerce should continue efforts to develop the job market, adding emphasis on finding out what types of jobs are available now and what will be in demand in the next five years, with focus on identifying those jobs that, through accommodation and other supports, can be successfully accomplished by people with severe disabilities, including those in supported employment; and economic development to create needed jobs, emphasizing those jobs that, through accommodation and other supports, can be successfully accomplished by people with severe disabilities. <MI>

The Michigan Department of Commerce, using expertise and support from Michigan Rehabilitation Service and the Handicapper Small Business Association, should explore the feasibility of establishing a Small Business Incubator program from people with disabilities in Michigan. <MI>

The Michigan Developmental Disabilities Council, with Independent Living Centers and other advocacy organizations, should develop programs to empower people with disabilities to access and choose the job services they need. <MI>

Provide education, technical assistance, and information for service providers on setting up programs, funding, program transformation, transportation approaches, management and personnel issues; and provide education for people with disabilities and their families on supported and community employment. <MI>

The Michigan Department of Labor should explore developing more employer incentives for hiring people with disabilities, such as expanded tax credits and health insurance pools to address "high risk" workers. <MI>

Appropriations and authority should be established in a way that allows federal rehabilitation support to be committed and spent in succeeding fiscal years. The Michigan Department of Management and Budget and the Legislature should establish a carry-forward spending authority for the Department of Education and Michigan Rehabilitation Services of federal dollars, including the required general fund match. <MI>

The Michigan State Board of Education should direct the Department of Education to submit appropriation requests for Michigan Rehabilitation Services (MRS) at full Rehabilitation Act authorization level. The Legislature should establish MRS' spending authority to allow capture of national funds that are often available for redistribution near the end of the fiscal year from other states' rehabilitation programs. <MI>

Michigan Rehabilitation Services should start a statewide employers' council to promote supported employment and other work initiatives. <MI>

The Michigan Departments of Commerce and Labor, with the help of advocacy groups, should work with employers, employers associations union officials and members, relevant state agencies, and others, to explore strategies for educating employers and the general public about the value of hiring and working with people who have disabilities; working with unions to educate their members about the advantages of working with people with disabilities; and developing and carrying out innovative approaches to job modification and accommodation, to enable more handicappers to work. <MI>

The Governor's Cabinet Council on Human Investment and Michigan Rehabilitation Services should develop a mechanism to allow MRS' involvement in the work of the Governor's Council on Human Investment, to address issues of people with disabilities. <MI>

The Governor's Cabinet Council on Human Investment, with Michigan Rehabilitation Services and others who are knowledgeable about disability, should develop strategies to assure that all government-administered job programs give job-ready handicappers equal consideration for hire. <MI>

Congress should reinstate specific funding for the rehabilitation needs of SSI and SSDI recipients. <MI>

The Michigan Association of Rehabilitation Facilities, with help from Michigan Rehabilitation Services, and in consultation with providers of supported employment services, should identify innovative models for transportation services that enable people with disabilities to work in the community. Develop a plan for improving work related transportation services for Michigan citizens with disabilities. <MI>

The Legislature, state agencies, and consumer advocates should continue and expand efforts to make the state's affirmative action policies and practices for handicappers consistent with those for other protection groups. <MI>

Passage of the Americans With Disabilities Act (ADA) is critical to improving access to the job market for people with disabilities. Passage of the ADA would enable them to establish their place in the employment market during the coming period of high demand for employees. Consumer and advocacy organizations should support passage and vigorous enforcement of the Americans With Disabilities Act. They also should advocate to assure that existing Equal Employment Opportunity and Affirmative Action laws are more stringently monitored and enforced. <MI>

It is recommended that the Division of Developmental Disabilities establish a supported employment training and technical assistance unit. <NJ>

We must develop and implement comprehensive employment programs for persons with disabilities that: emphasize our commitment to meaningful work, in integrated settings, for equitable pay, in an atmosphere of job and support security, with the opportunity for relationships for all adults, regardless of type or severity of disability; and recognize that individual citizens, including those with disabilities, have a fundamental responsibility to contribute to the social and economic life of the community. <MN>

Day and vocational programs must ensure that individuals discover the unique contributions they can bring to the community, and are supported to make those contributions. <MN>

We must develop and implement comprehensive employment programs for persons with disabilities that: recognize that community organizations (business, associational groups, recreational and leisure organizations, etc.) should welcome and support citizens with disabilities to contribute and participate in the activities of those organizations; develop employment and support options in generic community locations, and organizations for individuals who are currently unserved and underserved, rather than placing such individuals in existing services when such services do not respond to their needs; and provide for age-appropriate retirement. <MN>

The MPC and other groups should advocate for the Americans With Disabilities Act (ADA) and other legislation which supports and encourages employment of people with developmental disabilities. <MO>

In order to offer an array of integrated community work settings, additional funding sources for job development should be identified by state agencies and community based programs serving people with developmental disabilities (e.g., JTPA, Carl Perkins, VR, sheltered workshops). <MO>

The definition of "handicapped persons" as stated in Sheltered Work Statutes (RSMo. 178.900 and SB52) should be amended so that it more accurately reflects the habilitative functions described in the stated purposes of sheltered workshops (RSMo. 178.910), to: (2) "Handicapped Persons," a lower range educable or upper range trainable mentally retarded or other handicapped person sixteen years of age who has had school training and has a productive work capacity in a sheltered environment adapted to the abilities of the mentally retarded but whose limited capabilities currently make him non-employable in competitive business and industry. <MO>

The Council and other groups should advocate for increased funding for the Department of Elementary and Secondary Education to provide per diems reflective of the needed supports of individuals in sheltered workshops. <MO>

Increased technical assistance and training in supported and competitive employment should be available to professionals (e.g., sheltered workshops, VR, developmental centers, day programs, etc.). A commitment of resources should be made by the appropriate agencies. <MO>

The Divisions of MR/DD and CPS should develop retirement options for elderly persons with developmental disabilities. <MO>

A policy on the employment of people with developmental disabilities should be developed for Mississippi with the goal of achieving a high rate of employment and labor force participation for people with developmental disabilities between the ages of 18 and 64. <MS>

The Jobs Training and Partnership Act program should register consistently with Vocational Rehabilitation (VR) those individuals who have developmental disabilities. <MS>

There should be an authority to collect data on employment and labor force participation by people with disabilities. These data should be reported along with current labor statistics by functional and diagnostic characteristics of the disability. <MS>

Employers should be made aware of the advantages of hiring workers from a supported employment program. <MS>

All state agencies should have employees who are participating in a supported employment program. <MS>

Mississippi's rehabilitation personnel should be encouraged to provide consultation and direct assistance in their areas of expertise within as well as outside the school setting. If the vocational development of youth with severe disabilities is to succeed, there must be a "marriage" between special education and rehabilitation. Public schools, rehabilitation agencies, training facilities, and other programs should practice and encourage maximum career development opportunities for our society's youth with developmental disabilities. <MS>

Federal policy should be amended so that supported employment opportunities are available for people with disabilities who can work less than 20 hours a week. <MS>

The Mississippi Legislature should provide permanent funding to expand and maintain long-term supported employment opportunities for persons with severe physical, sensory, and/or mental disabilities. This must include funding to provide for appropriately trained personnel necessary for supported employment activities. <MS>

The Mississippi Legislature should create state tax incentives which will benefit employers who hire and provide long-term supports which allow persons with developmental disabilities to maintain remunerative employment. <MS>

Mississippi's commitment to affirmative action in hiring persons with disabilities within state government should be strengthened through education, directives, and monitoring. <MS>

Funding and opportunities for persons with disabilities to participate in supported employment programs in rural settings must be expanded to include a broader range of clients. <MT>

Integrated adult day services must be increased and more appropriately suited to the clients' needs. <MT>

Facility-based sheltered employment, work activities or prevocational services need to be available in sufficient quantities to make both the work and the resulting pay rewarding and beneficial and appropriately suited to individuals' needs. <MT>

Individuals need to be productively engaged in work or work-like life activities. It is important for policymakers to place an emphasis on funding activities which creatively develop functional real-world work activities for persons with disabilities. <MT>

A coherent policy on the employment of people with disabilities should be developed for the United States. Such a policy should have a particular emphasis on those people with severe and developmental disabilities. <MT>

Creative options for employment should continue to be pursued for persons who are currently denied services because their handicaps are too severe. <NC>

The Client Assistance Program within the Division of Vocational Rehabilitation Services (VR) should develop a mechanism that VR counselors can use to study cases of persons with developmental disabilities terminated due to "client refusal of service" and "failure to cooperate" in order to identify any barriers which can be resolved. The mechanism should be developed by October 1, 1990, and field tested during 1991. <NC>

Federal eligibility criteria in the Rehabilitation Act, as it relates to the requirement for a "reasonable expectation for employability," needs to be reviewed in light of new models for employment of persons with severe disabilities. <NC>

The Council recommends use of a "least restrictive environment" standard in vocational placements like the one used in education and encourages federal and state funding to provide strong incentives for supported employment opportunities. Incentives should target state and locally funded programs and private industry. <NC>

The Council recommends that criteria currently used to justify placement in sheltered workshops and criteria used to review such placement decisions be studied and revised, if needed. <NC>

The Council recommends that Section 14(c) authorizing the Secretary of Labor to issue special minimum wage certificates for workers with handicaps be reexamined to reflect a more equitable balance between the desires of employed persons with developmental disabilities to earn a respectable wage for their efforts, and the needs of employers to match labor costs with potential revenues. Congress should consider new approaches to this issue immediately and amend the Fair Labor Standards Act as quickly as possible. <NC>

The Council recommends a strong initiative to make employers more aware of the employment potential of persons with developmental disabilities, creating a partnership with employers to meet the goal of full and fair employment for all people with developmental disabilities. This initiative will be promoted by the Council on Developmental Disabilities, advocacy groups or individuals who have an interest in the full employment agenda. <NC>

OSERS policy needs to recognize that with few exceptions, complete economic self-sufficiency for persons with developmental disabilities is an unrealistic expectation, particularly when the employment opportunities available are marginal and jeopardize public assistance benefits. Therefore, OSERS should abolish its 20 hours of work per week requirement and instead promote employment of persons with developmental disabilities solely for the purpose of enhancing their dignity, self worth, independence and integration. <ND>

Continuing efforts by DHS should be made to assure that North Dakota's Medicaid waiver is implemented in a non-discriminatory manner so that persons with developmental disabilities who are not past residents of an ICF/MR will be eligible to receive supported employment services. <ND>

Continuing support for Congressional efforts to enact federal Medicaid Reform Legislation (as initially proposed in S. 384 and H.R. 854) should be maintained by all appropriate North Dakota officials. Such reform legislation would require or permit supported employment services for any person with developmental disabilities regardless of past or present linkage to a Title XIX-funded ICF/MR or institution. <ND>

The North Dakota Department of Human Services should establish a committee consisting of representatives of its DD Division, its Office of Vocational Rehabilitation and community DD service provider organizations. This committee's mission should be to cooperatively formulate a mutually agreeable definition of work activity and to determine how costs for work activity as well as prevocational services should be allocated and reimbursed to providers. <ND>

North Dakota state government should set an example for private sector employers by taking the lead in employing persons with developmental disabilities. <ND>

Adult service providers should operate their employment placement programs based on business principles rather than community service ones. The goal of job placement should not only be a job but a just wage and benefits as well. <NE>

The Division of Rehabilitation Services should widen their scope to include programs to serve persons with severe developmental disabilities. <NE>

The Office of Special Education and Rehabilitative Services along with Congress should provide adequate funding for supported employment services for people with severe disabilities. Supported employment service goals should be competitive jobs in community settings. <NE>

The Office of Special Education and Rehabilitative Services should require all state vocational rehabilitation agencies to indicate those individuals who have developmental disabilities in its statistics. <NE>

Disincentives for persons with developmental disabilities to become employed should be eliminated in federal and state laws. <NE>

Employment opportunities for persons with development disabilities should have a goal insuring adequate salary levels including benefits. <NE>

Employment should continue to be a priority of the Developmental Disabilities Planning Council. Productivity is a value supported by consumers and their families. Competitive jobs should be the goal when possible. When sheltered employment is appropriate, a just wage must be the goal. Policies and regulations that prove to be a disincentive to persons seeking employment must be examined and corrected. When pre-vocational activities are appropriate, it is important that goals be set and when possible that payment for work be pursued. <NE>

Funding rates for career services should reflect a financial incentive for the development of individualized supported employment services. Adequate technical assistance and training should be made available to service providers to decrease reliance on day habilitation, facility-based work and group employment models and to increase the cost-effectiveness of service. <NH>

Efforts to increase the educational qualifications and training of rehabilitation counselors and vocational service personnel should continue. The number of persons served by Vocational Rehabilitation Counselors in the Division of Vocational Rehabilitation (their "caseload") should be decreased to a level sufficient to allow for individual career planning and guidance. <NH>

In some cases, services under the Vocational Rehabilitation basic state grant can be a sufficient amount of support for individuals with developmental disabilities. Continuing efforts should be made to utilize post-employment services and innovative mechanisms such as PASS plans in cases where competitive employment is a realistic goal. <NH>

The vocational rehabilitation program is largely controlled by federal statutes. At present these statutes mandate that services be provided in a time-limited fashion. Many people with developmental disabilities require employment supports over an extended period of time. Therefore serious consideration should be given to increasing the flexibility of this program at the federal level. <NH>

Cooperation between the Division of Mental Health and Developmental Services and the Division of Vocational Rehabilitation should include (a) consistent use of a single definition of supported employment based on federal statute that requires ongoing interactions (not merely the opportunity for interactions) between supported employees and co-workers and (b) a mechanism for the assessment of social interactions at employment settings. <NH>

Service providers should be aware that up to 18 months of supported employment services are available through the individual rehabilitation system. Sponsorship for less than 18 months should be based solely on acquisition of job skills and adjustment to the work place as determined by the professionals directly involved, and in the context of effective management and support practices. <NH>

It is recommended that facility-based services be converted and redirected to integrated employment opportunities. <NJ>

It is recommended that the N.J. Department of Labor reconsider the inclusion of "socially maladjusted" as a handicapping condition within the Job Training Partnership Act program. It is further recommended that the department initiate the collaborative study of income limits used by the JTPA and the effect on eligibility in New Jersey. <NJ>

It is recommended that the Division of Vocational Rehabilitation Services, disability organizations, advocates and the National Association of Developmental Disabilities Councils study the Handicapped Assistance Loan program and chart a political strategy for invigorating the program and expanding responsiveness to the needs of business people with disabilities. <NJ>

It is recommended that the Division of Developmental Disability develop a plan to increase the number of job coaches in the state. <NJ>

It is recommended that employment services be provided through local community organizations, agencies and coalitions. It is further recommended that county or regional services be established with effective interagency coordination, and that the Division of Developmental Disability promote, oversee and monitor a localized service delivery system. <NJ>

It is recommended that the N.J. Department of Higher Education undertake a comprehensive review of physical and programmatic access in New Jersey's colleges and universities. It is further recommended that this review go beyond existing survey techniques and include on-site visits and administrative procedures. Where problems are found, the department should require immediate corrective action as a condition for funding renewal. <NJ>

It is recommended that constituency groups be educated on the critical need to increase, through legislative budgetary action, the state match for Titles I, II, VI and VII of the Rehabilitation Act of 1973 as amended in 1986 and as administered by the Division of Vocational Rehabilitation Services. <NJ>

It is recommended that business and industry organizations, employer groups and Chambers of Commerce be educated on the benefits of limited employer subsidies for transportation for employees with developmental disabilities. <NJ>

Economic development activities should be increased, especially in rural areas of the state to increase employment opportunities. <NM>

In New Mexico long term funding should be established to maximize use of federal supported employment funds. <NM>

Employment service resources should be increased to meet unsatisfied demand and to provide access to services for special education graduates reaching working age. <NM>

Continued development of employment options should be encouraged to meet the needs of workers with developmental disabilities and employers. A system that has a broad array of services should be encouraged and supported. <NM>

ICF/MR regulations should be changed to encourage vocational services as part of "Active Treatment." <NM>

Work incentives should be improved for SSDI recipients. Public information about SSI work incentives should be improved. "Workfare" programs should encourage participation by recipients with disabilities. <NM>

Training and employment opportunities for income support recipients should be extended to people with disabilities, including essential supports and adaptations that enable them to benefit as fully as those without disabilities. <NM>

Incentives for employers to hire persons with disabilities, in addition to TJTC, should be promoted. <NV>

Employer concerns about individuals with disabilities, particularly about their being insurance risks and other stereotyping, need to be decreased. <NV>

Strategies to address lack of work histories among individuals with developmental disabilities through competitive placements, particularly through supported employment, should be provided. <NV>

Job placement services which recognize the unique culture and capabilities of people with deafness should be established in Northern Nevada and expanded in Las Vegas. <NV>

Vocational counselors' experience with "real world of work" which may improve their ability to properly assess the skills of consumers should be increased. <NV>

Labor market opportunities in rural areas for placement of consumers with disabilities should be analyzed and increased. <NV>

Utilization of VR 110 funding for purchase of supported employment should be substantially increased. <NV>

Statutory authority to utilize Community Training Center funding for supported employment should be established in the 1990 legislature. <NV>

Co-worker and supervisor attitudes and biases need to be changed through education. <NV>

Job accommodation/modification should be examined in every appropriate case. <NV>

The VR counselor's primary responsibility should be job development and individualized placement for people with severe disabilities. <NV>

Technology related supported employment should be implemented to reduce reliance on public resources among consumers with disabilities. <NV>

State vocational rehabilitation programs should be encouraged to implement an order of selection process assuring services to people with severe disabilities as a priority. <NV>

Community Training Center funding should include a supported employment option which could be selected by the consumer and his/her family when appropriate. <NV>

State administered sheltered employment programs utilizing federal funding should include the provision that consumers and their families be allowed to choose supported employment as an alternative to sheltered work. <NV>

The minimum wage should be raised and health/medical insurance mandated to provide needed incentives to bring more people with severe disabilities into the competitive labor market. <NV>

People with mildly disabling conditions capable of finding their own jobs should be encouraged to seek employment opportunities through more traditional employment agencies such as ESD and JTPA. Congress should act immediately to increase the level of financial support for supported employment programs and to provide funding mechanisms for follow-along services to people with severe physical disabilities who can potentially benefit from services. <NV>

The Rehabilitation Services Administration should mandate individualized, competitive job development and placement for people with moderate and severe disabilities including developmental disabilities as the primary responsibility and purpose of the vocational rehabilitation program and its counselors. Placements should be carefully planned to match not only the capabilities and interests of persons with disabilities but should reflect the need for medical and health benefits, and the economic and transportation requirements necessary for continuing employment. Placements should include consideration of future potential and should include assessment of appropriate technology for maximizing employment potential. <NV>

People with developmental disabilities who can work must be provided with real job opportunities. A greatly increased involvement of the private sector is needed to bring this about. <NY>

All agencies and services must loosen their territorial grip and focus their energies and resources to serving people, rather than continuing the current system of increasing the size and complexity of bureaucracies and facilities, thereby further complicating the system for people with developmental disabilities. <OH>

Promote a comprehensive approach to employment for all persons with disabilities in Ohio. Call for the implementation of state level agreements on employment between and among all appropriate agencies. Facilitate the development and implementation of agreements between local agencies (County Boards of MR/DD, Rehabilitation Services Commission, UCPs, Goodwills, private businesses, etc.). <OH>

Place a moratorium on the funding of new construction for sheltered facilities that employ people with developmental disabilities. <OH>

Promote the use of private employment agencies in obtaining jobs for people with developmental disabilities through contracts, training of staff, etc. <OH>

Encourage and support private businesses to hire people with developmental disabilities by initiating a marketing campaign to promote the employability of persons with disabilities and by providing better employment incentives. <OH>

Provide fiscal incentives to County Boards of MR/DD and other service providers to make greater use of supported and competitive employment. Provide disincentives to those agencies which choose to continue to operate segregated facilities. <OH>

Promote the use of case management as a means to help people with developmental disabilities obtain the services, information, and supports they need to obtain and maintain employment. This case management function should extend to all relevant agencies, and job or income supports should be provided in a coordinated manner. <OH>

The Council should provide the leadership and direct the efforts of advocacy groups, as well as public and private providers, to develop public awareness concerning available incentives for employers to hire people with disabilities, i.e., the Jobs Tax Credit Program. <OK>

The executive branch of the Oklahoma state government should coordinate employment related programs from Education, Vocational Rehabilitation Services, Developmental Disabilities Services Division, and other agencies to be sure that they are working in concert and not in competition with one another. <OK>

The Council should provide the leadership and direct the efforts of advocacy groups, as well as public and private providers, to create public awareness by providing information to the state and local Chambers of Commerce, trade and professional associations, labor unions and public/private personnel agencies. Emphasis should be on the value of the employees with disabilities, success stories, low turnover and high loyalty, and pride in work. <OK>

The Council should provide the leadership and direct the efforts of advocacy groups, as well as public and private providers, to organize efforts to secure increased funding from the legislature for sheltered workshops as an incentive for providing quality sheltered employment experiences and to attract quality providers to perform these services. Oklahoma's present rate of reimbursement is \$13.81 per day, compared to the national average of \$28.00. <OK>

The Council should provide the leadership and direct the efforts of advocacy groups, as well as public and private providers, to support the Americans with Disabilities Act which addresses discrimination in employment. <OK>

State government must take the leadership of addressing employment of persons with disabilities by increasing its effort to employ. Persons with developmental disabilities are not highly recruited by federal, state or municipal governments. It is only fitting that state government take an aggressive initiative to improve the situation. <OK>

Financial data must be gathered to show that persons with developmental disabilities are indeed productive employees, have cut down on significant turnover costs, and take pride in their work. They have been characterized as excellent employees and good for the employer's community public relations. In turn, we must gain support inside the business community to work with us in making adaptations in the work place when needed, and to give individuals with developmental disabilities an opportunity to be considered for employment in positions not traditionally filled by people with disabilities. <OK>

Obtain approval for the hiring of vocational rehabilitation counselors. Statewide hiring freezes and attrition have led to unfilled positions for counselors despite sufficient funding for these positions. This in turn has led to large caseloads, waiting lists and delays in service. <PA>

Continue concerted efforts to utilize federal funding streams available for supported employment. <PA>

A specific jobs initiative for competitive and supported employment of persons with physical disabilities is needed. This initiative should involve the utilization of ancillary supports (transportation, job accommodation, incentives for employers) in order to promote employment opportunities. <PA>

It is proposed that the Puerto Rico Department of Labor and Human Resources shall be responsible for developing and promoting employment services for persons with developmental and other disabilities. <PR>

It is proposed that the Puerto Rico Department of Public Instruction shall be responsible for developing pre-vocational and vocational programs for people with disabilities who are not being served. <PR>

Services will assist persons in gaining meaningful employment: careers. <RI>

A dedicated system of tracking persons with developmental disabilities is essential if state and local agencies are to plan effectively. Strategies for evaluation of employment outcomes for adults with developmental disabilities should be pursued. <SC>

Expand the capacity of the current system to serve those waiting for supported employment programs. <SC>

State government should set a precedent for hiring persons with developmental disabilities. <SC>

Target more JTPA funds for job coach programs and have PIC Councils focus on the school drop out rates with emphasis on those students in special education. <SC>

Congress should extend the TJTC indefinitely. <SC>

Expand employment opportunities for people with disabilities through awareness to employers (public and private sectors), increased availability of job coaches, assistive technology services, and necessary support services (such as attendant care and transportation. <SC>

We recommend that the state amend its HCB waiver program to incorporate the coverage of prevocational and supported employment services for eligible persons. This step will permit a wider variety of daytime service options to be made available on behalf of HCB waiver recipients. Current federal administrative policies permit prevocational and supported employment services to be furnished to a considerable number of HCB waiver recipients. It is likely that Congressional action within the next year or so will permit all HCB waiver recipients to receive such services. This step will allow the state to redirect existing dollars to support vocationally-oriented service initiatives. <SD>

The state's current level of effort with respect to the provision of supported employment services should be reassessed and reorganized. <SD>

There should be tax reform in Tennessee to provide appropriate resources for employment programs, including ongoing support, for all Tennesseans with disabilities. <TN>

Tennessee should assume a leadership role for adopting an aggressive state policy to promote employment of Tennesseans with disabilities. <TN>

State and private agencies, advocacy groups, and others interested in employment of people with developmental disabilities should join in a strategic initiative to reach out and secure the active support and participation of employers in Tennessee. Employers should be encouraged to adopt specific policies and programs which focus on hiring people with developmental disabilities. <TN>

A percentage of all funds appropriated to the Job Training Partnership Act program should be designated to each Service Delivery Area in the state for skills training and employability training for people with disabilities. <TN>

The Texas Planning Council recommends the Texas Legislature designate the Texas Rehabilitation Commission (TRC) to be responsible for providing all vocational and employment services to people with developmental disabilities and other disabilities, with the exception that the Texas Commission for the Blind (TCB) shall continue to be responsible for providing services to people who are blind or visually impaired. Further, the Texas Planning Council recommends the Texas Legislature amend the Texas Department of Mental Health and Mental Retardation (TDMHMR) Act to remove responsibility for vocational and employment services and transfer funds for these services from the TDMHMR to the TRC. <TX>

The Texas Planning Council recommends the Texas Legislature and local service providers increase funding to expand supported employment for people with disabilities and also redirect existing resources for individuals in sheltered programs to transition into integrated employment. <TX>

The Council recommends that the agencies that provide employment services to the general population be required to serve people with disabilities as well. The recommendation would also include broadening the definitions for reporting employment statistics by the Job Training and Placement Agency, Job Service, and DRS. This would insure that the effectiveness of these programs was accounted for but also track the numbers of people with disabilities that are actually in the work place. <UT>

The Council recommends that the Targeted Jobs Tax Credit program be extended to a period greater than one year to provide an incentive for employers to hire people with disabilities. <UT>

The Council recommends that there be increased funding for transportation access, barrier free environment access and the establishment of life long support, management supported employment or whatever it takes to sustain employment for people with disabilities. <UT>

Address public attitudes to encourage employment of people with disabilities. <UT>

The General Assembly should provide funding for a voucher system to provide needed ancillary support services (e.g. transportation; procurement of adaptive equipment, mobility aids, or communication devices; child care; etc) to allow employment and promote the independence of individuals with developmental disabilities. <VA>

The General Assembly should mandate the implementation of a coordinated, interagency job-matching placement and follow-along system for persons with disabilities. This system should include the collaborative efforts and participation of all appropriate, publicly-supported state and local agencies and programs. <VA>

The General Assembly should provide incentive funding to encourage rehabilitation facilities with sheltered workshops to develop and expand community supported employment opportunities. <VA>

The General Assembly should provide sufficient permanent funding to expand and maintain long-term supported employment opportunities for persons with severe physical, sensory and/or mental disabilities. This should include funding to provide for appropriately trained personnel necessary for supported employment activities. <VA>

The General Assembly should mandate the Secretary of Administration and the Department of Personnel and Training to strengthen Virginia's commitment to affirmative action in hiring and promoting persons with disabilities within all areas of state government through explicit directives, education, and monitoring. <VA>

The General Assembly should create state tax incentives which will benefit employers who hire and/or provide long-term supports which allow persons with developmental disabilities to maintain remunerative employment. <VA>

Secure the funds necessary to expand the capability of existing effective job training and supported employment programs so that all who need the services receive them. <VT>

Pass legislation to create tax credits and/or low interest loans for employers who want to modify existing job sites or create new job sites that will be accessible to the needs of the employee with a disability. <VT>

Implement a coordinated, aggressive campaign to educate all employers about the facts concerning people with severe disabilities as workers. Additional attention should be given to this public education effort by groups such as the Governor's Committee on Employment of People with Disabilities, the Developmental Disabilities Council, the Vermont Center for Independent Living as well as the Division of Vocational Rehabilitation, Special Education, and Vocational Education. <VT>

Supplement existing federal programs with state programs that serve people currently excluded and add services that are not adequately provided now. <VT>

Develop a comprehensive policy on job training and employment for people with severe disabilities, including medical coverage for low income workers. This policy should be forward thinking with a goal of "whatever it takes" to have all persons who want to work be employed by the year 2000. This policy should also include a strong affirmative action statement for state government and state contractors. <VT>

Employers should be encouraged to provide equal benefit packages to all employees. <WA>

More emphasis should be placed on the importance of job-related social skills. Current funding levels do not adequately address this issue. <WA>

Career planning (not just job retention) should be a major focus in long-term support. <WA>

A focus on job retention skills as well as an expanded eligibility period for JTPA benefits is crucial. <WA>

Transition services geared specifically for people leaving sheltered employment and moving into community-based jobs should be planned and funded. <WA>

Collaborative efforts between agencies, employment service providers, employers, workers and the family must be developed and maintained. Ideas developed through business advisory councils and community task forces could be used to assist businesses to gradually assume long-term employment support. <WA>

No individual should be forced to accept an inappropriate or undesired employment position. Choice should be an inherent part of the employment assessment process. <WA>

Continue to provide employers with relevant education, training and ongoing assistance. <WA>

Give support and incentives to employers to increase employment opportunities. <WA>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to pursue the career of one's choice, and to have an equal opportunity to be trained and employed in work that is meaningful to oneself, with fair and equitable compensation. <WI>

Assess vocational counselor caseload sizes to ensure that people receiving services are placed in appropriate work and training programs that meet all the vocational needs of each individual. <WI>

Follow-up on the employment of each DVR client at least 9-12 months after the close of each case to ensure the suitability of employment, the adequacy of on-the-job supports, and the provision of continued, long-term supports when needed for persons with severe disabilities. <WI>

Ensure that the groups identified in the 1988 DVR Needs Assessment as the least well served (i.e., people with chronic mental illness, developmental disabilities, and severe developmental disabilities) receive adequate and appropriate services by substantially increasing funding and staff resources to these groups. Ensure more comprehensive DVR local planning and individual needs planning so that a wider range of vocational services are provided to these groups (e.g., assessment and training for competitive employment, supported employment, job placement services, etc.) <WI>

Strengthen private and public employers' commitment to the rights of people with disabilities to make career choices, to have access to appropriate training and to receive adequate support to work. <WI>

Initiate a legislative study to review and make recommendations for a legislative proposal regarding how much people with disabilities are paid compared to others in the same or similar positions and recommendations for improving the pay status of people with disabilities, qualifications of vocational rehabilitation counselors and recommendations for establishing minimum standards for certification, the employment opportunities that exist in the private sector as compared to those in the public sector, and how to increase state and/or federal funding support for vocational services that help facilitate the employment of individuals with disabilities. <WI>

Conduct federal and state studies of the quality of employment (type/duration of work, hours per week, wage/benefit levels, nature and extent of "underemployment", upward potential) of people with developmental disabilities. <WI>

Include supported employment as a priority function in each position description for DVR field staff and DCS regional staff. <WI>

Continue to increase and, when necessary, redirect funding in the 51/HSD community service system to enable adults to participate and receive benefit from supported employment and other community placement employment options. <WI>

Develop plans for the continuation and expansion of the DVR Supported Employment Program that include making the program available to everyone who is eligible for it, continuing the program with DVR priority funding after the 5-year federal grant expires,

expanding the eligibility criteria to include all people with disabilities, and continuing to operate supported employment as a separately identifiable program within DHSS. <WI>

Clarify the roles of the Division of Community Services and the DVR in the area of employment for people with disabilities. <WI>

Establish a formal mechanism that facilitates a cooperative ongoing relationship between the DVR and the county 51/HSD service system, determines which agency (DVR, county 51/HSD, other) will provide long-term services when necessary, and ensures continuity of services when people move from one system to the other. This would include the automatic referral of clients and provision of adequate funds and staff to the agency responsible for providing continued services to avoid any gaps in services. <WI>

Develop a rehabilitation and employment policy which recognizes that some people with severe disabilities need long term vocational rehabilitation services and that DVR is responsible for either providing these services or making cooperative arrangements with other agencies to ensure that these services are provided. <WI>

Develop outreach efforts to reach people who do not proactively seek services from, or are not aware of the services of, the DVR or the 51/HSD community services system. <WI>

Modify the vocational rehabilitation data collection system to enable there to be more consistent and accurate reporting between the federal Rehabilitation Services Administration and the state Division of Vocational Rehabilitation. <WI>

State agencies should evaluate their own policies and practices that limit supported employment opportunities for people with developmental disabilities. To the extent of their authority, state agencies should shift available funds from segregated to integrated vocational options. Increased planning and coordination among the state agencies that fund supported employment needed. <WV>

State agencies should place a moratorium on the expansion of vocational and day programs provided in segregated settings. <WV>

Training and technical assistance should be offered to providers and potential providers of supported employment in West Virginia. <WV>

The federal agencies involved in funding vocational and day programs need to clarify their representative roles and responsibilities and develop a coherent policy for work-related services that will promote independence, productivity and integration for people with developmental disabilities. Confusion at state and local levels will continue until such a policy exists. <WV>

People with disabilities and their families need complete and accurate information about supported employment. <WV>

More vocational training for people with disabilities should occur in programs and facilities used by nondisabled people. In particular, efforts should be made to incorporate people with developmental disabilities in existing vocational/technical training programs. Technical assistance and support should be provided to instructors for the inclusion of people with disabilities. <WV>

A coherent policy on the employment of people with disabilities also should be a specific written goal of the Wyoming Department of Employment. <WY>

A coherent policy on the employment of people with disabilities should be developed for the United States. <WY>

INCOME BARRIERS

Multiple States

Many needy people eligible for SSI — especially children — are not receiving benefits. <CA,HI,ID,IN,MT,UT,WA,WY>

Increased poverty among people with disabilities has been affected by tightened disability insurance eligibility, as well as by the factors associated with general increases in poverty. <CA,ID,IN,MA,MT,NM>

The average income for the lowest fifth of the population dropped nearly 11 percent from 1973 to 1987; average income for the top fifth rose 24 percent during the same period. Most of the change occurred between 1979 and 1987. <CA,HI,ID,IN,MI,MT,UT,WY>

The number of people living in poverty increased significantly between 1979 and 1987, from 26.1 million to 32.5 million. The largest contributing factor was the reduced effectiveness of means-tested welfare programs (such as SSI and Aid for Families with Dependent Children), which accounted for 36 percent of the increase; followed by population growth (26 percent); net reduction in income from employment or "market income" (13 percent); reduced effectiveness of social insurance programs, such as SSDI (11 percent); and the reduced effectiveness of federal tax policy (5 percent), according to an analysis conducted by the Congressional Research Service. <CA,HI,ID,IN,MT,UT,WY>

People with the most severe disabilities are the most likely to live in low income household; 63 percent of individuals with very severe disabilities were in households with incomes of less than \$15,000 in 1984. <HI,ID,IN,MA,MI,MT,TN,WA,WV,WY>

Individuals with disabilities are twice as likely to live in a low-income household (\$15,000 or less) as households which do not include a person with a disability. <CA,HI,ID,IN,MT,TN,WA,WV,WY>

There have been some improvements in procedures to determine and review eligibility for federal SSDI and SSI benefits for people with disabilities. Loss of these benefits has been a factor in the increase in poverty and homelessness among people with disabilities. <CA,ID,MT,UT>

With the exception of people who are elderly, average household income has declined for individuals and families in the lower economic strata while rising consistently for those in the middle and upper income segments. This occurred despite general economic growth in most areas of the country during that period. <ID,LA,MT,UT>

During the same period the official poverty rate increased from 11.7 to 13.5 percent, while the aggregate "poverty gap" — the difference between a poor family's disposable

income and the official poverty level — increased 45 percent or by \$12.8 billion. <LA,MT,UT>

The number of people classified as poor increased nearly 25 percent from 1979 to 1987, from 26.1 million to 32.5 million people (Committee on Ways and Means, U.S. House of Representatives, 1989). <LA,MT,UT>

Even using the poverty level standard (\$11,611 for a family of four in 1987), income support programs fall well below this level. <LA,MT,UT,WY>

Payment levels in publicly-funded programs are too low to provide for basic needs. The use of the poverty level as the goal rather than an income level sufficient to provide a basic standard of living is a related critical issue. <ID,IN,LA,MT,UT,WY>

Under both the WIN and JOBS programs people who are ill or "incapacitated" or needed in the home because of the illness or incapacity of another member of the household are exempt from participation. There is no strategy included in these requirements for low income people with disabilities to be supported appropriately in the job training program so that they have the same opportunity go get off the AFDC rolls as those without disabilities. <CA,ID,MT,UT>

The Substantial Gainful Activity (SGA) limit on earnings from employment used by the Social Security Administration to determine work-related disability and eligibility for SSI has not been raised from \$300 per month since 1980; the SGA amount for Social Security Disability Insurance (SSDI) recipients who are blind is currently (1989) \$720 per month and increases annually. <AK,CA,IN,MT,NM,UT,WY>

SSI recipients in Medicaid-supported nursing homes and residential programs receive only a \$30 per month "personal needs" allowance. <ID,IN,MT,TN,UT>

Nationally, SSDI benefit levels have failed to keep pace with inflation; the median decline in benefit levels adjusted for inflation was 37 percent from 1970 to 1989. <CA,IN,MT,TN,UT>

Despite the success of the Work Incentive (1619) Program in encouraging SSI recipients with disabilities to move into employment, there is no similar program for people with disabilities who receive SSDI, although legislation has been introduced in the 101st Congress to address this. <CA,IN,MT,NM,TN,UT,WY>

The federal poverty level in FY 1987 was \$481.50 per month; the average federal Supplemental Security Income (SSI) benefit to people with disabilities in FY 1987 was \$251 per month. Although some states provide supplementary state payments (SSP), many people with disabilities receive only the federal SSI benefit. Mandatory SSP benefits now apply to fewer than 8,000 people nationwide. <CA,IN,MA,MT,TN,UT,WA,WY>

Because Medicaid benefits are linked to SSI status, the restrictiveness in SSI eligibility for children means that many low income children with disabilities are also not receiving access to needed health care available through the Medicaid program. <CA,HI,ID,IN,MA,MT,NM,TN,UT,WA,WY>

The federal SSI eligibility criteria for children with disabilities are inappropriately excluding many needy children; there are minimal outreach efforts to smooth the application process. Although their eligibility is supposed to be based on the presence of a disability that is comparable in severity to one that would define an adult's eligibility (i.e., the inability to engage in "substantial gainful activity"), children have not received individual assessments of their functional limitations comparable to those provided for adults in the SSI application process. <CA,ID,LA,MT,TN,UT>

There is tremendous variation in income supports available through the AFDC program in the absence of any federal minimum standard; in many states the level of AFDC benefits is considerably below the federally-determined lower standard of living level specific to the state. <MT,WY>

People with disabilities who earn more than \$300 per month/\$3,600 per year (the Substantial Gainful Activity or SGA threshold, unchanged from 1880 until January 1, 1990) are not considered disabled for purposes of SSI eligibility, despite the severity of their actual disability and their need for supplementary income support while attempting to be productive and independent. <CA,ID,LA,MT,TN,UT,WY>

The SGA level for people with disabilities other than blindness who receive SSDI benefits is \$300 per month (in 1989), compared to \$720 per month permitted SSDI beneficiaries who are blind. <AK,CA,LA,MI,MT,UT,WY>

Especially in the absence of expanded mandates for state supplements, the amount of the federal SSI benefit is totally inadequate in relation to standards of minimal (i.e., poverty level) income support. <ID,LA,MT,NM,UT>

Current SSI regulations place some limitations on the ability of SSI recipients to retain benefits if they receive inheritances or housing assistance from their families designed to help them avoid institutional placements, if the amounts received place them above SSI income and resource limits. <ID,LA,MT,WY>

There is no work incentive program for SSDI recipients comparable to the 1619 program for SSI recipients. <AK,CA,ID,LA,MI,MT,IN,UT,WA>

AFDC benefit amounts have significantly failed to keep pace with inflation in virtually all states; despite favorable federal matching rates in many states, there is continuing unwillingness to provide state matching funds for increased benefits. <MT,UT>

There continues to be a prevailing attitude that increases in income supports — even up to minimal standards accepted in the public policy realm — contribute to dependency and larger "welfare rolls". Although people with disabilities are frequently not intended to be included in these references, the resultant lack of support for increased benefits adversely affects their chance of moving out of abject poverty. <ID,LA,MT,NM,TN,UT,W,Y>

Data on participation and benefits for people with developmental disabilities are available to considerable extent for the SSI, 1619, and SSDI programs. There are virtually no comparable data on generic income support programs such as AFDC and food stamps, nor on the impact of policy changes such as the work registration requirements and the related exemption of people with disabilities among AFDC applications. <ID,LA,MI,MT,UT,WY>

The belief that "welfare" is attractive to and thus discourages people from working ignores information such as findings from the Harris poll that 82 percent of people with disabilities receiving benefits as a result of their disability would give them up if they had a job. <ID,LA,MT,TN,UT,WA>

The \$300 SGA limit for SSI is inequitable when compared with SGA for blind recipients of SSDI, the poverty level, and minimum wage levels. The SGA level does not reflect the income needed to achieve reasonable self-sufficiency in the community. <AK>

People interviewed for the Consumer Survey said that they wanted to work more hours than they do currently. The low Substantial Gainful Activity (SGA) level for Social Security restricts many people from working to their full potential for fear of losing the income protection and other benefits associated with SSI and SSDI benefits. <AK>

The Section 1619(b) provision of the Social Security Act, which is intended to allow people to "take a risk" with employment opportunities without fear of losing medical coverage, is clearly underutilized in Alaska. The state had the second lowest percentage of state population (.4%) receiving SSI benefits nationally. The national average in 1985 was 1.1%. <AK>

Half of all Americans who experience disabilities, aged 16 and above, had a household income for 1984 of \$15,000 or less. Among non-disabled Americans, only 25% were in this income bracket. <AK>

In Alabama a frequently requested service was financial assistance. Financial assistance, in this instance, includes actual cash assistance, food stamps, and assistance managing the money individuals had. <AL>

A federal law was enacted in 1987 to amend the Social Security Act to allow a category of "disabled and working." The Work Incentives Law allows individuals to remain SSI eligible and not lose medical benefits. If Congress enacts the Bartlett Bill (HR #8, 1989),

it would stimulate employment by providing the same "working and disabled" status for SSDI recipients. <AZ>

The PASS and IRWE programs can be applied for at local Social Security Offices for individuals to earn more than \$85/month and not lose SSI benefits. In Arizona, few Social Security workers are familiar with the work incentive programs of PASS and IRWE. <AZ>

Based on poverty levels at either the state or federal base, individuals receiving SSI/SSP live well within the poverty range. <CA>

SSI recipients in Medicaid-supported nursing homes and residential programs receive only a \$30 per month "personal needs" allowance in federal funds. California supplements this allowance for SSI/SSP recipients, bringing the total to \$79 per month for personal and incidental monies (FY 1989). <CA>

People with developmental disabilities are not receiving adequate education and training in the use of the Section 1619 programs. Participation rates in the Section 1619 programs are extremely low in all states and especially in California. <CA>

SSI regulations place limitations on the ability to retain SSI benefits for individuals who receive inheritances or housing assistance from their families designed to help them avoid institutional placements. <CA>

California provides a supplementary state payment (SSP) of \$364 in addition to the \$238 SSI allotment for Californians with disabilities, for a total SSI/SSP of \$602 per month for a single person with disabilities. While this amounts to slightly more than the federal poverty maximum, California has significantly higher housing costs relative to many areas across the nation. Individuals with developmental disabilities have stated that even with SSI and SSP it is very difficult to survive in the community. Most rental units costs more than the entire monthly income assistance. <CA>

Lack of access to SSI and other supports for persons with epilepsy because of not being disabled enough to meet eligibility requirements. <CO>

The loss of needed health care coverage can be a powerful disincentive to work. For some persons with disabilities, the ongoing cost of health care is as much, and sometimes more, than the amount of SSI benefits received. Other people with disabilities are at considerable risk of high and unexpected medical bills. The problem is complicated by the fact that some SSI recipients who return to work will be unable to obtain health care coverage either as a fringe benefit where they work or as an individual because some insurance companies will not cover people with certain types of preexisting conditions. <CT>

It seems obvious from the DD Council's person-centered approach to describing effective job supports that people with disabilities who give up their SSI benefits and return to work should end up with a significant net increase in their disposable income. Otherwise, why bother? Unfortunately, the rules governing SSI virtually assure that some recipients who return to work will end up with a very small increase in disposable income over the public payment they would continue to receive from not working. <CT>

It is unfortunate that an SSI applicant must convince the State Disability Determination Unit of his or her inability to engage in substantial gainful activity (SGA) employment in order to be declared eligible for SSI. The very application process, which often takes two months and more, is harmful to the applicant's attitudes toward work. During this phase, the applicant is focusing on all the negative aspects of his or her condition. What is more, the applicant will be encouraged and coached by social workers, family, and others to prove that he or she cannot work. After eligibility is established, many SSI recipients and others around them are convinced that they cannot work. Thus, the application process becomes a self-fulfilling prophecy. <CT>

Persons with blindness are more favorably treated than other persons with disabilities. This statutory differential is a reflection of historical effort of political constituencies rather than a reflection of the disabling nature of different impairments. It is not indicative of the individual's capacity to work. The effect of this distinction between the impairment of blindness and other impairments is inequitable treatment of disabilities. The mental or physical impairments of persons with mental illness or developmental disabilities frequently limit them to part-time employment, sporadic employment, or employment with hourly wages and health benefits. For these individuals, monthly earnings above the SGA level do not indicate a lessening of their disability. Earnings above the current SGA level simply show a great effort to increase their work in spite of their mental or physical impairments, and in spite of the extra time, assistance and external support which it takes for them to work. <CT>

People with disabilities are much more likely to be poor than the non-disabled. The poverty rate for people with disabilities is 33 percent, more than twice the poverty rate of 16 percent for the non-disabled. <DC>

While some of the financial barriers to employment have lessened, (e.g., 1619 (a)), there are still some in existence which discourage people with developmental disabilities from seeking regular employment. <DC>

Income supports such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and Aid to Families With Dependent Children (AFDC) do not provide recipients with income that is sufficient to meet their basic life needs. <DC>

The average monthly household food stamp allotment for 1988 was \$110.00 for a recipient household size of 2.27 persons. While food stamps are a valuable income supplement for

the poor, they do not begin to provide recipients with an adequate standard of living. <DC>

In 1988, there were 21,808 persons receiving SSI District-wide. Less than half that number (10,716) also received Medicaid while fewer than 25 percent (5,032) received SSI, Medicaid and food stamps together. A total of 73,815 persons received AFDC in 1988. Only 16,144 (22 percent) received both AFDC and Medicaid, while 46,136 (58 percent) received AFDC and Medicaid and food stamps combined. These figures indicate that there are a significant number of individuals residing in the District in need of services that they currently do not receive. Information specifically geared to people with developmental disabilities is hard to come by except when looking at SSI. <DC>

There is a need for income assistance including Supplemental Security Income (SSI) for individuals with development disabilities. <GU>

The Social Security Administration should mandate local agencies to provide education and outreach work-related activities. <HI>

The \$200 Substantial Gainful Activity increase in 1990 is the first since 1980 and it is too little given the cost of living in 1990. <HI>

While the policy analysis rating shows support for productivity in the program, many consumers find that productivity is discouraged by the income and resource eligibility requirements of SSI. Comments indicate that the program does not reflect an understanding of the realities of life for an individual with a disability, nor for families that depend on that income to keep an individual with a disability at home. <IA>

Farm families seem particularly hard hit by the "assets" assessments and by limitations on vehicles. One farm family was told by SSI personnel that "This program is not for farmers." <IA>

About three-fourths of the respondents who use the SSI program report some degree of dissatisfaction, citing difficult application requirements and procedures, a restrictive waiting period, insufficient levels of financial support, and problems with unpredictable monthly variations in the amount of financial support received. <IA>

Corresponding with the policy analysis, consumers and surrogates do not feel that the SSI program is supportive of independence. A typical comment is that you either get help or you don't and you are offered no further choices. Similarly, consumers do not see the program as promoting productivity. While the financial support is helpful, the withdrawal of support if productivity (i.e., income or personal resources) increases is seen as a direct disincentive to employment and thus to productivity. <IA>

The Supplementary Security Income program was discussed extensively at the public forums. It is clearly a program that reaches many individuals and families with special needs and is an important component of the service system. Because the need for this program is great, frustrations with it have a powerful impact on those who use it. This impact is much amplified because it is used, with a few exceptions, as an eligibility criteria for receiving Medicaid health coverage. Frustrations are primarily related to eligibility requirements, the tie to health coverage, and waiting periods. <IA>

About 6 of every 10 consumers surveyed report that the State Supplemental Assistance program provides adequate support for independence. For the 3 of 10 who are unsatisfied, an inadequate level of financial support is the major issue. <IA>

The analysis of the program of the State Supplemental Assistance program indicates that the policy fails to promote independence or integration in all of the areas examined. The policy analysis finds that neither independence nor integration are explicitly cited as goals of the SSA program. The policy support of independence is also negatively rated ("not promote") due to eligibility being based upon a client's categorization as "medically needy" (having income and/or assets above the levels allowed for the classification of "categorically needy"), thus potentially excluding persons with other needs. In addition, the current housing options supported by this program—Residential Care, Family Life Home, Dependent Person, and In-home Health-related Care—do not represent residential services that will serve all levels of independence and integration possible for Iowa consumers. <IA>

The monthly personal needs allowance in Idaho for SSI recipients living in shelter care, foster care, semi-independent homes or room and board homes, is \$53, from all sources. <ID>

The federal poverty level in FY 1987 was \$481.50 per month; the average federal Supplemental Security Income (SSI) benefit to people with disabilities in FY 1987 was \$251 per month. <ID>

In 1987, 60% of all poor families with children were families in which someone worked during the year — the working poor. <ID>

SSI and SSDI constitute the major portion of income for individuals with disabilities and the amounts are far too low. <ID>

Another source of income financed by the State of Idaho is the State Supplementary Payment. This is considered a personal payment to individuals that live in shelter homes, adult foster care, independent living arrangements, semi-independent living, unlicensed shelter homes, room and board settings, or living in a relative's home. This program is also referred to as the Aid to the Aged, Blind and Disabled (AABD). This allowance is typically the difference between the personal income from a variety of sources and the

cost for the living allowance paid to the facility operator or living arrangement owner. Usually the allowance amount is either \$53 or \$73 depending upon the Department of Health and Welfare regional policy. Each region has a different policy and a resident may receive more personal allowance merely by living in a different location. Conversely, the resident may be penalized for choosing to live in a region that only allows the lower amount. <ID>

Money is the basis of all society's operations. It is the medium for meeting basic human needs. It takes money to buy clothing, shelter, food and transportation. But of all Idahoans, those with disabilities are most likely to have the least money. They get less than \$50 a month in personal spending allowances in group homes. They make less than minimum wage in workshops. Idahoans with mobility disabilities have to ride "special" public transit if they don't have a vehicle, and this service is \$1 to \$2 per one-way trip in town. Citizens with a disability do not typically have pensions or retirement funds. <ID>

AFDC benefit amounts have significantly failed to keep pace with inflation in Idaho; despite a very favorable federal matching rate (over 73%), there is continuing unwillingness to provide state matching funds for increased benefits. <ID>

Since 1980 the Social Security Administration has established \$300 a month as the level of Substantial Gainful Activity, or the amount of earnings that a person with a work disability can earn. The amount is expected to be raised to \$500 in 1990. This amount is \$150 a month below poverty level (1986) and \$276 per month less than minimum wage. <ID>

Potential loss of income and medical benefits from SSI or SSDI, associated with small increases in income levels, has acted as a major employment disincentive to people with disabilities. The SSI 1619 program some of these employment disincentives. However, people's views toward SSI remain and the potential loss of SSDI benefits still exists. <ID>

In Indiana, SSP payment is to individuals who are aged, blind or have a disability in domiciliary facilities or other group living arrangements as defined under SSI. The supplement does not vary in income standard according to cost-of-living differences. Persons with developmental disabilities are excluded from benefits under this program, however, since persons with these disabilities are not admitted to domiciliary facilities. <IN>

Low participating rates nationwide for SSI are alarming. It is estimated that nearly half of elderly persons eligible for SSI are not receiving benefits - principally because of a lack of awareness. In 1987, Indiana's SSI rate was only 68 percent of the U.S. rate. <IN>

The average combined federal SSI benefit and optional SSP benefit for needy individuals in Indiana in 1987 was \$215.34, or \$266 less than the federal poverty level. Indiana does not provide SSP to persons with developmental disabilities. <IN>

Indiana's low utilization rate for SSI may indicate one or more conditions: (1) the state's economy is strong and unemployment rates are low; (2) the state is effective in promoting employment for people with disabilities; or (3) many people eligible for SSI do not apply for benefits because of lack of awareness on their part or because of differences in the application of disability determination procedures. A preliminary analysis suggests that Indiana is not getting the word out to eligible persons about the benefits due them. <IN>

People with developmental disabilities and their families find the application process for SSI and other assistance programs to be confusing and difficult. Adequate referral, coordination, and case management services are lacking. <KS>

Adequate legal aid services for those wishing to appeal ineligibility determination and other actions is lacking. <KS>

People with developmental disabilities and their families often find the system for income assistance humiliating and degrading. Efforts are needed to establish pre and in-service training for all staff working within the system to understand the needs of people with developmental disabilities. <KS>

AFDC benefit levels in Louisiana have not changed since 1981, which translates into a real benefit decline (when adjusted for inflation) of approximately 35%. <LA>

The Optional State Supplementary Payments Program in Louisiana is only available to persons who are institutionalized. <LA>

There is tremendous variation in income supports available through the AFDC program in the absence of any federal minimum standard; in Louisiana the level of AFDC benefits is considerably below the federally-determined lower standard of living level specific to the state. <LA>

With the exception of people who are elderly, average household income has declined for individuals and families in the lower economic strata while rising consistently for those in the middle and upper income segments. This occurred despite general economic growth in most areas of the country during this period. <LA>

Since 1987, Louisiana has had the highest unemployment rate in the country with some parishes having rates in excess of 30%. However, Aid to Families with Dependent Children of Unemployed Parents will not begin until October 1990. <LA>

The average combined federal Supplemental Security Income (SSI) benefit and mandatory State Supplementary Payment (SSP) for needy individuals with disabilities in Louisiana in 1987 was \$210.84 per month, or less than half the federal poverty level. The average monthly benefit for Mandatory State Supplementary Payments (SSP) in Louisiana is \$12.65, the lowest amount in the nation except for three states who do not provide such a benefit. <LA>

The maximum AFDC grant in 1989 for a one-parent family of three persons was \$190 in urban parishes (i.e. East Baton Rouge, Orleans, Jefferson, and St. Bernard) and \$174 for the rest of the State. This is compared to the national median of \$360. <LA>

Many individuals with hearing impairments have a difficult time receiving services from the Social Security Administration due to a lack of interpreter services and telecommunication devices for the deaf. <LA>

Today, average rents in cities in Massachusetts for a two-bedroom apartment are over \$500, the same amount as the entire AFDC grant for one month for a family of three. A March 1989 study by the state determined that a family of three in private housing needs \$12,500 yearly, and in subsidized housing \$9,950. Basic AFDC benefits are currently half of this level and General Relief benefits are even less. The situation for AFDC families is worsening: last year they were 25% below poverty level; this year after budget cuts they are at 28% below the poverty line. <MA>

The Department of Public Welfare predicted 5,700 AFDC families would become homeless between July 1988 and June 1989, most because they cannot effort to pay rent. Homelessness is increasing in Massachusetts at a rate of thirty percent per year. <MA>

25% of all individuals with disabilities are members of families who live below the poverty level, while 11% of all Americans live below this standard. <MA>

People with disabilities are much poorer than the general population. <MI>

It is important for the Social Security Administration to develop policies to deal with income earned from supported work, especially regarding subsidy (i.e., job coach time). <MI>

Many more people could benefit from the Social Security Administration's work incentive provisions. They are not widely used, partly because people who could use them do not know they are available. More information needs to be made available to people with disabilities and to those who work with them. <MI>

All work incentive provisions of the Social Security Act should be available to people who receive Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). <MI>

Current state policy allows more personal needs funds for people in institutions than for people in the community. This is counter-productive to the principles of integrated community-based living. <MI>

The increase in SGA still will not keep pace with needs. <MI>

Even using the 1987 poverty level figures of \$481.50 per month for an individual, current benefits from income support programs fall well below poverty. They are also rapidly losing ground to the cost of living. <MI>

Because they have difficulty obtaining work, people with disabilities are much poorer than the nondisabled population. They rely heavily on income assistance programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The average income of the lowest fifth (income level) of the population dropped nearly 11% from 1973 to 1987. Average income for the top fifth rose 24% during the same period, thereby increasing the gap between the extremes. (Committee on Ways and Means, U.S. House of Representatives, 1989). In a Harris Poll, 63% of all people with severe disabilities age 16 and above had a household income in 1984 of \$15,000 or less. Among nondisabled American households, only 25% are in this bracket. The more severe the disability, the greater the poverty. (Harris Poll, 1986) Seventy-six percent of the respondents to the Michigan consumer survey received SSI. Thirty-four percent received SSDI. (Some respondents received both SSI and SSDI.) Eighty-two percent of people with disabilities who receive benefits would give them up if they had a job (Harris Poll, 1986). This contradicts the public perception that public assistance programs are attractive enough to discourage people from working. <MI>

People with disabilities at the CRI Forums felt trapped in poverty. Their income is low, but they report that their expenses are very high compared to the general population. They described SSI as inadequate for special needs, for married couples, and for becoming independent. People said that if they attempted to increase their income, they would lose SSI benefits, which they couldn't afford to do. <MI>

Eligibility requirements for receiving income supports (SSDI) continue to act as disincentives for people with developmental disabilities who are seeking supported/competitive employment. <MO>

Essentially, persons with disabilities earning approximately minimum wage cannot work more than 22 hours per week ($\$3.35 \times 22 \text{ hrs.} \times 4 \text{ wks.} = \$294.89/\text{mo.}$) or they will stand to lose their benefits because they are then over SGA. We are therefore saddled with a regressive system which threatens the pride, confidence, and integration of persons with disabilities into the work-place, jeopardizing their benefits for earning too much. <MT>

There is no SSI in American Samoa, Guam, Puerto Rico, and the Virgin Islands. <MT>

Data collected through the consumer survey, agency analysis and public hearings indicate that income supports for persons with developmental disabilities are inadequate and result in some people not receiving basic support services that promote independence, productivity and integration into the community. <NC>

Some consumers report having support benefits penalized as a result of wages exceeding a certain ceiling. This ceiling is set below the poverty level and disregards the special needs and increased expenses of daily living for persons with developmental disabilities and their families. <NC>

Current disincentives to employment in several income assistance programs should be changed. The additional expense that a disability may bring, as well as the difficulty in getting reasonable health insurance, may require changes in programs such as Supplemental Security Income and Social Security Disability Insurance. <NE>

Low income can be a problem for any person, but when that person has a developmental disability it has many effects. Many persons with developmental disabilities experience serious problems locating full-time employment which could potentially make a better way of life more accessible to them. It is not always easy to differentiate what problems of integration and independence are due to disability and what to poverty. Persons with developmental disabilities may frequently have basic needs met as far as a home, food, and medical care. But their access to disposable income which permits participation in typical community activities may be minimal. <NE>

There is no doubt that limited income underlines many of the problems faced by persons with the developmental disabilities. The solution may not lie completely in increasing benefits but also in increasing job opportunities and salaries for persons with disabilities. <NE>

When a person has a developmental disability which necessitates physical assistance and/or medical care, the problem of income can be exacerbated. These additional costs easily deplete resources. If accessible housing is needed, the rent may be higher. Transportation may require a van and life. Diapers, catheters, special diets and so on, all may add extraordinary expenses to families who cannot financially qualify for assistance programs but who have major disability related expenses. <NE>

Problems arise from the fact that even those work incentives that are available are not being used. For example, there are practically no PASS Plans in effect in the state, and the number of people qualifying for work expense exemptions under SSI and APTD who deduct these expenses appears to be very small. Consumers report that they receive little or no information about these work incentives from any source. Part of the problem may be the mind-boggling complexity and obscurity of the regulations themselves. It is common for individuals to be required to fill out forms for four or more different agencies to obtain benefits. Even professionals who have studied and worked with these benefits

programs for many years commonly disagree and are confused about the meaning of various provisions, and it may well be that there is not a single individual who fully understands New Hampshire's Medicaid/Waiver/SSI/APTD system. <NH>

People with developmental disabilities and their families often become impoverished and need additional income because of higher costs associated with disabilities and a proportionately greater need to buy supports and assistance for the individual and the family. The severity of the disability frequently defines the level of cost and the likelihood of poverty. <NM>

Because Medicaid benefits are linked to SSI status, restrictive SSI eligibility for children means many low income children with disabilities are also not receiving access to needed health care. <NM>

Increased poverty among people with disabilities has also been affected by tightened disability insurance eligibility, as well as factors associated with general increases in poverty. <NM>

The Substantial Gainful Activity (SGA) limit on earnings from employment used by the Social Security Administration to determine work related disability and eligibility for SSDI has not been raised from \$300.00 per month since 1980; the SGA amount for recipients who are blind is currently(1989) \$740.00 per month and increases annually. <NM>

The Income Support Division of the Human Services Department provides a subsidy of \$85.00 per month to residents of group homes. This subsidy is not available to persons in supervised living arrangements. This policy interferes with the movement toward less restrictive environments. <NM>

In the absence of expanded mandates for state supplements, the amount of the federal SSI benefit is inadequate in relations to standards of minimal (i.e., poverty level) income support, let alone support at the level of basic standard of living. <NM>

Most adults with developmental disabilities are poor. Thirty-eight adults with mental retardation who were surveyed in the Developmental Disabilities Planning Council's Consumer Survey, who described themselves as being employed part- or full-time, reported that they worked on average of only 20 hours/week. Their average weekly wage was reported to be only \$21. Twenty-five adults in the same survey who had physical or sensory impairments, and also described themselves as working part or full-time, reported that they work an average of only 22 hours per week. Their average weekly wage was reported to be \$56. Deleting the results for one worker who reported an income of \$500/week reduced the average income for the group to \$37/week. Compare these figures to the federal poverty level (as of 1987) which was \$110/week. The average monthly SSI benefit to people with disabilities in Ohio that year was only \$251. Although some states

provide a supplement to these federal payments, Ohio does not. SSI recipients living in Medicaid-funded residential programs receive only \$30/month as a personal needs allowance. <OH>

Historically, there have been strong fiscal disincentives to work. A national study showed that almost 55% of the respondents had their Social Security benefits decreased after they were employed. Due to recent revisions within the SSI program, people are now able to earn income while protecting cash and medical benefits. This revision has resulted in an increase in the number of people with disabilities working in the community. Unfortunately, this provision is not currently available to SSDI beneficiaries. <OH>

Social Security Insurance (SSI), a monthly cash assistance, is available to persons with developmental disabilities beginning at the age of 18. At this age, the parents' income is no longer "deemed" and income eligibility can be established for individuals. The exception to this rule is an individual with mental retardation who qualifies for Title XIX Home and Community Based Waivered Services. In addition, the Assistance to the Disabled which is a small state supplement also becomes available to the individual upon receiving SSI. However, for both programs an individual must be determined SSI eligible by income and disability. <OK>

The number per 100,000 population receiving SSI because of a disability is lower than the national rate, but higher than three of the other New England states. <RI>

Frequently mentioned was the disincentive to work inherent in the Supplemental Security Income and the Social Security Disability Insurance systems, and the fear of families that a person with developmental disability may lose medical benefits and services if employed. <SC>

Sensitive screening of persons in the work support program is critical to persons with developmental disabilities. <SC>

Inequities in the Work Incentives Program (1619) will hold many persons back from trying to become gainfully employed: a distinct barrier to independence, productivity and integration. <SC>

The marriage penalty and the one-third reduction rules are barriers to independence, productivity and integration. <SC>

Poverty in households with family members who have a developmental disability is a critical issue. <SC>

The SGA is set unproportionately low for persons drawing SSI and DAC as compared to the level set for persons drawing SSDI. <SC>

The average combined federal Supplemental Security Income (SSI) benefit and optional State Supplementary Payment (SSP) for needy individuals with disabilities in Tennessee in 1987 was \$230.45 per month or \$227.88 less than the poverty level in Tennessee—only slightly more than half of the poverty level. <TN>

Payment levels in publicly-funded programs are too low to provide for basic needs. <TN>

Since many families of children with developmental disabilities are single-parent families, the limitations of the AFDC program in Tennessee are particularly significant to these families. <TN>

In many states the level of AFDC benefits is considerably below the state's poverty level. In fiscal year 1987 approximately \$102 million in federal AFDC benefits were received in Tennessee. The maximum AFDC grant in Tennessee in 1989 for one-parent family of three persons was \$184, compared to the national median of \$360. A monthly payment of \$184 provides an annual income of \$2,208, which is 15 percent of the poverty level income of \$14,140 for a family of three in Tennessee. <TN>

Because the basic income provided by SSI is so low, most people with disabilities live with their families or other people. The SSI income becomes an integral part of the family income. This interdependence creates further disincentives to risk the guaranteed income by going to work and families discourage the family member with a disability from taking a chance. <UT>

These factors do have a negative effect upon the resources available to the state for the provision of income supports to people with disabilities. Only 23% of Utah's citizens are taxpayers and the child population creates a tremendous drain on the state treasury for education. This leaves a limited amount of tax revenues for the provision of income supports. <UT>

One major barrier created by the 1619 regulations concerns school-age students with disabilities that participate in community-referenced educational programs. These programs result in employment before the age of 18 and renders participants ineligible for SSI and therefore unable to participate in the 1619 Program. This creates a situation where students are forced to quit their jobs for at least 30 days, apply for SSI and Medicaid in order to qualify for the 1619 Program, and then turn around and try to get their jobs back or find other employment. <UT>

There are no statistics or tracking systems developed in Utah that account for the level of income for most of Utah's population of people with disabilities. This is especially significant regarding the people that are not involved in specific programs but are trying to exist independently and who are not known to the state. In order to gain legislative appropriations for supplementary programs to fulfill the vision of income for people living below the poverty level, it is necessary to track or account for their needs. <UT>

SSI and SSDI do not provide adequate funds for housing for people in group homes or supervised apartments. Presently, DSH must subsidize group and apartments for clients on SSI who are not Medicaid reimbursed. <UT>

The most consistent perceptions of satisfaction and need were related to financial welfare. Thus, high levels of need were indicated for income assistance, food assistance, financial management assistance, private health insurance, payment for medication, and payment or provision of medical equipment. Why is this area of assistance of such importance? Because having adequate income allows independence, community integration and productivity, values strongly endorsed by consumers. And because the ideal is so discrepant from reality - adult respondents to the survey had an estimated average annual earned income of \$5,600. <VA>

Statistics show that children are this country's largest poverty group. Approximately one-quarter of the children in this state live in households where the income is below poverty level. These children are definitely "at risk." <WA>

Some 213,000 children in Washington State live in poverty. Chances of falling below the poverty line exceed 50 percent if the household is headed by a woman and she has children under the age of six. In 1985, some 66 percent of black children, over 70 percent of Hispanic children, and nearly one half of all white children living in female-headed households lived in poverty. <WA>

The average gross weekly wage of 80 employed Consumer Satisfaction Survey respondents was \$63.24. This represents only 21.9% of a poverty level weekly income. People working at that income level obviously need the assurance of continued income and medical benefit coverage. <WA>

Persons applying for SSI must still prove their inability to earn wages above the SGA level. This requirement places qualifying conditions in direct opposition to the intent and purpose of the Employment Opportunities for Disabled Americans Act of 1986. The law explicitly permits SSI recipients to have earnings up to a "break even" point set by the federal government. Workers have to surpass this "break even" point before losing entitlement to SSI payments and even higher earnings before losing entitlement to Medicaid. <WA>

Different rules regarding payment of benefits under SSDI and SSI programs also cause serious employment disincentives. <WA>

The optional State Supplemental Payment (SSP) is defined by the state in terms of specific eligibility requirements and targeting. For example, some states focus on SSI recipients who live independently. Others target those who live in residential service programs. Nationally, about 42% of all SSI recipients receive an additional SSP benefit. In most states, people living independently usually receive less money than do people in supervised living arrangements. <WA>

Persons receiving Medicaid benefits still must fall below an annual income level in order to maintain SSI eligibility. This has caused some SSI recipients to refuse promotions and to reduce work hours. This is also a particularly important consideration as some SSI recipients are refused coverage under private medical plans. <WA>

Nationally, AFDC benefit levels have failed to keep pace with inflation. <WA>

Under rules outlined by Substantial Gainful Activity (SGA) regulations, a limit on employment earnings is used by the Social Security Administration to determine eligibility for SSI. This allowable earning limit was raised in January 1990 from a \$300 per month cap to \$500 per month. This represents the first SGA increase since 1980. People who earn more than the set amount are not considered disabled for purposes of SSI eligibility. This rule stands despite the severity of disability or the need for supplementary income support. <WA>

The SSI eligibility criteria for children with disabilities inappropriately excludes many because they do not receive individual assessments of their functional limitations. These assessments are provided for adults during the SSI application process. <WA>

The average combined federal SSI benefit and the optional State Supplementary Payment (SSP) for needy individuals with disabilities was \$271.17 per month, or \$210.33 less than the federal poverty level in 1987.<WA>

Assistance payment levels are too low to provide for basic needs. Even considering poverty level standards (\$11,611 for a family of four using 1987 estimates), income support programs fall well below this level. <WA>

Wisconsin currently ranks 17th in the nation in the percentage of people who are receiving Supplementary Security Income (SSI) who are also participating in the 1619 Program. The 1619 Program is a program that allows people to work and still receive SSI and Medicaid benefits. There are still many people who are not aware of the availability of this program and still others who currently do not qualify. <WI>

22.3% of West Virginians live below the poverty level. People with disabilities comprise a disproportionate share of this group. This problem is exacerbated by West Virginia's heavy investment in the types of vocational and day programs that generate the least amount of income for their participants. Over half of the almost \$12 million spent in this area is invested in non-vocational day programs which provide activities for which people receive no wages. Less than fifteen percent of the total is spent on helping people get jobs in the community, which have the greatest income-generating potential. <WV>

Most states provide an optional supplement to SSI; West Virginia is one of seven states that does not. In 1987, the average SSI payment made to persons with disabilities in West

Virginia was \$266.20, more than \$200 below the 1987 federal poverty level of \$481.50. <WV>

In addition to the particular needs associated with caring for a child with a disability, many West Virginia families face the added challenges of poverty. A report published by the West Virginia Human Resources Association stated that, in 1986, half of all West Virginia families had incomes below \$10,800. Nearly a quarter (22.3%) of the state's population lives below the poverty level and the state ranks second nationally in the growth of the percentage of residents living in poverty. The report also indicates that the number of children born into poverty in West Virginia doubled from 25% in 1983, to 52% in 1987. A quarter of the state's children are being raised in poverty, and only 60% of these children receive Aid to Families with Dependent Children (AFDC). As of July, 1987, West Virginia's maximum monthly AFDC benefit for a family of three was \$249, a payment level that ranked forty-third in the nation. <WV>

There is evidence that many people who are homeless have disabilities. News stories and tragedies have highlighted the fact that many are people with chronic mental illness. Some may have been so since childhood and so may meet the definition of developmental disability. Lack of a permanent address should not be a barrier to receiving federal income support. This issue also needs to be addressed at the state level. <WY>

The average combined federal Supplemental Security Income (SSI) benefit and optional State Supplemental Payment (SSP) for needy individuals with disabilities in Wyoming in 1987 was \$218.71 per month, or \$262.79 less than the federal poverty level. The average SSI payment in Wyoming is \$198.09 which is below the national average of \$218.39. The average Wyoming state support payment is \$19.62. The maximum payment in Wyoming is \$20. <WY>

INCOME: RECOMMENDATIONS

Multiple States

The federal government should consider various ways to use the disability benefits which an SSDI beneficiary would have been entitled to as a potential funding source for some of the health related services which an SSDI beneficiary needs to maintain employment. <MT,WY>

The federal government should extend the employer mandate for COBRA continuation coverage for 29 months for persons ending work as a result of disability which would permit SSDI beneficiaries to purchase continuation coverage if they are fortunate enough to have an existing group plan and if they can afford both the employer's premium and the employee premium while completing the two year waiting period for Medicare. <MT,NM,WY>

For people who are eligible for SSI, there should be a greater effort to use Section 1619 of the Social Security Act to qualify for Medicaid when they are employed. <ID,MT,WY>

The SGA level should be raised to at least the \$720 per month level which is now (1989) permitted SSDI beneficiaries with blindness. .<AK,HI,LA,MI,MT,NM,TN,WY>

Income supports should complement the efforts of people with disabilities to be gainfully employed. <HI,MT,TN,WA,WY>

The work incentive (1619) program should be extended to SSDI beneficiaries. <AK,CA,HI,ID,LA,MA,ME,MT,NM,TN,WY>

Continuing outreach efforts should be made to expand the use of the 1619 program among SSI recipients with disabilities. <LA,MT,NM,TN,WY>

Both means-tested and "social insurance" programs should be redefined as income support programs, designed to provide sufficient assistance to those in need to enable them to maintain a basic standard of living. <ID,LA,MT,TN,WY>

The United States should have a national income policy that guarantees a livable income, sufficient to meet the basic needs of all people. The official "poverty line" should be raised to an adequate standard. <LA,MT,TN,WY>

Training and employment opportunities for AFDC recipients should be extended to people with disabilities, including essential supports and adaptations that enable them to benefit as fully as those without disabilities. <ID,LA,MT,TN,WY>

SSI eligibility determination for children with disabilities should be revised to require consideration of the individual child's functional limitations and require presumptive eligibility for children with certain genetic and congenital impairments that indicate a developmental disability. <ID,LA,MS,MT,NM,TN,WA,WY>

Given the failure of optional SSP programs in most states to sufficiently complement the federal SSI payment in providing even minimal levels of income support, consideration should be given to new approaches to SSP such as updating and expanding federally-mandated SSP and joint federal/state cost-sharing of SSP programs. <LA,MT,WY>

Individual States

The Division of Vocational Rehabilitation, the Division of Mental Health and Developmental Disabilities, and the Social Security Administration should work jointly to develop methods to encourage fuller utilization of the Section 1619(b) program. <AK>

SGA levels should increase annually to compensate for inflation. <AK>

Educational efforts to utilize the "work incentive" programs of Social Security, through the Program to Assure Self-Sufficiency (PASS) and Impairment-Related Work Expenses (IWRE) for SSI recipients to stimulate employment and relieve families of fear of loss of benefits when family members start working, must be supported. <AZ>

Limits on SSI/SSP benefits should be raised to pull individuals out of the poverty range. Geographic differences within California should be taken into consideration. Benefits should be based on the individual's income/earning as an independent adult, and not based on availability of family support. <CA>

SSI eligibility requirements for children living at home with their families should be reviewed. Eligibility should be based on real financial need — not on arbitrary regulations, such as extensive medical need. <CA>

Substantial Gainful Activity (SGA) limits should be raised to the level of individuals who have blindness — \$720/month so that there is no discrimination among disabilities and so that there is incentive to be substantially employed. <CA>

Outreach and training is needed to increase participation in Section 1619 Work Incentive programs. <CA>

Support legislation to extend 1619(a) and (b) work incentives to SSDI. <CO>

A stronger emphasis must be placed by the SSI Program on the provision of cost-effective rehabilitative services such as integrated employment and supported employment. Closer

relationships should be forged between SSA district offices and the Division of Rehabilitation Services. <CT>

Consider eliminating the emphasis on providing that an applicant for SSI cannot work. Instead, require applicants to prove that they have great difficulty in obtaining employment because of their disabling condition. In this approach, eligibility can be granted without assuming that, until work disability has been proven, there is no point in providing vocational rehabilitation services. In fact, it would make sense to require that vocational services be accepted as early in the application phase as possible, and a concerted effort made by the state rehabilitation agency to return the person to work. <CT>

The SGA level must be consistent across disability programs and should be set at the level that is used with people with blindness/visual impairment. <CT>

A tracking and monitoring system should be put into place for all poverty and low income individuals with developmental disabilities and their families to insure, to the greatest extent possible, that they do not suffer greater hardships. <DC>

The Council should develop, in collaboration with the appropriate departments and agencies of the Government of the District of Columbia, procedures for identifying individuals with developmental disabilities and their families whose incomes are (1) below the poverty level, (2) are not receiving food stamps, (3) eligible but not receiving SSI, (4) eligible but not receiving SSDI and (5) other available income and related support programs. <DC>

The Council should develop, document and validate the need for increasing the official poverty level(s), particularly for individuals with developmental disabilities and their families. <DC>

In the area of income assistance, as well as all other critical life areas, attention must be given to provision of comprehensive case management services for individuals with developmental disabilities. <FL>

Secure state supplement for federal SSI benefits. A state dollar supplement to Supplemental Security Income (SSI) should be considered which could mean the difference between life and death for some people with developmental disabilities. Georgia is one of the eight states that fails to supplement SSI. <GA>

The state needs to raise the personal spending allowance for people who live in state supported community residential options. <GA>

Agencies and advocacy groups need to identify and eliminate disincentives to employment of persons with developmental disabilities including: if persons with developmental

disabilities do work, other means for their financial support should not be withdrawn. <GA>

The Council recommendation is to petition Congress to extend Supplemental Security Income (SSI) to Guam for individuals with developmental disabilities. <GU>

Congress should direct the Department of Health and Human Services to raise the official poverty line to guarantee basic needs such as shelter, food and clothing are being met. <HI>

The Supplemental Security Income Earned Income Allowance should be increased. <HI>

Providers of services should make a greater effort to use Section 1619 of the Social Security Act to qualify people for Medicaid when they are employed. <HI>

Develop a better system within Iowa for disseminating information to clients, families, and providers about the SSI program, about SSI Amendments 1619 (a) and (b) and about SSDI. <IA>

Create SSI policy guidelines that insure an immediate program response once eligibility is established. <IA>

Study the effects of removing the disincentive to employment/productivity by phasing out SSI benefits more gradually as productivity increases. <IA>

Simplify the application procedures for SSI. <IA>

Study the effects of removing eligibility requirements that demand participation in other programs in order to receive SSI benefits. <IA>

Reduce the time of the waiting period between loss of SSI benefits and reapplication. <IA>

Revise SSI policy to redefine asset levels as these affect the eligibility for services of farm families. <IA>

Enhance the effectiveness of the program by establishing policy that requires more effective dissemination of information about the program to individuals, families, and service providers. <IA>

Study the expansion of housing options eligible for support through the State Supplemental Assistance program to include more independent settings, such as the client's home. <IA>

Enhance State Supplemental Assistance program effectiveness by requiring policy to explicitly cite independence and integration as program goals. <IA>

Review policy and procedure to identify ways to simplify the process of maintaining eligibility. <IA>

The State of Idaho should have an income policy that guarantees a livable income, sufficient to meet the basic needs of all Idahoans. The official "poverty line" should be raised to an adequate standard. <ID>

The Idaho legislature must increase the personal needs allowance for individuals as providers' rates are increased. Most importantly, the Idaho legislature must allow full consumer control over income supports rather than paying providers. Individuals must be involved in transacting the business of their own care. <ID>

The U.S. Congress should take action to improve SSI and SSDI as follows: increase the SGA for people on SSI and SSDI to equal the SGA for people with blindness, within two years; increase SSI and SSDI payments to be at least consistent with the cost of living index; develop a simpler and more flexible system for adjusting program payments to a person's earnings (e.g. quarterly computation of earned income); develop eligibility based on disability and not on work capacity; and allow people with developmental disabilities to marry with no reduction of benefits. <ID>

If all people with developmental disabilities were to receive a general SSDI increase in Substantial Gainful Activity to \$720, it would encourage them to work up to their full potential by reducing the fear of losing SSI and SSDI benefits. <ID>

Indiana shall target information and training to key professionals on existing work incentives and provide clear details on how the incentives can be used (e.g., social security personnel, case managers, residential providers). <IN>

Indiana shall review income assistance as a secondary strategy to competitive employment, but when necessary, provide it in a way that promotes dignity and encourages movement toward independence and autonomy. <IN>

The SSDI program should be changed to include 1619 work incentives, to increase the SGA level to \$720 per month, and to eliminate the waiting period for Medicare for people with insurance. <IN>

Congress should change SSI laws to allow children with developmental disabilities to receive benefits regardless of their parents' income while living at home. <LA>

The Social Security Administration should provide in-service training to their own personnel and training workshops for service providers and parents of persons with developmental disabilities concerning the impact employment has on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits. <LA>

Congress should change the SSDI and SSI laws to include more incentives for persons with disabilities to work, such as allowing persons to retain their eligibility for Medicaid indefinitely and increased credit for work-related expenses such as transportation, personal care assistance and job coaching. These incentives should be explained to all persons applying for SSDI or SSI and by mail to those already receiving benefits. <LA>

The Social Security Administration should have personnel with financial management and planning competencies available to persons with disabilities and their families at the time of application for benefits and also at any time thereafter. This service should be offered to every individual or family at the time of application and by mail to those already receiving benefits. Interpreters for people with hearing impairments should be available to transmit such information. <LA>

The Advocacy Center for the Elderly and Disabled (ACED), in conjunction with the Bar Association, should develop and disseminate written materials for lawyers and families on long term financial planning. <LA>

The new federal Family Support Act of 1988 (P.L. 100-485) should be supplemented with a strategy to include job training for low-income people with disabilities through the Job Opportunities and Basic Skills Training (JOBS) Program so they have the same opportunities to get off the AFDC rolls as those without disabilities. <MA>

The Social Security Administration should ensure that SSI and SSDI recipients wanting to work are given the information, training and support to do so. <MA>

Public assistance payments must offer a decent standard of living to low-income individuals and families, and be significant enough to prevent the incidence of disabilities related to poverty conditions. A standard should be developed that reflects the real costs of living instead of the present "federal poverty level" nomenclature so the cycle of intergenerational impoverishment can be broken. <MA>

As a society we should support a wide range of significant federal and state income tax credits and deductions so that the final costs of disability related expenses are minimized for individuals and families, employers, builders, etc. <MA>

The exceptional costs faced by people with disabilities and their families should be considered within the financial criteria for eligibility for means related income support programs and for sliding-fee scales or copayments for services. <MA>

Public assistance and income support programs should be designed and offered in a manner that encourages individual dignity and increased independence and autonomy. Any financial supports must simultaneously provide encouragement to the individual with a disability to obtain and maintain employment rather than discourage such efforts. <MA>

The Disability Determination Service should make referrals to Vocational Rehabilitation so people know about employment opportunities but are not forced beyond their capacities. <MA>

Supplemental Security Income eligibility for children is too restrictive. Federal legislation should be passed which would improve procedures for the assessment of disabilities/functional limitations among needy children applying for SSI benefits. <MA>

Support federal regulatory changes to expand the definition for Title XVI (SSI) disability eligibility for very young children with developmental disabilities (mental impairment listings, Down syndrome and multiple body systems listings) and other favorable changes proposed on childhood eligibility for SSI/Medicaid benefits. <MA>

Remove all remaining work disincentives in all Social Security programs. Turn this and other federal programs around so people clearly benefit from working. Most want to work, and can do so with minimal supports. <MA>

Expand outreach to ensure that individuals with disabilities are informed of and receive federal benefits (e.g., Work Incentives Improvement Act, Tax Reform, Section 1619 (a) and (b), Public Law 99-514, Labor Standards Act, Social Security Act/SSI and SSDI, Vocational Rehabilitation Act, Targeted Jobs Tax Credit,, etc.) and advocate for revisions to existing legislation, regulation and policies. <MA>

Information should be provided employers on the benefits and various incentive programs available for hiring persons with disabilities. <ME>

Removal of marriage disincentives in the Supplemental Security Income programs. Specifically, recipients should not receive deduction in payments when they marry. <ME>

Increases in Social Security Disability Insurance and Supplemental Security Income payments to reflect support for a reasonable standard of living. <ME>

The Bureau of Rehabilitation and Social Security Administration should conduct, at least annually, training programs for families, consumers and service providers in the SSA Sec. 1619 Work Incentive Program. <ME>

The Human Services Cabinet should coordinate aggressive out-reach efforts, with citizen advocacy groups and others, to secure full benefits from existing federally supported programs, especially Supplemental Security Income (SSI), Medicaid, Social Security Disability Insurance (SSDI), Housing and Urban Development (HUD) rent subsidy certificates, and food stamps. <MI>

The Social Security Administration (SSA), with the help of the Michigan Interagency Task force on Disability (MITF/D), should organize and cosponsor with other appropriate

organizations periodic statewide work incentive trainings. Training should aim to increase use of work provisions and promote understanding of the needs of people with developmental disabilities. Participants should include SSA, rehabilitation agencies, handicappers and their parents, service providers, job placement agencies, and case managers. <MI>

The Social Security Administration (SSA), with input from the Office of Special Education and Rehabilitation Services (OSERS) and the Administration on Developmental Disabilities, should revise SSA policies that deal with income derived from supported work programs. Employer subsidy, including job coach time, should receive particular consideration as an income offset for determining eligibility and for benefit calculations. <MI>

The Social Security Administration and Michigan Rehabilitation Services should work to increase awareness about programs such as Plans to Achieve Self Support (PASS) and Vocational Rehabilitation Plans (Section 301), in order to encourage their use by handicappers. <MI>

Allow handicappers to marry with no reduction of benefits. <MI>

The Michigan Legislature should increase the personal needs allowance for Adult Foster Care residents at the same percentage that providers' rates are increased. <MI>

The Social Security Administration, in cooperation with Special Education Services, should increase outreach to families about the availability of SSI for children with disabilities. <MI>

Congress should pass H.R. 868. <MI>

The Michigan Developmental Disabilities Council, through its participation in the Michigan Interagency Task Force on Disability (MITF/D), should continue to advocate for release of the revised children's listings. <MI>

The Department of Social Services should adjust its data gathering system to enable the identification of people with developmental disabilities who receive various income support programs. <MI>

Develop eligibility criteria based on disability and not on work capacity. <MI>

Extend the length of the Trial Work Period. <MI>

Tie the level of SSI and SSDI payments for all recipients to increases in the cost of living. <MI>

Develop a simpler and more flexible system for adjusting program payments to an individual's earnings (e.g., quarterly computation of earned income), and avoid overpayments, which cause hardship for the recipient when they are deducted from later checks. <MI>

Current SSI rules which affect property ownership should be made more lenient to allow eligibility of individuals who have personal assets. <MO>

Income assistance, food assistance, payment for medication, etc., for Mississippi's citizens with developmental disabilities is very important as most of the consumers surveyed are on Supplemental Security Income (SSI). There should be an additional income allowance that will allow for more independence, community integration and productivity. <MS>

Food assistance/food stamps must be made increasingly available in a manner adapted and individualized to accommodate the clients' needs. <MT>

Information regarding regulations for maximum allowable income and other specifications as they relate to SSI benefits must be more readily available and comprehensible. <MT>

A method for filing the required court reports by representative payees needs to be developed which is not overly expensive. <MT>

Implement a state-funded income assistance program for adults with developmental disabilities who move from a state-licensed facility or a state-operated facility to a more independent living situation which would maintain their income at the same level as when they were living in the previous facility. <NC>

Revise the SSI eligibility criteria for children with developmental disabilities to require presumptive eligibility for children with specific genetic and congenital impairments, or to require consideration of the child's functional limitations; and to disregard one-half of the family's income in determining eligibility. <NC>

Increase the Personal Needs Allowance for SSI recipients from \$30 to \$75 per month with an automatic increase each year indexed to inflation. <NC>

Increase the Personal Needs Allowance from \$30 to \$60 per month for individuals residing in Intermediate Care Facilities for the Mentally Retarded with an automatic increase each year indexed to inflation. <NC>

For individuals who receive SSI, increase the maximum allowable income earned in Substantial Gainful Activity (SGA) from \$300 to \$740 per month (the level of SGA for SSDI beneficiaries with blindness) with an automatic increase each year indexed to inflation. <NC>

Increase the maximum SSI and SSDI payments to \$481.50 per month (the federal poverty level for individuals) with an automatic increase each year indexed to inflation. <NC>

The Council recommends that eligibility for health and support services for persons with developmental disabilities not be determined on the basis of income, but rather on some standard of need which recognizes the additional financial burden placed on this population which is beyond their control to eliminate. This standard must be established at the federal level. <NC>

Income supports should complement the efforts of people with disabilities to be gainfully employed. <NE>

The living allowance within state and federal monthly entitlements should be sufficient to meet personal needs. <NE>

The federal SSI rate for all disabilities should be raised to the current level provided to people with visual impairments. <NH>

The staff of Area Agencies for Developmental Services should develop close working relationships with benefits providers and an expertise in the utilization of available work-incentive provisions of benefit programs to insure that employees are not needlessly restricted in their earning capacity or their receipt of support services. <NH>

Procedures for eligibility and payments for Medicaid and the New Hampshire state supplement to Supplemental Security Income (Aid to the Permanently and Totally Disabled) should be simplified and brought into close alignment with those of the Social Security Administration. New Hampshire could establish an agreement for federal administration of the state supplement. As an alternative, the Division of Human Services and regional offices of the Social Security Administration should work towards maximum coordination of rules and procedures, such as the use of shared office space, interchangeable forms and data programs, and identical eligibility standards, resource limits, and work incentives, the goal being reduction in confusion currently experienced by consumers. <NH>

It is recommended that the New Jersey congressional delegation be made aware of the need to make parallel provisions in Title II of the Social Security Act, both for disabled worker beneficiaries and for adult disabled child beneficiaries. <NJ>

It is recommended that a continuing effort be made to alert providers, advocates, SSI recipients and their families to the advantages of engaging in gainful employment and invoking the benefits of Section 1619 together with associated provisions. <NJ>

It is recommended that married persons with disabilities retain their individual payment level, as permitted in the case of a Social Security beneficiary with a disability. This can be effected by the state adjusting its supplementation. <NJ>

It is recommended that the state supplemental be raised for an eligible individual living with an ineligible spouse so that the combined federal and state level is equal to 150 percent of the individual level, based on combined income. <NJ>

It is recommended that New Jersey raise its individual SSI supplement to a point where the combined federal and state payment level equals at least 90 percent of the poverty level. It is further recommended that, once elevated, the state supplement be indexed in the same way as the federal portion. <NJ>

It is allowable to include Impairment Related Work Expenses and employer subsidies as earned income in determining substantial gainful activity at the time of the initial SSI application. Advocacy groups should publicize these underused provisions to help minimize the negative result of the "screening effect" of the low SGA level. <NJ>

Letters of assurance should be provided to individuals who wish to explore gainful employment and use the benefits of Section 1619 (a) and (b). This assurance should be modeled after the present Social Security Administration Personal Earnings and Benefit Estimate Statement. <NJ>

Ongoing training should be provided on the work incentive provisions and other changes to the disability programs contained in The Employment Opportunities for Disabled Americans Act (P.L. 99-643). This would ensure a well-trained Social Security Administration workforce and lead to consistency in the treatment of applicants and benefit recipients. <NJ>

Income support should be primarily a federal responsibility. <NM>

New Mexico should consider an SSP program to complement SSI payment in providing minimal levels of income support; consideration should be given to new approaches. <NM>

The work incentive 1619 program should be extended to SSDI beneficiaries. <NM>

The Substantial Gainful Activity level should be raised to at least \$720.00 per month, which is now permitted to SSDI beneficiaries with blindness. <NM>

Continued outreach efforts should be made to expand the use of the 1619 program among SSI recipients with disabilities. <NM>

SSI eligibility determination for children with disabilities should be revised to require consideration of the individual child's functional limitations and require presumptive eligibility for children with certain genetic and congenital impairments that indicate a developmental disability. <NM>

Disincentives of the Social Security system, particularly loss of medical benefits once employment has been secured, should be removed. <NV>

A temporary disability program should be established by the Nevada legislature for persons with disabilities not eligible for SSI/SSDI because of the "permanent disability" clause in SSA criteria. <NV>

Support enactment at the federal level of a work incentive program for SSDI recipients similar to that currently available under the SSI Program. <OH>

Initiate a state supplement for SSI recipients. <OH>

The Social Security Administration might provide the means by which persons with developmental disabilities could be freed from work disincentives permanently. The establishment of a policy which would allow persons who have not medically recovered to participate in the same earnings test provided for individuals age 65 and older is felt to be a possible solution. <SC>

The Optional Supplement program has a bias toward residential care facilities and should be changed to include financial support in independent housing as well. <SC>

Persons with developmental disabilities and their families need work incentive education. <SC>

The Work Incentives legislation (1619 Program for Title II recipients) should be carefully reviewed and passed with allowances for retention of benefits for the Disabled Adult Child just as they are allowed for recipients of the Supplemental Security Income Program. <SC>

The Substantial Gainful Activity limit should be raised for individuals in the Supplemental Security Income and Title II Disabled Adult Child programs to at least the poverty level, with annual cost of living increases mandated. <SC>

Persons with disabilities who wish to marry should not be penalized by having to sacrifice \$183 of their SSI entitlement. <SC>

The one-third reduction penalty (SSI) for parents who maintain their child/children with disabilities in the family home should be eliminated. <SC>

Supplemental Security Disability Insurance recipients should have the option of buying-in their Medicare coverage after they have completed the 48 month trial work period, which is when coverage is automatically cut-off. Many of these persons would be excluded (or restricted) from benefits of their employer's group or could be working for themselves and

be uninsurable. The potential loss of government insurance keeps many persons from rejoining the workforce. <SC>

SSI eligibility criteria for children with disabilities should be developed and implemented by professionals with expertise in pediatrics and youth; assessments should be age-specific and should include the most current scientific knowledge; determinations should not be exclusively physician-driven. <TN>

The Social Security Administration should provide incentives to individual states that encourage employment without a resulting automatic cut in SSI protection. Any SSI savings should be redirected to other supported employment. <WA>

People with developmental disabilities who are employed (or who could be) must be assured of continued income and medical benefit coverage. Social Security Work Incentives legislation should be supported to ensure the provision of such income and health insurance benefits for SSDI participants. <WA>

While recognizing the increase in the Social Security Administration's SGA level to \$500 by January 1990, it must be emphasized that cost of living adjustments should be built into SGA. <WA>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to have the same opportunity as anyone else in one's community to a sufficient level of income to meet one's basic needs and maintain self-respect, with the same opportunity to pursue a higher standard of living. <WI>

Encourage and expand the use of benefits now available under Section 1619 of the Social Security Act to enable people who receive SSDI and others who are not SSI eligible to be able to receive some needed medical and financial supports when becoming employed and earning wages. <WI>

Measures to alleviate poverty among children and families must be rigorously pursued. Specialized supports for families of children with developmental disabilities must be developed in conjunction with programs that ensure that people's basic needs are met. Strategies need to be implemented that address both the immediate needs of families through increased funds for AFDC and day care, as well as promote long-term self-sufficiency through improved education and job training. <WV>

Individuals and their families need information about the protection of their SSI and Medical Assistance benefits under Sections 1619 (a) and (b) of the Social Security Act, and about the range of community employment possibilities in order to make informed decisions. <WV>

A HOME: BARRIERS

Multiple States

The Fair Housing Act is not being accepted everywhere and the states will have to play a vital role in seeing that its promise is fulfilled. <MT,UT>

Many people with developmental disabilities are unaware of existence of the Fair Housing Act and what its potential can mean to them personally in gaining desirable housing in the community and enabling them to make choices and achieve independence and integration. <CA,LA,MT,UT,WY>

A recent national survey found estimates of more than 60,000 people with mental retardation awaiting some type of residential option. <CA,IN,MA,MT,NJ,UT>

Almost 52,000 people with mental retardation and related conditions currently reside in nursing homes. Reviews of people with developmental disabilities living in nursing homes have found many who are neither elderly nor in need of nursing care, as well as a lack of habilitation and therapeutic services designed for people with developmental disabilities. <CA,ID,IN,MT,NJ,TN,UT>

Federal funding for the 202 program, and therefore the number of projects, has been reduced significantly, from a high of 30,000 projects in FY 1976 to a low of 10,300 in FY 1989. The average time from loan application approval to occupancy of the housing by people with developmental disabilities is three to four years. <CA,ID,MI,MT,NJ>

The combined factors of the shortage of affordable housing, increases in the overall poverty rate, and lack of community services/deinstitutionalization of people with mental illness are primarily responsible for the significant increase in homelessness over the past several years. <CA,MA,MT,NJ,UT>

In 1985 almost half (47.6 percent) of the households below the poverty line paid more than 50 percent of their income for rent; two-thirds of these households paid more than 70 percent. <CA,MI,MT,NJ,UT,WA>

There is a severe national shortage of housing that is affordable for people with low incomes. Many people with developmental disabilities have low incomes because of their dependence on income support programs that provide income at below the poverty level (e.g., SSI) or because their employment income is similarly at or below the poverty level. <CA,IN,MA,MT,NJ,UT>

The supply of Section 8 certificates in many areas is far less than the number of requests. Because low income rental assistance is not an entitlement, subsidies are available only to the extent that federal funds are available. In 1985, for example, less than one-quarter

of the nation's poorest families in rental housing were receiving such assistance. <CA,ID,IN,MT,NJ,UT>

Significant numbers of incidents involving physical and sexual abuse of board and care residents and neglect of residents medical needs are taking place; many residents of board and care facilities are people with developmental disabilities. <ID,LA,MT,NJ,UT,WY>

Despite the broadbased support for family homes for children with developmental disabilities, there are major gaps in the systems of care for children who are medically fragile and/or technology dependent. These children have minimal access to home-based care and other "least restrictive environment" alternatives. <ID,LA,MT,NJ,UT>

The new Fair Housing Amendments are significant, but much remains to be done in assuring access and non-discrimination on the basis of disability. <ID,MT,NJ,UT>

Significant numbers of incidents involving physical and sexual abuse of board and care residents and neglect of residents' medical needs are taking place; many residents of board and care facilities are people with developmental disabilities. <LA,MT,NJ,UT,WY>

Federal resources that can be used to support housing, modify environments and promote independent living are minimal, especially when compared to the \$5.6 billion (approximately 52 percent federal/48 percent state funds) being expended on the ICF/MR program. New findings on the cost-effectiveness of non-institutional alternatives, in particular the individual housing support models, have not been translated into fiscal policies. <LA,MA,MT,NJ,UT,WY>

There is widespread ignorance among community members as well as policymakers outside the field of developmental disabilities of the overwhelming evidence that people who live in the community have much greater gains in independence, productivity and integration than their counterparts in the institution. There is a comparable level of ignorance about the proven ability of people with severe disabilities, people who are technology-dependent, and people with challenging behaviors to live in homes in the community and to be integrated with people who are without visible disabilities. <ID,LA,MT,NJ,TN,UT,WY>

The "not in my backyard" (NIMBY) syndrome continues to reduce opportunities for housing for people with developmental disabilities in some neighborhoods and communities. New federal Fair Housing Amendments, however, consider this discrimination and therefore actionable. <ID,LA,MT,TN,UT>

There is a lack of data on residents with developmental disabilities in board and care facilities, as well as widespread difficulties in the monitoring of conditions in board and care units, especially those that are unlicensed. <ID,LA,MT,NJ,UT>

There are insufficient data on the numbers and characteristics of people with developmental disabilities in "generic" housing programs, such as low income rental assistance. More information also is needed on the people with developmental disabilities who are found among the homeless population. <ID,LA,NJ,UT,WY>

There are major unresolved questions about the principles that should be observed in monitoring places where people with developmental disabilities live and the services received there, including federal versus state and local standards; separation of responsibility between monitoring and provider status; and the difficulties of using nursing home oriented monitoring procedures, as with the ICF/MR program. <AZ,ID,LA,MT,NJ,UT,WY>

The infusion of resources through the McKinney Act is helpful but woefully inadequate in comparison to the need for more support for the development of low income housing. <LA,MT,NJ,TN,UT>

The impact of the new ICF/MR standards and the implementation of P.L. 100-203, requiring relocation of several thousand people with developmental disabilities currently inappropriately housed in nursing homes, is unknown. If resources are increased to expand/improve institutions rather than to use the HCB waiver and other supported housing alternatives, it will significantly erode further the availability of resources for community service development. <ID,LA,MT,UT,WY>

There is much more demand for housing supports and residential alternatives than there are funds available. Most states have extensive waiting lists for homes in the community. <LA,MT,NJ,TN,UT,WY>

There is a national crisis in the availability of affordable housing, especially for those with the lowest income levels. The rapid growth in homelessness throughout the 1980s has affected many people with disabilities and their families. They are especially vulnerable because of their low income status and, in some cases, because of discrimination and other factors associated with the disability itself. <ID,LA,MT,UT>

Many people with developmental disabilities do not get to choose their home and their housemates, but instead are "placed" in a residential care facility. <ID,LA,MT,NJ,UT,WY>

The medically-oriented, congregate long term care model of the ICF/MR program is inappropriate for most people with developmental disabilities; even when the level of care is technically appropriate, the ICF/MR model is extremely difficult to use in ways that promote independence, productivity and community integration because of its medical care facility orientation. <AZ,HI,LA,MA,MI,MT,TN,UT>

The lack of available supports and residential alternatives continues to force people with developmental disabilities into inappropriate and unnecessary residential placements. <AZ,MI,MT,UT>

The primary emphasis is still on facility-based residential care, in particular the use of large congregate facilities and institutions, especially in federally-supported programs. The major exception, the Supplemental Security Income (SSI) program, provides benefits well below the poverty line, where the shortage of affordable housing is the most acute. <ID,LA,MT,UT>

The approach to housing for people with developmental disabilities needs a "paradigm shift" from residential services to supported housing so that people are living in their own homes rather than being "placed" in a residential care facility. <ID,LA,MT,NJ,TN,UT>

There is a lack of alternatives to funding housing for people with developmental disabilities through the medical care system, despite the general inappropriateness of the medical care model. <ID,IN,LA,MT,TN,UT>

There is a need to shift resources from institutional and facility-based care to individual and family supports that are tailored to the needs and wishes of the individual with developmental disabilities. <AZ,LA,MT,NJ,TN,UT>

The availability of a "free and appropriate" public school education for children with disabilities has been a significant factor in the reduction of institutional admissions. The overwhelming majority of people with developmental disabilities and their families expect community living opportunities, including continuing opportunities to interact with people without a disability. <ID,LA,MT,UT>

Individual States

There are 320 people on waiting lists for community residential services from the Division of Mental Health and Developmental Disabilities (DMHDD). <AK>

Medicaid reimbursement has an institutional bias. Because Alaska has not sought waivers, Medicaid funds cannot be used to fund community based services. <AK>

Residential options are nearly nonexistent in rural areas of the state. People from these areas must leave their home community, family and culture to get the services they need in an urban setting. <AK>

Newborns who are "medically fragile" or "technology dependent" often spend extended periods of time during their first months living in neonatal intensive care units or nursing homes. Newborns from the rural areas of Alaska often spend the first two or three years of their lives there waiting for placement in an urban foster home. <AK>

Affordable housing is a problem for most low income people, including people who experience disabilities. Accessible, barrier-free, affordable living arrangements are scarce and in high demand. <AK>

Nationally, 25 to 30 percent of people who experience disabilities report housing difficulties, including problems with access, physical structures and neighborhoods. A national study found persons with cerebral palsy, spinal cord injuries, multiple sclerosis and seizure disorders among those with high levels of dissatisfaction with their living arrangements. <AK>

In compliance with P.L. 100-203 (OBRA 1987 Nursing Home Reforms), Alaska is moving some residents of nursing homes who experience developmental disabilities to community residential settings. The federal government, through the Medicaid program, pays 50% of the cost of care in nursing homes. The state will be required to pay 100% of the cost of community based care for these same individuals. Many other states will be able to recover 50% of the cost of community placements for nursing home residents from the federal government through the use of Medicaid waivers. <AK>

There is currently only one program in Alaska that provides home modifications to consumers. This project is a collaboration between ACCESS Alaska in Fairbanks (a Center for Independent Living) and the Carpenter's Union. <AK>

There are no developmental disability program standards or monitoring system in place to assure the quality of community residential programs funded by the DMHDD. <AK>

Screening evaluations of individuals currently residing in nursing homes are presently underway. Already, approximately 200 individuals have been identified as needing active treatment. These individuals lack medical problems that would continue to make them eligible to reside in a nursing home. The director of the Social Security Administration has granted Alabama an extension of time in order to develop suitable community living arrangements for these individuals. Efforts must be accelerated to meet the training and community living needs of these persons. These needs must be met in the least restrictive environments possible and close to their family members and friends. <AL>

Residential options for persons with severe, multihandicapping conditions, including severe mental retardation, are almost non-existent. The exception is a group home which is sponsored by the Volunteers of America (VOA) and funded by state and federal DD dollars. This facility, which is located in Huntsville, is the only program of its type in the state. <AL>

Adults who sustain severe physical impairments (such as quadriplegia) often need and want a variety of community living situations; however, these types of residential arrangements are limited to a few geographic areas. For example, the Gerry Fullan House sponsored by the United Cerebral Palsy Association of Greater Birmingham (UCPGB) is the only

out-of-family semi-independent housing available in the area for people who have severe physical disabilities, with or without mild mental retardation. In a metropolitan area of more than 800,000 people, the Gerry Fullan House can serve only eight at one time. <AL>

There is a very strong need for community residential services in Alabama, especially for the individual with cognitive, physical, sensory, or emotional impairments, or a combination of these disabling conditions. <AL>

A number of people commented on the need for architectural modifications in private homes, but often did not have these adaptations in place due to the costs involved. <AL>

Although in order to receive funds, the services provided must meet federal and state licensing standards, these standards do not adequately assess many aspects pertinent to the quality of a person's life, such as the opportunity to have friends, to make choices and to fully participate in community life. Monitoring by consumers, parents, advocates and other concerned citizens who are uniquely qualified to address quality of life issues offers an additional perspective from the community to how specialized services promote quality lifestyles. <AR>

The Human Development Centers are a focus of extensive controversy. It is important to remember that at the time the first facilities were built, they represented best-practice services. Parents fought hard to get something where there was nothing. The achievements and basis for parents' efforts today are based on those of an earlier generation. But "best-practice" has changed. Consistent research results demonstrate that the change is for the better. This does not deny the value of what has gone before. It does, however, place new emphasis on keeping families together and on persons with disabilities living in their home communities in typical homes. It is important that Arkansas reduce dependence on large congregate services, an area where it has lagged behind much of the nation. <AR>

Many individuals who currently reside in large ICR/MR facilities do not need an intensive level of support, yet because of the unavailability of community services, they must remain in a more restrictive setting. In another example, children who are at risk of institutionalization could remain home with the help of individualized family supports, with a potential cost savings to the state. <AR>

Arkansas has neglected to provide community services for people with challenging behaviors and severe physical disabilities. This has occurred primarily because of the lack of adequate funds for staffing and treatment in existing residential services. <AR>

The salary and benefits for community direct care workers are notoriously low and usually compare unfavorably with salaries paid for institutional staff. This isn't surprising given the generally underfunded status of human service programs and the high proportion of the total budget that staff expenses claim. Low pay contributes to high turnover and

difficulties in recruitment. These problems are continuously at the forefront of labor issues. <AR>

Where funding follows the adult in a residence of four people and one person leaves, the remaining people may have to find another less expensive place to live because three cannot meet expenses. <AR>

In addition to the information from the utilization review process, it was evident in touring the various facilities and talking to the superintendents and their staff that a number of persons are served in state institutions primarily because there are simply no community alternatives. <AR>

Over 1,300 individuals currently reside in six Arkansas' Human Development Centers which are large, congregate, ICF/MR residential facilities. Many of these residents have little or no meaningful interaction with their families. <AR>

The skills required of direct care staff are no less demanding than those required of human services professionals. Indeed, line staff are called upon to implement the very habilitation strategies that professionals design. Nonetheless, the condition of underfunding, low pay and high turnover contribute to a staff force that has little or no systematic training. While the effects of limited training have not received substantial research, nonetheless the deleterious effects of unprepared staff seem significant. <AR>

With the ICF/MR option large amounts of money needed to pay construction and borrowing costs are diverted from other potential uses. <AR>

In Arkansas, very little has happened in the way of formal, active citizen monitoring. On the whole, families who have children receiving residential services appear to be uninformed of service alternatives, client and family rights, and components of quality services. In addition, there is in this state a unique and pervasive phenomenon that one parent calls an "attitude of gratitude." According to its originator, the parent of a child with severe physical and mental challenges, the term refers to individuals with disabilities and their families who are so grateful for any services at all that they do not question the services being provided. Those who do have questions may not know how to effectively address them. This perspective has been underscored by the fact that, for many years, there simply were no services for people with disabilities in this state. Some parents have even expressed fear that if they "make waves," not only might their child lose the services provided but his/her personal safety could be jeopardized. <AR>

In sorting out the factors contributing to an unstable and unprepared workforce, numerous issues have been pointed to that can be placed under the umbrella of quality of work life. These include: highly limited promotional opportunity, limited autonomy or participation in decision making, staff injuries, undesirable working hours, isolation and/or inadequate support. <AR>

Implementation of the Medicaid Community-Based Waiver Program is important for the services it will provide to consumers and for the positive momentum it provides to the whole system. It is not an easy process, however, because of the demands it places on state agency personnel and providers to learn the new systems required for its effective operation. Further, provisions within the program may need to be changed to ensure that people get appropriate services in the appropriate locations. <AR>

The State Office of Long Term Care conducted a survey that revealed that 1459 additional persons who have a primary or secondary diagnosis of MR/DD reside in nursing homes throughout the state. It is likely that the number of these individuals with active families is quite small. The presumption is that these individuals have limited access to the outside world and therefore may not truly be able to make decisions which could be construed as voluntary. <AR>

The investment in the ICF/MR program covered under the regular Medicaid program comes just at the time when the new community-based waiver makes it possible to serve individuals with similar support needs under more flexible, less restrictive options; the costs of the ICF/MR option are expected to become increasingly prohibitive as review standards focus more closely on active treatment. This is particularly true in Arkansas with presently has one of the lowest average daily costs for residents of ICFs/MR in the nation (about \$108/day). It is unknown what impact review standards may have upon renewal applications for waivers. <AR>

Even with more than 100 community providers offering services to about 4,000 individuals with disabilities, the service system is sparse, particularly in the more rural, poverty-laden areas of the state. <AR>

The issue of the thirty new ICFs/MR that are projected to serve 300 persons is one of the more controversial ones facing Arkansas. Certain of these new facilities apparently have been built and are in operation. It is clear that these facilities do not meet the intent of Public Law 100-146 and are not consistent and the values outlines in the DDPC mission statement. <AR>

Arizona needs to continue its process of deinstitutionalization. Emphasis is still being placed on institutional settings by converting to ICF/MR. <AZ>

The Arizona Housing Statute (ARS 36-582) is clearly in direct conflict with the new federal Fair Housing Amendment Act of 1988, and its accompanying regulations in the Federal Register of January 23, 1989. The Arizona statute is also in violation of the grievance provisions of the federal law. <AZ>

The rate methodology for community residences is based upon Inventory for Client and Agency Planning (ICAP) scores and level of supervision required. The calculation of rates does not incorporate differential cost factors related to rents (which vary from rural to

urban areas); differences in utilities. While the rates recognize that fixed costs remain the same, regardless of the level of functioning of the person being served, rate setting is a guide to be used during contract negotiations; and some providers do not feel negotiated rates are adequate. <AZ>

At this time, salaries allowed for community services employees are lower than those paid to state employees performing the same job. DDD has requested funds to increase provider employees' salaries. As a result of this low rate of pay, community residential service providers are experiencing a high turnover of staff. Turnover rates vary from 50% - 130%, as reported by various agencies. The number one reason for this turnover is attributed to low salaries. There is awareness that this high turnover rate will negatively impact quality of services. While provider salaries have increased over the past two years, they are not where they should be to maintain a state system. <AZ>

DES/DDD monitoring and licensing unit needs to tighten up licensing regulations, thus eliminating borderline homes that do not meet full standards. A policy to establish conformity and consistency with rules and regulations is needed. <AZ>

The eligibility determination procedure for long term care services needs to be reviewed. The possibility of the PASS evaluation instrument being overly restrictive is a concern. <AZ>

Rates for community residential providers are not adequate to provide the quality of care and living opportunities that people with developmental disabilities need in order to maximize their independence, productivity, and integration. <CA>

Licensing problems exist throughout the state. There is a serious lack of coordination between licensing agencies and regional centers. <CA>

There is no career ladder in the community to encourage people to remain in the residential field. <CA>

Individuals who have behavior problems, mental health problems, or who are medically fragile often need more specialized programs to meet their specific needs. Generic community care facilities are not trained or compensated to care for individuals with severe behavior problems or dual diagnoses. <CA>

Residential provider staff in the community are generally underpaid and undertrained which creates high turnover. Staff salaries are inequitable between public facilities (developmental centers) and private facilities (community facilities). <CA>

In California, this problem has been identified through the 1990 Study Consumer Forums, where people with disabilities stated that the Section 8 program is not always available and that there are long waiting lists to receive such assistance. <CA>

More residential options are needed for people with developmental disabilities. <CA>

Many individuals with developmental disabilities are not receiving much needed housing assistance through Section 8. <CA>

A number of very serious problems have arisen as a direct result of the community residential facility shortage. Most alarming is the increase in developmental center admissions. When a community facility closes, for one reason or another, what options exist for a relocating residents? The occupancy rate for negotiated rate and ARM Level 4 facilities is 95%, with ICF/DD, ICF/DD-H, and ICF/DD-N programs operating at occupancy levels of 97-99%. During the period July 1, 1987 to November 1, 1989, 188 people were admitted to developmental centers due to the closure of 11 community facilities. <CA>

The developmental center (state facility) system will reach licensed capacity within the next five years if current trends continue. <CA>

There is a serious shortage of appropriate community residential facilities. The greatest shortage is among those programs which serve people with more severe disabilities. <CA>

Start-up funding for new residential programs is severely limited and does not meet the demand. <CA>

Nearly 2,000 developmental center (state facility) residents are ready for community living, but remain institutionalized. <CA>

The state developmental center population is increasing due to a shortage of community residential programs. Funding for resource development is seriously inadequate, and this problem impacts the entire service delivery system. If people are entitled to services, as guaranteed in the Lanterman Act, then a commitment to resource development is needed to meet this legal obligation. <CA>

Some people with various clinical syndromes such as Prader-Willi syndrome are not receiving appropriate residential services due to a lack of specialized programs designed to meet very unique needs. These individuals may be served through developmental centers, ICF/DD-H facilities or community care facilities, but parents and professionals have testified that these facilities are not appropriate to meet the specific needs of these populations. Individuals with dual diagnoses, head injuries, hearing impairments, as well as other special problems, often do not receive appropriate services due to a rigid service system where individuals must fit into existing programs. <CA>

783 people who currently live in group homes could live more independently and be more integrated in a supervised apartment or other form of integrated living. An additional

5,240 people who presently live with their families were also identified as ready candidates for independent living, if opportunities were available. <CA>

Programs are not being adequately monitored, and accountability is lacking for many programs. Quality of residential community programs is sometimes inconsistent at best and poor at worst. Regional centers do not receive adequate resources to provide the level of monitoring needed to assure quality programs. <CA>

Some individuals are not receiving treatment in least restrictive settings, a violation of the Lanterman Act S. 4502 (a). Due to serious shortages of appropriate community facilities, some individuals, including children, are being placed in facilities which are either more restrictive than needed or are not specialized to meet unique needs. Close to 2,000 people living in developmental centers are ready for community placement less restrictive living, but are remaining in more restrictive settings due to facility shortages. In addition, some individuals remain in community care facilities when they could be living independently or semi-independently if supports were available. <CA>

Significant barriers exist to recruiting and maintaining residential providers for ICF/DD-H and ICF/DD-N facilities. <CA>

Some residential living arrangements in the community are not stable. A number of community residential programs across the state have closed or are facing closure, funding problems, and management and staffing fluctuations. <CA>

Many private homes and apartments are not physically accessible, so choices are limited to those with ground floor access and/or elevators. In addition, few units have been built or retrofitted to accommodate persons in wheelchairs. <CO>

Placement alternatives for people with autism in other areas of the state are rare or non-existent. <CO>

Affordable housing is not available. Because people with epilepsy are reluctant to identify themselves as being disabled, they do not qualify for housing subsidies. <CO>

At present, many of these children who have especially challenging health care needs are cared for in foster care and institutional settings such as the Regional Centers and hospitals. Although some group homes and other programs which provide residential services have been developed for these children, there remains a great need for more normalizing environments such as individual family homes. <CO>

It appears that many people with severe medical or physical disabilities who do not have cognitive impairments reside in nursing homes because there are not adequate community supports for them. Various initiatives, such as the OBRA nursing home reform, have

concentrated on people with mental illness or mental retardation, but scant attention has been paid to the living situations of other disability groups to date. <CO>

Additional specialized residential services are needed. Many persons with cerebral palsy currently living at home have been on the waiting list maintained by the Division for Developmental Disabilities for many years. <CO>

People already living in skilled nursing facilities will be able to get support from the Department of Mental Health but this support is not available to people who are not presently in nursing facilities. <CT>

It should be noted that most of the accessible units mentioned in this report have only one bedroom. Families in which a parent or child has a disability often cannot use these resources. <CT>

In Connecticut, the ICF/MR program is limited to people with mental retardation. Federal regulations, however, allow for the program to be used with people with "related conditions." Fortunately, Connecticut chose not to include other people. 693 deficiency criteria, plus rules, regulations and procedures, govern ICF/MRs but they do not necessarily overcome deficiencies related to care and caregivers and they do not contribute to community participation. People who live in ICF/MRs have no incentives to work since regulations require most earned income to be turned over to the facility. <CT>

The Department of Mental Health is in the awkward position of having the power to deny admission to skilled nursing facilities to people with mental retardation and other related conditions, but it does not have the statutory authority to provide support to people other than people labeled mentally retarded. Also, the Department will have difficulty when a person wishes to stay in a nursing facility but all assessments indicate nursing facility services are not needed. <CT>

Congregate living, generally, does not foster community participation. Most group homes may look like other homes in the neighborhood. Group homes, however, group together people who may not choose to live together if they had a choice, in a house they don't want or own and, sometimes, in a neighborhood where they aren't wanted. <CT>

Many of the rental or ownership subsidy programs (perhaps all) have a prohibition against unrelated people living together. This is a real problem for people who need a roommate or a live-in personal assistant. There are also income limits on these units which do not recognize the necessity for some people who have live-in assistance in order to live independently. <CT>

Several factors make actual presence and participation difficult: licensing, congregate living, agency ownership, and ICF/MR certification. ICF/MRs are the least preferred

residences. Many are, within themselves, mini-institutions with the bureaucratization of residential care. <CT>

While the housing vision should and must be kept in focus, there are some undeniable, realistic and seemingly unsolvable problems in this area. Housing problems are compounded for persons with developmental disabilities and their families. <DC>

Affordable housing is a major policy issue in both the public and private sectors of this country. For moderate and low income individuals and their families, the availability of decent and affordable rental housing is a problem of great magnitude. Home ownership presents an even greater problem. <DC>

The transfer of Saint Elizabeths Hospital from federal to District of Columbia control came at a point in time when a series of laws, court decrees, and mandates called for broad based deinstitutionalization efforts. Along with deinstitutionalization were other pressures for congregate living, half way houses, intermediate care facilities and group homes for people with mental retardation, with mental illness, juvenile delinquents, the elderly, youth and adult prison populations. This set of conditions, along with the absence of affordable housing and the shortage of available housing stock, all converged to contribute to a number of attendant social problems. Two of the outcomes were an increase in doubled-up housing and in the homeless population in the District of Columbia. <DC>

Although the number of children in foster care has remained relatively constant over the past three years, the complexity of the cases has intensified. The need for more specialized services has increased as well as the need for treatment of foster children with multiple disorders. <DC>

The frequency with which this sample of persons with developmental disabilities moves is indicative of the way the system which provides services to them works. It is also indicative of the barriers which act as impediments to the establishment of permanent, social relationships and contributes to the lack of effective integration into a healthy community. <DC>

Three out of four service providers contended that persons with developmental disabilities have limited access to independent living programs. <DC>

There is a need to maintain an effective quality assurance system to measure quality of care and performance in meeting Medicaid "active treatment" requirements. <DE>

The pace of deinstitutionalization is primarily controlled by the level of funding of new community residential placements. In spite of the progress made to date, Delaware's reliance on institutional services is at 5.4 persons per 10,000 of its total population which

is higher than national average of four persons per 10,000 of a state's total population. <DE>

Institutional costs have increased primarily due to staffing increases necessary to meet Medicaid "active treatment" requirements. Per diem increases at Stockley (state facility) is also a reflection of population decreases in which total fixed costs are spread over a smaller resident population. <DE>

There is a need to attract and retain quality nurses, psychiatrists, and staff at the Delaware State Hospital. There is a need to maintain accreditation, certification, and licensure at the Delaware State Hospital. <DE>

The waiting lists of persons with disabilities/elderly cumulatively show a possible need for 2,333 new "handicapped housing" units. Additional "barriers" to persons with disabilities seeking shelter are elderly persons who currently occupy "handicapped units" or who in lieu of persons with disabilities will take possession of "handicapped units" as soon as they become available. Delaware State Housing Authority (DSHA) waiting lists, for example, show low-income families with children mainly; DSHA places persons with disabilities in accessible units when appropriate. <DE>

Low-income housing has been voiced as a major need in the state. Due primarily to the rising cost of housing, the large percent of substandard housing and the increasing demand for low cost housing, the supply of affordable housing is diminishing rapidly. The need for deinstitutionalization has further increased the problem for special groups. Many special groups, specifically persons with disabilities, have found themselves without adequate community-based housing options. <DE>

An area of concern for persons with disabilities is housing "discrimination" which has appeared in two basic forms. The first form is in terms of architectural accessibility, e.g., lack of ramps, automatic door entrances, elevators, adequately wide doorways. These barriers usually affect those with physical disabilities rather than those with mental disabilities. However, the second form of discrimination which affects persons with developmental disabilities includes zoning ordinances that place conditions on the location of group homes and other residential facilities for persons with handicaps. <DE>

Current legislation requiring a minimum distance of 5,000 feet between group homes is making it increasingly difficult to locate sites for houses, especially in upper New Castle County. Recently passed fair housing legislation by the U.S. Congress makes it questionable that such restrictions in the housing of persons with disabilities are even legal. <DE>

The lack of a sufficient number of "handicapped housing" units within the state coupled with non-handicapped elderly persons occupying "handicapped units" place an increasing burden on person(s) with disabilities who are on waiting lists for adequate housing. <DE>

Medicaid requirements for the provision of an active treatment program for all ICF/MR clients is putting increasing demands on the current staff structure at Stockley [state] Center and in ICF/MR group homes. The current program model (7.5 to 8.0 FTE per home) is especially strained in the group homes as clients now being deinstitutionalized from Stockley have much greater needs than in previous years. <DE>

The 1987 OBRA legislation and the new Delaware Medicaid reimbursement methodology create a more complex and costly administrative environment for facility managers as well as requiring all levels of staff to respond to these changes. <DE>

Encourage and help consumers to make choices about where and with whom they live. <FL>

Advocates and providers reported that consumers are experiencing difficulties in obtaining appropriate housing. <FL>

Adults with developmental disabilities could benefit from the development of adult foster care homes. The Division of Family and Children Services needs support in creating such residential services. <GA>

There is a need to develop an array of residential alternatives, from the individual home to residential care facility with appropriate support services. <GU>

Hawaii spends less for Title IV-E programs than any other state. The state should review its program to determine if there are families in need that are not being reached. <HI>

Programs serving people with disabilities need to develop and/or expand their services to include assisting with finding appropriate housing once the voucher has been obtained. Many are unable to find housing on their own prior to expiration of the voucher. <HI>

The Citizens Helping Administrators Monitor Programs (CHAMP), funded by the State Planning Council on Developmental Disabilities, found that residential service licensure and regulations appear not to have a correlation with quality and standards of care. <HI>

The lack of an adequate system to monitor the quality of residential services increases the opposition to the deinstitutionalization process for people with developmental disabilities. <HI>

Safe, decent and affordable rental housing for people with disabilities in suitable environments is very limited in Hawaii. <HI>

The present Section 8 program in Hawaii is not meeting the needs of people with disabilities. There are long waiting lists, and it is impossible to find rental units that meet the "30 percent of available income" and "fair market value" criteria. Even with the

voucher system, the rental market is too high (40 percent above national average) to be affordable for most people with disabilities. <HI>

Hawaii's use of the HCB waiver program has been limited when compared to other states. Other states of comparable size provide for more people to be served; they provide a richer array of services; and they use the program to move away from the ICF/MR medical model of care and to create new service systems. The decisions to use waiver programs only for Waimano Training School and Hospital residents and the lack of state matching funds has limited the potential of the HCB waiver. <HI>

New findings on cost effectiveness in particular, the individual housing support model, have not been translated into fiscal policies. Alternative approaches to residential living must be pursued that promote independence and integration into the community and consumer choice. <HI>

The lack of available supports and residential alternatives as a result of lack of resources continues to force people with developmental disabilities into inappropriate residential placements. <HI>

In focus groups conducted by the State Planning Council on Developmental Disabilities throughout the state, there was concern expressed about the inability to retain qualified staff in the residential care homes. There is a shortage of qualified people to provide services and the training and supports received are not appropriate or sufficient. This appears to be due to inadequate salaries which result in lack of staff or rapid staff turnover. <HI>

The Medicaid payments to Waimano finance \$125 of the facilities \$191 per diem cost for ICF/MR services, covering only 65 percent of facility costs (Smith, 1989). The gap is growing larger; in 1987, Medicaid payments covered 75 percent of the costs. According to Smith, 1989, this gap stems from the rate determination methodology, adopted several years ago, which establishes a rate by determining allowable costs in a base year and then updating in each succeeding year for the effects of general economic inflation. The rate setting method used does not take into account other factors influencing the per diem costs — the reduction in the facility's size and the costs of bringing the facility into compliance with ICF/MR regulations. The gap is also influenced by Waimano's difficulty in getting Medicaid reimbursement for specific services (physical therapy and similar ancillary services). <HI>

In 1988, Hawaii spent over \$14 million dollars on Waimano Training School and Hospital (WTSH) which had 245 residents and approximately \$10 million on all other community services. These expenditures reflect a Medicaid policy which is unsatisfactory to consumers and advocates because it does not conform to "best practices" of least restrictive alternative. <HI>

Even the Medicaid Home and Community-Based Waiver programs are tied to the "institutional" bias of the Medicaid program because in order to provide reimbursable services, the waiver program must show that the waiver recipients would otherwise require care in a skilled nursing facility or intermediate care facility at a cost equal to or less than the waiver program. <HI>

There is a shortage of appropriate community resources including adult activity programs; community residences (care homes, group homes, supported living); respite care; and case management. <HI>

In a 1987 report on "The Utilization of Medicaid on Behalf of Developmentally Disabled Citizens in Hawaii," Robert Gettings noted that "one of the most divisive issues facing the state at the present time is whether Waimano Training School and Hospital should pay a role in the state's future continuum of residential services for mentally retarded and other people with developmental disabilities, and if so, the nature of that role." This question has yet to be answered. <HI>

Under the Garrity v. Gregg (originally Garrity v. Gallen) class action court order which sought deinstitutionalization for residents of Laconia State School (now Laconia Developmental Services), members of the class have prioritized access to community-based services. In spite of compliance with the spirit and letter of that court order, a second layer of institutionalization for persons with developmental disabilities or with a "dual diagnosis" of developmental disability and mental illness remains unaffected by litigation. <NH>

Only half of the respondents, both consumers and surrogates, report having enough choices about ICF/MR program services, confirming the policy analysis conclusion that the program does not promote independence through the inclusion of language that encourages an individual to exercise control and choice in his or her own life. <IA>

Other forum participants saw the problems with the ICF/MR program as a function of a state policy that maintains a commitment to larger facilities, rather than diverting Medicaid dollars to some of the community-based options available. Some forum participants see this as a state level policy, not one determined by the federal agency. One parent comments, "We have let so much of our Title XIX (Medicaid) dollars go to larger institutions. That's why Iowa has problems in meeting needs at the community level. It's not that Title XIX funds couldn't be used differently. It's that we in Iowa have not opted to move in that direction." <IA>

A major concern of families is the necessity to place family members in Intermediate Care Facilities that are far from home because local options are not available. "Right now, from where I live," says one mother, "Glenwood is the closest and that's three hours away. That's so far that you can't make a weekly visit very easily." <IA>

The Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program currently serves persons identified by Medicaid as "categorically needy." "Medically needy" persons who have income and/or assets somewhat above the levels allowed for "categorically needy" are not served by this program, even though they have high medical expenses. <IA>

Analysis of ICF/MR program policy found that this policy does not promote independence. Only one of the seven areas analyzed is found to promote this outcome. Ratings of the other six areas reflect the need for increasing the policy's promotion of independence through language calling for more consumer choice in the selection of appropriate services, and through the inclusion of independence as an explicitly cited program goal. <IA>

Nor does the language of ICF/MR program policy consistently promote integration. In two areas, the policy inhibits integration: first, by excluding persons categorized as "medically needy" from eligibility for the program, and second, by encouraging the development of a segregated system for service delivery. Also lacking in ICF/MR policy is language calling for participation in the community, as is an explicit reference to integration as a goal of the program. <IA>

For housing, persons living in rural areas often find a very limited range of residential options — or no options at all. <IA>

The residential support system lacks training and educational support services for allowing parents to keep their children at home and ensure quality care by providers in facility living arrangements. Living facilities for people with disabilities are noted for lacking quality staff training programs. Of the people responding to the Idaho Needs Survey 84.2% agreed that living facilities for people with developmental disabilities should have better staff training programs. <ID>

We need to move away from organizational charts with housing units, staff, and coordinators and replace them with a fluid structure driven by individually determined living arrangements. <ID>

Many individuals with disabilities residing in ICFs/MR and shelter homes are not allowed to manage their personal spending money. <ID>

There is a lack of flexibility in designing individual residential placements for people with disabilities. What an individual has is determined by where they live. The Idaho Focus Group suggested this lack of choice in residential planning seriously undermines the building of relationships and sharing experiences with a variety of people. The state of Idaho currently provides minimal assistance to support people who want to live at home or alone. This forces them to participate in the more expensive residential care facilities or expecting families or the individuals themselves to bear the majority of any additional

cost. The residential service delivery system has focused on the delivery of services to people with developmental disabilities from a facility perspective rather than from an individual consumer perspective. <ID>

In Idaho it is estimated that nearly 210 people with developmental disabilities live in nursing homes and 45 of these individuals are in need of a different living arrangement to receive services to meet their needs. <ID>

Idaho has not made as much progress as possible to develop innovative approaches to make available affordable housing options for people with disabilities. For instance, to date little has been done to make use of federal tax credits to encourage development of low income housing. In addition, little has been done to explore private or cooperative ownership of single family homes by people with disabilities. This policy orientation runs counter to the findings of the Idaho Needs Survey, where 88% of the respondents felt there should be more small size living alternatives available to people with developmental disabilities. ID>

The Department of Health and Welfare estimates that \$5,000,000 in additional funds will be required to comply with the new nursing home reform requirements for OBRA for 1990. <ID>

In Idaho, it is estimated that the previous impact of federal "look behind" surveys to Idaho's only institution for individuals with developmental disabilities was approximately \$150,000 in capital improvements with an operating budget increase of \$20 per day per client or \$1,500,000 in additional cost to meet active treatment guidelines in the last two years. The budget for the Idaho State School and Hospital (ISSH) was approximately \$13,200,000 in 1987 and \$15,700,000 in 1988. The projected budget for ISSH in 1990 is \$17,150,00. <ID>

The Medicaid ICF/MR program, by linking services to placements, continues to force placement of individuals in segregated, dependency-fostering living arrangements with a full array of services they may not need. People attending the Public Forum in Pocatello complained that Medicaid reimbursement policies have an institutional bias. Even when the level of care in the ICF/MR program is appropriate, it is extremely difficult to use in promoting independence, productivity and community integration because of its medical model orientation. <ID>

Many parents, especially those who currently have a child placed in the Idaho State School and Hospital, feel that state-operated habilitation centers are the best placement for their child at this time; and given the current level of programmatic and financial commitment for community-based and supported living alternatives in Idaho this perspective has validity. <ID>

Federal resources available in Idaho in FY 1988 used to support housing, modify environments and promote independent living are minimal (\$4.4 million), especially when compared to the \$16 million (approximately 52% federal/48% state funds) being expended on the ICF/MR program. New findings on the cost-effectiveness of non-institutional alternatives, in particular the individual housing support models, have not been translated into fiscal policies for Idahoans with a disability. <ID>

Although ICFs/MR in Idaho are now limited in size to 15 or fewer persons, there are several facilities which are larger that may continue to operate under a "grandfathering" provision of the size limitations. Several 8-person homes have been developed because of the absence of restrictive zoning for eight or fewer persons with mental disability under Idaho Code and local zoning restrictions. <ID>

For some time, the Idaho State School and Hospital has been under scrutiny from the Health Care Financing Administration with regard to a number of repeated standards violations. Paramount among those was the issue raised by HCFA that individuals in the institution were not receiving active treatment as defined and required by Medicaid regulation. Other concerns involved client records, rights and protections, qualifications of staff, restraints and drug usage, facility physical plant, and treatment programs. In August 1989, HCFA withdrew certification and subsequent eligibility for Medicaid funding, a decision that the institution has appealed. The facility continues to operate with federal funding awaiting resolution of the appeals process. <ID>

The state facility census has been lowered by the discharge of individuals into the community, primarily into large congregate care facilities of six to 175 beds. <ID>

In Idaho, a range of residential services is provided to individuals with disabilities, but, for the most part, housing still clings to the continuum concept and means group care, and financial support to individuals is tied to where they reside. <ID>

For many years Idaho has been at the threshold of creating community living arrangements. Idaho has made gains in deinstitutionalization and small community facility development, has restructured some funding mechanisms and has removed some regulatory barriers. However, the state has stopped short of full integration. Because of the lack of a vision which holds persons with a disability living independently as a key priority, Idaho's housing services have been provider driven. The service system is heavily weighted toward staff concerns, facility costs and provider organizations' survival. <ID>

Idaho Focus Group members were concerned about the residential information needs of Idaho communities and parents of people with disabilities. Available services and living circumstances of people with disabilities need to be addressed. We need to have Idaho communities aware and involved in the movement toward integrated lifestyles. <ID>

In the Consumer Satisfaction Survey, two-thirds of the consumers indicated they were satisfied with where they presently lived (11% said they wanted to move to different settings) - 84% of these consumers lived in homes in the community. Illinois ranks 33rd among states in the amount of money (as divided by personal income) it spends on community services. <IL>

The Council finds that, in Illinois, the opportunity has not been extended to Illinois citizens with developmental disabilities to choose to live where they will be as independent, productive, and integrated into their communities as possible. <IL>

The ICF/MR program is perceived to be of diminishing value by most states. Since it does not promote the state-of-the-art in service delivery, projections for ICF/MR capacity in the future are for no growth or declines in the number of ICF/MR participants. Despite that trend, Indiana continues to develop Medicaid-funded group homes at a rapid pace and at rapid increases in expenditures. <IN>

There needs to be a conceptual shift from "residential services" to "supported housing" so every effort is made to allow people to live in their own home rather than being placed in a residential facility. Correspondingly, there is a need to shift resources from institutional and facility-based care to individual and family supports tailored to the needs and wishes of the individual with disabilities. <IN>

According to the Ernst & Whinney study, for the ICF/MR program to be technically appropriate, Indiana needs a Medicaid definition for mental retardation and related developmental disabilities and evaluated against the federal definition. These revised definitions must be included in the client assessment process so that Indiana Department of Mental Health (DMH) and Department of Public Welfare (DPW) staff are able to assess and appropriately place MR/DD clients in ICFs/MR. The "Interdisciplinary Staff Summary" designed by DMH and the medical needs assessment (DPW) should be refined so the comprehensive assessments can be clearly understood, acted upon and implemented. The DMH and DPW should strongly consider incorporating the Indiana Scales of Behavioral Development into the assessment tool to facilitate placement decisions and eliminate duplication of efforts. <IN>

The state of Indiana should consider utilization of non-institutional Medicaid funds for services to eligible MR/DD residents. Non-institutional Medicaid may not be able to be as broadly developed as waived services, but it could be more quickly incorporated into the current system. <IN>

High functioning MR/DD residents who are inappropriately placed and require support services rather than more intensive ICF/MR programs should be identified. <IN>

Training programs must be developed by state or private agencies to properly interpret active treatment and present case examples of how active treatment is delivered.

Training of individual staff in Indiana's ICFs/MR must be done by responsible facility professionals so that staff members will be able to implement the programs and services required for the client in the program plan. <IN>

DMH, DPW and Indiana State Board of Health should work with private ICFs/MR to define a licensure category for private ICFs/MR. This category should be sensitive to the medical needs of the residents but also should foster the development of programs and services consistent with the concepts of active treatment, normalization of living space, and the least restrictive, most development-enhancing environmental possible for clients. <IN>

The state of Indiana should implement the group home category, Basic Developmental. This category would serve MR/DD residents whose intellectual deficits are severe and profound. MR/DD clients currently residing in state facilities could be appropriately placed in these ICFs/MR. <IN>

Indiana has no plans for the systematic and timely establishment of semi-independent and alternative family living arrangements. No provisions are being made for likely strong demand for these residential alternatives. In 1987 the Semi Independent Living Program (SILP) and Alternative Family for Adults (AFA) lost their funding autonomy and, in light of the demand for the development of Supervised Group Living (SGLs) for nursing home residents, no additional funds have been allocated to meet the growing demand. While these programs are not "enhanced" group homes, they do appear to justify funding and reimbursement considerations similar to that of the SGL program. <IN>

The impact of the new ICF/MR standards and the implementation of P.L. 100-203, requiring relocation of several thousand people with developmental disabilities currently inappropriately housed in nursing homes, is unknown. The General Assembly will need to allocate new or redistribute present funds for the active treatment needs of persons with developmental disabilities who are eligible and choose to remain in nursing homes, and expand/improve supportive housing alternatives to match needed community service development. <IN>

According to estimates on the number of supervised living arrangements needed in the state, Indiana is currently providing only one-third the needed capacity. In terms of total non-state residential capacity, Indiana lags behind the nation and the region; in terms of small, non-state facilities, Indiana is at 95 percent of the nations rate and is 18 percent above the combined rate of states surrounding Indiana. <IN>

Nearly 42 percent of Indiana's Medicaid expenditures went for care of person in nursing homes (SNF or ICF level), a share nearly twice as high as neighboring states. Indiana spent about 62 percent of all Medicaid funds of inpatient services in hospitals and nursing homes (non-ICF/MR), compared with about 49 percent in area states. On the other hand, Indiana spent a very meager amount for less restrictive alternative services, such as Home

and Community-Based Services. The state spent 0.6 percent of Medicaid funds on home health care, but only \$25,000 on Home and Community-Based waived services. <IN>

Children with physical or mental disabilities are more likely to enter institutions, hospitals or nursing homes, or group homes and less likely to be placed in foster homes or the home of a relative than children without disabilities. <IN>

There appeared to be a large backlog of children with disabilities awaiting disposition in substitute care placement at the end of fiscal year 1989. <IN>

For children with disabilities who cannot live with their biological parents, a comprehensive permanency planning is lacking. <KS>

There is a lack of funding for start-up and maintenance of alternative residential programs for children, the elderly population, or people with dual diagnosis or challenging behaviors. <KS>

During the public meetings many parents and other family members with children and relatives living in state institutions strongly supported the system as it exists. <KS>

There is a lack of systematic planning for continued downsizing of institutions. Some people may be inappropriately placed in programs that are more restrictive than needed. <KS>

People choosing to live at home may not have services comparable to those in residential programs. <KS>

Independent living services are not available in all Kansas counties. <KS>

Concern about stability of funding for community-based programs is strong. Funding should be permanent, not year-to-year. <KS>

Over 550 people are on waiting lists for residential programs. <KS>

People with developmental disabilities are often not actively involved in choosing where they live. <KS>

No accurate information is available on how many of the population with developmental disabilities may be in nursing homes throughout the state. <KS>

Despite the substantial increase in community residential facilities, Louisiana still has the highest rate in the country of persons living in large facilities funded through the ICF/MR program. <LA>

Over 24% of the population of state residential facilities in Louisiana are children under the age of 22. This is the 6th highest percentage in the nation. <LA>

Louisiana continues to expand the ICF/MR program by using it as the sole funding source for community homes. <LA>

The Louisiana Department of Health and Hospitals estimates that it will cost approximately \$8,000,000 to implement the nursing home reform requirements. <LA>

Due to the present budget crisis the Department of Public Welfare has begun tightening Emergency Assistance benefits, thereby belying its stated purpose to keep people in their current apartments and avoid homelessness. With no increase in cash benefits, decreased availability of Emergency Assistance, fewer housing subsidies at EOCD and reductions in fuel assistance, there will be even more need for shelters for increasing numbers of homeless people and families. The FY 1990 Homeless account will not cover any new shelters. <MA>

According to the Coalition for the Homeless, between 18,000 and 23,000 people are homeless in Massachusetts during the course of the year. Seventy-five percent of the homeless are families. Ninety percent of these homeless families are on welfare with a single mother and two children. Twenty-five percent of the homeless are individuals (6,000 people). Forty percent of these 6,000 homeless individuals have substance abuse or mental illness problems. <MA>

The lack of available supports and residential alternatives continues to force people with developmental disabilities into inappropriate, expensive, and unnecessary residential placements. The most common "placements" are in private schools, nursing homes, and large public institutions such as DMR state schools or DMH psychiatric hospitals. Most states, including Massachusetts, have extensive waiting lists for homes in the community. <MA>

There is a comparable level of ignorance about the proven ability of people with severe disabilities, people who are technology-dependent, and people with challenging behaviors to live in homes in the community and to be integrated with people who are not similarly disabled. <MA>

There is widespread ignorance among communities and policymakers of the overwhelming evidence that people who live in the community make greater gains in independence, productivity and integration than their counterparts in the institution. Studies of over 1,200 people with developmental disabilities who moved from large state institutions to community residences found significant gains in daily living skills. None of these studies showed that people with developmental disabilities living in institutions did as well in developing skills as their peers living in the community. <MA>

The rapid growth in homelessness throughout the 1980s has affected many people with disabilities and their families. They are especially vulnerable because of their low income status and, in some cases, because of discrimination and other factors associated with the disability itself. <MA>

People with mental retardation living in DMH psychiatric hospitals but not meeting commitment standards. This population was identified at the time of the DMH split; approximately 200 remain. <MA>

Adults in nursing homes who do not need nursing-home levels of care. <MA>

Students in private residential schools, at tuitions paid by local communities and the state (sometimes in excess of \$100,000/year) who could be home and attending the local school if the same dollars were available to family and school in the youngster's own community. <MA>

Adults with developmental disabilities not involving mental illness or mental retardation, now living in nursing homes, should under federal law be offered community living opportunities or active treatment while staying in the nursing home. No state agency has been mandated or has otherwise taken responsibility to plan for this group, and oversee new services for them. <MA>

Persons over age 22 still live in pediatric nursing homes. OFC first learned of this issue in 1979, when 2 persons became "over-age"; there are now over 50 adults using a service designed for children and teens. <MA>

Massachusetts continues to spend disproportionately and heavily in institutions because: (1) the federal Medicaid program has an institutional bias which makes 50% reimbursements automatic for institutional expenditures (while many community services are not reimbursable at all or are offered only as limited options); and (2) the mental retardation consent decrees contain facility-related provisions that have been prioritized over other requirements that clients receive services in the least restrictive settings to meet their needs. <MA>

Overall, the Department of Mental Retardation (DMR) "system" needs to have the resources to implement close to 17,000 individual service plans (ISPs), and to accommodate those persons on waiting lists as well. ISPs for significant majorities of persons still living in the large institutions call for community services. Thus the challenge for DMR is to move resources with clients into a well-supported community system, while continuing to phase-down and close large facilities, while ensuring that no present client loses any needed services. Much more planning and "political will" is needed to accomplish this. <MA>

The Federal Fair Housing Act has been passed, but in order for it to be effective people with disabilities, the public, and the real estate community must learn of its existence and implications. No efforts have been made by this state to create a public information campaign to accomplish this task. <MA>

For most, housing is neither available, affordable, or accessible. One participant has been waiting nine years for a subsidized, accessible apartment. <MD>

A variety of appropriate community residential options and home improvement (allowing people to stay in their own homes) supports face long waiting lists or lack of funding for development. <ME>

Public policy and funding continues to favor institutional placements as against community alternatives. This is particularly true for children with emotional disturbance. <ME>

Because of Michigan's long history of deinstitutionalization, many adults with disabilities who never lived in institutions are now living with parents who are growing older. Michigan continues to place funding priority on moving people out of institutions. Adults who have never lived in institutions have a disadvantage in finding affordable, accessible housing, with the support they need in their home communities. <MI>

People with developmental disabilities want to live more independently and make choices about where they live and who will live with them. The wishes, preferences, and plans of people with developmental disabilities are too often considered peripheral to services planning, delivery, and monitoring. <MI>

People with disabilities face attitudinal, financial, and physical barriers to living where they choose. <MI>

Affordable housing is a critical problem for most low income people, including many people with disabilities. Decent and affordable living arrangements are scarce and in high demand. <MI>

Federal resources that can be used to support housing, modify environments, and promote independent living are minimal. The limited support is especially striking compared to the amount spent on the Medicaid Intermediate Care Facilities/Mental Retardation (ICF/MR) program, which funds institutional options. <MI>

Michigan has developed a wide array of community services options. Complex waiver applications, creative use of ICF/MR, and other creative approaches to using Medicaid have contributed. However, some critical community services are not reimbursable through ICF/MR or any other Medicaid program. In addition, use of demonstration waiver programs is potentially unstable, since waivers must be sought and approved, and individual waivers are time-limited. <MI>

Nationally, the costs of Medicaid ICF/MR are rising (73% over a 12-year period). The program is difficult to use for supporting community services. <MI>

Some people who need community living find that this kind of residential service is impossible for them to get, or that the wait is unreasonably long. <MI>

People with disabilities and their families report that there is much more demand for the housing and supports they need than there are funds available or flexible policy to accommodate. According to a 1989 Department of Mental Health survey of community mental health service needs, almost 1,600 people with developmental disabilities are on waiting lists for residential services. The same survey identified over 1,400 people with unmet residential needs who are not even on official waiting lists. The largest category, with 660 people, was of those who need semi-independent living arrangements. <MI>

Programs that focus on independence usually have inadequate resources. Disincentives presented by more traditional programs often block participation in more independence-oriented programs. Medicaid reimbursement policies have an institutional bias, yet this is nearly the only funding option for housing for people with developmental disabilities. <MI>

Multiple and overlapping monitoring and accountability responsibilities add confusion for families, providers, and the community; agencies need to articulate more clearly the checks and balances needed to assure safety, reduce risks, and prevent exploitation; the standards used for monitoring still stem from a medical model and focus on nursing care. They need to be revised to promote the integration, independence, and productivity of people who have disabilities. <MI>

Too many people with severe disabilities live in nursing homes. This is especially true for people with mental retardation. Michigan still has 500 people living in specialized nursing homes for people with mental retardation. State agencies and advocates agree that these people are not receiving appropriate services. However, plans to move them into community settings seem to advance very slowly. <MI>

Concerns about licensed Adult Foster Care (AFC) and board and care homes persist in Michigan, even with Michigan's Adult Foster Care Licensing Act (P.A. 218 of 1979, as amended.) The Michigan Department of Social Services (DSS) reported, in its budget presentation to the Michigan Developmental Disabilities Council (1989), that they performed the required licensing and monitoring inspections much less often than the Administrative Rules require because complaint investigations have a higher priority. DDS reported that they would need at least 15 additional field staff to bring the frequency of monitoring and inspection visits up to standard and to provide technical assistance to providers in meeting those standards. This would be a 25% increase in field staff capacity. <MI>

Best practice and state leadership favor community integration, but this is not yet generally accepted in all communities. We need to shift people's thinking to supports for independent living or supported housing, and away from residential services. <MI>

Although Permanency Planning Grants to Counties are intended to assure that children live with families that offer a safe, permanent relationship with nurturing parents or caretakers, there are indications that children with disabilities are placed out of the home for extended periods with no plan to return home. By far the largest number of children in long term substitute care are children with mental retardation. Over 87 percent of the children with disabilities have been in substitute and adoptive care for more than three years. <MN>

The deinstitutionalization trend in Missouri has not kept pace with the national trend. However, economic reality, and the continued empirical evidence coming forth that all people with developmental disabilities are able to receive needed support services in typical community-based living situations, will seriously challenge Missouri to follow the national trend of deinstitutionalization. <MO>

If the state of Missouri chooses to follow the national deinstitutionalization trends it will need to address the concerns of parents with family members in habilitation centers by assuring an extensive array of support services for community-based living, and by providing these parents with information that demonstrates that community-based living does increase the quality of life for people with developmental disabilities. <MO>

The Medicaid ICF/MR program through its linking of services to placements continues to encourage the placement of individuals in segregated, dependency-fostering living arrangements with a full array of support services they may not need. The HCBS Waiver currently being administered in the states requires an individual to either first be placed in a residential care setting, or to be at risk of being placed in a habilitation center. <MO>

In addition to addressing the concerns of parents, the state will also have to address the concerns of habilitation center employees, and the real economic concerns of those communities where the habilitation centers are located. However, careful consideration needs to be given that these economic concerns do not take precedence over quality of life considerations for people with developmental disabilities. <MO>

Review of the individuals with developmental disabilities residing in nursing homes required by the federal Omnibus Budget Reconciliation Act may present a challenge for Missouri as it has to address finding placement alternatives for those individuals determined to be inappropriately placed. One of the major challenges will be for the state to resist placing those individuals in state-operated habilitation centers. <MO>

Innovative housing approaches remain primarily unexplored. One recent approach in Missouri made use of HUD Section 8 dollars to subsidize apartment rent and obtained foundation dollars to provide independent living supports. Currently, there is no mechanism at the state level which encourages and supports the exploration of these types of innovative housing alternatives. <MO>

Because of increasing residential demands, escalating housing costs, increased understanding of the value of integrated, experiential learning opportunities, and more involvement from consumers and parents, Missouri, as all states, will find itself challenged to come up with innovative ways to address the residential needs of people with developmental disabilities in the 1990s. <MO>

Very little assistance exists to support individuals with developmental disabilities who desire to live at home or alone thus either forcing them to participate in the more expensive residential care facilities or expecting families or the individuals themselves to bear the majority of any additional cost. The above situation basically exist because many services are provided from a facility perspective rather than from the individual consumer perspective; and are provided from a categorical perspective (i.e. mental retardation) rather than the federal functional definition of developmental disabilities. <MO>

Community resistance to people with a severe disability residing in the community will continue as long as people with disabilities are placed in facilities, large or small, rather than in homes. <MO>

Many families continue to have to make the difficult decision to place their child with a severe disability in segregated, restricted environments because they are unable to receive the level of support needed to maintain the person at home or are unable to find viable community-based alternatives. <MO>

Research is needed that looks at comfort in community living, ranging from lighting, temperature and furnishings to positioning of people with severe physical impairments; from general aesthetics to the inclusion of personal preferences and privacy into the concept of a home's "comfort." <MO>

There is limited information about the housing needs of people with developmental disabilities in Mississippi. Such individuals are a diverse group, and the physical adaptations that help one type of disability are of no use to others. <MS>

The waiver-funded services have enabled the state to avoid, to some extent, spending substantial amounts of money to bring the institutions into compliance with Medicaid standards, while promoting development of community-based services for formerly institutionalized persons as well as those at risk of institutional placement. However, the avoidance has, as a result, created serious turmoil centered in this period of growth of

community services. This failing is predominantly an effect of the expense in operating two separate residential system: institutional and community-based. <MT>

Lack of sufficient community-based intensive residential services. All existing intensive group homes and intensive day services are full. Turnover is rare. Waiting lists are long and growing. People who need intensive services are being placed in the congregate care facilities simply because there are no vacancies in community-based intensive services. Nearly half the clients served in the two congregate care facilities could benefit if intensive services are increased. <MT>

Direct care staff in community-based programs are young, poorly paid, experience a high turnover rate and often lack and skills needed to provide appropriate habilitation services to individuals they serve. <MT>

Currently, the state faces the potential loss of \$7 million in federal Medicaid funds for the Montana Developmental Center due to insufficient active treatment services. <MT>

Lack of appropriate services for persons with developmental disabilities residing in nursing homes. <MT>

State of Montana Department of Family Services staff license the approximately 90 group homes throughout the state as a small part of their overall licensing responsibilities. The limitations on staff allow them to make only one announced visit per year to each home. Current resources for this function are inadequate, thus providing insufficient time for visits to homes and the lack of possibilities for unannounced visits to assure continued compliance. <MT>

Changing the focus of public funds (primarily Title XIX Medicaid Intermediate Care Facilities for the Mentally Retarded funds) from facilities to individuals is a necessary step to enable individuals to live in places of their own choosing, rather than those dictated by "where the money is." <NC>

Waiting lists of persons with mental retardation for community-based residential services existed prior to the expansion of the eligible population in 1987. There are now many more people waiting to get into a community-based residential setting. <NC>

The housing needs of persons with developmental disabilities who do not have mental retardation remains a significant problem in our state. For those with physical limitations, accessibility is a major problem in many areas of Nebraska. If persons need supervision or assistance beyond that of a personal care attendant, then major placement issues arise. Nebraska is hesitant to invest in major "brick and mortar" projects to build such residential programs for persons with developmental disabilities other than mental retardation. <NE>

A recent review of the foster care system in Nebraska found the 26% of the 3,134 children in out of home care were identified by their social service workers as having a handicapping condition. Of the total number of children, 1,985 are in family care and 19% of these are identified with handicapping conditions. Although not all of these children have a developmental disability, they do remain a significant issue for the foster care system. In addition, there is no transitional system in place for state wards with high needs who are in the foster care system when they become adults. The rate of reimbursement for caring for a high needs individual may drop as much as 700 percent on their 19th birthday when they move into the regular adult service system. Such a drastic change may make continued care by the same foster family unlikely. <NE>

Currently, the residential services are offered through a variety of vendors, both public and private. There is no current coordination between vendors as to who receives the service or why the service is received for a particular child. Each placement and financing is determined by the agency at organization. Interagency coordination and decision-making is currently being discussed but no resolution has occurred. <NE>

Nebraska has not yet defined who within its state and publicly operated agencies is responsible for determining when a child is eligible for an out of home residential placement and who will be responsible financially. In some instances the courts have directed placements. <NE>

Medicaid funding does not extend past the tenth day of absence from a certified residence. Because residences typically have no way to make up this loss of funding, consumers fear that extended hospitalization may result in the loss of their home, and are routinely barred from taking what for other adults is a customary and well-deserved two-week vacation each year. <NH>

Some families find the stresses of caring for a child with a severe disability to be extraordinarily great and these families require a great deal of assistance, including in some cases an alternative residence for the child. Under the current Interagency Agreement between the Department of Education and the Department of Health and Human Services, Education is responsible for educational services, including residential schooling when appropriate, for children between ages 3 and 21. Health and Human Services is responsible for non-educational children's services to substitute for family care when the need for such services results solely from the inability of the family to provide a place to live. But with two exceptions these services are subject to the availability of funding, while educational services are guaranteed under federal law. <NH>

In cases where a child is declared in need of supervision (CHINS) or a child's parents are declared neglectful or abusive, the Division for Children and Youth Services within Health and Human Services is required to assist the child. An accusation of delinquency, neglect or abuse, with the resulting emotional trauma to a family and loss of parental rights, is not an appropriate mechanism for initiating disability-related services. Parents who find

that the services available to them do not meet their support needs may attempt to force the school district to provide a residential school placement for their child. <NH>

People with developmental disabilities continue to be admitted to the Glencliff Home for the Elderly. The Division's statement that "all of these people are in need of a more structured and medically-oriented living environment" is belied by its demonstrated ability to develop an impressive array of home-like residences and individualized services for people with all levels of disability under the court order. <NH>

The overwhelming preference of people with special needs is for regular, integrated housing, with the predominant preference being for home ownership and flexible support services. Individualized Service Options (ISOs) are an important tool in this regard, since they tie residential support funding to a person rather than to a facility. But a lack of choice and control on the part of consumers remains a serious problem, one that will not necessarily be resolved by a simple expansion of ISOs. <NH>

A sample of ten local fire and safety inspectors were surveyed by the Council. While all use the same Life Safety Code standards, one uses the 1976 version, 6 use the 1981 version, one uses the 1985 version and 2 use the 1988 version. These respondents reported a bewildering array of different requirements. Eight towns reported requiring that exit doors swing out. Two require sprinkler systems; one requires an alarm system connected to the fire department. None required self-closing metal fire doors. Several local Fire Marshals appeared to be unaware of the difference between a family residence and a large group home. For example, one individual claimed that the state required hard-wired smoke detectors for any home to be certified. Clearly, fire and safety standards are necessary and some accommodation costs are justifiable. But it is equally important to insure that the availability of family placement is not being needlessly restricted at the local level. <NH>

Some individuals who have become or have considered becoming family care providers have experienced difficulties obtaining the necessary local fire and safety approval. The Division of Mental Health and Developmental Services does not require that such residences be licensed but does require that they be certified. Certification requires a local inspection and assurances that the premises meet local codes. In some cases, inspection procedures and standards have been experienced as arbitrary and counterproductive. As one prospective provider put it, "depending on what mood the Fire Marshal is in when they inspect, you either rebuild your house or you don't." Counterproductive requirements have included installation of insulated metal self-closing fire doors in a bedroom which prevented the smoke alert in the hall from being heard in the room. <NH>

At some point most adults choose to leave their parents' residence. Although continuing residence in the home of a parent or other close relative should be an available option, one that is supported through respite care and family support services, many parents feel

obligated to provide for their adult children at home not out of choice but due to a lack of available options. <NH>

Residential school placements remove children from the learning opportunities available in their home schools and home communities, and often remove children from close contact with their families. In addition, such placements are extraordinarily expensive. The 20 most expensive placements, taken together, cost \$1,500,000. And the adversarial proceedings involved in obtaining a residential placement create animosity between parents and school administrators and school boards. These proceedings themselves are also inordinately costly for schools in time and money. One Special Education Director estimates that she spends 30% of her time on court-related matters, while others spend virtually no time at all on these matters. <NH>

Service agencies have found that HUD's barebones policy of minimal standards for reimbursement coupled with the high housing, land and construction costs in New Jersey has necessitated them to add significant amounts of money to their projects in order to make them livable or rentable. There is also the problem of HUD's requirement that the agency guarantee the operating expenses before approving a project. The Division of Developmental Disabilities is the only agency that has provided operating expenses for these projects. Because of HUD's low funding levels, agencies have trouble meeting HUD's standards which must be met before operating expenses are committed. There is also the issue of the lack of expansion money in the DDD budget to provide those operating expenses. <NJ>

As New Jersey enters the 1990s the Division of Developmental Disabilities faces a waiting list of community residential programs of 2,100 persons that is reportedly growing at a rate of one person per day. This does not even take into account the estimated 1,500 individuals residing in developmental centers who have been identified as in need of less restrictive community housing or the estimated 500 individuals who have been identified as inappropriately placed in nursing homes. <NJ>

Despite the fact that ICF/MR reimbursement rates per resident in New Jersey's developmental centers has almost tripled over the past ten years, there continues to be problems in maintaining ICF/MR certification in many of the centers. The emphasis continues to be on "plans of correction" rather than on plans of depopulation with dollars being expended in crisis situations to bail a facility out of impending decertification. If resources are increased to expand/improve institutions rather than to use the HCB waiver and other supported housing alternatives, it will significantly erode further the availability of resources for community services development. <NJ>

There is a need for all state departments and provider agencies, consumers and advocates in New Jersey to look to more creative, more diversified methods of financing for housing alternatives. <NJ>

How New Jersey will approach the licensing of apartments and homes for people who are not in need of continuous monitoring (e.g. 24-hour staffing) and who are capable of self-direction is an issue of concern. <NJ>

The Division of Developmental Disabilities is mandated to serve individuals with all types of developmental disabilities. Individuals are often discouraged from applying, because services are not available. This is especially true when the service being sought is housing. Individuals have the right to apply for services and be determined eligible or not eligible regardless of whether or not the service is available. Only then will the Division be able to determine what is needed and how they can plan for those needs. <NJ>

There is not one "housing focused" agency in New Jersey that addresses all regulatory concerns. What results is that there are different standards for different types of providers as well as for different types of developmental disabilities. The range is from extensive review of everything from clinical care to financial feasibility, such as group homes for people with mental retardation, to absolutely no licensing or review standards whatsoever as with proprietary driven programs who operate group homes for individuals with head injuries. <NJ>

Upon attempting to collect data and information regarding future goals and direction, it became clear that there is an overriding need to develop a comprehensive plan to address housing issues in New Jersey. The Division of Developmental Disabilities estimates of need are driven primarily by an examination of the current and projected needs of people who have already been declared eligible for services. The Division has not attempted to systematically identify all those who are at present in need of housing or those who will need housing at any given time in the future. What results is a planning process that appears to be premised on expanding what is currently provided rather than on an examination of what needs to be done now and in the future. <NJ>

Interagency/interdepartmental planning on housing must take place to ensure the appropriate and effective response to need. Although the Division of Developmental Disabilities should be the "lead" agency in developing a plan for housing, without the inclusion of the various other agencies and departments involved, the plan would not fully address the various issues. Without a plan in place, decisions and projections cannot be made about the magnitude of the needs and the amounts of dollars necessary to address these needs, both now and in the future. <NJ>

The plan for housing must address the current waiting list "crisis" in New Jersey and take into account all individuals on every kind of waiting list for housing. This should include people on the community waiting list, the waiting list of individuals inappropriately placed in developmental centers, and individuals who are currently residing in psychiatric hospitals awaiting placement in DD funded community residential programs. Each waiting list cannot be considered independently, but must be prioritized based on need rather than on what is available and convenient. <NJ>

It has been determined by the Budget and Conscience Committee of the NJ Consortium on Disability, in its analysis and the FY 1990 Budget, that it will be impossible to provide the same residential services for the same number of individuals in 1990 as in 1988. The budget does not even take expansion into consideration. <NJ>

Almost all applicants (adults) in the pilot group were seeking alternative living arrangements. These applicants have had to compete with people being placed in the community from developmental centers and with people with mental retardation or autism who were already waitlisted in 1985 as well as those who have applied since. <NJ>

Providers assert state reimbursement rates are less than the costs of providing services and as a result programs are unable to meet the needs of residents with more severe disabilities, even if vacancies existed. <NM>

The shortage of available placements and supports continues to force people into programs which are more restrictive and expensive than is necessary. One hundred seventy two people are on waiting lists for community residential placements. <NM>

Architects, developers, builders, landlords, professionals and the public in general should be educated to move persons with disabilities to the least restrictive residential settings. <NV>

Because insurance carriers and landlords are not aware of the abilities of people with disabilities and of emerging technology, they are inhibiting access to equal housing opportunities. <NV>

Participants with severe disabilities believe there is a need to review current funding patterns for institutional care with an eye toward moving those dollars into community based care and service. <NV>

Community based residential care is particularly lacking for persons with severe disabilities and especially for the population with head injuries. <NV>

Lack of involvement of consumers with disabilities in planning appropriate housing. <NV>

Lack of knowledge by architects, builders, landlords and housing officials in housing issues of the people with severe disabilities. <NV>

Lack of leadership, networking by resource agencies and a formal planning mechanism or body. <NV>

Funding for residential services for children outside the natural home is inadequate and does not "follow" the child, i.e., dollars are allocated to service facilities rather than being available to pay for needed services wherever the child lives. <OH>

Many children with developmental disabilities do not have their "own" family or home - they remain in foster care for months or even years. Over the years children are often shuffled between many different residential facilities and foster families. Services are often determined by the needs of the system, rather than the needs of the child and family. <OH>

Most current out-of-home housing options sponsored by the MR/DD service system are facility-based and usually require people with developmental disabilities to live with relatively large numbers of co-residents, in settings that are owned or controlled by the service provider. <OH>

It is difficult for individuals to make choices about their living arrangements when options are limited or they do not have the experience and knowledge to select the option appropriate for their needs. Far too often vacancies in existing residential facilities dictate where the person will live. Simply put, most of the time people with developmental disabilities are expected to "fit" housing and program options that already exist or are being designed for a specific "type" of person. It is, therefore, not surprising that a lack of individualization is the major weakness in the existing system. <OH>

Housing and support services have traditionally been "linked" so that people have to live in specific "treatment" or service settings to access specialized services. For example, at present, when people with disabilities are seen as needing more intensive support or supervision they usually have to move to larger, more depersonalized settings to access these services. Intensive supports and specialized services are not usually available in housing arrangements that are typical of the greater community (apartments and homes), so people with disabilities who need intensive supports are usually forced to live in service facilities owned and controlled by other people. <OH>

Support services to assist adults to live in typical housing options are very limited. The budget for the Ohio Department of MR/DD's Supported Living Program, which can be used flexibly to support highly individualized options, makes up less than 5% of the Department's total residential services budget. The Personal Care Assistance Program funded through Ohio Rehabilitation Services Commission, which provides in-home attendant support, is cumbersome to use and often has a waiting list. <OH>

Current housing stock and building codes do not require that typical residential housing be accessible to persons with physical disabilities, which severely limits where persons with physical disabilities can live. In addition, the eligibility criteria for home modification programs are strict and funding mechanisms are very limited. The lack of readily available, accessible housing presents a major barrier to living in a typical residential setting for persons with substantial physical disabilities. <OH>

Few adults with substantial disabilities own or lease their own residence, and if they live in a residential facility they usually have little choice over whom they live with. In fact,

home ownership by a person with a disability may jeopardize eligibility for other essential benefits and services, creating a disincentive to the achievement of home ownership, which is clearly an aspiration shared by most Americans. <OH>

In 1987, the average size of a residential facility licensed or funded by ODMR/DD was 10 persons. This compares to a national average of 7.5 persons. <OH>

In November of 1989 ODMR/DD reported that there were more than 7,000 people on the waiting list for out-of-home residential services. Their report also indicated that there were at least 220 people who have been inappropriately placed in nursing homes and must be moved to other settings. <OH>

While there have been promising developments such as the Family Consortium and Supported Living Programs and the new Medicaid waiver initiatives, in 1989 almost all of the funds spent in the residential services area went to support facility-based services, such as group homes, Intermediate Care Facilities, etc., while only a small percentage of funds were allocated to provide individualized supports for persons to be able to live in the kinds of housing options available to people without disabilities. <OH>

It is important to note that (1) these waiting list figures are generally considered to be a conservative estimate of the need and (2) that they reflect primarily the needs of people with mental retardation. Many people with developmental disabilities other than mental retardation, such as severe head injury or spina bifida, are also desperately waiting for residential services. Their numbers have not yet even been counted. <OH>

Another barrier to the integration of people with disabilities is our continuum approach to service delivery. Ohio's current residential system is based on the notion that a continuum of residential settings, ranging from large to small, segregated to integrated, more restrictive to less restrictive, etc., is necessary to meet the needs of all the people with developmental disabilities. The presumption is that as people's skills improve they can move up the continuum towards independence. The primary role of the large segregated programs is to get people "ready" to move, and to prepare them for the next step in the continuum. The fact is that not very many people actually move up the continuum. We have also come to understand that people do not have to be ready to live in integrated settings, rather it is the settings that have to be "ready" to support the people. Rather than enduring the dislocations and confusion of moving from place to place, we now understand that it is possible to support people in typical living situations by providing a comprehensive array of supportive services. <OH>

Many of the services provided in Oklahoma are only available to persons with mental retardation, and this is especially true of residential programs. For persons having physical or emotional disabilities, there are no public residential options for them nor services provided under the Title XIX Home and Community Based Waiver, which could provide residential alternatives to them. Persons with cerebral palsy or autism who have

an IQ of 70 higher, or individuals who have epilepsy, for example, remain unserved in this state. <OK>

In the past two years, due to the Homeward Bound vs. The Hissom Memorial Center court decision, residential issues for persons with mental retardation have produced an environment of high emotion and polarization in the state between groups favoring institutionalization versus those favoring community residential placement. It would be irresponsible of this report not to acknowledge that there are diverse viewpoints on this issue. <OK>

Data show that there is a need to increase semi-independent, companion living and shared living opportunities and supported living programs for all levels of disabilities. These programs would use federal Medicaid dollars as the primary funding source. To accomplish this agenda, the state will need to attract private industry to participate as a provider for residential services utilizing Housing and Urban Renewal (HUD) Section 202 (Direct Loan and Rental Assistance) and other government and private financing approaches to make this a reality. <OK>

Although Oklahoma is moving toward increased community residential alternatives for persons with mental retardation, at the present time it has too few small residential options for people with severe mental handicaps or with multiple handicaps. Nearly 80% of those served by the present community programs are people with mild or moderate mental handicaps. <OK>

It is not possible at this time to cite Oklahoma data on the benefits or deficits of institutional versus non-institutional placement of individuals with developmental disabilities. However, national data show marked changes in the last 20 years from institutional to community placement and to an individualized approach to service delivery. The results of persons living in the community as opposed to living in an institution have demonstrated beneficial and appropriate outcomes nationwide. <OK>

The perceived relationship between funding for the Fairview Training Center and expended community services went further for a substantial number of respondents. These individuals questioned the level of support for Fairview itself (including "treatment" funding and wages of Fairview workers) as a disproportionate drain on the limited funds available to support more humane and effective community services. After all, went this argument, 90% of the people labelled developmentally disabled live in the community, not in Fairview, and many of them have just as intensive needs. <OR>

At a time when the state is trying to encourage community acceptance for people with developmental disabilities, it is planting the seeds of division and antagonism within that very group by the higher funding supports available to the Fairview Training Center's Community Integration Project clients. <OR>

Community based residential services tend to promote agency ownership of the house which in turn makes all housing costs (e.g., building maintenance, grounds upkeep, construction, and renovation) the responsibility of the provider agency. <PA>

Perhaps the foremost need of persons with disabilities is barrier-free housing. <PA>

The attachment of staffing and programming to the community group home diminishes the personal and proprietary sense that most people have about their home. <PA>

Community group homes limit the opportunity for individuals to express their preferences regarding where and with whom they want to live. <PA>

Home adaptations, crucial to the independent and community-based functioning of persons with disabilities is a largely unmet need in the Commonwealth. <PA>

Some claim that underfunding, high staff turnover rates and long waiting lists for services are bringing this system to the edge of collapse. Many individuals are still residing in institutions and adults living with their families are unable to get community-based services. It is clear that unless fiscal and other resources are brought to bear, these initial accomplishments of OMR may be lost. <PA>

There may be many persons and lending institutions who can be persuaded to invest in low-income housing projects that would feel disinclined to invest in housing that entails ownership by a service provider. <PA>

Lack of availability and accessibility are barriers. Low cost housing options for people with disabilities are scarce. <SC>

Long waiting lists for residential services for persons with developmental disabilities are a concern of professionals and consumers. <SC>

Laws governing licensure and programs for monitoring are areas requiring renewed focus, if improvement in the residential care facilities system is to be realized. <SC>

Lack of accessible transportation and attendant care is a barrier for many persons who wish to live independently. <SC>

A system is needed for tracking and reporting the number of placements and dollars spent for persons with developmental disabilities in the foster care and adoptive services programs. <SC>

Medicaid reimbursement has traditionally had an institutional bias: the state must access complex waiver programs to provide community services or make group homes into ICFs/MR which require active treatment. <SC>

Reviews of the needs of people in nursing homes, required by the federal Omnibus Budget Reconciliation Act, are placing added demands on the residential capabilities of DMR and DMH. <SC>

For people with challenging behaviors there are few residential services. <SC>

Section 8 (rental assistance) is underfunded. <SC>

The process of reaccessing Section 202 is complex, discouraging use. <SC>

Section 202 - Housing for Handicapped People is a section under HUD providing facilitation of mechanisms for housing alternatives and supports for persons with physical disabilities, individuals with chronic mental illness and for persons with developmental disabilities, yet HUD is reluctant in expediting initiatives utilizing this section. <SC>

South Dakota has clearly made substantial progress in reducing its reliance on the use of large institutional settings as a primary resource for persons with developmental disabilities. At the same time, however, concerns were expressed regarding the continuing pressure to admit such persons to Redfield and Custer State Hospital. <SD>

Recent policy changes regarding continued stay at the Crippled Children's Hospital and School have resulted in increased referrals to Redfield State Hospital and School. Specifically, if a child "plateaus" in terms of developmental progress, CCHS policies now call for discharging the child. <SD>

The Redfield and Custer superintendents stated that a majority of the admissions to their facilities represented readmissions following change to a community-based program. As a result, institutional officials expressed concern regarding the adequacy of funding for community-based services. <SD>

The future role of the institutions in the overall service delivery system is ambiguous. While continued reduction in the institutional population is viewed as an important objective by many system actors, the fact that admissions continue to be made has lead others to question the practicality of such an objective. As a result, there is considerable tension within the service delivery system regarding the next steps to be taken in the management of institutional population levels. <SD>

Community agencies point out that the imbalance between per capita spending in institutional and community-based programs severely restricts their collective capability to meet the needs of persons with complex disabling conditions. In contrast, a recent

Board of Charities and Corrections position paper has singled out the ongoing pressure for institutional admissions as evidence that SPCDD long-range plans call for a further reduction in institutional populations is impractical. <SD>

Despite efforts over the past several years to place institutional residents into more integrated community-based settings, the state's reliance on publicly-operated, large institutional settings is well above national norms. <SD>

In terms of the Medicaid program, the most critical issue facing the state currently is the response to recently enacted provisions regarding the placement of persons with developmental disabilities in general purpose nursing facilities. Administrative policy directions being adopted by HCFA will pose additional challenges to the state as it seeks to come into compliance. <SD>

In Tennessee approximately 700 persons with mental retardation are in the referral pool for community residential services. However, there is no source of information about housing needs of individuals with developmental disabilities other than mental retardation. <TN>

There is a need for educating both the public and policymakers about the need for, the advantages of, and the misunderstandings involved in creating community living alternatives for persons with developmental disabilities. <TN>

In the past five years, Utah State Training School (USTS) has risen from \$70.00 per day to \$128.00 per day. During this same time, over \$4.5 million have been appropriated to implement the outmovement of institutionalized people with disabilities into community settings. These expenditures were largely due to the fact that the USTS was under decertification action by HCFA. The result was that there were few resources left to develop less expensive and more effective community alternatives for people who have never lived in institutions. <UT>

Clients cannot functionally choose their place of residence in Utah because providers hold the right to refuse services; case managers take ownership in planning placements; and, limited openings dictate placements. <UT>

Consumers complain that Section 8 housing is taking as long as eight years to procure. Their locations are often out of the mainstream and inaccessible by public transportation. They also report that often the homes they can access are located in undesirable neighborhoods. <UT>

One of the problems with Medicaid (HCB) rules is that there is no allowance for persons with disabilities who cannot exit a facility independently unless the facility meets fire-life safety codes similar to those of an ICR/MR. Another restriction under the waiver prevents the use of Medicaid monies for board and room. The fire-life safety restrictions

make the costs of building these facilities prohibitive. Waiver clients do not generate enough SSI to pay the debt service for such a building. <UT>

Large, congregate care (ICF/MR) facilities create communities of people with disabilities. In order to integrate people with disabilities into the non-disabled community, it is essential that they integrate in small numbers. <UT>

Particularly acute is the need by all constituencies with developmental disabilities for housing and associated residential support services. In spite of significant initiatives by the General Assembly, the Virginia Housing and Development Authority, and DMHMRSAS, waiting lists for community-based residential services extend many years in most communities. <VA>

If one is elderly, a child, has a physical disability or experiencing multiple or severe disabilities, needed residential supports are very difficult, if not impossible to obtain. Extensive waiting lists continue in most localities of the Commonwealth. Several hundred individuals currently living in state operated training centers await community options, but are unable to locate available community residential placements. <VA>

Speakers noted that accessibility of housing continues to be a serious issue. Accessibility in terms of physical access and adaptability for persons with mobility or sensory impairments represents one aspect of this issue. Additionally, monetary accessibility, in terms of reasonable prices within the resources of most persons with disabilities represents another aspect of this issue. <VA>

People with disabilities should not be expected to relocate to take advantage of a certain type of housing unit nor should they have to live with neighbors with whom they may be uncomfortable. There is a danger that figures portraying housing unit numbers on a statewide basis overlook local needs on a regional or town basis - particularly the need for people to be located in proximity to services. <VT>

There is not always a match between the areas in the state in which the need for affordable and physically accessible housing exists and the location in which housing is being built or modified. <VT>

Federal resources are still largely directed toward a residential care facility approach to housing which creates a barrier for people to be able to use funds to assume places in the community. Federal resources which can be used to support housing, modify environments and promote independent living are minimal. In 1987, expenditures through the Intermediate Care Facilities for people with Mental Retardation (ICF/MR) program reached \$5.6 billion, yet only 25 percent of those dollars supported community-based living arrangements. <VT>

The fact that people with a disability are twice as likely as those without disabilities to live in a low income household (\$15,000 or less) makes this issue particularly critical. Although the housing ability crisis is becoming increasingly recognized, efforts to address this problem are recent and no solution is in sight. <VT>

When affordable housing does become available, the issue of physical accessibility often becomes a barrier. The Survey of Vermonters with Disabilities (Center for Rural Studies, 1989) found that approximately 1 of every 6 respondents with a disability indicated that they needed special modifications to make their home fully accessible. About one-third of those who needed home modifications did not have them with affordability frequently mentioned as a problem. <VT>

Current efforts to make physically accessible housing available through regulation and provision of a percentage of units in a development, though well-intended, can be restrictive in terms of choice. The individual needs of real persons may not be well accommodated in this approach. People may be presented with lengthy waiting periods or very limited options when units are available. For example, a young adult may be asked to occupy a physically accessible unit in a development designated as elderly housing. While the unit may be accessible, the young person may become isolated from his/her peers. <VT>

There is a lack of coordination in the effort to match people with disabilities in need of housing with the appropriate housing options. This need is being addressed in Vermont through a housing brokerage service at the Vermont Center for Independent Living; however, it appears that those with accessible rentals and people seeking those rentals do not fully utilize this service. <VT>

The greatest single issue related to housing for all person in Vermont today is affordability. Home ownership is beyond the reach of those on low or fixed incomes and affordable rental units are scarce. <VT>

Examination of information offered by respondents to the Vermont Consumer Satisfaction Survey (CSS) reveal that: 63% of respondents did not choose the place where they live; 93% do not own or hold the lease on their living quarters; 90% have no experience with the Department of Housing Urban Development (HUD) Section 8 Rent Certificate, a program in which qualified people with disabilities can receive assistance in obtaining and paying for rental housing. The person contributes a percentage of their income for rent and the remainder is paid by the Section 8 program. While 74% express satisfaction with their current housing arrangements, many of these people have very limited alternative experiences upon which to draw. <VT>

Many people with developmental disabilities are unaware of the Fair Housing Act Amendments (FHAA) and what its potential can mean to them personally in gaining desirable housing in the community. <VT>

Concerns about the quality of care for people in community care homes, e.g., medical services coordination. <VT>

Families need extensive support to make home health care successful. They need counseling, therapies, technical assistance, respite and education. When a child leaves the hospital, quite often the family is not provided with a realistic estimate of caring for their child at home. For example, nursing services may be covered but the supplies needed by the nurse may not be. Besides supplies, there are additional costs for electricity and other utilities, respite care, and various unforeseen support needs. Families often feel abandoned and resentful because reimbursements never equal actual costs. <WA>

The average cost for hospital care is \$17,903 per month. The average home care cost in Washington State is \$8,723 per month. This provides a substantial cost savings to Title XIX. Unfortunately, the current budget provided this option to only 21 children. As of June 1989, Washington case managers said some 44 children hoped to receive this option. <WA>

The number of children who need foster care has risen while the number of available families has decreased. This is particularly true for high-risk children. In addition, children affected by drug and alcohol use, babies born with the AIDS virus, and children with severe emotional and behavioral difficulties are flooding into the system. <WA>

Children in foster care who have developmental disabilities receive a cash add-on of \$120 per month or (in exceptional cases) an additional \$500 per month for supervision and respite care. However, even an extra \$120 per month does not cover a foster family's exceptional expenses. In 1989, a 10% increase in the basic payment rate was given to foster parents but even that accounted for only 54% of the true cost of caring for a child. The basic reimbursement rate and the special needs rates are unrealistically low. This contributes to the difficulty in finding and keeping qualified families. <WA>

The state is required by law and philosophically committed to finding an environment that best fulfills a child's need for a stable family. Sometimes, however, the rules and regulations don't support that position. Some parents — particularly those whose children have serious emotional difficulties — feel they are forced to relinquish custody of their children in order to obtain services. Other parents may place their child in foster care because they no longer have the emotional resources to deal with the realities of a disabling condition on a day-to-day basis. <WA>

Foster care issues lead to the debate of which agency should be responsible for the foster care needs of children with disabilities...DDD or the Foster Care System under the Division of Children and Family Services. If DDD operated its own foster care program a possibility for increased flexibility exists. <WA>

The lack of adequate pay and minimal job training for direct care providers adds up to less dependable, less all-around quality care. <WA>

Even when the federal government steps in to help pay for services, those dollars are more likely to be allocated to institutional care rather than to community-based support. In fiscal year 1988, federal expenditures for ICF/MR programs and large institutions (including nursing homes) were over \$3 billion. That's almost four times greater than expenditures for community-based services and supports to individuals and families and it is almost four times the amount allocated to such programs as the Social Services Block Grant and basic Medicaid coverage as well as the services provided through the Medicaid Home and Community-Based Service Waiver. <WA>

Since its inception in the early 1970s, the Intermediate Care Facility/Mental Retardation program (ICF/MR) had the emphasis placed on the delivery of health care. Services have focused on "taking care of people" rather than on promoting independence, productivity and integration. <WA>

Subsidized rental housing in Washington State increased by 15,000 units (or 44 percent) between 1980 and 1986. During that same time period, an additional 33,000 families found themselves in need of low-cost housing. To compound the problem, units renting for \$300 or less per month were often occupied by families with a moderate (rather than low) income level. All government housing programs combined presently serve only one out of four households in Washington State who need housing assistance. In 1986 alone, there were an estimated 171,000 low-income renter households with unmet housing needs. Of that number, an estimated 67,000 were people with disabilities who lived alone or in poverty. Sadly, only one in five received the services they needed. <WA>

As real estate and land prices soar in Washington State, there has been a corresponding loss of affordable housing for low-income people. This is evidenced by the increased need for rental subsidy, long waiting lists, growing homelessness, and inappropriately housed people. As people with developmental disabilities quite often have a low-income level as well as special physical requirements this situation hits them twice as hard. Out of 407 total Consumer Satisfaction Survey respondents, 84 indicated a need for housing subsidy, 57 reported being told that subsidies were simply not available. <WA>

According to figures released by the Division of Developmental Disabilities (DDD) late in 1988, some 1,000 additional Washington residents will be in need of residential services within the next two years. This estimate is probably low as it does not include current DDD clients who are underserved or inappropriately served. <WA>

In 1986, the 195,000 Washington State households had yearly incomes below \$15,000 and were paying more than 30% of that for housing. But in spite of that fact, federal programs still serve only one-third of the low-income population. <WA>

Unfortunately, the housing crunch is expected to get worse. Currently, there are some 26,000 rentals statewide that were originally built under federal low interest loan programs. Those loans were given in exchange for a lease commitment to use the low-income housing rentals for a specific number of years. Many of those leases are now expiring or being paid off early so the owners can sell those houses or apartments on the rising open market. Approximately, 7,000 low-income units are expected to be lost in the next five years. Washington has enacted a law requiring owners to notify the state before the sale of such property. <WA>

This year, there were only six applications to the Washington State Housing Trust Fund (out of more than 100) that dealt specifically with housing for people with developmental and physical disabilities. Since the Trust Fund provides money primarily for physical housing and very little for service supports, applicants must have another source of funding to provide the basic support services necessary to live in independent community settings. Because there are few dollars available for residential support services, the lack of funding for this crucial area is a major barrier to accessing the Trust Fund. <WA>

Expenses incurred in modifying a home for medical reasons are tax deductible under the IRS deduction for Modification of Residence. The problem is, many people with disabilities who need to make such alterations often have a limited income. As a result, deductions are quite often a moot point. Even if they get a tax deduction (and that's assuming their income is at a level to qualify) they still have to initially pay for the modifications out of pocket. This cost could be unreasonable for a low-income person, thus restricting access to a potential home and lessening the chances of living independently. <WA>

Many advocacy groups for those with developmental disabilities have failed to access the McKinney Act due to a lack of dollars to provide for personal assistance needs. <WA>

Most people would prefer to find their own housing because it gives them choices. Since an individual can only be on one housing assistance waiting list at a time, people are essentially forced to live indefinitely in situations that are quite inappropriate simply in order to remain eligible for Section 8. If a person chooses to move when an opening for better housing becomes available, it is often at great expense and with minimal notice. However, this is usually the better of the two choices. If applicants are not able to take immediate advantage of an opening, they lose their place on the Section 8 waiting list. Of course, moving with only two days notice means possibly breaking your lease and certainly losing your rent deposit, an additional financial and emotion burden. In addition, people fear moving into low-income areas that often have high crime rates. <WA>

When people live in public housing, they are not considered eligible for Section 8 housing. <WA>

Special needs populations are not generally given high priority for public housing, although advocates in some communities have changed this focus. Public housing residents say they consider housing authority policies to be strict, inflexible and arbitrary. Public housing often lacks security and this, too, can be an especially crucial point for people with disabilities. <WA>

Many landlords do not make housing available to rental subsidy programs because of the bureaucratic hassles. This further reduces the availability of low-income units. <WA>

The bottom line remains that residential support needs are greater than available resources and no new service funding is currently planned at the state level. Private, nonprofit organizations often try to fill in this gap, but reimbursements from the state do not cover their expenses. <WA>

Segregation is a barrier to affordable housing. Income levels as well as social attitudes and prejudices limit personal choices. Community acceptance and integration remain critical issues. <WA>

Substandard housing continues to be a problem, particularly for large families. Thirty percent of low-income renters who have three or more children live under substandard living conditions. <WA>

Even when low-income units become available, finding accessible housing for special physical needs is not always possible. <WA>

Lack of funding for residential support services is often a primary stumbling block when it comes to providing housing for persons with disabilities within the community. <WA>

Even with subsidies, many people cannot afford to pay market rental rates. This economic barrier is often much greater than is a mental or physical disability. <WA>

While federal funding for rental subsidies through vouchers and certificates is increasing, funding for new construction is decreasing. The dilemma this creates is that rental subsidies are a more temporary solution to a long-term need...they have to be reviewed every four to five years. New construction provides more stable and long-term housing. <WA>

Low-income housing is more likely to contain safety hazards, such as the presence of lead or asbestos, poor wiring or heating, and pest infestation, as well as lack of security. <WA>

The situation in Washington State simply reflects what is occurring on a nationwide basis: assistance from the federal government is limited, very little new construction is planned, and current subsidized housing is eroding. <WA>

Current funding supports at both the federal and state levels have a strong institutional bias. <WI>

Current funding supports for Intermediate Care Facilities for people with mental retardation appear to encourage placement into these facilities over community-based placements. <WI>

West Virginia has not applied for a Model Waiver program. <WV>

To date, West Virginia has not allocated the matching funds required to implement the TEFRA option. <WV>

One of the most frequent concerns expressed by families has been that the system supports costly out-of-home placements when families can no longer cope, but offers little support to natural families to prevent these placements from occurring. <WV>

A large percentage of the Medley class members who are still in institutions awaiting placement are people with challenging behaviors. In addition, the Court Monitor for the Hartly Plan found that the service system had not met its obligation to develop placements for persons with autism or behavioral disorders. The greatest barrier to the development of these placements is the expertise and resources of community service providers. <WV>

While substantial investments are presently made in costly congregate living situations, funding for individualized services is fragmented and inadequate. <WV>

At least eighty new community placements will need to be developed each year for the next four years just to meet the requirements of court orders and federal mandates. These numbers don't include any individuals who are living with their families and waiting for community living arrangements. Although few formal waiting lists exist that provide an accurate count, it is widely agreed that there is a substantial number of people living with their families who are waiting for services. These include individuals living with aging caregivers who will need alternate placements in the near future. <WV>

There is a large unmet need for community living arrangements for people with developmental disabilities in West Virginia. There are 119 Medley class members remaining in institutions who need to relocate to community living arrangements. There are an additional 60 non-Medley class members who live on the North/South Wing of the Colin Anderson Center who need community placement by the time that wing closes in 1991. <WV>

Because people with developmental disabilities tend to learn skills best in the settings in which they are to be used, there are built-in obstacles to competency-building when the service system requires people to relocate each time they reach a new level of skill.

There are also the risks of underestimating people's potential and placing them in settings that don't challenge them to learn. An alternative to the "continuum" is to offer an "array" of support services that are provided to people in their own homes or apartments and that can be modified as their needs change without requiring them to move. <WV>

The court monitor found that most group home residents had few friends who were not paid staff, that the homes "failed to foster the degree of independence of which many residents are capable", and that the ICF/MR facilities, particularly the newly constructed eight-bed homes, did not blend into residential neighborhoods. The report indicated that high staff turnover was a problem in many homes due to low staff salaries and limited fringe benefits. She also noted concerns about individualization and basis rights, stating: "Compared to the institutional settings from which many residents moved, the homes provide relatively greater privacy, respect for client choice, and opportunities for individualized activities. However, by their nature, the homes still mandate a degree of intrusion into individual privacy and individual decision-making beyond that mandated by the individuals' handicaps and beyond that which most Americans would find acceptable." <WV>

Wyoming does not currently receive federal funds for ICF/MR because there are no institutions which meet the federal certification requirements for such a facility. As a result the state is not eligible to receive the home and community based waiver funds. <WY>

In Wyoming the demand for housing supports and residential alternatives continues to be an area in need of development. Opportunities need to be created even before waiting lists can emerge. <WY>

Despite the broad-based support for family homes for children with developmental disabilities, there are major gaps in the systems of care of children who are medically fragile and/or technology dependent. These children have minimal access to home-based care and other "least restrictive environment" alternatives. <WY>

Wyoming does not keep statewide data on the disability status of children in foster or protective care. The State Department of Education, the court system, and the Department of Public Assistance and Social Services do not have an efficient method of tracking children handled by the judicial system because they are found to be children in need of supervision (CHINS) or because they are juvenile offenders. As a result, services to children with developmental disabilities within this group are not comprehensively tracked nor are their needs communicated across agency boundaries. <WY>

A HOME: RECOMMENDATIONS

Multiple States

Funding sources should be realigned to focus on resources to individuals rather than facilities; funding for housing should not be based on a medical care model. <ID,MT,NJ,WY>

Housing policy goals for people with developmental disabilities should be redefined to focus on supports, environmental adaptations, and housing characteristics selected by the individual and tailored to individual needs; empower individual adults to own or rent their own homes; and ensure that children live in a family home. <AK,ID,LA,MA,MT,NM,TN,WY>

National attention must be given to problems of neglect and abuse in board and care homes, such as consideration of the proposals to improve state monitoring of these facilities included in the National Board and Care Reform Act of 1989 (H.R. 2219). <ID,LA,MT>

The implementation of the new ICF/MR regulations and P.L. 100-203 (nursing home reforms) should be carried out in ways that promote the use of community alternatives rather than increased resources dedicated to institutions. <AK,ID,LA,MA,MT,NJ,WY>

The federal commitment to ensure the availability of decent, affordable housing must be reasserted and acted upon, such as the bipartisan-supported National Affordable Housing Act recently introduced (S. 565/566). <ID,LA,MA,MT,WY>

The Division of Mental Health and Developmental Disabilities and the Governor's Council for the Handicapped and Gifted should continue to foster the development of community services in rural areas. <AK>

The Department of Health and Social Services should work with regional health corporations hospitals to increase their capacity to admit infants who are "medically fragile" or "technologically dependent" into skilled nursing "swing beds" in their hospitals. This would allow more frequent contact between the child and family. <AK>

There must be a consumer driven array of specialized living arrangements. Community living options must be unique as the individuals needing the services and not limited to group homes and semi-independent living arrangements. <AL>

Emphasize the development of community alternatives for those individuals currently residing in state institutions who have been determined through the inspection of care review to be inappropriately placed. <AR>

Prepare and submit as soon as possible a Section 1915(c)(7)(B) waiver request to establish the option of furnishing HCB waiver services to nursing facility residents with developmental disabilities. <AR>

Create a stand-by cash flow buffer to protect nonprofit providers against reimbursement disruptions during the HCB waiver's initial year to allow for not uncommon first year problems synchronizing Medicaid payments with services furnished. <AR>

Prepare a three to four year plan, as mandated by Congress, to meet the needs of nursing facility residents with developmental disabilities and employ this plan as the basis for amendment of the state's alternative disposition plan. <AR>

Develop a long-range plan to reduce the total large ICFs-MR population without jeopardizing the quality of services received by current state facility residents and with attention to the concerns of involved families. These latter points cannot be emphasized enough. Families have legitimate concerns about the quality, stability and continuity of community services. There must be a concerted effort to mitigate their fears on all accounts. <AR>

Expand supporting living opportunities that meet individual needs and preferences in integrated housing, so that each person with disabilities has a full range of options for living that offers appropriate support at each age and level of need throughout life. Smaller, family-scale arrangements including houses and supported apartments should be the focus of future development. <AR>

Establish a task force of providers and representatives of the Division of Developmental Services (DDS) to convene periodically to identify and resolve problems as they arise during the first year of the HCB waiver program's operation. The aim of this task force would be to address implementation problems on as timely and decisive a basis as possible, to institute operational modifications as needed to recommend changes. <AR>

A corollary to this skewed philosophical premise (the "attitude of gratitude") is an attitude that when a particular program doesn't meet with success, it is often the individual with disabilities who is perceived to have failed, rather than the implementation of the program. This adds to the burden of inferiority already experienced by many consumers and to the insecurity and guilt experienced by many families.
<AR>

The TEFRA 134 waiver option exists to extend Medicaid coverage to children living at home where the provision of State Plan services would prevent institutionalization. DDS and Economic and Medical Services staff should convene to resolve conflicting impressions over the accessibility of this option for children with developmental disabilities as it can be important means of avoiding institutionalization if accessed properly. <AR>

Assure that the full implementation of the Home and Community Based Waiver Program is a success and make judicious use of the small ICFs/MR to help move individuals from large facilities toward the most integrated and independent settings in which they are capable of living and in which they choose to live. Arkansas's number one priority should be the successful refinement, implementation and expansion of the HCB waiver program. <AR>

The state should seriously reconsider its projected reliance on the ICF/MR model. Providers who wish to reconsider their plans for ICF-MR development should be given the opportunity to develop alternate services. <AR>

Conduct a thorough assessment of the needs of persons currently on the state institution waiting list as to the urgency and extent of their needs. Offer service blends to individuals on the waiting list and their families to create alternative community service plans, perhaps under the Medicaid Waiver Program. <AR>

Place a priority on the provision of alternatives for children. Arkansas's institutional population has one of the highest percentages of children in the country. Model family support services are currently available on a limited basis in certain parts of the state. These should be available to all interested families and children who are at risk of institutionalization. Every additional effort, including expansion of foster care opportunities, must be made to keep children in families, and family-like settings. The sum of these efforts should amount to a freeze on institutional admissions for children. <AR>

Extend indefinitely the current moratorium on certification of further ICFs/MR. Without the needed analysis of waiting list members and extensive evaluation of the facilities that are implemented from among the original thirty, it would not be good planning procedure to grant further permits of approval. <AR>

The Program Advisory Committee of the Arizona Office of Housing Development needs to do a comparative analysis of how federal Housing and Urban Development (HUD) funds are used in other states to assist persons with developmental disabilities, and prepare a report on what might be replicated in Arizona; review HUD programs which can be used as a potential resource for persons with developmental disabilities; and develop and implement a plan for utilization of all federal and state resources available for subsidizing housing costs and rental charges, and provide information to the Governor's Council on Developmental Disabilities. <AZ>

DDD must continue its review of the licensing process to identify problems and develop solutions which will result in an effective licensing procedure which, at minimum, addresses the needs of medically at risk individuals served in group homes, provides for safety monitoring in semi-independent living situations, and simplifies the licensing process

safety monitoring in semi-independent living situations, and simplifies the licensing process as much as possible. <AZ>

Funds currently used by Arizona State Hospital for individuals should be transferred to DDD for use in providing more appropriate services in the community. <AZ>

The Center for Law in the Public Interest should continue its efforts to provide assistance with appeals to persons in the Arizona State Hospital (ASH) whose diagnosis regarding a developmental disability is unclear. <AZ>

There should be a licensing process for community residences for persons with developmental disabilities. These types of residences should include all contracted or fee-for-service residential services, whether or not they serve individuals who are receiving financial support from the DDD, e.g. independent living centers, private group homes, private foster care providers, etc. <AZ>

In the monitoring of residential services, consistency must be assured across districts within the state. <AZ>

A national study of housing alternatives should be undertaken which examines what is available and identifies barriers to access. <CA>

The system needs more flexibility in moving toward the concepts of independent and supported living. The "six-bed" group home should not be considered as the least restrictive environment among residential alternatives. The existing array of residential services should be examined and enhanced with more creative service models which lead to increased independence and integration. One step in achieving this flexibility is to eliminate financial incentives to placement in more restrictive, large congregate settings, including the promotion of Medicaid reform at the federal level. <CA>

In order to build a stronger, more stable community care workforce, the salary and benefits structure must be comparable to that received by care providers in institutional settings. This could be provided through a rate increase which guarantees a pass-through to community care staff. <CA>

There must be a real commitment to community placement and to meeting the growth in population needing residential services. This must include elimination of the backlog of people requiring community placement; greater infusion of start-up funds; elimination of licensing issues and other barriers and developing community residential programs; and improved coordination among agencies in interpreting regulations and requirements for program development. <CA>

Service quality in community residential care must be assured. A systemwide set of standards for quality assurance must be adopted, monitored and enforced. The rate

structure must allow for meeting the standards, along with geographical cost differentials and the intensity of services needed by the individual. There must be an ongoing support system for residential providers to ensure continued stability within the community services system on a statewide basis. <CA>

Training modules and incentives to complete training must be built into the community care system, and must be designed for cost-effectiveness and efficiency, given the high turnover and mobility of staff within community services. <CA>

In order to ensure more stability in the community services system for populations with special needs (such as individuals with severe behavior problems or technological dependency), state-owned and operated community facilities should be piloted. <CA>

The state must continue to support program models such as ICF/DD-N which will allow children and adults with more severe disabilities and medical needs to live in a less restrictive, more home-like environment. <CA>

A stronger commitment is needed to establish flexibility and adaptability of programming within the service system, especially to meet specialized residential needs such as intensive behavior management, medical care, and dual diagnosis (DD/MI). <CA>

Develop capacity to serve people on waiting lists who are not currently receiving publicly funded residential services. <CO>

Ways must be found to meet the legitimate health and safety needs of individuals, especially those who choose to live independently (or semi-independently), but need ongoing training, support, and assistance without necessarily relying on sometimes archaic licensing practices. <CT>

A series of development activities should be established to provide "community builders" staff with start-up ideas and follow-along to support effective implementation of community building ideas. <CT>

Medicaid reform must set a limit on the size of any new community living arrangement to be funded with Medicaid dollars. <CT>

Develop non-facility based housing support agencies. <CT>

The Department of Income Maintenance must be supported in expanding the Katie Beckett Waiver program. <CT>

Restructure of the Medicaid Waiver, so as to support residential alternatives to "facilities" providing 24-hour care and supervision. Use of a residential Medicaid waiver, in lieu of a case management waiver, to fund alternative living arrangements. Wisconsin, Colorado,

North Dakota and several other states have been successful in developing language in their Medicaid waivers which permits the funding of individualized community supports. This option has significantly increased the opportunities for persons with severe disabilities to live in typical, community residential environments. A residential waiver, rather than a case management waiver, may make a greater contribution to the well-being of people with disabilities, their families, and the public. <CT>

Advocacy for licensing waivers (and/or changes in statute and regulation) to encourage pilots of non-traditional, residential options. <CT>

All state agencies providing residential services or support should provide direct grants to individuals, modeled after the Department of Human Resources' Personal Care Assistance program, to hire people who can help them with daily needs. <CT>

More support options, especially for those living outside licensed homes, must be developed. Rates of pay for in-home support services must be increased and efforts should be made to tap new sources of manpower. <CT>

Options for support should include, at a minimum: live-in staff; on-call staff; non-paid or paid roommates; non-paid or paid neighbors; and supervised personal attendants. <CT>

A "Community Builders" program should be established, similar to the VISTA concept of volunteer service, in which interested staff spend an intensive period of time implementing a positive lifestyle for one person in local community life. Establish staff positions which focus exclusively in building community for people most in need of support. This staff should not carry the standard responsibilities of provider staff and they should spend very little time within the provider agency. They should spend most of their time in the local communities working intensively with only two or three people at a time. <CT>

The community training home program has some positive aspects in that people are integrated into typical homes and families, these families are usually very committed, and the Department of Mental Retardation has been increasing its commitment to these families. Children in these homes should be afforded permanency planning and adoption of these children should be encouraged. <CT>

More housing options must be developed. At a minimum, expanded housing options should include: living in one's own or rented home; shared rent or ownership; ownership cooperatives; and corporation owned or leased houses or apartments. These additional options can be promoted through nonprofit housing corporations, like Co-op Initiatives, sweat equity programs, and technical assistance for interested groups. <Ct>

Establish local community connections for people living in independent living arrangements (building community). <CT>

The Department of Mental Retardation needs to work to maintain family ties and, whenever possible, to reunite families. <CT>

A major recommendation is that the housing policy of the government of the District of Columbia be recast to clearly indicate that all old and new housing initiatives include specific provisions which are directly related to the housing needs of individuals with developmental disabilities and their families. <DC>

There should be established within the Office of the Executive Director of the Council a management information system for collecting, analyzing and storing for easy retrieval, relevant housing data which impacts or may impact upon the lives of individuals with developmental disabilities. <DC>

Existing housing initiatives should be reexamined for the purpose of making a determination of the extent to which they contribute to the achievement of independence, productivity and integration of persons with developmental disabilities and their families. <DC>

There should be a set aside program established to insure that no less than one out of every ten new housing starts, public housing and housing assistance efforts be for individuals with developmental disabilities and their families. <DC>

There should be a system put into place to reduce the potential of ICF/MRs and other community based residential facilities from becoming "mini-institutions." <DC>

Efforts should be mounted, through intra and inter agency collaboration, which would preclude the potential for doubled-up households leading to homelessness. <DC>

There should be greater use of scattered site housing opportunities for individuals with developmental disabilities and their families. <DC>

Procedures should be put into place to ascertain the extent to which the public housing rehabilitation program focuses on the needs of individuals with developmental disabilities. <DC>

Establish funding for sufficient housing for clients with mental retardation where aging parents are less and less able to care for their sons and daughters at home. <DE>

Meet the community residential needs of (especially young) adults with developmental disabilities in institutions. Prepare these adults for transition into the community. <DE>

Improve contractual funding by FY 1993 to enhance quality of care and effective program operations at Delaware State Hospital. <DE>

Funders and providers of housing need to identify situations where non-disabled elderly persons or other groups are residing in "handicapped-accessible" units preempting persons with disabilities on waiting lists for "handicapped units." These funders-providers need to develop strategies for solving this problem. <DE>

Enhance the therapeutic environment of the existing Kent/Sussex and Carvel patient units at the Delaware State Hospital. The existing structures for the patient units were designed and constructed in the mid-1960s and are no longer appropriate for the therapeutic milieu of a modern, psychiatric hospital. Improvements are necessary to meet the Joint Commission's accreditation standards for the therapeutic environment. <DE>

Enhance funding for contractual psychiatrists by FY 1991 for the Delaware State Hospital (DSH). <DE>

Provide effective training at Delaware State Hospital. <DE>

Maintain Medicaid certification for all appropriate programs (Stockley Center and community programs) as measured by annual license renewal in FY'90, FY'91, FY'92, and FY'93. <DE>

Reduce the residential population of Stockley Center as measured by population level (345 in FY'90, 335 in FY'91, 325 in FY'92, 315 in FY'93). <DE>

Construct an apartment complex on the Delaware Hospital for the Chronically ill (DHCI) campus for independent and assisted living to serve the elderly and persons with disabilities. <DE>

Coordinate a competitive and focused program for the recruitment and retention of qualified health professionals. <DE>

Provide services which are not available in the private sector and develop public/private partnerships in the creation of needed services. <DE>

Convert one of the cottages located on the grounds of Governor Bacon Health Center to serve as a transition to a community placement for young adults with disabilities. <DE>

Convert the Banton Building on the Bissell Campus from an 84 bed ICF facility to the Banton Assisted Living Center which would offer apartment-like units for persons who can no longer manage independently. <DE>

FY 1991: Expand congregate living for young adults with disabilities to serve as a transition for community placement. FY 1992: support the conversion and operation of congregate living for approximately 8 young adults with disabilities. <DE>

Provide inpatient rehabilitation, specialized treatment and maintenance services for young adults with disabilities. <DE>

FY 1991: Develop an apartment complex on the DHCI (state facility) campus for independent and assisted living serving the elderly and persons with disabilities. <DE>

FY 1992: Conduct a program and financial feasibility study for the development of alternative housing options serving the elderly and persons with disabilities on the DHCI (state facility) campus. Facilitate financing options in supporting supervised community residential programs for people who are elderly and who have disabilities by service providers. <DE>

Service system managers should, in a coalition, address the "handicapped unit" waiting list issue and develop an appropriate plan for provision of accessible housing units to those of the 2,333 elderly/persons with disabilities with such a need. <DE>

The private sector should develop affordable housing for persons with disabilities. The major private sector resources that should be examined are: private lending institutions, foundations and other nonprofit organizations, individual partnerships and corporations. These resources can prove invaluable in determining the success or failure of housing for persons with disabilities. <DE>

Local governments should amend their local zoning ordinances to eliminate any "exclusionary" provisions which currently prevent persons with disabilities from living together in group homes within their jurisdiction. <DE>

The Delaware General Assembly should pass a state Fair Housing Law that is comparable to the federal Fair Housing Amendments Act of 1988. <DE>

Housing funders/managers should develop a strategy which would promote utilization of "handicapped units" by persons with disabilities who are on waiting lists. <DE>

Advocacy groups and concerned community leaders should continue to seek funding under the Department of Housing and Urban Development (HUD) Section 202 program for the Elderly and Handicapped Housing Program. <DE>

Private non-profits and others should apply for renovation funds under HUD's Transitional/Supportive Housing Demonstration Program which places major emphasis on the provision of housing for persons who have disabilities and are homeless. Crisis House in Georgetown successfully completed a 1989 project renovating five apartments, one of which is accessible. <DE>

Private and public lending institutions should finance housing acquisition, construction and rehabilitation through federal mortgage insurance programs. The two mortgage insurance

programs designed specifically for persons with disabilities are the Mortgage Insurance for Housing for the Elderly, Section 231, and the Nursing Home and Intermediate Care Facilities Program, Section 232. <DE>

Funders and developers should expand use of federal housing programs emphasizing accessibility, affordability, and rehabilitation of existing houses, and supporting or enriching community and neighborhood building programs. <DE>

Public hearing participants recommend that system modifications need to be implemented which will ensure quality and stability of group home staff. Public hearing participants expressed a need for the state to make a long-term commitment to staffing responsibilities and reduce the high rate of turnover currently experienced in group homes and other residential facilities. <DE>

Public hearing participants recommend making use of the private and non-profit resources already located within the state in an effort to increase the level of support, both financial and educational, toward the expanded availability of housing for persons with developmental disabilities. The creation of public/private partnerships should help to alleviate this critical problem. Matching dollars with the private sector improves public/private relationships and makes use of an innovative approach in creating permanent housing opportunities for persons with developmental disabilities. <DE>

Develop additional levels of care for the Adult Foster Care Program so that a more dependent population can be served. <DE>

Establish a process for short-term foster care placement to provide care for clients during the application process for permanent Adult Foster Care placement. <DE>

Provide adequate funding for community residential homes. Increase both the number of community home placements available and the level of fiscal support provided for each individual's placement in a community home. <FL>

Encourage and help consumers to make choices about where and with whom they live. <FL>

Develop adult foster care placements. <GA>

Expand community based residential services. Efforts should focus on accelerating deinstitutionalization and expanding community-based residential services. The public and private sector should be encouraged to create specialized community-based residential services that are affordable and are programmed with appropriate levels of services geared to special needs of individuals residing in the homes. <GA>

State assistance in long-term planning of residential services is recommended. <GA>

Support attempts to make all single living dwellings minimally accessible; identify architects, developers, builders, and contractors who are interested in designing, constructing, and modifying buildings. <GA>

Planning should be initiated with legislators, state agencies, advocacy groups, and caregivers for creative community-based, integrated living environments for adults with developmental disabilities. <GA>

A loan fund should be established to provide direct, low interest loans to people with disabilities for the purpose of home purchases and/or modifications. <GA>

Some families would like their family member to assume ownership of the family with a disability home. A demonstration project, resulting in a "how-to" guide, could assist families toward this end. <GA>

Develop consumer and family conference on residential services. Establish a housing "think tank." A housing "thing tank" needs to be established whose purpose is to learn about state-of-the-art approaches to community living and develop financing strategies for a project such as a housing cooperative that includes both people with and without disabilities as joint owners. <GA>

The Council recommendation is to investigate the feasibility of establishing a residential care facility of Guam. <GU>

Congress and the state of Hawaii should make mandatory that developers provide 20 percent barrier-free units in both public and private developments. Plans should be developed and implemented to modify existing public housing so that 20 percent of all units are barrier-free and made available to people with disabilities. <HI>

Congress should direct the Department of Housing and Urban Development to include a program of demonstration grants to agencies such as Independent Living Centers to develop model housing options, including transitional living programs, group residences, and other alternatives. <HI>

The Department of Housing and Urban Development (HUD) should initiate additional programs to encourage private sector funding and to provide incentives and financial resources for the development and housing opportunities for people with disabilities. <HI>

Congress should direct the Department of Housing and Urban Development (HUD) to provide rent subsidies for persons with disabilities through both Section 8 certificates and the Housing Voucher Program. These programs should be made permanent and given a high priority. <HI>

The state of Hawaii should increase the number of "beds" in the Home and Community-Based (HCB) Waiver Program. <HI>

The state of Hawaii should adopt as a high priority the development of an array of residential alternatives, including family homes, supported living units, group homes, skilled nursing facilities of 15 or less beds in all the counties. These facilities should have the appropriate and necessary support services. The Department of Health's Developmental Disabilities Division will be the lead agency and review all residential placements using the residential placement criteria. <HI>

Medicaid financing should be maximized, as discussed previously, but because of its limitations, the state of Hawaii must plan for alternative financing mechanisms for residential care, possibly by converting small ICF/MR-C facilities to non-certified units or supported living arrangements. <HI>

Within two years, the Department of Health's Developmental Disabilities Division should recruit, screen and train direct care staff, case managers and housing providers in a systematic and coordinated manner. <HI>

The State Planning Council on Developmental Disabilities should develop the capacity for a quality assurance system to monitor residential placement and care for persons with developmental disabilities. <HI>

The state of Hawaii should revise the process for establishing the Medicaid payment rate for Skilled Nursing Facility (SNF), Intermediate Care Facilities (ICF), and Intermediate Care Facilities/Mentally Retarded and Other Related Conditions (ICF/MR) beds. <HI>

Congress should require the Health Care Financing Administration to remove the institutional bias within its programs for persons with disabilities. <HI>

The Department of Health should complete a comprehensive plan for Waimano Training School and Hospital (WTSH) no later than January 1991. This plan should include facilities, land, programs and staff; and should contain the provision that the Developmental Disabilities Division will reorganize to have a Residential Services Branch under which there will be a community services section and a Waimano section. <HI>

The Department of Health should establish a quality residential program for children who are medically fragile and ventilator dependent, with health professionals trained to work with the population. <HI>

Revise the state ICF/MR program policy to explicitly cite independence, productivity and integration as program goals. <IA>

Study the impact of expanding the current eligibility criteria for the ICF/MR program to include persons categorized by Medicaid as "medically needy." <IA>

Build language into ICF/MR program policy that explicitly calls for individual and family involvement in control of service choices made as part of the individual's personal care plan. <IA>

Expand state ICF/MR program policy to require ICF/MR programs to be located in family-sized homes, and provide clients the opportunity and the support they need to participate in the community. <IA>

Individualized funding for residential services should be created based on increasing and decreasing needs of the person with a disability whereby the entitlement the person receives goes with the individual wherever he or she chooses to live. Long range plans should be developed to move toward a residential support system based on individualized funding. <ID>

Idaho must address the concerns of parents with family members in state operated facilities by extending an extensive array of support services for community-based living, and by providing these parents with information that demonstrates that community-based living does increase the quality of life for people with developmental disabilities. <ID>

There needs to be monitoring and enforcement of residential care facilities along with adequate requirements for education and training of residential facility providers and a mechanism for immediate sanctions for deficiencies per Department of Health and Welfare, Licensing and Certification review. <ID>

The state must develop public awareness programs about integrated housing options. <ID>

Residents of nursing homes must not include Idahoans with a disability unless they are retired and over age 65. Otherwise, individuals should live in real homes and be provided the supports they need regardless of medical orientation. If they are children, there must be a policy to allow them to live in their own home. <ID>

The existing semi-independent living program should be modified to finance the person living there and not the program or the licensee. <ID>

Semi-independent reimbursement should provide rent subsidies for the residents and utilize Section 8 rental assistance when possible. <ID>

Policies governing financial reimbursement must focus on the resident, not the facility or provider. <ID>

No additional shelter homes should be built in isolated geographic areas away from transportation system or generic services. <ID>

Competitive HUD housing subsidies currently pursued by each HUD office throughout Idaho must be consolidated and coordinated with Idaho's independent living centers and regional developmental disability programs. <ID>

The Idaho State School and Hospital should immediately plan a strategic phase down with closure as a goal by the year 2000. <ID>

The policy must be created that caps any new ICF/MR housing. <ID>

All laws and policy governing housing for Idahoans with a disability should restrict such housing to less than eight but ideally no larger than 4 residents. <ID>

Those people who are significant in the lives of people with disabilities should be allowed to live with them in an integrated setting. <ID>

Federal and state funds targeted for expansion of residential services should be utilized to provide individualized community supports, such as Community-Integrated Living Arrangements, for people with developmental disabilities, including severe mental illness. These services should be monitored to ensure that a satisfactory quality of life for consumers is maintained. <IL>

Indiana shall consolidate its service delivery system for community living arrangements to eliminate duplication and to serve people more effectively. <IN>

Indiana shall provide small-scale residential programs for 1-5 people as an alternative to the Medicaid model. <IN>

Indiana shall place greater emphasis on residential programs which integrate people with physical and sensory disabilities with non-disabled people who have compatible interests and intellectual activities. <IN>

Indiana shall provide financial support for initial training and ongoing staff development for personnel in all community living arrangement settings (e.g., in home attendant care, behavior management, sensory impairments, etc). <IN>

Indiana shall provide a system whereby people with disabilities and family members or advocates are actively involved in residential placement decisions. <IN>

Indiana shall designate a centralized agency funded to develop residential options, provide information on available programs, and evaluate the quality of all residential alternatives based on outcome information. <IN>

Indiana shall provide a lifetime partnership with people with disabilities and their families that ensures the availability, acceptability, and appropriateness of residential programs and services. <IN>

Indiana shall provide and fund supported living arrangements that enable people to live as independently as possible. <IN>

Indiana shall refocus funding and programs, including case management, so that people with disabilities and their families can live in a home of their choice. <IN>

Indiana's state definition of developmental disabilities shall include all people with severe disabilities for the purpose of providing community residential services. <IN>

MRI (contractor) recommends that the state make a commitment of the necessary funding and staff resources to undertake a complete enumeration of all placements of persons with developmental disabilities in the state, including those in skilled nursing facilities or intermediate care facilities. <KS>

The Office of Human Services should establish the community support system to provide individualized and flexible housing and supports for adults with developmental disabilities. <LA>

HUD should enforce the Fair Housing Amendments and educate people with disabilities about its provisions. <LA>

Congress should enact legislation to provide tax exemptions to landlords for expenses for making rental housing accessible for persons with physical disabilities. <LA>

The Division of Mental Retardation/Developmental Disabilities should develop a strategy to shift funding to community homes away from the ICF/MR Program to a combination of Waiver funding and generic income supports. <LA>

The Office of Human Services should determine training needs of community home staff by (1) assessing deficiencies of ICF/MR survey reports and (2) surveying community home staff. DHH should develop standards for community home field-based training which addresses these needs. <LA>

Congress should fund a subsidy program within the Department of Housing and Urban Development (HUD) for persons with physical disabilities to make their housing accessible. <LA>

The Office of Human Services should expand its in-home and family support program to fund assistance to families and persons with disabilities to make housing accessible. <LA>

The Louisiana and local Housing Finance Agencies should allocate a percentage of its low interest loans for persons with disabilities. <LA>

HUD should revise the Section 202 Program to allow for the development of integrated housing construction and renovation programs for persons with disabilities. <LA>

The Office of Human Services should establish a process for statewide planning for housing alternatives with input from consumers, parents, advocates, and the private sector. <LA>

Disseminate information concerning existing available-and-accessible housing throughout the state by locality, through the maintenance of a clearinghouse. <MA>

Provide technical assistance to private, non-profit organizations/families/persons with disabilities concerning how to develop and implement creative housing planning opportunities, including planning and financing strategies, negotiating the state bureaucracy, barrier-free designs, and actual renovation and construction. <MA>

Develop a comprehensive state policy and designate a single oversight agency (e.g., EOCD) from housing services for persons with disabilities, to coordinate the many federal and state housing programs such as Sections or Chapters 8, 689, 202, 605, 707 MIFA, etc. EOCD should be funded and otherwise supported to staff its Bureau of Handicapped Housing. <MA>

Ensure that publicly supported housing programs offer a range of accessible and affordable housing options throughout all communities in the state in order to meet individual/family needs in a flexible manner. The range of housing options should include: independent living, congregate living facilities with staff support, small house/apartment with or without live-in-staff, traditional or cooperative/condominium ownership, etc. Publicly-subsidized housing must meet the varying needs of families (e.g., 3 and 4 bedroom units), must exist in every community throughout the state and should not be restricted to elderly apartment complexes. <MA>

EOHS must designate a "lead agency" to plan for nursing home residents with developmental disabilities. <MA>

Cities and towns, in cooperation and state agencies, schools and pediatric and adult nursing homes, aging parents, etc., who have "clients" desiring homes, should continue to develop creative and flexible ways to develop private and public partnerships and linkages to maximize innovative housing programs for persons with disabilities, persons from a broad range of backgrounds, income and ages, and offering "generic" support services such as child care, local shuttles, security (when necessary), etc. <MA>

Provide appropriate housing options (without requiring people to move) for persons with disabilities who have progressive disabilities (such as AIDS/HIV infection) or are elderly,

and therefore in need of increasingly supportive environments. Housing programs for persons with disabilities should include a supportive services component on-site. <MA>

Eliminate the long-standing salary gap between state institutional and community private sector "hands-on" workers. <MA>

Develop a system-wide approach towards permanency planning for children which would decrease the need for placing them in out-of-home care. <MA>

Create and support caregiving alternatives for families, such as specialized foster care. <MA>

The Massachusetts Commission Against Discrimination should undertake a major public information campaign to inform the public, the real estate business, and people with disabilities about the new federal Fair Housing Act and its applicability to them. <MA>

Initiate a campaign, which includes all offices of state government and leadership from the Governor, to assure that discrimination towards persons receiving community residential services is not tolerated. Conduct a comprehensive examination of state laws, regulations and policies to identify and rescind any provisions that violate or negate the Fair Housing Amendments Act; eliminate use of terms such as "community acceptance" and "community saturation" which are frequent euphemisms for discriminatory behavior or attitudes concerning persons with disabilities. <MD>

Discourage and seek alternatives to proposals to develop larger community residences to accomplish economies of scale which minimize community integration opportunities. Accelerate development of individualized residential support services, and adhere to the Developmental Disabilities Administration's policy of funding community residential programs for three or fewer people, which encourage community integration and should not, under any circumstances, be altered to achieve economies of scale. <MD>

Aggressively implement the state's plan to decrease participation in Intermediate Care Facilities for the Mentally Retarded funding provided in state residential centers/institutions. Proceed with careful planning and adequately funded community alternative. <MD>

Exercise fully options by which state and federal housing dollars may follow people with disabilities, rather than being assigned to specific housing sites as are Section 8 Moderate Rehabilitation funds. <MD>

Expand opportunities for consumer housing ownership such as holding company options, co-ops and other creative housing solutions to stimulate investments in people, not in property. <MD>

Provide incentives for individuals to make bequests of homes to provider agencies in order to increase the housing pool. <MD>

Establish a state housing policy which actively promotes and endorses integration and independence of persons with disabilities. <MD>

Expand the focus of the Housing Development Advisory Service in the Department of Housing and Community Development to support and encourage additional accessible barrier-free housing. <MD>

Establish a centralized information and referral resources center for people with disabilities, possibly within the Department of Housing and Community Development. This one stop center should have a community liaison and/or an access ombudsman and provide community education and training on housing programs and issues. <MD>

Identify and utilize, in addition to federal funds, other funding options for accessible, subsidized housing, including, but not limited to, business partnerships, tax-exempt bonds, and surplus funds. <MD>

Explore development of guidelines and/or regulations to allow private developers to set aside moderately priced and low-income accessible housing for persons with disabilities. <MD>

Continue the provider recertification process for Project Home, an Adult Foster Care program administered by the Department of Human Resources, with changes. <MD>

Children and adults both in out-of-state and out-of-home placements should be assigned individual advocates to assure that all rights guaranteed under Maine law, policy and regulation are observed in residential care and treatment agencies. No placement should occur in any agency that refuses to comply with all relevant state statute and regulatory requirements for rights protection. <ME>

The State of Maine should comply with Title IX (OBRA) requirements for active treatment and appropriate placement of persons with developmental disabilities who reside in intermediate care or skilled nursing care facilities. <ME>

The National Affordable Housing Act and amendments placing special emphasis on persons with disabilities and the McKinney Act. <ME>

The Bureau of Child and Family Services should request funds adequate to assure appropriate placement of all children with disabilities in state custody. <ME>

State statutes governing agencies responsible for placement of children should be revised to reflect a clear state policy preference for avoidance of unnecessary placement outside

the child's own home and placement in the least restrictive, appropriate community based alternative. <ME>

The Interdepartmental Council should be directed to develop an "Annual Plan for Assuring Continued Deinstitutionalization of Children and Adults." The plan should annually assess the needs of children and adults with developmental disabilities for appropriate least restrictive community based alternatives; and include recommendations to the Governor and Legislature for the development of needed community alternatives. The goal of the plan should be to increase the proportion of state and federal resources allocated to community based alternatives compared to institutional alternatives. <ME>

Maine should undertake all appropriate actions to utilize federal housing assistance programs to develop community residential options for persons with disabilities. Affordable, accessible housing should be available in all Maine communities and should be integral part of larger plans to assure a community system that supports independence and integration. <ME>

Congress should enact legislation to establish minimum standards for board and care homes. Legislation should encourage and support states' monitoring and inspection, and support remedial action and efforts to assure individual rights. It should provide federal financial participation in state implementation, with a 90% federally matched program, such as proposed in the National Board and Care Reform Act of 1989 (H.R. 2219), which would amend Titles II and XVI of the Social Security Act in ways that complement Michigan's statutes. <MI>

The state and the U.S. Department of Health and Human Services should collect and analyze data to monitor the impact of residential services on residents in terms of independence, integration and productivity; evaluate costs; and guide improvements in the system of services. <MI>

The Michigan Commission on Handicapper Concerns and other advocacy organizations should improve housing options in the community for people with developmental disabilities by promoting public acceptance of people with differences, through a program of education and training regarding the human and civil rights of people with disabilities. <MI>

State and local governments, in collaboration with the private sector, should increase the percentage of available housing that is barrier free. <MI>

The governor should direct, and the legislature should support, expanded rehabilitation of existing housing stock and use of creative financing methods to increase the number and kinds of housing options. <MI>

State and federal governments, in partnership with the private sector, should increase the availability of affordable, accessible housing, emphasizing the following housing policy goals for people with developmental disabilities: housing policy will focus on supports, environmental adaptations, and housing selected by the individual and tailored to individual needs; policy will emphasize providing flexible supports in the way the person with disabilities wants them to be provided; housing policy will empower people with disabilities to live in integrated neighborhoods among people without disabilities, to own or rent their own homes, and to live with people they choose; assure that children live in family homes; and housing financing will focus on providing resources to people rather than to facilities. Funding for housing should be based on an empowerment model, not on a medical care model. <MI>

Congress should expand federal housing program leadership, emphasizing accessibility, affordability, and rehabilitation of existing houses, in ways that support or enrich community and neighborhood building programs. <MI>

The governor should direct, and the legislature should support aggressive expansion of supported independent living programs. Expansion should include developing co-ops, shared housing. <MI>

Congress should enact comprehensive Medicaid reform (e.g., the Chafee Amendments) that will shift financial incentives from institutional, facility-based care and residences to individualized supports and living arrangements. <MI>

Develop tax credits for investors or contractors who create additional accessible housing units that meet consumer needs and provide tax incentives and low-interest loans for modifications and renovations to existing buildings in the community. <MI>

Expand federal HUD Section 8 housing subsidies or other means of flexible financial support, and providing a set-aside for people with disabilities. <MI>

Enact legislation such as the bipartisan-supported National Affordable Housing Act of 1988 (S.565/566) <MI>

Service providers and advocacy organizations should provide more information to people with disabilities, to help them find, choose, and maintain the housing that best meets their individual needs. <MI>

The state, regardless of Medicaid requirements, should expand and strengthen community services development and public planning processes. This should include a broad array of housing options and use multiple public and private financing sources. Efforts should emphasize options that promote independence, productivity, and integration into the community. <MI>

The Michigan Department of Mental Health should provide housing options with supports for at least 500 additional people with developmental disabilities per year who have never lived in institutions, and for 500 per year who are moving out of institutions, including nursing homes. <MI>

The Michigan Developmental Disabilities Council and other organizations should support development of a consumer-oriented central housing resource clearinghouse, within an organization such as Housing Alternatives. <MI>

The state and federal governments should explore alternative uses for the real estate of large institutional programs. Investment income derived from these properties should be used exclusively to support community-based programs. <MI>

The Michigan Departments of Mental Health, Social Services, and Public Health should strengthen regulatory oversight for health and safety standards by jointly clarifying responsibilities and the checks and balances in the system continually reviewing and revising licensing standards to assure that they are not barriers to independence, productivity and integration in the community for residents of supervised community residential programs; and, with legislative support, increasing capacity to enforce existing licensing regulations by enabling closer, more frequent inspections of AIS, Adult Foster Care and contract homes. <MI>

Michigan must comply with the new Medicaid Intermediate Care Facility/Mental Retardation (ICF/MR) regulations and P.L. 100-203 (nursing home reforms) in ways that promote the use of community alternatives rather than increase resources dedicated to institutions. <MI>

The Michigan Departments of Mental Health and Social Services, with advocacy organizations and people with disabilities, should develop an interagency process to screen, train, and monitor direct care staff, case managers, and housing providers, in the issues of normalization, respect, dignity, quality of life, and individual needs planning. Agency budgets should be increased, if necessary, to train case managers and housing providers on housing options, quality care, and activities to support and promote independence. <MI>

We must develop and implement comprehensive housing and home living for persons with disabilities to ensure that: children will live with and as members of family, not in group or congregate settings; adults will have a choice in the style, location, and nature of their housing, and be assured of tenure in that housing; and support services and adoptions will be provided so that individuals can live in the housing of their choice. <MN>

We must develop and implement comprehensive housing and home living for persons with disabilities to ensure that the use of existing housing stock will be emphasized, and that new housing is developed which is "typical" in nature; individuals will have the right to

choose the people with whom they live; accountability (to prevent abuse and neglect) will be based on the degree to which an individual's housing and home life is developed and supported so as to maximize the individual's independence, productivity, and integration into the life of the community; and eligibility for supportive housing (typical housing with special support, rather than special housing) will be based on the need for support, rather than any diagnosis or label which implies the need for support. <MN>

Priority attention will be given to the development of new housing and home support options for individuals who are currently unserved or underserved, rather than placing such individuals in existing services that do not respond to their needs. <MN>

Federal and state funding for housing and home living must be reformed to ensure that individuals with physical disabilities, emotional problems, and sensory impairments have full access and that these programs support individuals and their families. <MN>

All new dollars for the Divisions of MR/DD and CPS related to placement and housing should be channelled into supporting individuals to live in a full array of housing alternatives within the community. <MO>

An array of accessible housing options within the community should be developed for all persons with developmental disabilities. <MO>

Housing options should be developed using a variety of generic funding sources (e.g., HUD, low income housing assistance, etc. <MO>

An array of support services should be developed which assists persons with developmental disabilities to live in the residence of their choice. <MO>

Missouri statutes which exclude persons with developmental disabilities other than mental retardation from community placement through the Division of MR/DD should be revised. <MO>

When making placement decisions, families and consumers should be presented with options which promote community integration. Family counseling should be offered to families who are placing a family member. <MS>

Special efforts should be made to work with the state's vocational rehabilitation agencies, the Mississippi Council on Developmental Disabilities and other experts to identify housing needs of people with disabilities and develop strategies to address identified needs. <MS>

In-home services should be expanded by all state agencies now providing them to reduce the demand for placement of consumers with developmental disabilities in congregate care facilities. <MS>

The state should access all available federal funds for providing housing for people with disabilities. <MS>

The implementation of the new ICF/MR regulations and P.L. 100-203 (nursing home reforms) should be carried out in ways that promote the use of community alternatives such as apartments. <MS>

The availability of small community-based housing should be expanded so that more residential options are available for consumers with developmental disabilities when their natural homes are not an option. <MS>

Housing policy goals for people with developmental disabilities should be focused on supports, environmental adaptations, and housing characteristics selected by the individual and tailored to individual needs. <MS>

State agencies should examine existing models of "shared housing" and determine its applicability for Mississippi. <MS>

Additional efforts to improve access should include an increase in the number of group homes for people with chronic mental illness, operated by state hospitals or regional mental health/mental retardation centers, and the opening of group homes for children with emotional disturbances to prevent institutional placement or to provide placement for adolescents ready for discharge from the state hospital. It is recommended that further development of long-term care beds specifically designed to serve the MR/DD population should be located outside existing institutions and if possible be 15 beds or less in size. <MS>

The federal Fair Housing Act should be fully implemented in Mississippi so that all citizens with disabilities have the right to reside wherever they wish. <MS>

The federal government should create a set-aside portion of Community Development Block Grant funds to be used for developing or modifying housing for people with developmental disabilities. <MS>

Federal regulations should be amended so that in all housing subsidized with federal funds, standard definitions of "disability" are included and the requirement that 10% of all tenants be people with disabilities is enforced. <MS>

The state should access all available funds and use all existing resources to increase the numbers of people with developmental disabilities earning minimum wage or less who are able to live in subsidized housing. <MS>

Federal and state funds targeted for expansion of residential services should be utilized to provide small community-based housing for people with developmental disabilities. If

possible, this housing should contain the same number of residents as do the homes in the neighborhood in which non-disabled people reside. <MS>

Rental assistance for low income housing for persons with disabilities should be established. <MS>

The Mississippi Legislature should establish state tax credits/tax deductions to families or individuals who provide a home and supervision/care for family members or other persons with developmental disabilities. <MS>

More residential services must be developed for persons with disabilities, with some of them designated for specific groups of person with disabilities (e.g., Prader-Willi syndrome, children, elderly persons). <MT>

Attention should be given to dissatisfactions expressed by persons residing in group homes to determine the source of their difficulties. <MT>

Supervised independent living arrangements need to become increasingly available as more persons with disabilities become capable of residing in those settings. <MT>

Homemaking assistance and training needs to be increased. <MT>

Housing subsidies (e.g., section 8) need to be increasingly available and procedures for acquiring them need to be more manageable. <MT>

Residential services should be more individualized to the specific needs of persons with disabilities rather than making them match the services offered. <MT>

Residential staffing in group homes should be sufficiently flexible to accommodate elderly persons with disabilities remaining at home on "retirement" status instead of being required to spend their days at a day program. <MT>

Service providers in residential facilities must receive higher quality training and sufficient pay to reduce staff turnover and assure that clients receive capable and competent services. <MT>

The state of North Carolina, through the Department of Human Resources, must make a commitment to serving individuals in the setting of their choice with necessary supports. It is essential that a broad spectrum of residential models be identified as options. Settings which maximize the degree of independence that people with developmental disabilities can achieve should be emphasized. <NC>

The Department of Human Resources must work closely with all agencies and organizations who currently have waiting lists to accurately assess (i.e., avoiding duplications) the level of unmet need. This information must be incorporated into the planning process for residential plans. <NC>

Efforts must begin immediately to upgrade salaries and fringe benefits for employees in community residential settings. They should, minimally, equal salaries and benefits for institution employee by SFY 1995-1996. <NC>

A statewide ten year plan which identifies critical variation in residential requirements and charts a timeline for development of new services should be completed by the Department of Human Resources no later than July 1, 1992. <NC>

Plans to demonstrate residential staff training programs through the state's community colleges should be pushed forward. Opportunities to initiate training programs in four-year colleges and universities as well as efforts to improve in-service training will be explored by the Council on Developmental Disabilities. Issues concerning certification of all residential staff should be studied and resolved by January 1, 1992. <NC>

The state must develop a policy for children who need out of home placement. <NE>

Support services must be developed to assist families who wish to care for members with developmental disabilities in the home. <NE>

Permanency plans including transition into adult life need to be developed for all children with developmental disabilities within the foster care system. <NE>

The availability of supervised residential services for persons with developmental disabilities other than mental retardation should be provided. <NE>

The Council should assist agencies in responding to "second generation" issues arising from deinstitutionalization. Community Development Projects which are currently being initiated are a good first step. Application for federal/private grants, in order to address systems flexibility issues should also be considered. <NH>

The APTD program, as currently established, should base different "standard of need" levels for supplementation on differences in need for residential support services and not on the type of residence, in order to remove a current financial incentive for grouping people with disabilities into residential facilities. <NH>

The Department of Education and the Department of Health and Human Services should evaluate the service outcomes achieved under the current Inter-agency Agreement for

the provision of services to students with severe disabilities at risk of being placed in residential schools when their parents cannot support them at home. Revisions or implementation plans should be developed as needed to achieve the goals of the agreement. Consideration should be given to (a) delineating the respective responsibilities of the Departmental Services and Division of Children and Youth Services more explicitly and (b) establishing a mechanism for the joint funding by both departments of a comprehensive plan of services. <NH>

School districts should be allowed and encouraged to submit plans for the expenditure of state Catastrophic Aid funding to purchase services, including family/community residential supports, which (a) achieve the goal of insuring an appropriate education within the district for students currently served in a residential placement out of district and (b) reduce the cost to the state below the cost of residential placements. This will require legislative attention. <NH>

A mechanism should be available within the State Department of Health and Human Services for the provision of alternative family care for children with developmental disabilities when their natural parents are unable to maintain them at home. Such mechanism should not require an accusation of delinquency, abuse or neglect, and should allow for involvement on the part of parents in decision-making and the child's care. <NH>

Efforts to individualize the funding of residential supports should continue. A mechanism that should be given consideration is the development of a "Recipient Funding Plan" option. Through Recipient Funding Plans a consumer, with assistance from their family, guardian, or case manager, would have the opportunity to propose a plan for residential assistance and receive the funding to contract directly for needed services upon approval. <NH>

A study of local government home inspection procedures and certification requirements for family residences should be undertaken to insure that these requirements are consistently applied and directly related to the health and safety of residents. <NH>

Residential service providers should establish linkages with groups assisting low-income individuals to find affordable housing. These include regional housing authorities, city planning offices, banks and investment brokers. Agreements should be developed with representatives of each group to insure that people with developmental disabilities are afforded the maximum utilization of available housing programs and incentives. Statewide efforts could be highlighted by the creation of Governor's Task Force on Housing Disability. <NH>

Efforts to decrease the number of persons with developmental disabilities within institutional settings should continue. Alternative arrangements for the use of Laconia Developmental Services buildings and grounds should be developed as the resident

population continues to decrease. In addition, long-range cooperative planning will be required to develop adequate community residential options that provide alternatives to the admission of people with developmental disabilities to other institutions, and allow the same opportunities for discharge of New Hampshire Hospital residents with developmental disabilities as other residents. <NH>

A Task Force on Housing should be convened composed of representatives of appropriate state agencies, private providers, builders, realtors, and consumers to construct a state policy on housing for people with disabilities, develop a comprehensive housing plan, and recommend appropriate actions, including legislation and funding. <NJ>

The Task Force on Housing should be consumer driven and provide ongoing examination of all of the critical issues identified in this report including, but not limited to: innovative methods of public and private funding for housing (more agencies are needed to "cultivate" housing than currently exist) cost reduction possibilities for construction of new housing for persons with disabilities; housing needs throughout the state; and strategies for increasing community involvement and support. It is recommended that the Developmental Disabilities Council be the agency that convenes this body. <NJ>

The Division of Developmental Disabilities must establish a consistent policy in their approach toward housing that will provide direction to their management people. Policy goals should be redefined to focus on supports; environmental adaptations, and housing characteristics selected by the individual and tailored to individual needs; empower individual adults to own or rent their own homes; and ensure that children live in a family home. <NJ>

Affordable housing and homelessness will be a major issue confronting New Jersey over the next several years. It is essential that policy makers and legislators are made aware of and address disability issues in the area of housing as the development of policy and programs regarding affordable housing and homelessness evolves in New Jersey. <NJ>

It is recommended that the Department of Human Services create a Housing Development and Technical Assistance Center to promote new housing opportunities for people with disabilities by encouraging and supporting participation by private investors, families, agencies, family and boarding home operators in the development of housing alternatives; providing technical assistance in zoning, prior notification of plans to municipalities, fire codes, building codes and rooming and boarding home regulations; providing training and management assistance for less experienced sponsors; and developing and coordinating the delivery of education programs to help create a public climate more conducive to the acceptance of people with developmental disabilities in the community. <NJ>

The state should re-examine its policy of providing direct institutional services and contracting for community services. State employees and facilities could be used to provide services in less restrictive settings. <NM>

Continued development of housing options should be encouraged to meet the needs of persons with developmental disabilities. A system that has a broad array of services should be encouraged and supported. <NM>

Boarding and Care Homes in New Mexico should be licensed and monitored to assure appropriate services are provided to residents. <NM>

Housing policy goals for people with developmental disabilities should be redefined to focus on supports, environmental adaptations, and housing characteristics selected by the individuals and tailored to individual needs; empower individual adults to own or rent their own homes; and ensure that children live in a family home. <NM>

Identify methods of using the Housing and Urban Development Section 202 Direct Loan Program in New Mexico. <NM>

Identify methods of expanding the number of affordable housing units in New Mexico. <NM>

Housing availability (residential group homes, supervised and semi-supervised apartment living and transitional housing) must be established in all geographic areas of the state for persons with physically disabilities. <NV>

Planning for establishment of specialized housing must include provisions for ventilator dependent residents. <NV>

Affordable and accessible independent living alternatives, meals, attendants and transportation need to be increased. <NV>

Funding utilized for institutional care should be diverted to community-based alternatives. <NV>

A legislative subcommittee should be established to identify and assess the housing needs of consumers with severe disabilities. <NV>

Housing alternatives and choices should be provided to assure that younger individuals with disabilities not be placed in facilities primarily servicing geriatric populations. <NV>

Consumer appointments to housing authorities and planning boards should be required to assure consistent input into housing issues by the consumer population. <NV>

Statutory housing rights for a full range of disabilities should be legislated. <NV>

The option to provide rehabilitation services including non-ICF, non-hospital based residential placement through Medicaid resources should be implemented and adequately funded. <NV>

Subsidized housing should insure nonsegregation of people with disabilities and should include them in all planning activities. <NV>

Congress should act to remove restrictive language tying eligibility for the Medicaid home and community based service waiver to eligibility for institutional services. <NV>

Legislation should be developed and enacted to remove the restriction that Title XIX Medicaid funding may be used only for residential/rehabilitative placement which occurs in a hospital based or intermediate care facility (ICF) setting. <NV>

Additional residential options are needed. Efforts must be made to identify a whole range of residential options so that the limited selection now available can be expanded. Attention must be given to accessing more resources that are available to all citizens and focusing the limited dollars that target services to individuals with developmental disabilities on specialized services. Not only families but also individuals with developmental disabilities must be equal partners in the design and planning of new housing initiatives, remembering that the insights of these two groups are not necessarily the same. <NY>

People with severe and multiple disabilities, including those who are medically fragile or deaf-blind, must have appropriate community based residential options close to their families. Other specialized residential models for people with high specialized needs, including those with traumatic brain injury and Prader-Willi syndrome, must continue to be developed. <NY>

Salaries and benefits for staff of residential programs must be commensurate with the job responsibilities and be more consistent between state and private providers. <NY>

Ensure the expansion of individualized community living options by (1) limiting the expansion of our facility-based residential system and (2) allocating new funds to programs, such as the Supported Living and Medicaid waiver programs. <OH>

Work to obtain increased state and federal dollars, and begin to reallocate the funding currently appropriated to our facility-based institutional and community service programs to support expansion of more individualized residential support services. <OH>

Develop incentives for service providers to convert from the current facility-based system to a system that focuses on providing supports for individuals in their own homes. <OH>

For individuals with disabilities to live in typical housing options in residential neighborhoods with person(s) of their choice, a strong and comprehensive community-based system of supports and services is essential. <OH>

Encourage the development of public and private initiatives to provide loans and expand housing finance options for people with developmental disabilities. <OH>

Ensure that housing for persons with developmental disabilities is affordable, through a system that provides government assistance directly to individuals to be used for rental or purchase of typical residential housing. <OH>

We must break the funding and program link between housing and services. The funding mechanisms for assisting people with disabilities in securing housing should be separate from those used to fund support services. This will provide people much more freedom in choosing where they live and also allow services and funding to "follow the person." <OH>

Expand housing options and develop a more comprehensive approach to ensuring that housing can be made accessible to people with physical handicaps. <OH>

We must abandon the continuum and readiness approach to the delivery of residential services. People with developmental disabilities should not be required to "work" their way to community living. Rather than suffering the dislocation and disruption involved in moving through a continuum of different facilities, an array of services should be available to support people in small home settings. <OH>

Develop an easy-to-use consumer guide concerning accessibility issues, designed and field tested with the assistance of people with disabilities, which can be used to educate architects, builders, inspectors and realtors concerning the housing needs of persons with disabilities. <OH>

Educate people with disabilities, advocates, government officials, service providers, realty boards, apartment associations, etc., about the rights of people with disabilities, especially with respect to the Fair Housing Amendments. If necessary, pass state legislation to facilitate compliance with the Amendments. <OH>

Expand housing options to provide all people with developmental disabilities who need housing with a place to live. <OH>

The present initiatives of the Developmental Disabilities Services Division must be encouraged to continue the movement for increased community services that would make it possible for individuals and families to have a choice in residential alternatives other than large institutions. <OK>

Housing advocacy groups and appropriate state agencies should coordinate and promote the needs of persons with developmental disabilities with the real estate industry in Oklahoma. <OK>

Advocacy groups and appropriate state agencies should establish contact and liaison with the building trade associations to facilitate housing and architectural modification of single and multiple dwelling units. <OK>

Prepare a comprehensive approach to housing. This involves developing strategies to secure the funding described in the beginning of this report to provide for the urgent housing needs of Pennsylvania's citizens with disabilities. <PA>

10% of all Section 202 units build for the elderly must be wheelchair accessible. However, frequently these units are not rented to persons with disabilities. Deliberate efforts must be made to disseminate the availability of these units to the disability community. <PA>

It is recommended that the funding sources be utilized by a state-wide program for home adaptations. This program could employ an incentive program to encourage the private sector to build fully accessible housing and it could disseminate the implications of the Fair Housing Act Amendments. <PA>

It is recommended that a concerted effort be made by state planners to utilize the following housing funding streams in order to expand housing opportunities for citizens with disabilities: U.S. Department of Housing and Urban Development Section 202 funds, Section 8 Existing Housing Certificates and Voucher program, low income tax credits, Farmer's Homes Administration Home Ownership Loan program, the Low Income Housing Demonstration Program and provisions of the Community Reinvestment Act. <PA>

It is proposed that the Puerto Rico Department of Housing shall be responsible for promoting and providing accessible and affordable housing options for people with disabilities. <PR>

Services will allow persons to live at home, not in institutions, and funding will be transferred from institutional based services to home based services. <RI>

The full set of housing alternatives will be available. <RI>

The shortage of residential services for persons with developmental disabilities is crucial. Projections indicate the need will increase faster than the provision of these services. Housing policy goals must reflect this shortage with focus on direction of resources for community based residential facilities. <SC>

Foster care and adoptive services programs require fiscal strengthening to meet the placement demand for special needs consumers. <SC>

A strong consumer/advocate monitoring program is in demand for all residential facilities providing housing for persons with disabilities including foster care, residential care facilities, group homes, supervised apartment facilities, and ICFs/MR. <SC>

Gaps must be narrowed and alternatives utilized to allow children who are medically fragile and/or technology dependent to have home based care. <SC>

The impact of the Omnibus Budget Reconciliation Act of 1987 requiring relocation of persons inappropriately placed in nursing homes and the provision of active treatment required by the legislation has not yet been felt, but it is not premature to suggest that resources will need to be increased to support housing alternatives for this population of consumers. The Home and Community Based Waiver could be utilized to extend fiscal help for compliance to this legislation. <SC>

Community and individual housing support models should be translated into fiscal policies. <SC>

Foster care and adoptive subsidies for special needs children should reflect the realistic financial assistance required in providing for the often complex medical services children with special needs are likely to have. <SC>

South Dakotans should examine the experiences of other states that have used supported living arrangements as a means of meeting the diverse residential services needs of persons with developmental disabilities and determine the steps necessary to implement such programs across the state. <SD>

We recommend that the state continue with its plan to employ the HCB waiver program as the primary means of responding to the needs of persons with developmental disabilities who are displaced as a result of the nursing home reform provisions of OBRA-87. The HCB waiver program provides significant opportunities for the state to tailor individualized programs to meet the needs of such persons. <SD>

South Dakota should commit itself to taking the steps necessary to reduce the number of persons served at Redfield and Custer State Hospitals to 250 or fewer individuals within the next three-to-five years, preferably as part of the recommended strategic planning process. <SD>

There should be Medicaid reform to promote the use of community alternatives rather than increased resources in institutions. Funding for housing should not be based on a medical care model. <TN>

There should be more creative/flexible federal and state funding for housing available to persons with developmental disabilities. <TN>

The Tennessee Independent Living Centers should develop and share with communities across Tennessee ways of implementing the 1988 Fair Housing Act Amendments as they relate to persons with developmental disabilities. <TN>

The Tennessee Housing Development Agency, with consumer participation, should develop a plan to promote appropriate housing opportunities for Tennesseans with developmental disabilities. <TN>

The Department of Housing and Community Development should expand financial and technical assistance for modifying existing housing units to increase accessible housing opportunities for persons with disabilities. <VA>

Agencies of state government providing housing and other services to persons with disabilities and disability advocacy organizations should work collaboratively with the housing industry to make residences and support services, including personal assistance, available to people with disabilities. <VA>

The General Assembly should establish and fund a rental assistance program for persons with disabilities who meet low income criteria. <VA>

The Board of Housing and Community Development should insure compliance with the federal Fair Housing Amendments Act of 1988 through the Uniform Statewide Building Code. Enforcement of the Act's adaptability and accessibility requirements should receive high priority from the Department of Housing and Community Development, and continuing education and training should be provided to building designers and inspectors. <VA>

The General Assembly should establish state tax credits/tax deductions for families or individuals who provide a home and supervision/care for family members or other persons with developmental disabilities, if such living arrangement and care represents the "least restrictive environment" available during the applicable tax year. <VA>

Eligibility standards for various types of housing must include more flexibility to accommodate people requiring a variety of supports. For example, a single person requiring a personal care attendant should be eligible for a two bedroom apartment, as was done in the South Meadow Project in Burlington. <VT>

Funding for housing must be based on a model which focuses on the provisions of medical care. Funds to expand and support community living options on an individual basis should be shifted from medically oriented programs as quickly as possible. <VT>

The state of Vermont must promote the coordination of various incentives and initiatives for affordable and accessible housing such that all regions of the state have the opportunity to participate and to insure that persons with disabilities will be able to live

in the region of the state of their choice. The state must recognize that housing must be made available in reasonable proximity to services that people with developmental disabilities may need. For example, support for more programs like the Community Land Trusts in which several communities in the state are participating. <VT>

Housing regulations must require that all units in a development be designed so that they can readily and economically be made physically accessible, thus promoting freedom of choice for all prospective residents. <VT>

Funding must be provided which will permit increased opportunities for accessibility modifications to existing housing, thus permitting more people with disabilities to stay in their own homes. <VT>

Funding sources must be realigned to focus on resources to individuals rather than facilities (for example, the Section 8 Housing vouchers.) <VT>

Housing policy goals for people with developmental disabilities must be redefined to focus on individual needs, to empower individuals to own or rent their own homes, and to emphasize that children live in a family home. <VT>

Professional foster homes should be developed and supported for the placement of severely involved, medically fragile children. <WA>

The basic foster care rate should be increased to adequately reflect the real cost to families, especially for children with special needs. <WA>

Promote meaningful, supported integration in the community. Costs of home modification to increase integration, accessibility and independence should be covered by the Home and Community-Based Waiver or by the Personal Care Option. Direct reimbursement would also be a strong option. <WA>

Provide public education and technical assistance to access current housing programs. Promote public and private finance partnerships. <WA>

Simplify, combine and coordinate all government housing programs and services. In particular, combine rental assistance programs. Establish uniform policies where possible. <WA>

The state must provide more money to deliver personal assistance services so families can take advantage of community housing. Addressing this issue would allow the Housing Trust Fund service support component to be utilized. <WA>

Give people as many options and opportunities to make meaningful residential choices as is possible. Foster the trend toward home ownership and tenant management opportunities. <WA>

Provide an array of housing options and services to meet individual needs at any given point in the natural life cycle. <WA>

Provide a fair proportion of both new and existing subsidized housing for people with disabilities. <WA>

Raise rent subsidies to a realistic, local marketplace level. <WA>

Provide incentives for owners of new buildings to maintain a percentage of their units for low-income individuals and families. <WA>

Create incentives and options for nonprofit agencies and organizations to buy, build and maintain low-income and special needs housing. <WA>

Provide nonprofit agencies with the technical assistance necessary to put together financial packages for low-income housing. <WA>

Increase affordable, available low-income housing: provide more dollars for both new construction and rehabilitation of existing structures; increase the number of housing assistance vouchers available; and keep housing that was built with public subsidies or incentives available for low-income families. <WA>

Develop a comprehensive, unified national and state housing policy that encompasses the vision, goals and recommendations for this report. <WA>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to live in a home that provides security, comfort, personal space, and a sense of ownership. <WI>

Develop clear state policies and a long-term state plan regarding the current and future roles, respectively, of the State Centers for the Developmentally Disabled. Policies and plans should address adopting and implementing the state institution down-sizing and depopulation recommendations included in the Ernst and Whinney study, full implementation and monitoring of the timetable to reduce the State DD Center population by 40% by 1993, and development of a plan for the training and redirecting of employees displaced as a result of DD Center resident reductions. <WI>

Develop clear state policies and a long-term state plan regarding the current and future roles of nursing homes and ICFs/MR in serving people with developmental disabilities, focusing on the substantial reduction of this practice. Policies and plans should include

a timetable for reducing the number of individuals with developmental disabilities currently in distinct-part ICFs/MR with 16+ residents, particularly for those people under age 65, a limitation on the number of new distinct-part ICFs/MR that can be certified, an assessment of the trend of placement alternative being used to meet the requirements of the 1987 OBRA Act, the development of recommendations concerning the use of appropriate community-based alternatives rather than distinct-part ICFs/MR, an overall policy emphasis on funding small community-based options for re-locating and diverting people from ICFs/MR and regular nursing homes, a policy statement that residents currently in large ICFs/MR and regular nursing homes should be considered to be there on a temporary basis, pending aggressive placement efforts in community-based settings. <WT>

The human service system's priorities and resources need to be shifted from out-of-home placements to in-home supports. <WV>

Changes are needed at the federal level that make individualized, home-based supports an entitlement under Medicaid, rather than a state option that is available only to children who would otherwise be institutionalized. <WV>

Training and technical assistance should be provided to people with developmental disabilities, their families and service providers regarding the development of individualized services. The service design process used by the Medley Project should be extended to non-Medley individuals as well. <WV>

Better systems are needed for supporting people with challenging behaviors in community living arrangements. <WV>

The most critical reforms needed at the federal level are revisions in Medicaid that include individualized supportive living arrangements and related services as entitlements for people with disabilities. Also needed is expansion in funding to support people in affordable and accessible homes. <WV>

The current moratorium on the development of new ICF/MR facilities should be continued and extended to non-ICF/MR group home development as well. <WV>

A major overhaul is needed of present policies and funding mechanisms for living arrangements in order to support more integrated and individualized options. Public policies and funding should encourage people with developmental disabilities living in their own homes, with people of their own choosing and in the neighborhoods they prefer. <WV>

Funding strategies for community living arrangements need to include enhancements in direct service staff wages and benefits in order to recruit and retain qualified personnel. As recommended by the former Court Monitor, the Department of Health and Human

Resources should convene a task force to study the issue of staff salaries and make recommendations for improvements. <WV>

With Wyoming's effort to obtain an ICF/MR unit good data on costs and services need to be maintained in order to enhance community-based options along with the ICF/MR option. <WY>

HEALTH: BARRIERS

Multiple States

States have total discretion in determining how much of their Maternal and Child Health block grant funds are allocated to PCSHCN activities. <ID,IN,MT,TN,UT,WY>

Many states ration their limited PCSHCN service dollars by favoring younger children over older children or by excluding from coverage such major childhood disabilities as diabetes, cancer, asthma, sickle cell anemia, mental illness, or developmental disabilities. This has created inequities in serving certain groups while rejecting others who are just as deserving. As a result, political advocacy has influenced the resource allocation more than a rational planning process which is guided by general principles oriented to improving access to health care for all children with special health care needs. <ID,IN,LA,MT,TN,UT>

Fiscal constraints limit the capacity of the Children with Special Health Care Needs (PCSHCN) programs to provide a gap-filling role for all children with special health care needs. To limit the great demand for scarce public funds to supplement the inadequacy of acute care private health insurance, many states have arbitrarily limited eligibility to this program by targeting different diagnostic groups or ages of children. <HI,ID,IN,LA,MT,TN,UT>

Many people with disabilities who do not meet the income, asset, and disability criteria for SSI are not eligible for Medicaid even when private health insurance is unavailable to them or inadequate for their health care needs. <ID,LA,MT,NJ,UT,WY>

Fiscal issues underlie most of the limitations of public health care programs. <MT,TN,UT,WY>

States are generally hesitant to amend their Medicaid plans to add optional services or increase benefit levels because Medicaid requires them to extend those services to all people who meet the eligibility criteria. <MT,TN,UT,WY>

As recently as 1945, only one-quarter of the U.S. population had any health insurance, and it wasn't until the mid-1960s that the majority of Americans had more than hospitalization insurance. <MT,UT>

Employers are not required to provide health insurance to their employees or to their dependents as they are required to provide Social Security contributions, workers compensation, unemployment compensation, and minimum wages. <ID,LA,MT,NJ,UT>

The linkage of Medicaid to SSI in most states provides access to health care for many people with disabilities who are eligible for SSI. In 14 states referred to as 209(b) states,

however, a more restrictive eligibility criteria is used to determine eligibility for Medicaid. <LA,MT,UT>

The right to health care is available only to people over 65 who are eligible for Medicare. This is limited to acute care needs, however. <ID,LA,MT,NJ,UT,WY>

While high risk pools allow some people to purchase health insurance who would otherwise not be able to, the high risk pool creates certain problems. By concentrating people with high risk in one pool which does not contain people of lower risk, the average cost is high which creates pressure for high premiums, high deductibles, and high co-payments. High risk pools are generally very expensive for the consumer. <ID,MT,UT>

Private insurers are permitted to develop and utilize their own actuarial methods to assess risk, and to exercise wide discretion in rejecting applicants, imposing pre-existing condition exclusions, or raising premiums. <LA,MT,UT>

Self-insured employers are exempt from state regulation due to the federal Employee Retirement and Income Security Act (ERISA) law which ironically does not contain any federal standards for health insurance. <MT,UT>

Insurance is supposedly regulated at the state level but only two states (Hawaii and Massachusetts) have passed laws requiring employers to provide health insurance. <LA,MI,MT,UT>

Although the American public increasingly views health care as a right and the health care system as operated to ensure access to comprehensive health related services, the right to health care remains underdeveloped in public policy. <ID,LA,MT,UT,WY>

Medicaid does not cover over 60 percent of the low income population. <ID,MT,UT,WY>

The establishment of high risk pools runs the danger of legitimating the exclusion of so-called high risk people from private health insurance and may create incentives for dumping by private insurers. <ID,LA,MT,UT>

The federal ERISA law prevents states from requiring contributions to the high risk pool from self-insured employers, which excludes the fastest growing sector of group insurance policies. <ID,MT,UT>

By modeling high risk pool benefits after major medical insurance plans for people without disabilities, many health related services needed by people with disabilities are not covered by high risk pools. <ID,LA,MT,UT>

People should not have to sacrifice their access to health insurance by working. <MT,WY>

In addition to data collection on the adequacy of private insurance, states have an important role to monitor the quality of health care available to people with disabilities. This means the level of training, accessibility, and availability of providers. <MT,UT>

Even though the federal government is expected to provide a subsidy of over \$37 billion in 1989 to employers who contribute to the health insurance of their employees, by permitting the use of tax-free dollars, the federal government has not specified the minimum essential features of a group health insurance plan. <MT,UT>

The federal and state governments do not regulate the medical underwriting process or maintain actuarial statistics which the insurance industry must use or often the insurance industry claims it cannot develop a premium for a specific disability group because it does not have sufficient actuarial data on that group which it has continued to deny for insurance. <ID,MT,NJ,UT,WY>

Although the federal government provides a higher Medicaid matching rate for poorer states, the wealthier states continue to spend more Medicaid dollars per capita than the poorer states. The differential matching rate does not increase the capacity of the poorer states to generate their own revenues which would be required to expand the Medicaid program. <MT,TN,UT,WY>

The determination of who is eligible for health insurance has largely been left to the discretion of private insurers who are more concerned about making a profit than about spreading health related costs equitably throughout the population. <ID,MT,UT,WY>

Existing national surveys do not reveal the extent to which people with specific disabilities have pre-existing condition exclusions or pay a catastrophic percentage of their income in out-of-pocket costs. <ID,MT,UT>

Many people with disabilities do not have private health insurance even when employed. <ID,IN,LA,MT,UT,WA,WY>

The move toward capitated payments has been encouraged as a cost containment strategy by both private and public payors of health insurance. One area where capitated payments are used is in health maintenance organizations (HMOs). The impact of HMOs on people with disabilities or chronic illness needs to be closely monitored. <IN,MT,UT>

Primary gatekeepers in HMOs are often not sufficiently knowledgeable about special health care needs nor empowered to authorize referrals to specialists who are not affiliated with the HMO. <IN,LA,MT,UT>

HMOs offer limited benefits for extensive hospitalization or rehabilitation. <IN,LA,MT,UT>

There is an institutional bias among both private and public third party payors to limit coverage to people whose health condition is of sufficient severity to require hospitalization. This institutional bias limits access to covered services for many people with disabilities, and results in many services being provided in an institutional setting which interferes with normal activities associated with living independently or productively. <HI,ID,IN,LA,MT,NM,UT,WY>

Private health insurance has evolved in the U.S. to cover acute medical needs, not on-going maintenance needs. <ID,IN,LA,MT,WY>

Medicaid reimbursement levels are generally far below the reasonable and customary rates even though providers may have to spend considerably more time with people with disabilities, and are required to accept the Medicaid reimbursement as payment in full. <IN,MT,NJ,TN,UT,WY>

As many as one-third of SSDI beneficiaries are uninsured at some point during the two year waiting period for Medicare. <AZ,IN,LA,MI,MT,NJ,NM,TN,UT,WA,WY>

People who qualify for Medicare on the basis of disability are eligible only after a 24 month waiting period. <AZ,ID,IN,LA,MT,NJ,NM,TN,UT,WA,WY>

Federal and state laws restrict Medicaid to people who meet the income, asset, and disability criteria for eligibility. <IN,LA,MT,TN>

Although public health care programs play an important role in substituting for private health insurance, they have many critical limitations. <ID,IN,LA,MT,TN,UT,WA,WY>

In the absence of a 1619 type protection in the SSDI program, the loss of Medicare for people with permanent disabilities could create a disincentive for SSDI beneficiaries to enter the labor force if they anticipate difficulties purchasing private health insurance. <IN,LA,MT,UT,WY>

Medicare will not cover rehabilitation therapies for people who are not expected to make measurable functional progress even though they are likely to functionally degenerate without the rehabilitation therapies. <AZ,HI,ID,IN,LA,MT,TN,UT,WY>

While Medicare will cover wheelchairs as durable medical equipment, Medicare does not cover augmentative communication devices for a person who does not have the capacity to speak or hearing aids for a person who has difficulty hearing. <AZ,HI,ID,IN,LA,MT,NM,TN,UT,WY>

Medicare benefits do not include many of the health related services which are crucial to the ongoing health support for people with disabilities. <HI,ID,IN,LA,MT,NM,TN,UT,WY>

The waiting period for Medicare can interfere with early medical rehabilitation which is essential for helping people increase their functional capacity. <AZ,HI,IN,LA,MI,MT,NJ,TN,UT,WA,WY>

Many SSDI beneficiaries die before becoming eligible for Medicare. <IN,LA,MI,MT,UT,WY>

To promote cost-containment, the major payors of health insurance have resisted cost-shifting by health care providers which reduces their capacity to provide uncompensated care. <IN,MT,UT>

Increased use of medical testing and advances in the technology of predictive tests are likely to be used by the private insurance industry for denying people health insurance coverage rather than for expanding access to preventive services. <ID,IN,MT,UT>

The move from community rating to experience rating has segmented the insurance market. People with higher risks are increasingly isolated from people with lower risks. <IN,LA,MT,TN,UT,WY>

Many people with disabilities and their families have been forced to bankrupt themselves in an effort to meet ongoing health care costs often leading to unnecessary and expensive institutionalization. <HI,ID,IN,LA,MT,UT,WA,WY>

Many people with disabilities have higher health care costs than people without disabilities. The health care costs are higher because of the greater use of acute care services, rehabilitation services, and on-going maintenance services. <HI,IN,LA,MT,TN,UT,WA,WY>

The health care costs are not well known for people of different ages and levels of severity, and different disabilities. The lack of data reflects the limitations of national surveys which have difficulty both identifying persons with low prevalence conditions and measuring health care costs from self-reported data. <MT,UT>

Insurers are not required to provide health insurance to people who need it at an affordable price. <IN,LA,MT,UT>

Families of children with mental retardation and physical disabilities were three to four times more likely to experience out-of-pocket costs over 5 percent or 10 percent of their income than families of children with mental retardation without accompanying physical disabilities. <ID,IN,LA,MT>

As long as private insurers are permitted to view disability as a pre-existing condition with predictable higher health care costs, they have an incentive to reject people with

disabilities, impose pre-existing condition exclusions, or raise premiums, sometimes to an unaffordable level. <ID,IN,LA,MT,UT,WY>

Among all children with severe or profound levels of mental retardation who had private health insurance, the private health insurance paid approximately 50 percent of their medical expenses, uncompensated care accounted for 25 percent, families contributed around 15 percent, Medicaid paid about 5 percent, the state Program for Children with Special Health Care Needs contributed around 1 percent, and other payors provided around 5 percent. <IN,LA,MT>

Data are generally lacking on the health care costs associated with specific chronic conditions. <LA,MT,UT>

Risk avoidance by the private health insurance industry reduces the spreading of risk throughout the population and increases demand for public health care. <IN,LA,MT,UT,WY>

People with disabilities or chronic illness are increasingly squeezed between a private health insurance system which is designed to charge according the probability of risk, and a public health care system which subsidizes health care on the basis of age, poverty status, and an inability to work. <HI,ID,IN,LA,MT,SC,UT>

Consumers are concerned about higher premiums, deductibles, and co-payments, inadequate coverage, and the growing number of uninsured people. <IN,LA,MT,NJ,UT,WY>

People with disabilities are increasingly vulnerable to restrictive medical underwriting practices of insurers for small groups and individual plans on the one hand and the use of medical testing by large employers on the other hand. <ID,IN,LA,MT,NM,UT,WY>

The federal government is concerned about the prospects of a growing number of people being dumped from private health insurance because of poverty or pre-existing health conditions. <IN,MT,NJ,UT,WY>

The uninsured population has grown to 37 million people, especially among poor children, pregnant mothers, and working-age people with pre-existing conditions such as chronic health conditions or lifelong disabilities. <ID,IN,LA,MT,NJ,UT,WA,WV,WY>

Health care providers are facing uncompensated care of approximately \$10 billion a year which is disproportionately burdening public and non-profit providers that serve low income people. <IN,LA,MT,NJ,UT,WY>

While improvements in the health care system have increased the survivability of people with disabilities, there are growing obstacles to their access to health care. <IN,LA,MT,UT>

Employers are concerned about rising health insurance premiums of close to 20 percent in 1988 which cuts into their profits and undermines their capacity to compete. <ID,IN,LA,MT,NJ,UT,WY>

The health care system is in crisis. Health care costs are continuing to rise rapidly, generating pressure for the major payors of health care to emphasize cost containment. This has led to greater cost-shifting to the health care user and more restrictive health insurance. It has also led to greater use of HMOs and capitated payments which create special problems for people with disabilities. <HI,IN,LA,MT,TN,UT,WY>

Individual States

Given that a disproportionate number of persons who have developmental disabilities are not employed, the question of adequate health care becomes tantamount to their basic survival. Unemployment implies a lack of resources to pay for insurance coverage, to cover out-of-pocket medical expenses (co-payments, prescriptions, equipment, etc.) and transportation to health services. Data from the Harris Poll revealed that even when these individuals are able to secure employment, they often do not have access to private health insurance. <AL>

In Alabama, a state in which there are many rural communities, comprehensive health care services are less readily accessible than in more urbanized states. When a client has developmental disabilities, it is even more difficult to access services. For example, transportation services for people with special problems often do not match with the times that health care services are available. <AL>

A recent study conducted by the Robert Wood Johnson Foundation found that one million Americans are denied health care each year because they cannot afford it. An additional 14 million do not even seek health care because they know they cannot afford it...a comment frequently noted in the Alabama consumer survey data and public hearings. <AL>

As many of the people will have special health care problems that cannot be managed solely by a primary health care provider, it is often necessary for them to commute to centers offering specialized care. When a family member is receiving specialized care, the family often neglects primary care, falsely assuming that primary care is part of the service that they are receiving. <AL>

There is a high incidence of dental abnormalities in persons with developmental disabilities, especially as they age. Thirty-four percent of the 301 persons who responded to this question did not see a dentist regularly. <AL>

Health care services are often inadequate for persons with developmental disabilities. There are many reasons cited for this, and they generally include factors related to the

client population as well as societal conditions such as the preparation of health care providers and the financing of health care. <AL>

Persons with developmental disabilities have reported on several occasions (in the consumer survey) the dilemma they face in obtaining adequate health services due to minimal or absent support services (transportation, architectural, modifications, knowledge of services available, coordination of complex needs, etc.). <AL>

Thirty-seven million Americans have no health insurance coverage — and the number has been rising by almost a million each year since 1980. An additional 60 million Americans have some type of insurance, but that coverage is inadequate. <AL>

Another serious concern in the arena of adequate health care focuses on the number of community hospitals that have closed in the recent past forcing prospective patients to seek medical attention at great distances or not at all. Information provided by the Alabama Department of Public Health, Division of Licensure and Certification reports that ten hospitals across the state have closed in the last two years. <AL>

An investigation of infant mortality rates by county is even more startling. Two counties, Blount and Marshall, report non-white infant mortality rates of 83.3 and 69.0/1000 live births respectively (extrapolated). When compared to data provided by the United Nations' Department of Economic and Social Affairs' Population and Vital Statistics Report, these two counties have higher infant mortality rates than Nicaragua (61.7), Egypt (45.1), and the Dominican Republic (37.6). The irony here is that Alabama has one of the worlds' finest medical centers at the University of Alabama at Birmingham and yet many of its citizens do not or cannot take advantage of those health care resources. <AL>

Fifty three percent of the clients did not have a vision test and 51% did not have a hearing test during the previous year. At least yearly evaluations of these sensory systems are recommended for persons with developmental disabilities. The data also suggested that when an eye examination was conducted, 41.5% of the persons required corrective lenses, verifying the need for these periodical examinations. <AL>

Medicaid is the major national supplier of health insurance to individuals with developmental disabilities. However, health care providers who accept Medicaid-insured patients face a number of financial disincentives that may result in denial of service to those types of patients in the future. Many health care professionals report that treating a person with a developmental disability often requires more time than a patient who does not have a life long and pervasive disability. Should the health care professional extend that extra-precious commodity of time to effectively serve the Medicaid-supported patient, the reimbursement rate is often far below the "reasonable and customary rates." <AL>

When health care services are provided only during the daytime, many of the families who are already financially strained by having a family member with a health care problem find it difficult to take time off from work to keep appointments. <AL>

For the people who have spent part of their lives in institutions, getting access to primary health care in the community is often difficult as there is frequently a lack of knowledge about their past medical history and the management of their health problems. As many of the clients are not good historians, it is often difficult for the new providers to assess the impact of these past health problems on their current and future health status. <AL>

The clients were asked if they had medical insurance. Of this sample, 83% stated they had insurance but 38% of the total (n=112) felt their coverage was inadequate. Additionally, 17% did not have medical insurance. These data continue to document that medical insurance coverage for persons with developmental disabilities is an area that needs attention if people are to receive comprehensive health care services. <AL>

A major barrier to adequate health service is not necessarily a lack of services (except in rural areas) but rather access (transportation) to those services. <AL>

If one gets by accessibility and attitudinal barriers, the person who has a developmental disability may then find the provider unable to knowledgeably handle either the primary or secondary complications resulting from their disability. Information on developmental disabilities is rarely taught in the basic preparation curricula of providers (e.g., physicians, nurses, dentists, physical therapists). Even in specialization programs, little attention is given to the person who has a developmental disability and who is aging, in part because very little is known. <AL>

Of additional concern are those people who do not meet the Medicaid categorically needy criteria and do not have insurance, those who have met the cap on their insurance coverage, those who cannot get insurance due to pre-existing conditions, those with inadequate coverage, and those who cannot use their insurance due to the high cost of an established co-payment. <AL>

Even when health services are available to the general public and transportation or related services is not an issue, there are still problems for those who have developmental disabilities. Regrettably, a number of consumers reported that there were many health care providers who did not want "people who look so different in the waiting room because

the other patients will be offended or repulsed." There is yet much work to be done in the attitudinal area. <AL>

Providing adequate health care services to Alabama's citizens with disabling conditions is an area of urgent concern. The lack of adequate health care services impacts on the

health of future Alabamians. For example, national data from 1986 regarding infant mortality place Alabama as the state with the 5th highest infant mortality rate. <AL>

There are some service areas in which the nationally structured Medicaid program is restrictive as formulated in Alabama. Despite a high rate of federal reimbursement, Alabama extends eligibility to only a portion of applicants for Medicaid services. As is the case in 15 other states, Medicaid eligibility in Alabama is only extended to the categorically needy (CN); that is, those individuals who meet low income criteria. Excluded from eligibility are those individuals who are medically needy, such as the aged, persons with blindness or other disabilities, whose income is above the categorically needy income criterion for the state. <AL>

Other significant health problems in our state have the potential of increasing the numbers of individuals who are at risk for developmental disabilities. Some of those at-risk situations include homelessness, substance abuse (crack, IV drugs, alcohol), and AIDS. <AL>

Most private insurance companies either refuse to insure or will limit coverage for persons with pre-existing health conditions (e.g., people with disabilities.) <AK>

Many people with disabilities who do not meet the income, asset, and disability criteria for SSI are not eligible for Medicaid even when private health insurance is unavailable to them or inadequate for their health care needs. <AZ>

Children's Rehabilitative Services needs adequate funding to enable it to meet all eligible children's needs without long waits. <AZ>

The Arizona Medical program as the safety net for Arizona's uninsured, (AHCCCS) has experienced increasing problems with the "notch group" — anyone who makes too much money to qualify for benefits but who does not have health insurance. The medical community and taxpayers bear the costs when the uninsured become seriously ill; in 1987, Arizona hospitals provided over \$171 million in uncompensated care. <AZ>

In Arizona, a significant proportion of health care for persons with developmental disabilities is provided through Medicaid. Although Medicaid has the potential of being the most comprehensive health care program which can cover most of the health related needs of people with disabilities, it has some serious limitations. The basic state Medicaid plan consists of federally mandated and optional services which the state is obligated to provide to all people who meet the basic financial and disabled criteria for eligibility. Because the Medicaid program is state administered, states can set the "amount, duration, and scope" for all Medicaid services. <AZ>

Children's Rehabilitative Services (CRS) serves children aged 0-21 with special health needs. CRS has also been authorized to serve adults with Cystic Fibrosis and Sickle Cell

Anemia. If a person with a developmental disability does not have one of the disabilities required by the state's definition or cystic fibrosis or sickle cell anemia, they can receive no further services after they reach age 21. <AZ>

Arizona, like other states, is experiencing a growing problem of newborn infants afflicted with substance abuse, the effects of substance abuse, and infection with the HIV virus. At this time the Governor's Council is not aware of any specific programs in Arizona established to deal with developmental disabilities related to these three conditions. <AZ>

Existing national surveys do not reveal the extent to which people with specific disabilities have pre-existing condition exclusions or pay a catastrophic percentage of their income for health care costs. <AZ>

A recent article published by the National Coalition on Prevention of Mental Retardation indicates that children with congenital AIDS usually have central nervous system dysfunction and a developmental disability. The number affected appears to be growing significantly. Children with AIDS will require developmental and educational services in increasing numbers. <AZ>

Attempts to address the "risk pool" problem were made in the 1989 Legislature through a bill to establish an Arizona risk pool. Unfortunately, the bill was defeated. <AZ>

California Children's Services (CCS) excludes many children with chronic conditions even though medical care is needed to prevent regression or to maintain a current level of functioning. <CA>

Many of the more than 29,000 people with epilepsy meeting the federal definition of developmental disability often cannot purchase health insurance. <CA>

Psychotropic and neuroleptic (antipsychotic) medications are sometimes over-utilized in both the developmental centers and in the community as tools to control behavior problems. <CA>

MediCal coverage is often the only way for people with epilepsy to receive the health care that they need, and this constitutes a serious disincentive to employment for this group. Many individuals will remain on SSI to receive MediCal and avoid health insurance struggles, despite work incentive programs such as Section 1619. <CA>

MediCal does not meet the needs of all people with developmental disabilities who require preventive medical intervention and services that foster independence and least restrictive living. <CA>

California Children's Service eligibility is lost for people after age 21 years, often leaving individuals without needed services. <CA>

There is a shortage of medical professionals trained to identifying developmental disabilities. Most physicians receive only minimal training in developmental disabilities while in medical school, and not enough go on to study developmental pediatrics in residency programs. <CA>

There is a serious shortage of health care professionals willing to serve people who pay with MediCal — specifically physicians, dentists, physical therapists, and occupational therapists. Inadequate reimbursement rates along with extensive paperwork and lengthy processing periods are a significant disincentive for professionals to serve people on MediCal. <CA>

There currently is no independent appeals process for California Children's Services. At present, families are not being provided with due process protections. Administrative and eligibility matters are handled informally on a case-by-case basis, not by an independent and impartial due process appeals process. Families need to be able to select their own physicians for second opinions, not solely those who are on CCS lists. <CA>

It is critical that longer-term medical insurance support be available to newly arrived refugees and immigrants. Medicaid benefits extend only eighteen (18) months. However, many refugees become very depressed at a later point, commonly three to six years after arrival, and they cannot care adequately for their children during this time. They have no extended family like many other Asians, and rely on the delivery system or community leaders for support. Most of these people are in menial jobs which do not provide health insurance. <CO>

The special vulnerability of people with disabilities to the limitations of private and public health insurance raises crucial issues that can affect the direction of health insurance reform in the U.S. <CT>

It has been reported that nationally there will be 3,000 pediatric AIDs cases and a possible 20,000 children will have HIV by 1991. Within the next five years HIV may become the largest infectious cause of mental retardation and encephalopathy in children under age thirteen in the United States. <DC>

One in five or 13 million children live in poverty in the United States. There are 12 million who have no health insurance coverage and often go without medical care. The absence of health insurance means that poor mothers are more likely to go without prenatal care, resulting in higher rates of infant mortality and low-birth weight babies. <DC>

Between 1980 and 1986 the average infant mortality rate in the District of Columbia was 21.4 deaths per 1,000 births. The rate for 1988 increased 23.2 percent. The rate for Black infants was 23.9 percent per 1,000 live births. It has been reported that during the

first half of 1989 this rate had increased to 32.2 deaths per 1,000. The dramatic rise in infant mortality is directly related to the epidemic use of crack cocaine which can prompt premature labor and other fetal problems. It is estimated that at least 1,500 "crack babies" are born in the District of Columbia each year. <DC>

A critical nurse/direct-care staff shortage exists now and is expected to grow worse in the future. Public facilities have been less well equipped to compete for the limited number of direct care staff available and have therefore been more severely affected by the shortage. The most visible signs of this trend in the public facilities are citations for deficiencies in quality of care compliance. <DE>

Future residents served by the Long Term Care (LTC) Section of the Division of Public Health will have more diverse problems and more serious and specialized illnesses requiring a broader array of services to be provided. Service gap will continue to exist for multiple disabilities which will require DHSS to serve as a "safety net" filling those service gaps. <DE>

A critical nurse/direct care staff shortage exists now and is expected to grow worse in the future. The Division of Public Health employs professionals from several disciplines that are in a state of severe shortage (i.e., nurses, physical and occupational therapists, speech pathologists, audiologists, and dentists). <DE>

The population aged 75 and older will grow by 42% by the year 1995. This trend will increase the demand for health services in general and for long-term care services in particular. <DE>

Access to necessary health care for the uninsured population is a growing problem especially when the population has special needs. <DE>

The malpractice liability crisis will continue to present challenges to the Department of Public Health in recruitment and retention of staff and ability to maintain an array of health care contractual services.. <DE>

Health care costs in Delaware are increasing more rapidly than the general rate of inflation.. <DE>

Advocates and providers reported that consumers encounter difficulties in obtaining needed, prescribed medications. <FL>

Many physicians will not accept Medicaid patients. They complain that the paper work which is required to be a Medicaid provider is not worth the reimbursement. Some providers will not take patients who have a chronic illness, except on an emergency basis. <FL>

Advocates and providers questioned the evenness in scope and quality of services provided by the County Public Health Units across geographic areas. <FL>

Individuals with developmental disabilities may not meet specific eligibility criteria, such as age or financial status, for existing programs and their health care needs remain unmet. <FL>

Most individuals with developmental disabilities are rejected by insurance providers, even in group policies. If individuals are able to work at a level which results in reduction or loss of Supplemental Security Income (SSI), they may not have access to any health insurance. <FL>

Preventive care and services need to be increased. <GA>

Early intervention services for both AIDS babies and babies born addicted to crack/cocaine need to be expanded. <GA>

Hawaii's PCSHCN program does not have adequate resources to provide services for early identification, follow-up and monitoring. It also lacks adequate resources for "optimal" case management services. <HI>

Poor coordination and communication between private care providers and public agencies, as well as between government agencies, was cited by the PCSHCN program as major barriers. This has created inequities by serving certain groups while rejecting others who are just as deserving. <HI>

Political advocacy has influenced the PCSHCN resource allocation rather than a rational planning process which is guided by general principles oriented to improving access to health care for all children with special health care needs. <HI>

Hawaii has a law requiring employers to provide health insurance; approximately 95 percent of Hawaii's population is covered by some form of private insurance. Employers, however, do not have to provide coverage to part-time employees (under 20 hours per week). A significant percent of people with developmental disabilities do not have full-time jobs. <HI>

The Department of Human Services (DHS) indicates that although Hawaii is a 209(b) State, they generally follow SSI eligibility criteria. DHS Medicaid Administration has indicated that the difficulty with changing to 1634 status lies not with covering the estimated 5,000 additional people, but with revamping the existing application procedures and satisfying federal requirements. <HI>

Many physicians are not trained to provide medical care to people with developmental disabilities. They lack the training to cope with some of the behaviors and are often reluctant to take a patient with a developmental disability. <HI>

In focus groups conducted by the State Planning Council on Developmental Disabilities in 1989, respondents on the islands of Hawaii, Manu, Molokai and Kauai all identified the need for physicians to provide services, particularly the need for dentists and OB/GYNs. <HI>

Many people with developmental disabilities are Medicaid-eligible, however, physicians are not adequately reimbursed for their services and they do not want to take Medicaid patients. <HI>

There is a serious lack of professionals needed to provide appropriate and timely care for people with developmental disabilities. The need is particularly acute among physical therapists and registered nurses. Hawaii does not have a program to train physical therapists and is reliant upon people either coming from the Mainland or local people going to the Mainland for schooling and then returning. Given Hawaii's living costs and low wages, this occurs less and less. <HI>

Among those receiving services from the Medicaid Optional Services program, about seven of every ten consumers and surrogates (68.7%) identify aspects of the program with which they are dissatisfied, including lack of choices about care, denial of services by some providers, billing problems, and an application process that is embarrassing to clients. Some respondents indicate that they receive poorer quality services than persons who do not have developmental disabilities. For example, some providers only see these clients on certain days or after regular business hours. <IA>

It is clear from the consumer forums that Medicaid health coverage for persons with developmental disabilities is both a key service and major source of concern. Consumer comments indicate that this program strongly influences—both positively and negatively— independence, productivity and community integration. The possibility of losing Medicaid benefits is a common fear of people with disabilities and their families. As one parent put it, "I will do anything to make sure my kids get medical and special education coverage. It seems like so much of the time if you don't have a Medicaid card, you aren't going to get help." <IA>

Overall, the SSI eligibility criteria for Medicaid received the greatest negative comment. Families and individuals find this coverage essential and feel the criteria do not realistically reflect the cost of care for a person with disabilities. <IA>

It is clear that each individual's needs are unique, but that the programs available under Medicaid aren't flexible enough to meet those needs. Problems with the requirement for using generic drugs, the complexities of the application process, and the refusal of care

providers to deal with Medicaid clients because of the reimbursement rates are also mentioned. <IA>

Parents are generally unaware Idaho has provisions for waiving parental income in extending Medicaid eligibility to children with developmental disabilities who remain in their family home. <ID>

In Idaho, there exists a gap in service provision to those with developmental disabilities and medically fragile. Currently, Idaho has no community-based program to deliver federally subsidized daily skilled nursing services in the home setting. The obvious question is, what happens when the million dollar insurance policy runs out? The obvious answer is that the child is forced out of the home into a more restrictive institutional setting in order that life-saving services can be provided. <ID>

The impact of HMOs on people with disabilities or chronic illness needs to be closely monitored. <ID>

The concept of non-discrimination does not extend to people seeking medical services on the basis of disability. The Idaho Focus Group noted that in effect, due process rights do not exist in medical services. <ID>

There is a general lack of published information for public consumption concerning health care statistics. <ID>

More post acute care needs to be available for families who want to keep their family member at home rather than institutionalize him or her. <ID>

People attending the Idaho Public Forums believe there is a need for experienced professionals to provide services in communities to individuals with complex medical needs. <ID>

Access to private insurance depends largely on the size of the group with whom one shares risk, not one one's medical condition. <ID>

Idaho Focus Group participants were concerned that where you live drives the medical services you receive. They noted that individuals living in ICF/MRs receive more health related services than those living in shelter care. <ID>

The Idaho Focus Group outlined the need for service flexibility in crisis situations for people who do not have the proper supports. <ID>

For many people, the difference between receiving a related service or not is being institutionalized to receive the "package" of service the facility provides or living at home and not receiving services. Without appropriate health related services, some people with

disabilities would not be able to live at home, get around, work, or participate in the community. <ID>

Clearly, some children with special health care needs are not being served. Because of budgetary limitations, whole categories of children with disabilities are excluded from program coverage, with attendant financial hardship for families. Some are high cost, high incidence conditions. For example, congenital defects of the gastrointestinal or genitourinary tracts are not covered by the Children's Special Health Program and are also ineligible for other programs like SSI. <ID>

Private health insurance is regulated at the state level and changes could be made. There needs to be equal and appropriate insurance coverage across disability groups. <ID>

People attending the Idaho Public Forums felt there should be a Medicaid payment mechanism for registered nurse care for kids using ventilators. <ID>

Idaho Public Forum discussions noted a trustee and benefit budget category should be available for individuals not eligible for Medicaid or in-home assistance. This would be used to pay for incidental medical care such as treatment of middle ear disease. <ID>

Often, children with disabilities are not only uninsured, but uninsurable, because of exclusions by private insurance (e.g., pre-existing conditions). Even insured children may not have coverage for ongoing therapies. Idaho's counties, with their responsibility for indigent medical care, would have difficulty assuming fiscal responsibility for children with special health care needs and the case management functions these children require. <ID>

It is estimated that 198,800 people in Idaho have no form of health care insurance coverage, public or private. <ID>

Idaho Focus Group participants feel there is a lack of coordination between Medicaid, Medicare and Social Security. Information needs to be distributed which details the relationships between the services to better outline what benefits are available. <ID>

Idaho needs a medically needy program that addresses the problems of people who have medical bills which they cannot pay, yet do not qualify for Medicaid. An estimated 18,000 children under five live in households below federal poverty thresholds. There is no catastrophic or "medically needy" category under Medicaid in Idaho, and "Qualified Child" eligibility levels are decreasing to as little as 35% of federal poverty guidelines. <ID>

The health care system is in financial crisis. Many people with disabilities have higher health care costs than people without disabilities. Fiscal issues underlie most of the limitations of public health care programs. Health care costs are continuing to rise rapidly generating pressure for the major payers of health care to emphasize cost containment. <ID>

People with developmental disabilities have difficulties purchasing private health insurance. There are many reasons why accessing private health insurance is a problem but the three most common are: 1) they cannot afford the high cost of insurance premiums; 2) their disability is considered to be a pre-existing condition which disqualifies them from coverage; and 3) their employer does not offer health insurance benefits. <ID>

The Council finds that, in Illinois, many citizens with developmental disabilities do not have access to health or mental health care which would allow them to function independently, at home or at work. <IL>

Indiana is a 209(b) state and applies more stringent categorically needy (CN) criteria for people receiving SSI benefits. As a result of Indiana's more stringent CN criteria for people receiving SSI benefits, the state has proportionately fewer Medicaid beneficiaries in its Medicaid program. Indiana's share of the U.S. population in 1987 was 2.3 percent; its share of FY 1986 Medicaid beneficiaries, however, was 1.3 percent. The surrounding states of Illinois, Kentucky Michigan and Ohio had Medicaid rates which were comparable to a rate higher than their population rates. <IN>

Considerably less spending for EPSDT occurs for people with disabilities in Indiana than would be expected based on their numbers when compared with other Medicaid eligible individuals. <IN>

The Indiana EPSDT program is underfunded in comparison to neighboring states. In FY 1987, Indiana spent about \$.07 per capita for EPSDT while states surrounding Indiana were spending about \$.67 per capita. <IN>

The administrative definition of a child eligible for services for children with special health care needs in Indiana reflects the traditional focus on children with orthopedic conditions. The statute specifically excludes mental retardation and other such conditions "for which responsibility is held by other agencies of the state government" [470 IAC 4-2-3]. Over the past few years, most states have redesignated these "crippled children services" as "services to children with special health care needs" (CSHCN) in line with the redesignation in federal legislation (OBRA - 1986, P.L. 99-509). <IN>

In addition to the MCH Block Grant, local health departments also expend funds for maternal and child health in Indiana. The Indiana State Board of Health contracts with 13 local health departments and 15 non-profit agencies or hospitals to provide MCH services. Several counties that receive funding provide services on a multi-county basis. However, since MCH services are not required to be provided by local health departments, there is an apparent uneven ability of service across the state. Currently, only 39 of Indiana's 92 counties receive some type of MCH Block Grant service. <IN>

The EPSDT program in Indiana has a participation rate of only 9-10 percent of eligible children. This rate varies among Indiana counties from a high of 46 percent of a low of 1 percent. Currently, 14 are lacking providers of EPSDT services. <IN>

Vocational rehabilitation is an important source of funding for health related services that would enable a person with a disability to seek employment. Once a person is rehabilitated and placed on a job, however, the case is closed and there is no further follow-along service. <IN>

There is a lack of prenatal and postnatal care for low income and minority mothers. <KS>

Adequate obstetric, gynecological, and pre-natal care is lacking in some communities. <KS>

Accessing available medical support services, obtaining and keeping eligibility status and obtaining needed follow-up services is a major problem for many families. <KS>

Many families are unable to obtain affordable private health insurance. <KS>

Comprehensive medical assistance for people who are technology-supported is unavailable. Financial support is often available only in the most restrictive environment. <KS>

There has been a progressive reduction in Medicaid coverage (e.g., dental, eyeglasses, some prescriptions). Changing eligibility criteria are often confusing. <KS>

The health care costs are not well known for people of different ages and levels of severity, and different disabilities. This lack of data reflects the limitations of national surveys which have difficulty both identifying persons with low prevalence conditions and measuring health care costs from self-reported data. <LA>

Medicaid reimbursement rates and slow payments create disincentives for all providers, who then become unwilling to serve people who are poor or have a disability. <MA>

Unequal access to health care is a serious problem in Massachusetts; poor people have less access to health care because of lack, of information, lack of transportation, and communication or language barriers (including deafness). High infant mortality rates and high percentages of low birthweight babies are concentrated in poorer communities in Massachusetts and among minorities. <MA>

The staff shortage in human services is exacerbated by a lack of providers who have experience working with people with developmental disabilities in the community. Medical and specialty providers (such as dentists, psychiatrists, gynecologists, and occupational and physical therapists) who are willing to serve and have expertise to work with persons with developmental disabilities are needed. <MA>

Over 600,000 people in Massachusetts are uninsured. The Health Care for All law was passed to address the problem, but premium rates for the Commonwealth are too high to be affordable or attractive for all families and the present fiscal crisis means slower implementation of this new program. <MA>

Poverty contributes to other preventable health problems. "...Persons from lower socioeconomic groups experience higher rates of deaths" (except motor-vehicle related deaths) according to the Staying Alive Report by DPH. However, low birth weight can be prevented through early and adequate prenatal care, and hearing loss in children can be prevented by attending to chronic ear infections. 1.2 million housing units in Massachusetts are likely to contain lead paint; minorities and poor people are at higher risk of exposure to lead hazards than the general population; and Black children are at higher risk for lead poisoning, independent of family income level and level of urbanization. <MA>

Adults with medical problems can obtain only limited services through the state system. Older people with disabilities whose income is too great to obtain Medicaid, but who are unable to obtain long-term care insurance, fear that nursing home care may be their only option. <MA>

The increase in the incidence of HIV/AIDS is a health concern for people of all ages; two populations particularly at risk are minority and poor women of child-bearing age and people with developmental disabilities who are vulnerable to sexual abuse. While Latinos compose about six percent of the Massachusetts population, they represent ten percent of all-AIDS cases reported in the state (fifteen percent of the cases among children and thirteen percent of the cases among women). <MA>

Federally funded programs like Women, Infants and Children have received federal cut-backs, for which Massachusetts has attempted to compensate. However, WIC has only reached about half of the eligible population in Massachusetts. Most of the health care system uses an acute care model (often called a "medical model"). The model assumes that the recipient will maintain a "sick" role of passive conformity to the requirements of the health care provider. The assumption contributes to conflicts and misunderstandings when people with disabilities assert dignity and independence. <MI>

Many people with disabilities need occupational therapy, physical therapy, medical equipment and supplies, and home health care in order to live independently in the community. The institutional funding bias (paying for services while in a hospital, nursing home, etc., but not in a person's own home) of health coverage plans is a serious concern for this population. <MI>

No matter how progressive a state has become in regulating private insurers to broaden the scope of coverage for people with disabilities, they cannot be fully effective as long

as the federal Employee Retirement and Income Security Act (ERISA) preemptions continue to exist. <MI>

Medicare's acute nature and its "medically necessary" approach has created major gaps in Medicare coverage for people with disabilities. Personal assistance with self-care and household chores are not covered. Coverage for durable medical equipment is limited. <MI>

The current health care financing system leaves many people vulnerable to bankruptcy from illness, accident, and ongoing disability; at least 1 million people in Michigan, out of a population of over 9 million, have no form of health care coverage, public or private. Thirty-one percent (over 300,000) of this group are children. <MI>

As long as insurers view a disability as a pre-existing condition with presumably higher health care costs, they are unlikely to provide adequate coverage. Most private insurance companies either refuse to insure, or limit coverage to those with pre-existing conditions. Blue Cross/Blue Shield is the only insurer in Michigan mandated by state law to offer the opportunity to purchase coverage to everyone regardless of pre-existing medical conditions. (MCLA 550.1101, the "Non-Profit Health Care corporation Reform Act"). However, cost may be so high and coverage so inadequate as to render it useless for people with disabilities. <MI>

Access to private insurance depends largely on the size of the group with whom one shares the risk, not on one's medical condition. <MI>

Funding for community based health services is an issue that will become more focused as more people with severe disabilities start to move to community living situation. <MO>

Consumers across the state continue to identify the need for all types of affordable health services. <MO>

Access to Medicaid funded health services that are needed by people with severe disabilities are still primarily connected with the facility based ICF/MR program, thus limiting access to community living options. <MO>

The phenomenon of the aging U.S. population is paralleled in the population subgroup of individuals with disabilities. Research is showing that many of the health related problems associated with aging in general are also being experienced by seniors with disabilities. Consequently Missouri can expect an increase in health related service needs as proportionately more individuals with disabilities reach the age where health related problems become more acute. <MO>

Information is needed on the implementation of basic health (medical care, fitness, nutrition) and safety (protection and instruction) programs in community settings. <MO>

Fully implement and fund the pioneering Universal Health Care Act, to ensure that all Massachusetts residents have a right to affordable health insurance. <MA>

Information is needed on how different residential sites, health care organizations and communities are responding to the health care needs of persons with extensive medical/health problems living in community settings. <MO>

Information about the health needs of individuals with developmental disabilities who live in the community is difficult to obtain, making it difficult to determine the level of need for community based health services. <MO>

Blue Cross does not cover the cost of rehabilitation care for its subscribers and family members. Blue Cross contracts generally cover acute medical care which does not include rehabilitation. Therefore rehabilitation facilities and services in Mississippi are greatly restricted in the number of Blue Cross subscribers that it can treat in a given period of time. <MS>

In Mississippi, the Medicaid program reimburses a limit of 30 days hospitalization per Medicaid-eligible per fiscal year. While this number of inpatient days may be adequate for most patients in an acute care setting, such day limitation is inadequate for long-term rehabilitation patients because the average length of stay in such hospitals or units is usually in excess of 30 days. Therefore, an inpatient rehabilitation facility or unit is very restricted in the number of Medicaid only eligible patients it can serve and still remain economically viable. The effect here is to greatly restrict the number and percentage of Medicaid patients, who receive care in such facilities. <MS>

The states have categorical Medicaid eligibility requirements that are even more restrictive than federal SSI eligibility criteria. <MT>

Some states have no provision for waiving parental income in extending Medicaid eligibility to children with developmental disabilities who remain in their family home. <MT>

Operated under a profit motive and financed largely by employers with publicly-subsidized premiums, private health insurance has evolved restrictive definitions of "medical necessity" to limit access to acute care needs. <MT>

Persons with developmental disabilities have great difficulty in accessing and maintaining private health insurance coverage. <NC>

Persons with developmental disabilities and their families have great difficulty locating physicians, dentists and nurses with expertise in developmental disabilities and techniques for assisting persons with special needs. <NC>

Individuals with developmental disabilities and their families indicated in the survey and public hearings that the extraordinary costs of medical care and support services are significantly beyond the resources of most families. <NC>

Health care costs are a major problem in Nebraska just as they are for other parts of the country. Indigent care, that is medical care for persons who are uninsured or underinsured, is the responsibility of county government. Persons with developmental disabilities who are not covered by Medicaid but do not have private health insurance find themselves in serious debt. Although this is a problem for many, the most serious impact may be on families without adequate insurance and experiencing the birth of a child with special health care needs. <NE>

The rural nature of Nebraska also impacts on service delivery. The majority of specialists are located in the southeastern corner of the state. Persons requiring these services find themselves traveling great distances or opting to move their family to one of the metropolitan areas. <NE>

Without a state administered public health system, Nebraska finds itself with areas of the state where no health services are available. There are 14 local health departments in Nebraska covering 19 of its 93 counties. However, the offered services vary greatly and most services fall under the category of health education. <NE>

Many persons with developmental disabilities are eligible for Medicaid to cover their medical costs. However, this does not insure appropriate medical care. Since Medicaid reimbursements are quite low, the number of physicians willing to accept Medicaid patients has decreased. This can become a real problem in areas of the state where few physicians are available, and the cost is still a heavy burden for many families. The frequent office visits sometimes required by individuals with chronic medical conditions are typically not covered by health insurance. In addition, the medications that are needed by the person are often expensive and not a covered item. This latter issue is especially critical to persons with epilepsy who may depend on medications for seizure control. <NE>

Nebraska is grappling with the issue of nursing scope of practice. As individuals with high medical needs return to their communities, there is a consequent need for respite, educational services, and residential services. Needed medical procedures which have traditionally been provided by nurses are now being performed by family members. As caregivers outside the family become involved, the issue of scope of practice looms. Those who support a strict interpretation argue that these procedures which can be taught to parents can be taught to other caregivers as well. Nursing care is not available in many parts of the state and very expensive when available. If persons with medical needs are to be given the option to live in their own communities then alternate methods of

delivering these health services must be located. This is a critical issue in Nebraska and one which needs serious discussion within the next few years. <NE>

For persons with epilepsy who are covered by Medicaid, there is the additional issue of generic drugs. Federal Medicaid regulations require that generic drugs be dispensed unless there is a physician order to the contrary. With the narrow therapeutic range of anti-convulsants, some persons with epilepsy report problems when switched from a trade name drug to a generic one or from one generic to another generic. Persons with epilepsy express concern about needing a period of adjustment to get optimum seizure control with a drug. Even a change from one generic drug to the same drug manufactured by another drug company may require a new adjustment period. The Department of Social Services does have a simple process to permit payment of trade name drugs. Since consumers continue to report this is a problem there appears to be a communication problem between consumers, pharmacists and physicians. <NE>

The absence of a public statewide health care delivery system is perceived by some as a problem in Nebraska. Not only does it make accessibility and quality of services an issue, but it also makes it more difficult for the state to have a forum for health care issues, identify needs, and implement changes in anything but a very fragmented way. <NE>

There are some issues in Nebraska in the area of health that have been identified in this process. First is the lack of specialized care in rural areas. It is doubtful that this situation itself will change but it does mean that Nebraska must think of innovative ways to provide access to these health services in all areas of the state. The use of the medical centers as tertiary consultants, training programs for primary health care providers, and greater use of itinerant specialists may be possible alternatives. For children's services, proposed changes in the Medically Handicapped Children's Program may provide a potential system for better health care delivery throughout the state. <NE>

Urban hospitals in the state report that more than one in five babies born to mothers with cocaine addiction acquire the addiction in addition to physical abnormalities and developmental delays. <NJ>

The health needs of people with developmental disabilities living in the community are only beginning to be examined. Up to now, studies primarily have been based on institutionalized populations. <NJ>

Medical training programs do not adequately address treatment for people with developmental disabilities or provide clinical experience for students, except those in pediatric programs. Such training and experience is critical for practitioners at all levels. <NJ>

The delivery of health care is fragmented, with only informal, inconsistent links between primary care physicians and specialists. Service fragmentation can result in an unreliable,

unpredictable system that presents a greater risk of health problems. Laws and regulations may reinforce fragmentation. <NJ>

Agencies that provide health care to people with developmental disabilities are often isolated from other agencies with related responsibilities. For example, transportation, direct care and payment may be handled separately. <NJ>

There is a severe shortage of neurodevelopmental pediatricians in the southern-most counties of the state. No obstetricians or gynecologists in Atlantic County currently accept Medicaid. <NJ>

While the American public views access to health care as a basic right, public policy does not reflect that view. <NJ>

Certain counties may not pay the cost of transportation for doctor visits across county lines. <NJ>

The lack of barrier-free doctor's offices and available transportation are major obstacles to community health care services for people with disabilities. <NJ>

Pediatric AIDS is the most widespread infectious disease leading to developmental disabilities in New Jersey. New Jersey has the highest percentage of women and children infected with the AIDS virus. Though mid 1989, nearly 200 cases of pediatric AIDS have been reported in the state. A 1988 study suggests that approximately 240 HIV-infected babies are born each year in New Jersey, mostly in poor, urban areas among minority populations. This growing number of infected infants will generate an increased demand for health care and social services. The recent report of the Pediatric AIDS Advisory Committee, Generations in Jeopardy, cited New Jersey's lack of a plan to deal with the crisis. <NJ>

The cumbersome paperwork associated with Medicaid is often acknowledged by physicians as one of the major barriers to serving people with developmental disabilities. The New Jersey Foundation of Dentistry of the Handicapped found that paperwork is so extensive that dentists would rather treat patients free of charge than accept Medicaid. <NJ>

New Jersey continues to provide one of the lowest fee-for service reimbursements in the nation, with doctors receiving \$12 per office visit. <NJ>

People who qualify for Medicare on the basis of disability are eligible only after a 24 month waiting period. As many as one-third of SSDI beneficiaries are uninsured at some point during the two year waiting period for Medicare. <NM>

Medicare benefits do not include many of the health related services which are crucial to the ongoing health support for people with disabilities. While Medicare will cover wheel

chairs as durable medical equipment, it will not cover rehabilitation therapies for people who are not expected to make measurable functional progress even though they are likely to functionally degenerate without the rehabilitation therapies. <NM>

The application and eligibility processes for Medicaid are long, cumbersome and difficult for many individuals with disabilities to complete unassisted. <NM>

There is an institutional bias among both private and public third party payers to limit coverage to people whose health condition is of sufficient severity to require hospitalization. This institutional bias limits access to covered services for many people with disabilities, and result in many services being provided in hospitals, institutions, ICFs/MR and nursing homes which interferes with normal activities associated with living independently or productively. <NM>

The number of children served by the medically fragile program has been reduced because the cost of the plan of care, and the state not having additional general fund moneys to match federal dollars. At the present time a waiting list exists. <NM>

People with disabilities are increasingly vulnerable to restrictive medical underwriting practices of insurers for small groups and individual plans. People with disabilities or chronic illness are increasingly squeezed between a private health insurance system which is designed to charge according to the probability of risk, and a public health care system which subsidizes health care on the basis of age, poverty status, and the inability to work. <NM>

Many people with disabilities have higher health care costs because of greater use of acute care services and ongoing maintenance services. <NM>

From 1966 to 1982, per capita health care costs in Ohio more than doubled. In 1982, Ohio was in the top third of states in per capita expenditures for health care. <OH>

In 1988, the infant mortality rate in Ohio was 10.3 for each 1,000 births, which is higher than most European countries. The U.S. ranked 17th among developed nations in infant mortality. <OH>

There are many barriers to obtaining accessible, adequate, and affordable health care for people with developmental disabilities in Ohio's current health care system. The barriers, in some cases, relate to the consumer (lack of interest or knowledge, communication problems, disruptive behaviors, etc.); or to the provider (lack of knowledge concerning developmental disabilities, limited interest, concerns about reimbursement limitations etc.); or to the system (poor coordination between caregivers, over-regulation, fiscal policies that discourage community-based health care, etc.). <OH>

In a recent survey by Ohio Easter Seals, 34% of respondents reported having difficulty obtaining or maintaining health care coverage. <OH>

Most private insurance companies limit coverage or simply do not insure persons with pre-existing conditions. Also, in 1988, private insurance covered on average 37% of the costs of hospital care and 43% of physician services but only 11% of the costs of medical equipment and 14% of medical supplies. <OH>

The parents were unable to get private insurance because it is too costly. However, they aren't eligible for Medicaid or general relief. <OH>

The lack of appropriate, accessible health care is often cited as a major barrier to people with profound handicaps being supported in the community. Transportation services to medical services are very often inadequate, particularly in rural communities. <OH>

In a 1988 Ohio survey of physicians, 90% reported that they were willing to see patients with developmental disabilities. However, only 64% would accept Medicaid payments for their services. <OH>

Some of the optional services not provided for under the state Medicaid plan are crucial to the independence and productivity of persons with disabilities (e.g., physical and occupational therapies; speech, hearing and language services; personal care; and rehabilitation services.) <PA>

Some of the programs in the Maternal and Child Health Service System have not spent all of their funds. This underuse is attributed to insufficient outreach and public awareness efforts to compensate for the shortage in public health nurses. <PA>

Informants also noted that there is insufficient coordination between Maternal and Child Health and other service agencies, especially with the Medicaid Early and Periodic Screening and Diagnostic Testing service and with child-find activities conducted by other agencies. <PA>

Not all parts of the state have adequate access to clinics including areas with high rates of poverty. <PA>

TEFRA entitles all children with disabilities to the services available through the state Medicaid plan. The drawback of this option is that it does not permit the state to target a specific group of children for TEFRA eligibility. The resulting risk of financial exposure has led Pennsylvania, like many other states, to reject this option. <PA>

While many adults with disabilities, because of their low incomes, are generally eligible for Medicaid and get their basic health needs met thereby, the case is not the same for

children with disabilities. Unless the family is very low income and Medicaid eligible, or the child is institutionalized, the family generally meets the child's costs for health care through private insurance and/or out of their own pocket. Private insurance often does not meet the needs of such families because of lifetime and other limits on payment. <PA>

Two major problems arise with respect to the Medicaid services available. One is the lack of participation by physicians in the Medicaid program, which is, in part explained by the second major problem: inadequate reimbursement levels to physicians for services. This means that even were Medicaid options to be expanded, many Medicaid eligible persons would have difficulty accessing good health care in their own community. <PA>

Families with private health insurance who have a member with a serious and/or chronic illness or disability often face having their savings depleted and their life-style diminished by the high costs of medical care. <PA>

Private physicians often do not have adaptive equipment such as examining tables for persons with disabilities. <PA>

Adults with disabilities who are ineligible for Medicaid face a range of problems in trying to access the generic health care system. Insurance companies generally disallow pre-existing conditions, place limits on certain health expenditures, don't cover the kinds of equipment needed by persons with disabilities and in other direct or subtle ways discriminate against persons with disabilities. <PA>

The potential loss of medical benefits is a critical issue for persons with disabilities. <SC>

The pre-existing insurability clause is a barrier for persons with developmental disabilities and other chronic health care conditions. If coverage is securable, premiums are generally "out-of-reach." <SC>

The difficulty in accessing providers (for Medicaid recipients) is critical issue. <SC>

Due to fiscal adjustments approximately 50% of the money allocated in Part III of this year's Budget for the Division of Children's Rehabilitative Services was cut. This will impact negatively on children with handicapping conditions requiring surgical intervention. <SC>

Relatively mixed evaluations were offered by state officials concerning the scope of services available through the Medicaid EPSDT program to meet the specialized needs of infants and toddlers with disabling conditions. <SD>

In Tennessee, as in the nation as a whole, because of the increasing practice of insurers of excluding coverage of dependents in group policies, the largest group of uninsured persons is children. A child with a disability is thus at increasing risk of having no insurance coverage. <TN>

In Tennessee there are 975,000 persons with no health insurance. The estimates of underinsured persons range from a conservative 650,000 to a number as high as the number of uninsured persons. This means a total of between 1.6 million and almost 2 million persons in a total population of approximately 5 million. At least 30,000 to 40,000 of these persons at risk because of little or no insurance are persons with developmental disabilities. The number is very likely to be much higher. <TN>

People with developmental disabilities have difficulty in securing adequate affordable health insurance. <TN>

In Tennessee the practice of risk rating of groups is increasing among group insurance carriers. Group insurance policies are now excluding individuals because of their medical history. This is a contrast to the concept of group insurance coverage as formerly practiced, with the basic premise that the individual is not being rated for medical risk. Even if the individual is not scrutinized, the group's record may be and the group rate doubled. The employers are sometimes told that unless the individual at high risk is dropped from the policy, the company's policy will be terminated. If the company resists, the insurer may rewrite a policy for only six months and continue to raise rates until the company or group either drops the high risk individual or drops the policy. These individuals are often persons with developmental disabilities. <TN>

The classification of disability as a pre-existing condition with predictable higher health care costs provides private insurers an incentive to reject people with disabilities, impose pre-existing condition exclusions, or raise premiums, sometimes to an unaffordable level. Testimony in public forums held in Tennessee in September and October 1989, documented the excessive and unreasonable difficulties of families in Tennessee in securing insurance for the costs associated with disabilities. Experiences were related which demonstrate the failure of regulations and policies of insurance companies to keep pace with medical technology and current knowledge about development disabilities. <TN>

The fact that in the United States insurance is generally based on employment, means that an employed person is generally limited to the coverage provided by the group policy of the employer, and the unemployed person is often without insurance coverage. Persons with less than full-time competitive employment, the type of jobs held by many persons with developmental disabilities, are more likely than persons with full-time jobs to have no health insurance. <TN>

Insurance companies often view disability as a preexisting condition that will be associated with high health costs. Insurance companies often reject people with disabilities, impose preexisting condition exclusions, or raise premiums to an unaffordable level. <TX>

To help the medically uninsurable, the 71st Texas Legislature passed Senate Bill 832 which will establish the Texas Health Insurance Risk Pool. Although high risk pool benefits are modeled after major medical insurance plans, many health related services needed by people with disabilities are not covered. <TX>

Many people with disabilities and their families have been forced to bankrupt themselves in order to meet health care costs. Often this leads to unnecessary and expensive institutionalization. <TX>

The Council received input from families who explained that even when they do have insurance coverage, it is either not adequate or efficient. Sometimes insurance will not pay for assistive devices or other services. Or insurance will pay for equipment, but only through the most expensive vendor. <TX>

Several parents expressed concern that they have been unable to obtain dental services for their children because dentists do not have the expertise and sensitivity necessary to perform dental work on the teeth of their children who have mental retardation. <TX>

Since Medicaid reimburses only 67% of services rendered, doctors have refused to accept Medicaid patients. This has resulted in a dearth of medical resources for people with disabilities in rural areas. <UT>

The Medicaid dental services program was reduced to "extractions only" for a period of time. The legislature assumed that if they cut a portion of the provisions, people would find other resources to obtain the care (in this case having cavities filled). Instead, because extractions were the only allowable expense, people had their teeth pulled whenever they were in need of filling. As a result, many people needed dentures by the time the program was fully reinstated. <UT>

Entry level positions seldom include health benefits. People with disabilities often have chronic health problems as a function of disability. Not only are these people medically vulnerable but private insurance companies refuse to cover their problems as they consider them pre-existing conditions. <UT>

The inclusion of "least intrusive accommodations", although intended to protect the person with the disability, are considered by some advocates and consumers as discriminatory. According to the Reproductive Rights Act, if a person with disabilities chooses sterilization, by law the person cannot choose anything but the least intrusive procedure to attain that choice. This law then would not allow a hysterectomy that would cease the menses, but would only "tie the tubes." On the other hand, anyone else could walk in and

explain their rationale for sterilization, describe which procedure they would prefer, and select one. In this case, a statute that is intended to protect people with disabilities from involuntary sterilization intrudes on personal choice. <UT>

There were a comparatively large number of comments about service issues. These included health professionals who had very little knowledge about people with disabilities, their disorders, and peripheral problems. Costs were especially of concern as well as the lack of availability and a limited array of services even in urban areas. <UT>

Some people complained of excessive paperwork involved in accessing health care assistance, others had been victims of discriminating policies and disincentives. Information issues ranged from confusion about how to access medical services to knowing their rights, lack of knowledge about disabilities, and the ignorance of the public. <UT>

Technological advances like CAT scans, computerized devices that enable communication, and our very own "Utah Arm" provide dramatic assistance to people with disabilities but are financially inaccessible. Some groups like the Shriners have contributed considerably to providing technological devices for people with disabilities, but insurance companies consider these assistive devices as luxuries and usually will not pay for them. <UT>

Medical costs are rising faster in Utah than anywhere in the country. <UT>

Medicaid is minimally funded and perhaps underfunded in Utah. It cannot accommodate its mission and the state must consider reform. <UT>

According to the Department of Health (DOH), Americans deliver poor care to all people with developmental disabilities, but we deliver especially poor health care to people of minorities with disabilities. This trend is no different in Utah. In Utah, minorities are people who live in rural pockets, inner city pockets, and on Native American reservations. These disadvantaged populations do not meet the national definition for minorities but need as much special attention as any other minority in the nation. The national trend toward addressing the needs of minorities is focused on specific minority groups but Utah has its own underserved people and many of them are only served at birth and just before death. <UT>

In Utah, the state requires recipients of the Medically Needy Program to "spend down" to \$375.00 per month. There is a basic attitude that anyone receiving medical benefits will have to live in poverty. Often this spend down requirement forces people with disabilities into out-of-home placements in order to receive medical care and let the rest of the family maintain a decent income. <UT>

Lack of access of affordable medical insurance, often complicated by pre-existing conditions. <VT>

Lack of effective treatment options for persons with more than one treatment need, for example, a person with a disability who also has a substance abuse problem or a person who has two uniquely different disabilities. <VT>

Out-of-state adoption may have the undesirable effect of decreasing quality medical care. Under Title IV-E when a child is adopted out of state, the receiving state must cover medical expenses. Since Washington has better benefits than some states, quality of medical care can drop. <WA>

Although costs per child have decreased, basic medical expenses on the whole have risen. As the state serves more children with developmental disabilities, medical costs go up, especially without appropriate early intervention services. Adding to the medical cost total are the rising adoption rates of older children whose emotional and physical problems may have gone undiagnosed or untreated. This places additional stress on both the family and the system. <WA>

Information about possible coverage is piecemeal and difficult to find. Systems lack coordination of information as well as coverage. Medical programs are not coordinated. This results in multiple billings instead of one bill. <WA>

Providers are discouraged to serve medical program recipients because the process demands a myriad of paperwork and results in delayed reimbursement. Standards of quality care are also lacking. This leads to confusion when determining just how much something should cost. <WA>

Health care is complicated by the fact that needs of people with disabilities are often much greater than nondisabled people. Getting to medical appointments, maintaining adequate home health hygiene and treatment needs quite often require additional assistance. In many cases, community caregivers play a central role in identifying health care needs but they are hard-pressed to find appropriate supports to ensure that persons living in the community have those needs met. <WA>

Due to inadequate case management resources, families living together at home often lack the assistance and information they need to ensure special health care needs are met in an appropriate and timely manner. <WA>

As the consumer survey data indicate, a considerable number of people chose not to respond to the health-related questions which pertained to services received over the previous one-year period. This raises concern because it may indicate that a considerable number of people with disabilities had not seen a doctor for over a year. <WA>

The consumer survey indicates that many people are not receiving needed health-related services. The most common barrier expressed was that services were too expensive (112

people). This reason would primarily pertain to people whose income levels were above the eligibility level for medical assistance. The second most common barrier given was that people were on waiting lists for services which were limited (111 people). The third most common barrier was that services were not appropriate (89 people.) <WA>

Under Medicaid law, providers must accept the set upon reimbursement as "payment in full." Medicaid payments as set by Washington State cover — on the average — only 50% of the rate normally charged by health care providers. Access to services can be greatly reduced if few medical professionals choose to participate in the program either because of low payment rates or cumbersome reimbursement procedures. <WA>

Children who are given early assessment services have much lower medical costs over a longer period of time. However, only 13% of those eligible for EPSDT in Washington State are taking advantage of the services. Of those receiving medical services assistance (except those who are members of health maintenance organizations), only 22% receive EPSDT services. Although families are generally told about EPSDT at the time they apply for Medicaid services, there is very little follow up. Due to staff and funding shortages, linking families with supplemental sources of support is often neglected. <WA>

Existing programs such as Headstart and Health Maintenance Organizations are the primary source of identifying children who could benefit from early assessment. Children who are not involved in any type of existing organization or program are likely to fall between the cracks. The existence and scope of EPSDT is not widely publicized. <WA>

In Washington State, approximately 410,000 people are uninsured. Of that number, some 210,000 are at or below the poverty level. <WA>

With improvements in medical technology, there are more persons who survive acute conditions. This, in turn, contributes to the growing demand for rehabilitation and ongoing maintenance services. Private and public insurers — due to increased emphasis on cost — are increasingly resistant to include rehabilitation and ongoing maintenance services as covered benefits for comprehensive health insurance. While some insurers are willing to reimburse for rehabilitation services provided to persons with acute care problems, they are less willing to reimburse for rehabilitation when that acute care crisis has ended. This creates a problem because most rehabilitation is provided after a person's acute care needs have been stabilized. <WA>

Many people with disabilities who do not meet the income, asset, and disability criteria for SSI are not eligible for Medicaid even when private health insurance is unavailable or inadequate for their health care needs. <WA>

Sadly, many people with disabilities and their families have been forced into bankruptcy in an effort to meet ongoing health care costs. Even sadder, this often leads to

unnecessary and even more expensive institutionalization...a high cost for both society and the individual. <WA>

Providing good health care for a person with a disability is a catch 22 for both an individual and a health care provider. Because of the nature of many disabilities, health care costs are often higher than for the general population. On the other hand, without such expensive and specialized care, many people with disabilities could not live and work in the community. <WA>

No one knows just how much it will eventually cost for research and treatment of those with AIDS. As a result of the disabling effects of AIDS, health care, foster care and education costs will also rise. <WA>

The current health care financing system provides only a patchwork of private and public sources of coverage. These vary widely around the country — both in terms of cost and coverage — and it is unclear where you go to obtain such coverage. Both public and private plans have strong biases toward covering institutionalized care for children, even though our current knowledge indicates that many children can be better care for at home at less costs. <WA>

Red tape quite often discourages both the provider and the parents from seeking services under EPSDT. <WA>

All children under the federal poverty level who have a physical impairment are potentially eligible for child health services. However, due to limited budgets, only a small percent of the eligible population actually receive services. No data exist to indicate how many are eligible and how many are actually served. <WA>

Even when problems are identified during the screening process, resources for treatment are not always available or are, in many cases, very limited. <WA>

Families with members who have severe disabilities are three to four times more likely to have out-of-pocket expenses adding up to five to ten percent of their total income than the insured general population under the age of 65. For families with children who have special health care needs, finding ways to cover unpredictable costs is of critical importance to both the child's health and to the families' economic and emotional stability. <WA>

Access to health services for aging persons is often limited due to the emphasis placed on institutional care. The need to develop coordinated acute and long-term care options within the community will increase funding requirements. Fragmented and over-regulated health care programs also make existing services complicated and confusing and (as a result) inaccessible to many who could benefit. <WA>

Physicians serving people in the community are reimbursed at a rate substantially below standard rates for services provided. <WI>

Health care professionals and direct service workers generally are limited in training around the issues of preventive health care for people with developmental disabilities. <WI>

A 1989 report on the health care needs of adults with developmental disabilities living in the community (commissioned by the Wisconsin Council on Developmental Disabilities) found that primary health care is not planned for as consistently or effectively as expected. <WI>

Many recipients of Medicaid are not aware of the current services available to them with the medical card or do not have the familiarity with the program to make use of the options available. <WI>

The extent and scope of responsibility of private insurance carriers in ensuring that people with developmental disabilities have adequate health care coverage has not been assessed or established. <WI>

In addition to funding, the availability of health care providers is a problem in many parts of the state. As many as forty-seven of West Virginia's fifty-five counties do not have enough medical care for the population. <WV>

Individuals with assets over the state-established limits may become eligible for Medicaid upon exhausting their own resources to state-established levels. West Virginia has such a provision, however, the protected income level under this provision remains at a low \$200 per month, a level that no longer reflects current costs of living. <WV>

The state has the discretion of establishing income eligibility of pregnant women and children. The federal government allows for Medicaid coverage for people in this target population with family incomes of up to 185% of the poverty level. In West Virginia, the income limit is 150% of the poverty level for pregnant women and infants, and 100% for children ages one to eight. <WV>

In West Virginia in 1986, there were almost 300,000 uninsured persons, 32.2% of whom were under the age of seventeen. <WV>

One problem within the infant and toddler service system is the issue of "payor of last resort" in the EHA Part H legislation. In proposed rules for the Wyoming Childrens Health Services [Section 5 (a)] CHS is also listed as the payor or last resort "following all other third party payors including Indian Health Services" except for the Medicaid program. There is general agreement in Wyoming that parental financial responsibility and private insurance should be the first sources tapped. But for some parents without sufficient

income or insurance (but yet not eligible for Medicaid) the issue of which agency will assist is difficult when all are last. <WY>

While all private physicians in the state have information about Childrens Health Service, there are still children who for one reason or another are not promptly referred to the clinics. In other instances parents are confused about how their children might qualify for services and the amount of financial responsibility the state assumes they will shoulder. A sore point for parents is the decision from their private insurance provider that the infant's problem is a pre-existing one and not eligible for medical payment coverage. <WY>

Health services for individuals with developmental disabilities, especially, children, are limited in Wyoming's programs. <WY>

HEALTH: RECOMMENDATIONS

Multiple States

The public sector must regulate private insurance in order to ensure that comprehensive health care services are available and that health care costs are equitably distributed throughout the population. <ID,MT>

The federal government should use its leverage to require group insurance policies to meet certain minimal standards in order to qualify for a tax subsidy. <ID,MT>

Congress should create financing mechanisms that ensure that all people have equal access to the health care services which they need. <MT,WY>

Premiums should be based on income level (taking into account family size and disability related expenses), not on the probability of risk. Out-of-pocket costs for deductibles or coinsurance should be limited to a fixed amount or a certain percentage of a person's income. The financing mechanism should protect against excessive annual and lifetime out-of-pocket costs which can impoverish a family. <ID,MT,WY>

The eligibility of people for health care services should be based on health care needs, not income level, age, or the inability to work. <ID,MT,WY>

To avoid interfering with the integration, independence and productivity of people with chronic conditions, it is necessary to broaden the definition of health care beyond acute care services and reverse the institutional bias so that people with disabilities can receive health related services in their own homes and community settings. <ID,MT,NM,WY>

Surveys should be conducted at the national, state, and community levels to more precisely measure the extent of the limitations of private health insurance on people with disabilities and the impact on both their lives and on the social costs to society. <ID,LA,MT,WY>

The federal government could prohibit insurers from excluding, terminating, or otherwise limiting any individual from coverage based on apre-existing condition. It could also prohibit experience rating, which involves the setting of premiums on the basis of previous individual or group claims. <LA,MT,NJ,TN,WY>

The federal government may be able to increase the effectiveness of VR job placement by reimbursing VR for necessary follow-along services once a person has been rehabilitated and placed in employment under certain conditions. The VR program can better address the health related needs of working-age people who want to enter the labor force by improving its coordination with other service programs at the state level which can

provide continuing support services for people after they have been placed in employment. <ID,WY>

The state should make sure that Medicaid pays for covered services provided to children who are dually eligible for aid under both Medicaid and the Education for All Handicapped Children act as clarified by the Medicare Catastrophic Act of 1988. <ID,MT,WY>

The state/states should make sure that public school system is identifying all health related needs in the individualized education plan (IEP) which impact on publicly supported special education. <MS, MT,WY>

Remove the arbitrary distinction between acute care and chronic care in determining eligibility for Medicare coverage. <ID,MT>

The federal government should eliminate the two year waiting period for Medicare, or at least establish Medicare as a secondary payor for new SSDI beneficiaries. <ID,LA,MT,WY>

People with disabilities should have access to health care providers who are knowledgeable about their special health care needs, experienced in providing care, and comfortable relating to people with disabilities. To ensure the availability of competent providers, it is important that health care providers are adequately trained and adequately reimbursed to compensate for disincentives to serving people with disabilities. <ID,MT>

Medicaid reimbursement should reflect the time that providers must spend to provide quality care to people with disabilities. <ID,MT>

The federal government could/should permit states to use federal Medicaid dollars to make Medicaid benefits available to people on a sliding fee scale who do not meet the financial eligibility requirements for Medicaid. <HI,LA,TN,WY>

Given the barriers to access which HMOs impose on enrollees, people with disabilities should not be required to participate in an HMO. <ID,MT>

Because public policy has encouraged employment-linked health insurance, an employer mandate, such as Senator Kennedy's (D-MA) Basic Health Benefits For All Americans Act of 1989 (S.768) which requires all employers to provide health insurance to their employees and dependents, would significantly reduce the size of the uninsured population at minimal cost to federal and state governments. It is estimated that 24 million uninsured persons would be covered if all employers were required to provide health insurance to their employees and their dependents. <ID,MT>

Health care financing policies must be changed in order to promote universality, comprehensiveness, equitable financing, and cost-controls. <ID,MT>

Individual States

Legislators, state officials and consumers should actively support the Basic Health Benefits for All Americans Act of 1989 (S. 768) which requires all employers to provide health insurance to their employees and dependents. <AK>

The problems with health insurance should be examined and resolved to the benefit of people who have developmental disabilities and their families. <AL>

Ready access to quality health care for all citizens of Alabama, including those who have developmental disabilities, must be ensured. This necessitates additional funding in areas such as public health, prevention(of primary, secondary, and tertiary disabilities), screening, early intervention, education of professionals, and transportation. <AL>

Given Arkansas's generous financing limits under this program, the state should explore the ways in which EPSDT can be used to complement other sources of funding for early childhood services. The key area of focus is how to coordinate the services identified for children in early childhood programs with the EPSDT service delivery network. <AR>

Children's Rehabilitative Services (CRS) must have adequate funding to meet all eligible children's needs; family social services should be developed for individuals served by CRS who are not eligible for services provided by the DDD. <AZ>

Children's Rehabilitative Services should be given legislative authority to provide adult health services for individuals with other developmental disabilities, such as spina bifida, who have been served as children, but whose care as adults is not covered by any other agency. <AZ>

Administrative barriers to the provision of needed MediCal services should be eliminated. Those barriers include inadequate reimbursement rates to MediCal providers, and extensive paperwork (form processing) and lengthy reimbursement periods. This applies to both personal medical care and the provision of durable medical equipment. <CA>

Rather than providing only acute health care, MediCal services should be broadened to include preventive medical intervention,, and foster independence and least restrictive living. <CA>

There should be a focus on non-aversive behavior management in contrast to the over-use of medication and other aversive/controlling procedures in the service system. <CA>

More extensive curricula regarding developmental disabilities should be included in medical schools throughout the nation in order to ensure that pediatricians, other physicians, and health professionals are adequately trained to assess and provide services to children with developmental disabilities during the early developmental stages. <CA>

California Childrens Services eligibility should be broadened to include children with chronic conditions who need CCS services to prevent regression or maintain current levels of functioning. Services similar to CCS must be continued to serve individuals over age 21 who require them. <CA>

Private health insurance coverage should be available to people with developmental disabilities regardless of "preexisting condition." MediCal should not be their only option for medical/health coverage. <CA>

Extend Medicaid eligibility to women and infants in families with income up to 150% of poverty. <CO>

Age cohorts should be established in addition to the birth to 3 year old age cohort being tracked by the Commission of Public Health to include ages 4 through 21. These age cohorts would be tracked at regularly scheduled intervals for a minimum of ten years. <DC>

A health and health-related issues repository should be established within the Council for the purpose of ongoing data collection, cataloguing and storage for easy retrieval of all developmental disabilities health issues. <DC>

The Council should take the lead role in establishing and coordinating a network of persons with developmental disabilities and their families, public and private agencies and organizations in lobbying for the passage of health care insurance bills currently in the legislative hopper of the City Council of the District of Columbia. <DC>

There is a need for a more intensive outreach effort in the Early and Periodic Screening, Diagnosis and Treatment program. It is recommended that such an outreach effort be focused on Wards 6, 7, and 8. <DC>

The Council should join with other local and national agencies and organizations to promote national health care financing policies. <DC>

Provisions should be made for the establishment of a position and or the placement of bilingual personnel in all public health care facilities, inclusive of those vendors who are under contract to provide health care services. <DC>

There should be TTY numbers available in all public and private health service delivery facilities and other agencies and organizations which provide services to persons with hearing impairments. <DC>

A public-private task force should be established within the Council for the purpose of reducing the fiscal, physical and attitudinal barriers which impede persons with

developmental disabilities and their families from gaining access to health care services. <DC>

A major recommendation, as was the case with housing, is that the health policy of the government of the District of Columbia be recast to indicate that all old and new health initiatives include provisions which specifically address the needs and concerns of residents with developmental disabilities. <DC>

Continue to address the medically needy issue, including raising Medicaid coverage to help ensure access to and availability of quality health care services for uninsured citizens of Delaware. <DE>

Create and operationalize a Community Health Client Information System (CHCIS) that provides client registry, client tracking, service utilization data, and clinical performance data. <DE>

Reduce the incidence of substance abuse among pregnant women by providing family centered substance abuse treatment linked with prenatal care for up to 40 pregnant women in New Castle County in FY'91 and 40 additional women in FY'92 and FY'93. Provide drug counseling services to pregnant women in Kent and Sussex Counties in FY'91 with comprehensive services implemented in FY'92. <DE>

Expand the WIC (Women, Infants, and Children) program so that 95% of the eligible pregnant women and infants are served by 1991. Assure or provide prenatal care, primary care, case management, and multidisciplinary team care to at least 2,000 low-income pregnant and 15,000 low-income children. <DE>

Assure access to prenatal care and primary care for all children (0-5 years) and pregnant women in order to reduce infant mortality and morbidity and prevent adolescent pregnancy. <DE>

Require insurance carriers to allow individuals with developmental disabilities to participate in group coverage which they would otherwise be eligible for based on their employment status if they did not have a developmental disability. <FL>

Ensure that health services provided by County Public Health Units are equitable in scope and quality regardless of their geographic location. <FL>

Continue to seek ways to ease the paper procedures burden required of physicians and other health care providers to obtain Medicaid reimbursement. Provide training and technical assistance for providers and conduct public relations activities to further encourage participation. <FL>

Encourage the Insurance Commissioner to address the rising costs of insurance, limited and reduced coverage, and discriminatory practices. <GA>

Secure funding for implementation of SB 267, the Georgia High Risk Health Plan, passed by the state legislature in 1989, which will provide for health insurance coverage. <GA>

Encourage Medicaid and Medicare to expand their coverage of dental services. <GA>

Increase access to health care information. A consolidated listing of available health services needs to be created. <GA>

Promote health care reform and new services. <GA>

Efforts should be made to identify optional waivers available through the Medicaid program for persons with developmental disabilities. Although state matching funds for Medicaid are limited, the feasibility of using Medicaid funds to address some of the most critical medical needs should be explored. <GA>

The federal government should require states to allocate at least one-third of their Maternal and Child Health Block Grant to Children with Special Health Needs programs and to develop uniform eligibility criteria. <HI>

The Department of Health will work with the state Medicaid agency to maximize the "Katie Beckett" waiver. <HI>

The state Medicaid Plan should be amended by the Department of Human Services to broaden eligibility for Medicaid by disregarding family income if the child is at risk of institutionalization (TEFRA, P.L. 97-248). <HI>

The state should pursue every available avenue to help finance the cost of care while keeping the child at home. Medicaid is the only entitlement program available to persons with developmental disabilities to assist them in paying for the cost of care, and it should be utilized to its fullest extent. <HI>

Develop the mechanism for claiming Medicaid reimbursement for clinic support services. <HI>

Expand the mechanism for claiming reimbursement from the Medicaid EPSDT program for diagnostic, evaluation and treatment services provided to children, including health services provided to eligible special education children. <HI>

The Department of Human Services should remove the 209(b) status and use the Social Security income disability criteria for Medicaid eligibility. <HI>

The University Affiliated Program should develop an ongoing active education and information campaign to inform physicians and dentists about the health care needs of persons with developmental disabilities, including the value of prevention and early intervention. <HI>

The Department of Health should establish specialty clinics, where needed, to provide medical care for people with developmental disabilities. <HI>

The legislature should allocate funds to the Department of Health for establishing an incentive program for health professionals in "shortage categories," e.g., physical therapists, registered nurses. <HI>

Develop comprehensive program policy governing the provision of all Medicaid optional services, and increase program effectiveness by explicitly citing independence, productivity, and integration as program goals. <IA>

Revise Medicaid optional services policy to facilitate procedures for program application, payment for services, and response to consumer complaints. <IA>

Expand Medicaid optional services program policy to include requirements that (1) persons with developmental disabilities be informed about their rights under this program; (2) that the methods used to inform people of their rights be clearly documented; and (3) that the implementation of this policy be formally substantiated and evaluated. <IA>

Enhance Medicaid optional services program effectiveness by establishing policies that require more effective dissemination of information to clients, families, and providers about types of services available through this program. <IA>

Study the expansion of Medicaid optional service eligibility requirements to include persons categorized as "medically needy." <IA>

Investigate insurance and health care issues, and develop means to provide adequate health insurance for individuals with developmental disabilities. <IA>

The Idaho legislature should use state health insurance mandates to broaden the scope of health related services covered by private insurance and to close loopholes in private insurance coverage that people with disabilities fall through. While state mandates illustrate how the regulatory process can reduce gaps in private health insurance, this state level process is at best uneven and reflects the political power of different interest groups at the state level rather than some overarching principles of comprehensiveness of benefits or equity in access or affordability. <ID>

It is important to measure annual costs for all health related services and to project those to lifetime costs; secondly, it is important to distinguish between total costs and

out-of-pocket costs for which people with disabilities are not likely to have a third party payor; thirdly, it is important to analyze out-of-pocket costs in relation to family income in order to measure the financial burden of developmental disabilities on the family. <ID>

Idaho must make sure it considers all of its options for using Medicaid. These include: (1) amendment to the basic state plan; (2) utilization of the higher benefit levels in the Early Periodic Screening, Diagnosis and Treatment program (EPSDT) for low income children, birth through 21 years; and (3) Medicaid waivers for home and community-based services. <ID>

Based on the planning efforts in the states for Part H of EHA, it may be necessary for the federal government to allocate some federal funds for services identified in the IFSP in order to encourage states to make a legally binding commitment to ensure that eligible children and their families receive the early intervention services needed. <ID>

Idaho should broaden eligibility for Medicaid by: (1) disregarding family income if a child is at risk of institutionalization (TEFRA 134 option established in 1982); (2) raising the income threshold up to 185% of the poverty level for children and pregnant women; (3) removing the resource test; (4) expanding the medically needy program; and (5) establishing a broader-based Medicaid buy-in with sliding scale premium. <ID>

A Medicaid buy-in program could be an appropriate financing mechanism if the Medicaid benefit plan was comprehensive, and if the premium structure could be designed on an affordable sliding fee scale, and if the reimbursement levels are adequate. <ID>

Idaho should consider the range of options which are available to prevent people from being rejected by private insurance or to distribute their costs in an equitable way before resorting to a high risk pool. Idaho should consider state insurance pools which combine uninsured persons, people with pre-existing conditions, and persons in small employer groups who cannot purchase affordable or adequate health insurance in the private insurance market. <ID>

Idaho needs to make a strong commitment to the Children with Special Needs Program and appropriate state revenue to match federal funds. <ID>

Dental care must be an allowable cost/service for adults in shelter homes. <ID>

The U.S. Congress and the Idaho Legislature should create financing mechanisms that ensure that all people have equal access to the health care services they need. An equitable health care financing system would protect people from excessive health care costs in relation to their income. Families of people with disabilities should not have to pay a greater percentage of their income for health care than families without disabilities. Health insurance should protect people from all health care costs, not just unpredictable health care costs. <ID>

Individuals with developmental disabilities should have access to complete eye and ear examinations for little or no cost. This is necessary to eliminate physical problems that can be improved when parents lack the resources to pay for these services. <ID>

Indiana shall provide multidisciplinary services (including medical, dental, mental health, and other health services) uniformly throughout the state and provide them in flexible ways that increase access. <IN>

Indiana shall ensure that prenatal services and information that leads to healthy pregnancies are available to all families. <IN>

Indiana shall assure that people with and without disabilities have access to genetic counseling, sex education, and family planning services when desired. <IN>

Indiana shall require the provision of coursework on disabilities as a prerequisite to licensure for all health professionals. <IN>

Indiana shall mandate publicly-funded health screening programs across the state that emphasize early detection and treatment. <IN>

Indiana shall consolidate the planning and delivery of all health and early intervention services and mandate that children in need be served. <IN>

Indiana shall mandate that insurance companies provide affordable health insurance that does not exclude disabling conditions and shall monitor benefit terminations in order to end restrictive regulations regarding medications, therapies, durable equipment, and other special needs. <IN>

Indiana shall provide information and training to community providers of general health and social services to increase their sensitivity and capacity to serve people with disabilities. <IN>

Indiana shall revise the Medicaid Plan (1) to include all persons receiving SSI, (2) to exclude the deeming of parental or spousal income and resources as available to institutionalize persons and (3) to all children under 18 who would be eligible for Medicaid in an institutional setting to receive Medicaid at home. <IN>

Health insurance reform legislation should be enacted to insure that costs are distributed in an equitable manner and that preventive services and long-term supports are covered. <IN>

Maternal and Child Health Block grantees should be required to dedicate one-third of their funding to Children with Special Health Care Needs services, and to establish uniform eligibility standards related to the expenditure of federal funds. <IN>

Indiana entitlement eligibility requirements shall be changed to promote financial independence (e.g., present Medicaid liability and spend-down requirements force people into permanent dependence.) <IN>

Indiana shall enact enabling legislation that assures adequate and affordable health insurance to people with disabilities and which includes coverage for ongoing therapies. <IN>

Indiana shall develop an aggressive prevention program that promotes healthy pregnancies and healthy babies. <IN>

Indiana shall ensure that training programs for emergency personnel, law enforcement personnel, firemen, and emergency medical technicians incorporate course work regarding the special needs of people with disabilities in emergency situations. <IN>

Louisiana should broaden eligibility for Medicaid by: (1) disregarding family income if the child is at risk of institutionalization (TEFRA 134 option established in 1982); (2) raising the income threshold up to 185 percent of poverty for pregnant women and children, (3) removing resource tests; (4) expanding the medically needy program; and (5) establishing a Medical-Buy-in with sliding scale premium. <LA>

The Louisiana legislature should pass legislation to provide for assigned risk health insurance which would be available at a reasonable cost. <LA>

The Department of Health and Hospitals should increase the Medicaid reimbursement rate to physicians and hospitals and simplify and accelerate the reimbursement process. <LA>

The Human Development Center in New Orleans and the Children's Center in Shreveport should work cooperatively with medical, dental, and nursing schools to enhance training of medical personnel who work with persons with severe disabilities. Emphasis should be placed upon attitudes of personnel as well as diagnosis and treatment. <LA>

Louisiana should consider all of their options for using Medicaid. These include: (1) amendment to the basic state plan; (2) utilization of the higher benefit levels in the Early Periodic Screening Diagnosis and Treatment program (EPSDT) for low income children from birth through 21 years; and (3) Medicaid waivers for home and community-based services. <LA>

States should monitor the impact of HMOs on people with chronic health conditions in order to consider whether it may be necessary for provider risk to be separate from prepayment for high risk populations or for HMOs to make certain modifications in their administrative controls for chronic care. Given the barriers to access which HMOs impose on enrollees, people with disabilities should not be required to participate in an HMO. <LA>

The definition of health care should be broadened beyond acute care services and the institutional bias should be reversed so that people with disabilities can receive health related services in their own homes and community settings. It is also necessary to create a financing mechanism for equitably distributing the health care costs throughout the entire population. <LA>

Increase use of present options for Medicaid financing of additional services. <MA>

Fully implement and fund the pioneering Universal Health Care Act to ensure that all Massachusetts residents have a right to affordable health insurance. <MA>

Support community-based dental programs for people with developmental disabilities living in the community and include a component to increase the capacity of providers in the community. Advocate to increase funding for the dental programs funded through the Department of Public Health - these programs ensure dental screening and follow-up services to clients in the community. <MA>

People should be given the choice of using "generic services " or specialized services. Generic services need back-up to provide specialty information or consultation to develop the capacity of providers in the community. <MA>

Create a disability awareness program component in the education of all health professionals (in colleges, various training programs) and include hands-on, experiential learning through internships. <MA>

Provide training in basic health maintenance/prevention to families, state and provider staff (including management of medications, how to deal with seizures, etc.). <MA>

Assign the Department of Public Health (DPH) case management responsibility for the health care needs of adult people with developmental disabilities who are not mentally retarded (and provide DPH funding to implement this responsibility). Provide medical case management for people with developmental disabilities known to the state system, particularly the 4,000 children who formerly used the clinic system under the Department of Public Health. <MA>

Make generic health services (including mental health, dental health, and adolescent health services) truly accessible to people with variety of disabilities, including those persons with mental retardation and deafness. Genuine accessibility must be architectural, linguistic and cultural (for persons who are deaf or speak foreign languages), with transportation access; and must include outreach to un(der)served populations and communities. <MA>

Establish health care standards for all people. Project SERVE has established standards for health care services for children, and there are protocols for regular physical

examinations and immunizations for children under Project Good Health (Early Periodic Screening, Diagnosis and treatment program). The state needs to establish similar standards and protocols for regular physical examinations for adults, including gynecological exams and cholesterol screenings. <MA>

Expand the obligation of private health insurance carriers to cover health-related services and to transfer disability-related coverage when the insured changes jobs. Health-related services include: preventive care, early intervention, home care, medical respite services, and durable medical equipment. <MA>

Support the Department of Public Health and the Department of Education to take leading roles so that the local school systems can enable children with medical needs to live at home and go to school with their peers. Supplementary home health services may be needed as well. <MA>

Target resources and specialized programs to address the crisis imposed by HIV infection - assure that services are available, free from discrimination. This includes: education efforts and measures to prevent HIV infection in minority communities; sexuality and HIV education for adults with mental retardation and other developmental disabilities; and help for infants born with HIV infection and for children with HIV and AIDS. Support reasonable, scientifically sound policies for children with HIV/AIDS in school programs and day care. <MA>

Enact a comprehensive national health program that includes a broad range of medical, preventive, and long-term care provisions. <MA>

Assure that persons with developmental disabilities have access to quality health care services and continuity of physician relationships. Pilot a managed care initiative by the Medical Assistance Program whereby a selected primary care provider delivers or refers for all necessary health services; include financial incentives for primary care providers to assure their participation in the program. <MD>

Examine the administrative location of Children's Medical Services within the Family Health Administration of the Department of Health and Mental Hygiene to determine if another arrangement would promote the high visibility, administrative support and close affiliation with other services for persons with developmental disabilities necessary for the program to reach its full potential, including being part of the state's strategy to provide for early intervention services under P.L. 99-457. <MD>

Explore ways in which the Department of Health and Mental Hygiene may obtain federal matching funds to provide benefits specifically for children with disabilities available through the Early and Periodic Screening, Diagnosis and Treatment/Healthy Kids Program. <MD>

Strengthen the Maryland Medical Assistance Program's outreach and case management activities and encourage provider and participant involvement in the Early and Periodic Screening, Diagnosis and Treatment/Healthy Kids Program. <MD>

Support legislation enabling pre-existing medical conditions experienced by adopted children to be covered by private health insurance providers. <MD>

Medicaid reimbursement rates must be increased to the level of usual and customary charges in order to encourage health care providers to accept Medicaid patients on an equal footing with private pay patients. <ME>

The Bureau of Medical Services, in conjunction with the Interdepartmental Council, should review criteria for reimbursement of professional caregivers under Medicaid. To the extent it is appropriate and not in conflict with federal law, greater utilization of paraprofessionals under the supervision of licensed/certified professionals should be allowed. <ME>

Health Insurance reform to assure equitable access to private health insurance, including assurance of coverage for pre-existing conditions related to long term disabilities. <ME>

Congress should enact the following changes in the Medicare Program: eliminate the two year waiting period for Medicare; remove, in all new Medicare legislation initiatives in Congress, the distinctions between acute and chronic care needs, and the arbitrary exclusions for various assistive devices and environmental controls essential to improved functioning for people with disabilities; and develop a long term home care benefit, as proposed by the late Representative Claude Pepper (D-FL), that will benefit families with children with disabilities. <MI>

Congress should amend the federal Employee Retirement and Income Security Act (ERISA) to allow the state regulation of self-insured employers in regard to health insurance plans. The state of Michigan should take a stronger role in regulating private insurers to broaden the scope of coverage for people with disabilities. <MI>

The Human Services Cabinet Council should explore, the legislature should fund, and the Departments of Social Services, Public Health, and Mental Health should implement methods of financing home care for people with high health care needs, including family-centered home care for children with severe disabilities or chronic medical conditions. <MI>

The Department of Social Services, Medical Services Administration, should review the Medicaid payment and reimbursement system and streamline the reimbursement system for physicians; shorten the time needed for Medicaid prior authorizations; and assure that Medicaid reimbursements are sufficient to remove disincentives for service to people with disabilities. <MI>

The Michigan Department of Public Health, with handicapper groups and the Developmental Disabilities Institute at Wayne State University, should develop a plan to increase medical and health service providers' understanding of the health care and empowerment needs of handicappers. School curriculum for all programs leading to careers in the health care field should include training on this issue. This training must emphasize that people with disabilities are valuable, contributing members of society. <MI>

The governor and the legislature should expand active implementation of the Department of Public Health's Infant Mortality Prevention program. <MI>

Advocacy organizations and local service providers should develop outreach plans so that people with disabilities who need health care and community services know where to obtain them. <MI>

Congress should enact legislation prohibiting insurers from excluding, terminating, or otherwise limiting coverage to any individual based on a pre-existing condition. It also should prohibit "experience rating" to avoid excessively high premiums. HR 2649, the federal Health Insurance Equity Act of 1989, would accomplish this. <MI>

Medical and health insurance benefits must continue when a person begins to work. Adequate coverage for medical care, including psychiatric services, should be assured. <MI>

The federal government should use its leverage to require group insurance policies to meet certain minimal standards in order to qualify for a tax subsidy. Policies must look beyond budgetary implications to individual health care needs and assuring choices of providers. Standards should be established for all health insurance plans that take into account the range of individual health care needs. <MI>

The payment system should reinforce and promote prevention by favoring primary preventive care for all people. <MI>

The Michigan Coalition for Access to Health Care, serving as the liaison between the Governor's Task Force on Access to Health Care and people with disabilities and chronic illness, should work with advocacy groups, consumers, health care providers, and others to promote changes in national and state priorities. There should be one system of health care financing that addresses the needs of all. Health care for people with disabilities and their families should be addressed in the broader context of equitable health care for everyone. Health care financing should address need rather than income level, age, or ability to work (as with Medicaid and other public programs.) People with disabilities should not have to pay a greater percentage than others of their often already inadequate income for this coverage. <MI>

The Michigan Developmental Disabilities Council should provide funding to develop a project to help parents and professionals identify and access health care programs and supports for children with special health care needs and their **families**. **The** project should increase communication and coordination among providers and families to assure that families obtain appropriate supports. <MI>

Medicaid expansion should occur which includes the use of additional options available under the Medicaid Plan and the application for additional waivers. <MO>

Legislation should be introduced that establishes an insurance pool for high-risk individuals. <MO>

The state's 30-day Medicaid restriction on acute care reimbursement per eligible per year should be corrected. <MS>

The reimbursement realities in the rehabilitation industry need to be addressed in the future as it relates to public and private policy regarding this segment of the health care industry. <MS>

Children with special health care needs should have access to integrated and coordinated health services that are community based. Early medical intervention and surgical care can help children lead more productive lives and prevent developmental disabilities. <MS>

The Children's Medical Program should improve and expand services to children with special health care needs so that assistance can be provided to 100 percent of all qualified applicants for service. For example, services should be provided for neonatal screening to all newborns for metabolic disorders for which effective and efficient tests and treatment are available. <MS>

Generic community home health care should be expanded to allow improved access by people with developmental disabilities. <MS>

An equitable health care financing system should protect people from excessive health care costs in relation to their incomes. Families of persons with developmental disabilities should not have to pay a greater percentage of their income for health care than families without such disabilities. <MS>

Data should be collected on the limitations of private and public health insurance for persons with disabilities. Surveys should be conducted at the national, state, and the community levels to more precisely measure the extent of the limitations of private health insurance on persons with developmental disabilities and the impact both on their lives and on the social costs to society. <MS>

Medicaid options which will allow coverage of additional persons should be considered for adoption. <MS>

Payments for medications should be increased, and improvements should be made in the quality of medication provision procedures. <MT>

An adequate health insurance and Medicaid reimbursement system must be developed which is affordable, minimally complex, and individualized to address unique clients' needs. <MT>

The availability of quality, integrated, general medical services and emergency health services, particularly in rural areas, must be enhanced. Medical professionals should receive training in methods for effectively working with persons with disabilities and sensitivity regarding the dignity of persons with disabilities. <MT>

Should consider the range of options which they have to prevent people from being rejected by private insurance or to distribute their costs in an equitable way before resorting to a high risk pool. <MT>

The state should consider state insurance pools which combine uninsured persons, people with pre-existing conditions, and persons in small employer groups who cannot purchase affordable or adequate health insurance in the private insurance market. <MT>

Should develop financing mechanisms to spread risk throughout the population. If health care premiums, deductibles, and co-payments were viewed as "taxes", it would be easier to see the inequity of requiring people with disabilities to pay higher taxes because they use more health care services. <MT>

The federal government should require states to allocate at least one-third of their Maternal and Child Health block grant to PCSHCN and to develop uniform eligibility criteria for PCSHCN services to all children with special health care needs. <MT>

It is important for states to monitor the impact of HMOs on people with chronic health conditions in order to consider whether it may be necessary for provider risk to be separate from prepayment for high risk populations or for HMOs to make certain modifications in their administrative controls for chronic care. <MT>

It is necessary to create a financing mechanism for equitably distributing the health care costs throughout the entire population. <MT>

The Council recommends that national and state policymakers create financing mechanisms which ensure that all people have equal access to needed health care services. These mechanisms should protect people from excessive health care costs in relation to their incomes. Out-of-pocket costs for disability-related expenses should be limited to a

fixed amount or a percentage of a person's income. The financing mechanism should protect against excessive annual and lifetime out-of-pocket costs which can impoverish a family. <NC>

The state should regulate private insurance carriers to ensure that comprehensive health care services are available to persons with developmental disabilities and that health care benefits are not denied, reduced or eliminated on the basis of a person's disability. <NC>

The Council recommends that the Department of Environment, Health and Natural Resources and the Clinical Center for the Study of Development and Learning work with professional medical, dental and nursing associations to require two (2) hours of continuing education in developmental disabilities annually, to be effective January 1, 1992. <NC>

The Department of Environment, Health and Natural Resources and the Clinical Center for the Study of Development and Learning (CDL) must work with all medical, dental and nursing programs to implement education about developmental disabilities as a standard requirement in the curriculum by July 1, 1992. Furthermore, a short-term practicum providing interaction with persons with developmental disabilities should become a part of the curriculum by July 1, 1994. <NC>

The state should consider state-level insurance pools for individuals and groups who cannot purchase affordable or adequate health insurance in the private market. Such pools could combine uninsured persons, people with preexisting conditions, and persons in small employer groups. <NC>

North Carolina must join the majority of states in allowing Medicaid coverage for all SSI beneficiaries. The General Assembly should revise the eligibility criteria, making SSI recipients automatically eligible for Medicaid. This should be effective July 1, 1991. <NC>

Develop innovative models of health care delivery to meet specialized health needs in all areas of the state, urban and rural. <NE>

The Department of Health should take a more active role in identifying needs and promoting responsive health care policies for persons with disabilities. <NE>

Medicaid reimbursement levels should be sufficient to remove financial disincentives for serving people with disabilities. <NE>

Current scope of practice issues applicable to nursing and health professionals need to be examined weighing both available care of persons with medical needs in the community and the need for safeguards. <NE>

Community based coordinated care models need to be developed for children based on disability related need rather than on financial eligibility. <NE>

Prescribed medications should be available to all persons regardless of financial status. <NE>

Regulations governing the reimbursement of community health care providers under the medical assistance (Medicaid) program should include the same provisions for rate increases based on cost increases as are currently mandated (in 34 CFR sec. 447. 253 (b)) for institutional services. <NH>

It is recommended that Medicaid reimbursement levels be sufficient to remove financial disincentives associated with serving people with developmental disabilities. A special level of reimbursements should be developed that reflects the amount of time health care providers must spend to provide quality care. <NJ>

It is recommended that support be given for the Medicaid Reform Legislation and the Medicaid Home and Community Quality Services Act of 1989. <NJ>

It is recommended that the federal government eliminate the two-year waiting period for Medicare, or at least establish Medicare as a secondary payor for new SSDI beneficiaries. <NJ>

It is recommended that the state and advocacy organizations consider developing a "sick fund" or medical "tithing" system to cover health care costs. <NJ>

It is recommended that redundant and excessive paperwork be reduced. Accountability must be balanced with efficient recordkeeping. <NJ>

It is recommended that support be given to implementing the recommendations of the New Jersey Pediatric AIDS Advisory Committee. It is further recommended that a board be formed to take responsibility for developing a state agenda to deal with the pediatric/adolescent AIDS epidemic. <NJ>

It is recommended that the adequacy of private and public health insurance be carefully monitored at this stage of the health insurance reform movement. Existing national surveys do not reveal the extent to which people with specific disabilities have pre-existing condition exclusions or use a large percentage of their income in out-of-pocket costs. These studies should be conducted at the national, state and disability group level. <NJ>

It is recommended that employers be mandated to provide health insurance for employees and their dependents, as stipulated by the Basic Health Benefits for All Americans Act of 1989. <NJ>

It is recommended that the state assess shortages of physicians in any geographical area and develop methods to remedy the shortages. <NJ>

It is recommended that coordination of care be a component of the health care delivery system. <NJ>

It is recommended that health care services to people with developmental disabilities living in the community be reviewed and evaluated. <NJ>

It is recommended that all medical personnel receive training regarding treatment of patients with developmental disabilities. It is further recommended that fellowship programs be developed within New Jersey, including clinical work and rotation through a variety of disability programs. <NJ>

It is recommended that the health care delivery system ensure an adequate capacity to provide quality services to people with disabilities living in the community. It is further recommended that the state develop standards of care. <NJ>

It is recommended that a model for planning for the health care needs of persons with developmental disabilities be developed. <NJ>

Work toward improving Medicaid reimbursement levels, making them sufficient to remove disincentives for serving people with disabilities. <NM>

Change health care financing policies to promote universality, comprehensiveness, equitable financing, and cost control. <NM>

Congress should create financing mechanisms that ensure that all people have equal access to the health care services. <NM>

Implement mandatory employer provided health insurance for their employees and dependents which would significantly reduce the size of the uninsured population. <NM>

Encourage the federal government to eliminate the two year waiting period for Medicare, or establish Medicare as a secondary payor for new SSDI beneficiaries. <NM>

Develop a long term home care benefit under Medicare which would be available to current Medicare recipients and children with disabilities on the basis of functional limitations. <NM>

Extend the employer mandate for COBRA continuation coverage to 29 months for persons ending work as a result of disability which would permit SSDI beneficiaries to purchase continuation coverage while waiting for Medicare coverage. <NM>

Develop federal standards for health insurance plans. <NM>

Develop financing mechanisms for health care to spread risk throughout the population. <NM>

Examine state use of Medicaid funding and insure that all appropriate options are considered and used, including: 1) amendments to the basic state plan; 2) utilization of the higher benefit levels in the Early Periodic Screening, Diagnosis and Treatment program (EPSDT); 3) Medicaid waivers for home and community based services. <NM>

Encourage the broadening of eligibility for Medicaid by 1) disregarding family income if a child is at risk of institutionalization (TEFRA 134 option); 2) raising the income threshold for pregnant women and children; 3) expanding the medically needy program; and 4) establishing a Medicaid Buy-in-program with sliding scale premiums. <NM>

Expand the New Mexico Comprehensive Health Insurance Pool to serve individuals and families of middle and low income brackets. <NM>

Institute state health insurance regulations to broaden the scope of health related services covered by private insurance. <NM>

Services must be instituted which effectively address the very special needs and cultures of people with disabilities in need of substance abuse treatment, prevention and education services. Planning for such services should include consumers, especially those who can assist in identifying specialized supports for inclusion in programming, i.e., technology, interpreters, services, accessibility modification, etc. <NV>

The legislature should establish provisions for licensure of intermediate care facilities for the physically handicapped (ICF/PH) similar to the ICF/MR provision. <NV>

Federal block funding for alcohol and drug abuse treatment and prevention should include the provision that programming be developed which effectively addresses the very special needs and cultures of people with disabilities. Particular emphasis should be placed on those whose disability, i.e., deafness, blindness, head injury, etc., requires specialization beyond traditional approaches and unique supports such as technology, interpreters, cognitive retraining, etc. <NV>

The Planning Council should assist in the establishment of a health care planning task force. <OH>

The Ohio Developmental Disabilities Planning Council should, after sufficient review and formal adoption, strongly support the recommendations of the Health Insurance Task Force. The Council should promote the model developed by the Task Force at the national level. <OH>

The Planning Council should closely examine and provide direction regarding health care financing reform options for Ohio, including high risk pools, Medicaid by-ins, etc. <OH>

People with developmental disabilities and their families should be supported in making maximum use of typical community-based, generic health care services. Any inadequacies in the community-based system in meeting the medical care needs of people with developmental disabilities should be addressed by training and coordination initiatives within the generic medical service system rather than by creating a specialized, parallel system. <OH>

People with developmental disabilities should have access to adequate transportation to health care services. <OH>

The Ohio Developmental Disabilities Planning Council should thoroughly review the recommendations of the following entities and assist in their implementation when deemed appropriate: Prevention Task Force of the Ohio Department of MR/DD, Early Intervention Council, Medical Needs Project of the Ohio Developmental Disabilities Planning Council. <OH>

The relevant committees of the Planning Council, along with selected providers and advocates, should routinely review the service standards for health care services and specify recommendations for improvement. <OH>

The Planning Council should insure that people with developmental disabilities and their families are provided with competent, knowledgeable assistance in making informed choices and receiving appropriate health care. <OH>

Working agreements among and between the Ohio Department of Health, University Affiliated Programs, professional health care organizations, and advocates for people with developmental disabilities should be developed to ensure that all health related professionals (physicians, nurses, OTs, PTs, dentists, etc.) will receive appropriate training in issues related to the specific health care needs of people with developmental disabilities. <OH>

Medical colleges and universities in Ohio should ensure that an adequate supply of health care professionals trained in disability issues are available to serve people with developmental disabilities. <OH>

The Oklahoma Council on Health Care Delivery (Interim Report to the Oklahoma State Legislature, January 1989, page 4) has recommended the establishment of a health insurance risk pool in Oklahoma. The Oklahoma Planning Council on Developmental Disabilities recommends the establishment of a health insurance risk pool in Oklahoma and supports the Oklahoma Council on Health Care Delivery in their efforts in this area. <OK>

Prepare a comprehensive approach to health care for children with chronic illness or disability. <PA>

Pennsylvania has experience with acquiring and using Model Waivers for technology dependent children, so it is recommended that an aggressive policy be taken to acquire other Model Waivers to serve children with complex medical needs. <PA>

Substantial increases in the reimbursement rates for Medicaid rates are necessary to encourage physician participation in the program. <PA>

Many health care professionals, particularly dentists, lack training in the health care and other needs of individuals with disabilities. A concerted outreach effort is needed to educate health care professionals. This can be done by the Department of Education under the supervision of an advisory board of citizens with disabilities. <PA>

It is recommended that Pennsylvania state planners explore the following options to ensure that adequate health care coverage is available to low and moderate income families with children with disabilities: state high risk pools; state financed catastrophic health insurance; state subsidies for private health insurance; state mandated catastrophic health insurance; mandated employer based coverage. <PA>

It is proposed that the Puerto Rico Department of Health shall be responsible for implementing and improving medical, diagnostic and treatment services for the population with disabilities currently underserved or unserved. <PR>

It is proposed that the Puerto Rico Treasury Department shall be responsible for promoting that government employees' medical insurance plans provide for insurability and coverage of related services for people with developmental disabilities or their family at an affordable cost. <PR>

Children living with their families who are at risk of institutional placement should be qualified for Medicaid, regardless of the family income. <SC>

Cost containment of health services (both inpatient and outpatient costs and public and private insurance costs) must be a priority of our country's leaders. <SC>

Incorporating the developmental needs of infants and children into the health care delivery system needs to be a priority. <SC>

Policy is needed to address the inability of persons with pre-existing conditions to obtain private health insurance. <SC>

The institutional bias for certain health benefits should be removed allowing persons with disabilities to receive health related services in their homes and in other community settings. <SC>

Reimbursement procedures for Medicaid providers should be restructured in such a way that payment is more expedient and claims are less difficult to initiate. <SC>

A buy-in mechanism should be established for consumers and eligible employers so that Medicaid can be more accessible to the uninsured. <SC>

Facilitate programs which will increase health care services and make provisions for health insurance for children and adults with disabilities. <SC>

Tennessee should take advantage of the provisions of the Tax Equity and Financial Responsibility Act of 1982 which permit states to extend categorical Medicaid eligibility to children with severe disabilities and chronic health conditions who would otherwise only be eligible for Medicaid if they were hospitalized or in another institutional placement. <TN>

In order to achieve uniformity of Medicaid services, the Medicaid program should be administered by the state under federal guidelines which limit the states' options not to provide services. <TN>

In Tennessee, the deductible and the waiting period should be eliminated from the state insurance pool requirements. <TN>

The Texas Planning Council recommends the Texas Legislature monitor the implementation of Senate Bill 832 to establish the Texas Health Insurance Risk Pool; and direct the State Board of Insurance to expand health insurance coverage of therapies, home care and assistive technology. <TX>

The state should establish a state health insurance risk pool for "uninsurables" to treat disability related problems. This would function as excess liability "reinsurance or coinsurance" to supplement the mandated insurance provided by the employer. To finance this pool, a fee would be charged all insurance companies, thereby distributing the costs and eliminating the cost to any one insurance company or business sector. <UT>

The Council recommends the development of a health insurance program that would eliminate the employment disincentive of disability related health costs and yet still be funded from the private sector. <UT>

Utah's Medically Needy Program which is an optional provision through Medicaid is in jeopardy of being eliminated. For an immediate solution to prevent this action by the legislature, a technical amendment must be initiated to sustain the program. For a

permanent solution, we recommend rewriting the Medicaid Act to accommodate Utah's provision. <UT>

Consider a specialized Health Maintenance Organization for persons with disabilities. <UT>

Promote an insurance pool funded by private insurers contributing a percentage of their earnings to cover people with expensive needs. <UT>

Regulate private insurers to get better coverage of disabled persons' needs. <UT>

Reduce the paperwork necessary for all health care funding sources. <UT>

Continue the Medically Needy program, but obtain more input before recommending whether to use the federal method or the Utah method of attaining eligibility. <UT>

Address the "impoverishing" policy of the Medicaid spend down; supplement family incomes without impoverishment and without forcing them to surrender the person with the disability to state care. <UT>

The Department for the Rights of the Disabled should collaborate with Centers for Independent Living and disability advocacy organizations to sensitize/educate health care personnel in appropriate interaction with persons with developmental disabilities and their families and in the use of existing information and referral services which will assist them. <VA>

Medical programs serving the same populations should be coordinated. Provide sufficient resources and education to make this process effective and realistic. <WA>

People with developmental disabilities and their families should have choices when it comes to health service planning, coordination of services, and choice of providers. <WA>

A component of all medical training programs should include the ethics of treating people with disabilities. An emphasis should be placed on encouraging professionals to serve people in community settings rather than in institutions. <WA>

We stand behind the belief that all persons have the right to adequate health coverage regardless of their health status. <WA>

We need to support ongoing funding that assures the availability of community-based health care for persons with disabilities. <WA>

Medical programs and accounting services should be coordinated. Sufficient resources need to be provided to serve people with disabilities and their families in a less stressful, less complicated manner. This applies to both health-related procedures and billing

practices. A government entity would be responsible for cross-checking private insurance and public programs in order to appropriately cover services. <WA>

Place increased emphasis and value on the importance of family supports whenever appropriate by providing funding support to families, friends, and relatives providing health care supports to individuals with disabilities. <WI>

Provide adequate pay and benefits to health care professionals who are supporting individuals to live independently in the community. <WI>

Assess Medicaid reimbursement levels to health care providers to determine if the current Medicaid reimbursement level is appropriate, and if the current reimbursement is a disincentive to serving people with disabilities. <WI>

Incorporate primary health planning and illness prevention into the individualized planning processes used in implementing state programs, including the Medicaid Waiver programs, Community Options Program, Family Support, and Medical Assistance-funded case management. Update program implementation manuals to include guidance on developing primary health objectives for individualized service plans. <WI>

Appropriate adequate state general purpose revenues to supplement the federal MCH funds for the Maternal and Child Health Program, the Program for Children with Special Health Care Needs, and the Waisman Center. <WI>

Provide pre-service and in-service training of various community direct service workers in the health care needs of individuals with disabilities. <WI>

Provide increased pre-service and in-service training to health care providers in the health care needs of individuals with disabilities. <WI>

Update and circulate the Medicaid Beneficiary Handbook, making it available in other language translations and formats as necessary. <WI>

Involve private insurance carriers in planning, developing, and providing health care for individuals with developmental disabilities and become involved in current legislative and governmental efforts to develop programs for the under-insured. <WI>

Conduct a study to assess the utilization of health maintenance organizations (HMOs) by people with developmental disabilities and develop a cooperative plan to ensure the adequate provision of services by for-profit and not-for-profit health maintenance organizations. <WI>

More health care professionals are needed in underserved areas of the state, including providers who are knowledgeable about developmental disabilities. Efforts such as the

State Loan Repayment Program for physicians should be continued and expanded in order to provide incentives to health care professionals to practice in rural West Virginia. Also, programs such as the dental practicum for special needs patients at West Virginia University should be continued and replicated within other disciplines. <WV>

Eligibility under the Medicaid program should be maximized to promote both prevention and habilitation of developmental disabilities. The state should expand eligibility for Medicaid services by (1) implementing the TEFRA eligibility option, (2) raising the income eligibility level for pregnant women and children to 185% of federal poverty level, and (3) increasing protected income levels to reflect the current cost of living. <WV>

Health care funding policies and practices need to be modified to encourage more community oriented care. To avoid interfering with the independence, productivity and integration of people with chronic conditions, it is necessary to broaden the definition of health care beyond acute care services and reverse the institutional bias so that people with disabilities can receive health related services in their own homes and community settings. <WV>

Wyoming should make sure it considers all of its options for using Medicaid. These include: (1) amendment to the basic state plan; (2) utilization of the higher benefit levels in the Early Periodic Screening, Diagnosis and Treatment program (EPSDT) for low income children from birth through 21 years; and (3) Medicaid waivers for home and community-based services. <WY>

EARLY INTERVENTION: BARRIERS

The vast majority of states lack qualified personnel to deliver early intervention services. <AR>

A parallel system of specialized services exists for young children with developmental delays; as soon as a child is "identified," he or she is separated from many of the resources typically serving young children and families. <AR>

Arkansas' DHS Office of Medical Services has been notified by HCFA that the amendment to the state plan which was submitted in February 1989 to provide for the continuation of federal funding for services away from the clinic site has been denied. This plan amendment would have allowed Medicaid funds to be utilized for children with developmental delays or disabilities. The Department of Human Services must decide if they will adopt a reimbursement policy for services which are only delivered at a clinic site or if they will choose 1) to pursue an amendment to the state Medicaid plan to cover the services, 2) utilize the EPSDT program as a funding mechanism or 3) amend the home health care program and utilize provider targeted case management in order to continue the early intervention home-based services. <AR>

Less than ten states currently mandate services for infants with handicaps and disabilities from birth. Each state must develop eligibility criteria for early intervention services; fiscal limitations, rather than need, often determine the type and number of children eligible for early intervention services. <AR>

At least three early intervention programs were operative in Arkansas as early as 1974-75. Currently there are eleven programs around the state licensed to serve 286 infants and families. Home-based programs serve 139, 90 in center-based and 84 in home-based center-based models. All but three of the programs have a waiting list for services. <AR>

Few early interventionists have been trained specifically in the skills required for working with families, being members of interdisciplinary teams and collaborating with other agencies. Few states require or offer certification of infant interventionists. <AR>

The trend is for the services to come to the child, rather than requiring that the family bring the child to services. However, due to the shortage of physical, occupational and speech therapists in Arkansas, it may not be feasible for therapists to use time which could be utilized for therapy in travel to homes, especially in the rural areas of the state. <AR>

Infants born to mothers with addictions to illegal substances suffer severe medical problems in the newborn period related to the withdrawal symptoms created by their in utero addiction to these substances. The Council does not know of any well established data that links developmental disabilities specifically to the effects of perinatal addiction.

The issue is complicated by the fact that the mothers of the infants are or were addicted to illicit substances and therefore their infants are at high risk environmentally. It is difficult to separate the two potential causes. Prevention of DD is certainly indicated in these situations and any infants who do demonstrate developmental delays would be enrolled in regular early intervention programs. <AZ>

Fetal Alcohol Syndrome (FAS) is a well established problem associated with known developmental disabilities. The problem is particularly prevalent among the Native Americans in Arizona. The Indian Health Service has several programs, with an emphasis on preventive education and pre-natal services. The success of these programs has been limited. There are no specific early intervention programs for this population. Instead, the infants are enrolled in existing programs where available. Since FAS infants have obvious physical stigmata they can be referred to early intervention programs soon after birth. <AZ>

There is an increased awareness of the need for home-based visits for the medically at risk and younger children, ages birth to 2 years. <AZ>

Eight out of 10 providers contended that early preventive diagnostic screening is not fully utilized for expanding services to persons with developmental disabilities. <DC>

Parents in all income brackets have difficulty affording the wide array of services that children with special needs may require. Medicaid funds are often limited for some services, such as therapy, because of Indiana certification practices and other policies. For parents who do not meet Medicaid income eligibility requirements, services are costly and may not be covered by their own private insurance. <IN>

The public needs to be educated about the importance of early intervention and to be more aware of the special needs of children and their families. <IN>

Long-term funding for services for children with disabilities or at-risk from ages birth to three is lacking. <KS>

Adequate funding for services for children ages three to five is lacking. <KS>

As of November 1989, the waiting list for early intervention services is 1,000 children and families. <MA>

Families with very young children with developmental disabilities who could profit from early intervention services remain difficult to identify. <MO>

Due to funding resource limitations, North Dakota is one of many states that does not participate in an optional program to extend Medicaid benefits to pregnant women with incomes up to 185 percent of the federal poverty level. Therefore, near poverty pregnant

women who are not generally covered by health insurance also find that because what meager income they have still exceeds the poverty standard, they are disqualified from receiving Medicaid support. With little if any financial means available, these women have no alternative but to forego adequate prenatal care even though inadequate prenatal care is recognized as a major contributing factor to premature births, low birth weight and birth defects. Nationally, it is estimated that the cost of neonatal care for low birth weight or premature babies is often as high as \$30,000 per child. Prenatal care is far less expensive. <ND>

In the context of the federal DD Act, the goals of independence, productivity and integration are ascribed primarily for adolescents and adults with developmental disabilities. These goals, which are the primary purpose of the policy analysis report, are not at all appropriate for addressing policy concerns relative to prevention and early intervention. Even though the federal DD Act appears to have overlooked these two areas for purposes of the required policy analysis, it is the contention of the SCDD that North Dakota's policy analysis report would be incomplete unless it addresses prevention and early intervention issues. <ND>

Outreach to urban poor and minority families is difficult within the current system of early intervention. <NJ>

Child care workers in Camden, Middlesex, Union and Essex Counties report that more children are exhibiting language deprivation, a lack of eye contact, short attention spans, listlessness, and no response to affection. Administrators also report an increase in adolescent parents and parents who abuse drugs. <NJ>

While current criteria for state and federally funded early intervention programs allow services to be provided in the natural settings of a home or day care center, most agencies find it more cost-effective and efficient to provide center-based programs, with a homebound component exclusively for children who cannot attend a center. <NJ>

Another area of program weakness identified is services to infants, toddlers, and preschoolers with handicapping conditions and developmental delays. Substantial difficulties were reported in the coordination of such services. Except for children with the most severe handicapping conditions, a comprehensive range of services is not available. <SD>

At the present time, 16 federal programs provide funding to states for early intervention services. These programs address medical needs and health services. They also provide funding for training and education in such areas as prevention, early intervention, nutrition, mental health, social services, independent living, education and rehabilitation. Programs vary widely in their eligibility criteria as well as in their target populations. Such a patchwork of programs makes it difficult to holistically address the needs of children and their families. <WA>

Current supports and services are not adequate to meet the needs of at-risk children and their families. In October 1989, DDD provided early intervention services to 1,449 children statewide through school districts and county programs. Obviously, this covered just a fraction of the real need. Additionally, some 251 children from birth to age two were unserved because of lack of funds. The figures documenting this need are compelling. There are 20,000 to 60,000 children under the age of six in Washington who are at risk of developmental delays or other disabilities. Only about 10,500 of those children will receive early intervention services. This means one-third to one-half of the children who could benefit from early intervention services are not receiving them. <WA>

The major obstacle to providing adequate early childhood intervention services is a lack of money. There's just not enough money to meet the need for programs, parent education, staff training, and information. This situation remains constant even though the cost-effectiveness of prevention and early intervention activities in minimizing risk factors has been conclusively proven. It is relevant to note that the citizens of Washington recently voted down an initiative referred to as the "Children's Initiative." The Initiative would have raised an additional \$360 million a year for children's programs with a primary emphasis on prevention. Similarly, a comprehensive bill introduced in the legislature to implement early intervention services as state policy was not voted on during the 1989 session. <WA>

Possible reasons for the high number of children who could benefit from early intervention services and who will go unassisted include long waiting lists, no money to pay for services, not eligible under state criteria, an undiagnosed condition, no referral to available services, no appropriate services available in the local community, and different social and cultural philosophies. <WA>

Existing early intervention programs are not geared toward families that have special needs of their own. For example, it is extremely difficult to get coordinated treatment for a mother who has a substance abuse problem and her newborn baby. Programs (even when available) have different funding sources, use different facilities, and also have different licensing procedures and varying eligibility rules. Separating mother and child for needed medical assistance and support decreases the chances for successful treatment and crucial bonding. <WA>

There is a perception on the part of some parents and advocates that early intervention programs and the professionals intentionally set up roadblocks to independence and empowerment. Families generally realize that funding realities play a part in this scenario, but they also feel a partnership approach would foster more a supportive, enabling environment. <WA>

Where you live in relation to available support can be just as important as whether the supports are offered in the first place. In other words, if you can't get to a service, you

can't use it. This is a transportation issue to some extent, but primarily it is a question of how funds are disbursed. <WA>

In addition to the problems with accessibility and availability, the autonomy of various programs often gets in the way. Even though many early intervention programs operate under a myriad of regulations, they still have enough funding independence to drastically vary the services they offer. <WA>

It's no surprise that people in rural areas have a problem accessing services that are a considerable distance from home. Add transportation problems to other variables such as low income and disabilities and the whole package can be overwhelming. <WA>

Expansion is needed in both the number of children served and the level of service provided. Early intervention programs presently serve less than 20% of the estimated number of children in the state who have developmental delays. When children at risk of developmental delays are included, current programs are reaching only 6-10% of all eligible children. In addition, some of the children who currently participate in early intervention programs are not receiving the level of service they need. The provision of a comprehensive array of services based on individual needs is estimated to cost \$3,000 to \$4,000 per child per year, as compared to the \$2,500 presently spent. <WV>

EARLY INTERVENTION: RECOMMENDATIONS

Ensure that affordable early intervention services based on individual and family needs and preferences are available throughout the state to all children and their families. <AR>

The Office of Maternal and Child Health should connect with Special Education's Child Find Program, the Interagency Coordinating Council (ICC), the DDD and other relevant systems to support the ICC's efforts to establish a comprehensive, coordinated automated tracking system for infants and children with developmental disabilities. <AZ>

P.L. 99-457 requires that specific early intervention services be provided at no cost to families. The Connecticut Coalition for Families opposes the use of third party reimbursements to pay for these services. The Coalition supports the allocation of an interagency pool of dollars to enable families to receive early intervention services at no cost. <CT>

Support the development of an early childhood registry to help identify and track the incidence of developmental disabilities in Delaware and enable follow-up services. <DE>

Ensure that prevention and early identification and intervention efforts receive adequate visibility and resources. <FL>

The Zero-to Three Hawaii Project should be supported in developing a "tracking" system for all high risk infants; and in the development of coordinated, appropriate early intervention programs. An essential component should be planning for services to drug and alcohol-exposed and HIV-infected children and their families. <HI>

Expand early intervention services in Maryland to take advantage of the opportunities for the early identification of children with disabilities afforded by the Early and Periodic Screening, Diagnosis and Treatment/Healthy Kids Program. <MD>

Early intervention (birth - 5 years) services should be made available and accessible to all families who want them. Included in this initiative should be incentives for day care centers to become integrated. <MS>

Area Agencies, early intervention programs and schools should develop working relationships with community day care providers and other children's organizations to ensure the inclusion of children with developmental disabilities in generic programs. Greater utilization of such services as staff training, tuition reimbursement, shared staffing, technical assistance, start-up funding, and the provision of adapted equipment should be utilized as an alternative to the creation of specialized "handicapped" programs for young children. <NH>

The concept of focusing on supporting and developing individual and family competencies and of helping people with developmental disabilities to connect with and use natural community-based supports whenever possible is most critical in early childhood years. Efforts within the early childhood service delivery system that go in this direction must be supported. <NY>

Support the Ohio Department of MR/DD's policy for use of capital construction funds to renovate and/or construct collaborative innovative early intervention centers in cooperation with the Early Intervention Local Collaborative Groups. <OH>

Support passage of the Early Intervention Investment Act of 1990, now being considered by the Ohio Legislature, which contains the "Eleven Essential Components of Early Intervention Programs" (developed by the Council's Early Intervention Task Force). <OH>

Increase the availability, accessibility and affordability of preconceptional perinatal care, clinical genetic screening and counseling services, and perinatal and well infant/well child care. <WI>

Early intervention programs need to be expanded in order to enhance skills and reduce handicapping conditions of young children. <WV>

PREVENTION: BARRIERS

The drastic shortage of specialists in OB/GYN services threatens the prenatal health of the next generation of Alabamians and could place a number of those children at an increased risk for developing disabling conditions. <AL>

While specific data were not available at the time of this report regarding homelessness in Alabama, it is estimated that one of out ten homeless mothers are also substance abusers. Of the children born to these women nationwide, seven out of ten are victims of their mothers' drug abuse. Children born to these mothers are at high risk for low birth weight, mental retardation, deformities of body organs, deafness, and cerebral palsy. Often, these children are abandoned at the hospital where they were born. Consequently these children are called "boarder babies" due to the fact that, in the absence of an identified home, they "board" at the hospital. Federal government spending to support these children is estimated at \$2.5 billion. This is not an unfamiliar situation in Alabama. Doctors' efforts to serve these children are often hampered by bureaucratic constraints due to the absence of a parent to authorize treatment. <AL>

The council has identified prevention as a priority for many years in the belief that the State of California has a moral obligation not only to provide services for people with developmental disabilities, but also to prevent the occurrence of further developmental disability, where feasible. If this area is not fully addressed, service needs of the system will continue to expand at a rate which we cannot hope to meet with the current limited fiscal resources. <CA>

Colorado has one of the highest low birth weight rates in the country, with a high concentration in the mountainous rural areas. It is known that among pregnancies resulting in a low birth weight, developmental disabilities are found at a higher rate than in pregnancies resulting in births in the normal weight range. Also, prematurity at birth carries a higher than normal risk of developmental disabilities. The lack of trained medical personnel who can deal effectively with high risk pregnancies is especially acute in rural areas. In addition, the unwillingness of physicians to accept the low Medicaid reimbursement rates limit access to medical care for many of the rural poor. <CO>

There is a lack of coordinated efforts to prevent developmental disabilities (e.g., public education, prevention of adolescent pregnancy, education concerning effects of drugs, alcohol, and tobacco). <KS>

Commitments to prevention services at the state level have been fairly well established. There exists a need to expand this commitment level to the local level so that statewide prevention strategies can have stronger impact. <MO>

In North Dakota, many pregnant women with low incomes are determined to be ineligible for Medicaid on the basis of unrealistically low state poverty income standards which

have been in place since 1981. Without alternative resources available or with no access to the services of optimal pregnancy outcome programs, most of these women have no choice but to forego adequate prenatal medical care. Inadequate prenatal care is recognized as a major contributing factor to premature births and birth defects. <ND>

An estimated 220,000 preschool-aged children are at high risk of lead poisoning. Chronic lead poisoning causes serious neurological problems and learning disabilities, and can result in mental retardation or death. <NJ>

An estimated 30,000 teenagers in New Jersey become pregnant each year. Babies born to adolescents are at a higher risk of acquiring disabilities associated with poor prenatal care and poverty. <NJ>

In 1985, some 25 to 30 percent of the births in this state (between 17,000 to 22,000 babies) were at environmental risk due to such factors as adolescent parents, poverty and family dysfunction. In the United States, one of every six babies born will be born to a teenage mother. <WA>

A number of outreach programs have focused on prenatal care but many young women in their teens as well as women with special needs of their own still do not receive the early care both they and their babies need. <WA>

It is essential to collect meaningful data on the cost effectiveness of prevention programs. Meaningful statistics can be used to increase public awareness as well as to build political support for the funding necessary to start up prevention programs. Currently, we are faced with incomplete information and bureaucratic red tape when it comes to painting a true picture of preventable disabling conditions. Research can also be the key to preventing and treating many diseases and disabilities. <WA>

Many accidents and diseases could be prevented by investing in better living and working conditions. <WA>

Insurance coverage is usually not prevention oriented. And, even at that, many people go without because premiums are too high. <WA>

Preventing disabilities requires far-sighted expenditures with long-term savings. In other words, prevention costs less in the long run. This is a verifiable fact, but it doesn't always transfer to public policy or funding priorities. <WA>

All social service systems — whether they are to be associated with planning, funding, education or information — need to come together in a holistic way to address the causes of and ways to prevent disabling conditions. The current public policy does not reflect this goal. <WA>

Washington State lacks a unified, comprehensive prevention strategy that would coordinate all existing prevention efforts as well as focus on new public and private prevention initiatives. Building a statewide, comprehensive prevention program means addressing system inadequacies and funding problems as well as creating a quality public education and awareness campaign. <WA>

Wisconsin does not have a clear delineation of responsibility for prevention planning and services, nor a state plan for the prevention of developmental disabilities. Within the Department of Public Instruction activities include child abuse and neglect prevention, healthy behavior promotion, adolescent pregnancy prevention, alcohol and other drug abuse prevention, and AIDS prevention. Within the Department of Health and Social Services prevention activities occur primarily in two Divisions. The Division of Health administers the Maternal and Child Health Block Grants, and is currently in the process of finalizing the Wisconsin Public Health Plan for the Year 2000. This plan encompasses many areas of primary prevention of developmental disabilities. The Division of Community Services has a full time prevention specialist, a coordinating committee, and a few individuals in offices who do prevention work. There is no long range state plan for prevention activities. The Wisconsin Council on Developmental Disabilities has a full time position in prevention along with funds to stimulate the development of prevention activities. Prevention activities for the DD Council include both primary and secondary prevention and preventive health activities for people with disabilities. <WI>

Healthy births can be promoted if future parents are assessed for health behaviors, health information, and pregnancy risks. Pregnancy in adolescent women increases the risk of complications that can result in serious health consequences for the newborn infant. <WI>

Health care and educational efforts are needed to prevent developmental disabilities. Teenage pregnancies, poverty and poor prenatal care all contribute to higher incidences of handicapping conditions. Of particular concern in West Virginia is the high percentage of teenage pregnancies, comprising 17% of all births in the state in 1986, as compared to the national rate of 13%. The same year, 24.9% of babies born to white teens had low birthweights, the highest percentage of the nation. Low birthweight babies require costly medical care, estimated at \$1,000 per day per child, with lifetime cost as high as \$389,800. <WV>

PREVENTION: RECOMMENDATIONS

The Council encourages the ongoing provision of and expansion of prevention services in the areas of perinatal care, early intervention, genetic screening and counseling, public and professional education regarding environmental hazards, substance abuse and other causes of developmental disabilities, and management information to help identify causes of disabling conditions, and the need for specialized prevention and early intervention services. <CA>

The 1989 DD-funded Prevention Report recommends that the Department of Public Instruction (DPI) consider including a variety of prevention messages and activities in the public school curriculum at all levels. Furthermore, units on the nature and causes of disability should be included, with a focus on how disabilities can be prevented. It is also recommended that local school districts be encouraged to use the Comprehensive School Health Program developed by DPI to prevent substance abuse. <DE>

Disseminate prevention information. Public information and education are central to any prevention effort. The challenge is to change the private behavior of thousands of Delawareans, to motivate people to consider their children and their future, to make sure that they know the risks and where they are found. A strategic marketing plan is the key to a successful media campaign. <DE>

Indiana shall develop a public awareness campaign to identify children at risk or with disabilities. <IN>

Support initiatives aimed at prevention of disabilities or other amelioration targeted to children and the poor, such as programs for babies born to alcohol or drug-abusing mothers; violence and abuse prevention programs; injury prevention; early intervention; immunizations of children against measles, mumps, etc. <MA>

Legislation should be developed and introduced that emphasizes a commitment to a statewide prevention program including local-level commitment. <MO>

Local-level and state agency commitment should be made to support, fund and implement the prevention plan of the Council. <MO>

Mississippi should promote implementation of prevention strategies to minimize the occurrence of conditions which result in disabilities. <MS>

Improvements in the quality of available genetic counseling and screening should be undertaken. Because of the distance which individuals must travel in Montana to receive such services, increased assistance in the area of transportation should be addressed. <MT>

Prioritize the recommendations in the prevention plan; identify resources to implement those recommendations; and provide feedback to the appropriate departments, the North Carolina Medical Society, the Council on Developmental Disabilities, the University of North Carolina System, and the state's medical schools regarding additional resources needed for implementation. <NC>

The services of optimal pregnancy outcome programs (OPOPs) should be made available on a statewide basis to meet the prenatal care needs of pregnant women with low incomes who are ineligible for Medicaid and have no other resources available to pay for such care. OPOPs currently in operation should be maintained with adequate levels of funding and new OPOPs should be established in those regions of North Dakota without OPOP services with the DD Council as an optional source of startup funding support. <ND>

North Dakota should adopt a long term goal of eventually participating in the optional program to provide Medicaid benefits for prenatal care of pregnant women with incomes up to 185% of the federal poverty level. <ND>

North Dakota's poverty income standards should be adjusted to account for increased living since 1981 and more closely approximate federal poverty income standards. Sufficient legislative appropriations should be requested and authorized to enable the Department of Human Services to reasonably accommodate the increased usage of Medicaid for prenatal care that will result from this upward adjustment. <ND>

Develop and implement a comprehensive system to provide and promote activities for the prevention of disabilities. <SC>

Promote raising financial eligibility limits for the "Baby Your Baby" program for its preventive value. <UT>

The General Assembly should require and promote implementation of primary, secondary, and tertiary prevention strategies to minimize the occurrence of medical conditions or mental/physical impairments which may result in developmental disabilities. <VA>

Support research to prevent disabilities. <WA>

Make the reduction of environmental and socio-economic influences on disability a long-term goal. Improve data collecting methods to reflect the true needs of and effects on the targeted populations. <WA>

Conduct an extensive media campaign on prevention. Provide public and professional education on the importance and "ethic" of prevention. <WA>

Lobby for health insurance coverage of preventive medical procedures and educational services. <WA>

Redirect funds to address preventable disabilities before rather than after the fact. Expand and fully fund successful prevention programs. <WA>

Fund a state-level management structure to carry out the prevention strategy. The strategy should be reflected consistently throughout budgeting, planning, delivery of services and program evaluation. <WA>

Develop a unified, holistic, comprehensive, statewide prevention strategy. <WA>

Expand the Women, Infants, and Children (WIC) nutrition program to serve 100% of eligible women and children. <WI>

Support legislation to enable all women to receive maternity care, especially women who are uninsured or underinsured. <WI>

Encourage the study of the delivery of comprehensive services to pregnant women who are using alcohol, cocaine or other drugs, or other elements which adversely affect fetal development. <WI>

Increase funding for programs designed to avoid pregnancy among teenage girls. <WI>

Increase lead prevention activities in both urban and rural areas of the state. <WI>

MENTAL HEALTH: BARRIERS

Multiple States

Although services to adults with serious and persistent mental illness are a priority in many states, there is no systematic data collection on public expenditures for these services. <ID,LA,MT,UT,WY>

There is a lack of data on the services being provided to children with serious emotional disturbance, including some states which were unable to report even the total number of such children who had been placed out-of-state. <ID,LA,MT,UT,WY>

The community mental health system has not developed adequately to meet the needs of adults with persistent and serious mental illness who would previously have been long-term patients in state mental institutions, despite the proven effectiveness of the community support program model. <1N,MT,UT,WY>

Services for children with serious emotional disturbance are frequently limited to out-of-home placements, in many cases to facilities in other states, with little or no availability of community-based care and supports to families. <MT,UT>

Individual States

State statute (A.R.S.26-203) specifies several interactions between Arizona State Hospital and the Department of Economic Security (DES) in dealing with with mental retardation people who have been admitted to the State Hospital. ASH is exploring ways to transfer approximately 25 patients with mental retardation. Fifteen of these patients have been accepted as eligible for DDD services by DES, and will be transferred to DDD facilities when placements are available. The remaining ten patients are dually diagnosed mentally retarded/mentally ill, and have not been certified by DES. Arizona State Hospital reports that it is often difficult to document age of onset for patients because of difficulty in locating old records, which can make it difficult to obtain DES acceptance for services. The Center for Law is assisting these 10 persons with appeals. Sufficient funds have not been available to effectively accomplish the transfer mandated by the courts. <AZ>

People are sometimes committed to the State Hospital by the courts. In these instances, ASH refers the individual to DDD for an evaluation. If DDD does not certify them as "developmentally disabled" and accept them for placement, ASH keeps them at the Hospital. There is no provision in the law for the courts to commit people to DDD. <AZ>

Individuals with dual diagnoses (developmental disabilities and mental disorders) often fall through the cracks between the Department of Developmental Services (DDS) and the Department of Mental Health (DMH). In general, the DMH, through county mental health

agencies, does not serve individuals with developmental disabilities, and vice versa: DDS does not serve individuals with mental illness. <CA>

A memorandum of understanding (MOU) exists between DDS and DMH concerning the treatment of people with dual diagnoses. However, this MOU cannot be implemented within the current state law. DMH does not have the authority to force local mental health agencies to serve people with dual diagnoses, and planning and control is based at the local level. There has been a strong push for local level. There has been a strong push for local MOUs between regional mental health services which is critical. Without additional resources, most local mental health agencies will continue to serve people with serious mental illness before providing services to people who have less severe disabilities and/or dual diagnoses. <CA>

People with serious mental illness meeting the federal definition of developmental disabilities are not receiving adequate and equitable services. Due to the fact that the developmental services system in California has service entitlement in law, while the mental health services system does not, serious inequities exist in the provision of services to this latter population. Resources have been significantly cut for mental health services, and the lack of commitment at both the state and federal levels to meeting the needs of people with serious mental illness is of concern. <CA>

Few professionals specialize in the care and treatment of persons with a dual diagnosis of developmental disability/mental illness, and fewer still work with young children. <CO>

Especially if there are other children at home, the parents have great difficulty arranging transportation and child care for the children at home while they take the child with mental illness and another developmental disability to outpatient appointments. There are no statistics on the extent of unmet need in this area, but it was identified as "a real gap in services" by professionals and parents statewide. <CO>

Special needs funding has been used for interviews with consumers with challenging behaviors who reside in the community. However, the \$50,000 appropriated in this fund is inadequate to meet the needs of the approximately fifty (50) individuals with psychiatric or behavior disorders who need help each year. <CO>

One area need cited by numerous persons contacted is that of counseling and mental health therapy for young children who exhibit signs of chronic mental illness and their families. <CO>

Mental health and/or behavior intervention services for various sub-populations that the system is either currently not capable of providing or has chosen not to address. Among these are families of children with mental illness (and the children, as well); persons with dual diagnoses such as DD/MI; sexually aggressive persons with developmental disabilities; people with developmental disabilities who do not have cognitive impairments who need

extended counseling not paid for by Medicaid or their public assistance. It was reported that about 450 individuals with developmental disabilities served by the Division for Developmental Disabilities are on psychotropic medicines, and approximately one-half of them have never seen a psychiatrist, so efforts are underway to provide psychiatric consultations for these persons. Nevertheless, there remains a need to develop a long-range plan for meeting the needs of all these very challenging people. <CO>

There is a need to provide mental health and related services for older persons who have mental health problems and hearing impairments, as well as those with mental health problems who also are both visually and hearing impaired. In addition to a critical need for additional treatment services, employment and residential services are needed for many of these persons. <CO>

Access to mental health services for people with physical disabilities and no mental retardation is lacking. In many cases, they are told they can have only short-term therapy, and longer-term supportive services are not available. Many of these people need mental health services over an extended period of time. <CO>

There are no mental health funds specifically designated to assist individuals with developmental disabilities who live in the community. <FL>

The Community Support program was initiated at the federal level, with a commitment by the state to continue programs started with federal support when the federal involvement ended. Today, those programs are funded through the state's Mental Health and Mental Retardation Services Fund and Alcohol/Drug Abuse/Mental Health (ADM) Block Grant monies. The services fund is distributed to the counties by formula; whether a county chooses to have a Community Support program is a matter of local option. About one in three Iowa counties do not provide any component of the Community Support program, and of the remaining counties, many do not provide the full range of possible services. <IA>

Because of the way the Community Support program is designed and funded, many persons with developmental disabilities do not have access to this program. First, it is designed to help persons with chronic mental illness remain in the community. Second, the Mental Health/Mental Retardation Services Fund is not designed to be used for persons with developmental disabilities. While providers of Community Support services can tap other sources of funding, such as county property tax revenues and the ADM Block Grant, the provision of this service remains a local option. <IA>

The total dependence upon county resources to support Community Support services is seen as inhibiting integration to the extent that many Iowans live in counties where these services are unavailable or very limited. <IA>

As anticipated, given the fact that eligibility for these services is quite limited, that 30 Iowa counties do not provide any Community Support services, and that many other counties offer only a limited range of services from the options available, relatively few consumers use this program. Those who do cite more dissatisfaction with the program than might be expected, based upon the results of the policy analysis. Four of every five consumers express dissatisfaction, with primary concerns being the lack of consumer voice in the choice of counselor and in treatment to be used, requirements for substance abuse testing, and lack of consumer input about what medications are prescribed. <IA>

Although systemic changes are the principal aim of the Children and Adolescent Service System Program projects, many projects continue to use funding for one-on-one counseling services or other CMHC affiliated service components. <IN>

Not all Children and Adolescent Service System Programs are taking advantage of the potential for the use of Medicaid funds for P.L. 94-142 identified youth. <IN>

Continuity in Child and Adolescent Service System Program efforts is needed through the summer months. Not all programs maintain summer activities for the target population. <IN>

Although the participation of parents and organizations concerned about mental health is encouraged and must be addressed in each project, many Child and Adolescent Service System Program projects have been unable to establish parent support groups or maintain them effectively. Strong cooperation is needed from local Mental Health Associations and local Special Education Cooperatives. <IN>

There are many more children identified as needing support than are able to be served. It is not clear that children with the most serious emotional disabilities are served through each project, nor that students with dual diagnosis are represented in the students who are served. <IN>

Louisiana's Three Year State Mental Health Plan identified a number of weaknesses in the mental health service system, including insufficient services, the lack of a systems approach to service delivery, insufficient use of financial resources, and the lack of accountability. <LA>

There are substantial gaps in community mental health services for children, adolescents and adults. Meanwhile, the mission of the Department of Mental Health has been narrowed to serving only people with chronic mental illness. By October 1989, 6000-7000 persons were denied needed services or left on waiting lists. <MA>

There are not enough mental health services for persons who are deaf. The comments appearing in the Task Force Report concerning mental health services for the deaf should be incorporated into the recommendations. <MD>

For the most part, North Dakota's policymakers recognize the need for the support changing the state's institutionally-based mental health system to a community-based mental health system. However, because fiscal constraints have not permitted as rapid a transformation to a complete community-based system and many consumers and advocates would like, the state's mental health system remains largely institutionally based. Community mental health services are not yet adequately developed and funded to provide care and treatment comparable to what clients are able to obtain from the State Hospital, largely because of institutional funding biases that preclude institutional funding from supporting clients in community services. <ND>

The lack of mental health services for children and youth continues to be a serious problem in Nebraska. In addition, persons with mental retardation and mental health problems have a difficult time accessing services. Community mental health programs may feel inadequately trained to counsel this population. Persons with developmental disabilities must have access to mental health services if needed. The Consumer Satisfaction Survey indicated that 37% of the respondents felt they had a need for mental health or counseling services. Only a little over a third of these people were actually receiving this service, with the rest reporting problems such as the service being too expensive, not available, or not appropriate to their needs. <NE>

Residents of New Hampshire Hospital who have developmental disabilities remain hospitalized an average of 92 times longer than the general population. <NH>

While at least 1,000 of New Jersey's children and youths receive care in psychiatric residential centers or hospitals each year, transitional facilities are not readily available for those who cannot adapt to their homes or to independent living situations. An increasing number of youths under the auspices of the Department of Corrections manifest severe emotional problems. <NJ>

In addition to consumers and their families, agencies providing residential or day services to Division of Developmental Disabilities' clients have frequently complained of difficulty in getting clients accepted by community mental health centers or mental health practitioners. Part of the problem is inadequate public funding for these agencies, which leads to strategies for limiting caseloads. <NJ>

Problems with the community mental health system include counseling and outpatient services, and management of residential and inpatient services. While community mental health treatment resources exist, accessibility for people with mental retardation or people who are deaf is an issue. In each instance, counseling and therapy are more difficult for the patient, and more frustrating to the therapist, because of difficulties with interpersonal communication and social isolation of the patient. <NJ>

People with epilepsy and people with mild to moderate mental retardation are vulnerable to the perceived stigma associated with these disabilities. <NJ>

Another program for people with a dual diagnosis at Ancora is designed as a short-term placement - three to five months - that provides stabilization, the development of a treatment plan and intervention approaches, and the subsequent return of the individual to his or her original residence in an institution or community setting. Admission rules call for such extensive background information, however, that it has proved burdensome for already overwhelmed case managers. The program remains below census as well because there is resistance for sending authorities to have clients returned to them after a brief respite to Ancora. <NJ>

The Division of Developmental Disabilities, seeking to address the issue of individuals who are discharged pending placement, opened a specialized unit at Ancora Psychiatric Hospital in January 1987. The 60-resident Developmental Center at Ancora was designed to provide residents with a transition program into less restrictive community-based settings. The lack of community alternatives, unfortunately, has resulted in few community placements. <NJ>

Without access to a community mental health center in the event of an emergency, a community client of the Division of Developmental Disabilities is likely to arrive at a psychiatric hospital without having gone through the established screening procedures. The result is a domino effect: the client will probably lose his or her community placement, a decision in which the hospital treatment team is not involved. The client cannot be appropriately discharged and remains in the mental health system with a status of "discharged pending placement." Hospitals are then reluctant to admit clients with developmental disabilities. <NJ>

By Utah statute and policy, all mental health agencies must provide a specific range of services from in-patient to after care. The problem is that there is not enough money to serve the full range of services to all who need them and as a consequence the Division of Mental Health must make priorities that exclude some people from services they need. <UT>

There have recently been reports of resistance to serve people with developmental disabilities in the mental health system (Focus Groups, 1989). The problem seems to be a lack of training which is also linked to a lack of financial resources. <UT>

In Utah, the McKinney Act Block Grant provides the State with \$275,000 per year for people who are mentally ill and homeless. The money is earmarked for treatment only which is a disadvantage for this population. The money cannot be used for any crisis situation, no housing, nothing that would be a common need of people who are homeless. <UT>

Statewide, children with severe emotional disturbances who are enrolled in public schools account for some 6.7% of the total student population. In addition, a full 70.7 percent of all children served by DSHS programs are determined to be severely emotionally disturbed.

Yet an astounding 74.3% of all children and teenagers with severe emotional disturbances are never introduced into the DSHS system; neither do they find their way into community-based mental health treatment programs. <WA>

Another important and underfunded area is mental health services for children. Currently, the mental health system is constructed with the adult population in mind. Owing to the fact that the whole mental health system is severely underfunded, there is very little left over for children in need of immediate attention. A focus on prevention also loses out in the funding crunch. <WA>

Quite often, people with developmental disabilities do not have their mental health care needs addressed. Currently, the Community Mental Health Services Act (RCW 71.24) focuses priority on serving people who are acutely mentally ill. This fact, together with severe mental health funding shortages, prevents many people from receiving mental health services unless their situation reaches a crisis stage. <WA>

Because the mental health system is underfunded, prevention and treatment services for children is severely limited. <WA>

There is a great deal of confusion regarding diagnostic definitions used by the mental health and developmental disabilities communities. All of this results in a serious deficiency of available mental health services to people with developmental disabilities. <WA>

A lack of funding for mental health services also contributes to dysfunctional families who are either emotionally or financially unable to take preventive health measures. <WA>

MENTAL HEALTH: RECOMMENDATIONS

Arizona State Hospital and DDD should continue to work with the Center for Law in the Public Interest to identify dually diagnosed individuals to assure that appropriate services are provided to all persons with developmental disabilities. Procedures and regulations for admission to ASH should be reviewed to assure screening for developmental disabilities is included in the commitment process. <AZ>

Utilize existing provisions of P.L. 99-660 to expand availability of suitable community mental health and behavior intervention services, especially for subpopulations judged to be hard to serve. <CO>

Determine the adequacy of community-based mental health services for individuals with developmental disabilities and submit program and budget requests as may be needed to ensure that they have access to adequate mental health support and treatment in their local communities. <FL>

Study the possibility of developing a Community Support service system that would be available in every county in Iowa for all persons with developmental disabilities (not only those with chronic mental illness) who are members of the community <IA>

Enhance community support policy by requiring consumer participation in decisions about who provides services, how needs are assessed, and what services will be used. <IA>

Revise state policy to explicitly cite independence, productivity, and integration as program goals of the Community Support program. <IA>

Support the provision of mental health services to those in need before they reach crisis situations. The mission of the Department of Mental Health should be restated and restored to a commitment to serve all people with mental health problems, not only people with chronic mental health problems. <MA>

The model for care for people with mental illness should expand from a medical model to endorse the concept for self-help through the development of a component to address self-help needs and living in the community. <MA>

Develop flexible community based services tailored to meet individual needs including community based day programs and transitional services for people residing in hospital facilities, prevention programs, such as 24-hour out-patient psychiatric referral, and acute residential psychiatric treatment in individual's own communities. <MD>

Revise state laws and regulations to allow for easier movement in and OUT of mental hygiene hospitals. Accord persons with developmental disabilities other than mental

retardation (referred to as the NRDD) population) who are residing in mental health institutions the same rights and access to community residential programs that Knott Class (those with mental retardation who are in mental hygiene facilities and who no longer meet criteria for retention in those facilities) members have. <MD>

Increase Developmental Disabilities Administration funding to enable more individuals to receive community based residential services along with Knott Class members, enabling an end to segregating Knott Class members in the same living arrangements in order to meet their legal requirements for expedited appropriate placement. <MD>

Support the quality of Mental Hygiene Administration programs providing services to individuals with Developmental Disabilities Administration funding by requiring that such services meet Developmental Disabilities Administration licensing standards. <MD>

Continue the constructive cooperation between the Developmental Disabilities and Mental Hygiene Administrations in jointly serving Knott Class members. <MD>

Increase funding for services for children and adolescents in order to build upon new initiatives such as specialized community-based living arrangements and respite care, after-school/evening treatment programs, school-based and in-home mental health interventions. <MD>

Examine and strengthen program participant's rights in Mental Hygiene Administration services including the right to appeal discharge from services or to refuse medication. Provide for the same rights for participants in Mental Hygiene Administration programs as participants in Developmental Disabilities Administration programs have. <MD>

Develop local community programs to serve children with acute mental health disorders, such as personality, psychotic and affective disorders. Further develop and emphasize the concept of "least restrictive environment" for children needing mental health services. Make mental health services available where children naturally are - in their school and homes. <MD>

Give family support a higher priority so that children are not removed from their homes. <MD>

Maine should adopt a clear public policy favoring community based care for persons with mental illness. Implementation of this policy should entail greater emphasis on early intervention through family support services and services to seriously emotionally disturbed children and youth, a shift in the proportion of resources spent on inpatient psychiatric care to less restrictive community based support services and housing alternatives, greater emphasis on consumer and parent involvement in planning and priority setting at local and state levels, more community based residential treatment options as

opposed to larger centralized institutions, and creative use of public and private financing strategies. <ME>

Provide additional funding for prevention services, such as therapeutic nurseries and in-home intervention programs. <MD>

Efforts to educate families and consumers about how to access and choose mental health care should be made through a variety of mechanisms, including the State Board of Education and the media. <MS>

All state agencies serving children and adolescents with severe mental illness should separate, in their budgets, the funding mechanisms and amounts spent on services on this particular population. <MS>

Community mental health centers should increase services to people with developmental disabilities. <MS>

Legislation in Mississippi should be passed which would allow Medicaid to reimburse freestanding facilities for psychiatric services for children and adolescents. <MS>

Medicaid funding for mental health or counselling services specific to clients' needs must be increased in order to provide for adequate services for persons with disabilities. <MT>

The state's Mental Health Planning Council, in cooperation with the Department of Human Services Mental Health Division, should continue to assert a leadership role in the development of community-based mental health services across North Dakota. Mental health planning efforts should explore utilization of current institutional funding for community services; should clarify the role of the State Hospital relative to community mental health services; and should determine the best ways to coordinate client care between the State Hospital and community services. <ND>

In North Dakota, most community-based services for with developmental disabilities clients are purchased for private service provider organizations by the DHS Developmental Disabilities Division under a reimbursement system maintained by the Department. Based upon information from these service providers, it appears that DHS reimbursement practices under this system may be inconsistent and inequitable, thereby creating cash flow and depreciation-related problems which ultimately have a negative impact on direct services to clients. <ND>

A-system of mental health services for all ages and all persons regardless of disability must be encouraged. Responsibility for such a system must be identified. <NE>

It is recommended that the Divisions of Mental Health and Hospitals and Developmental Disabilities establish a regional "case mediation" mechanism, with each division having a

designated regional point person or liaison. The two regional designees should be charged with: 1) facilitating and expediting ad hoc case resolutions in conjunction with the case manager and 2) systematically gathering data concerning the nature of the cases and the outcomes. <NJ>

It is recommended that a detailed review of the programs for people with dual diagnosis at Ancora be undertaken, with emphasis on the degree to which it meets clients' needs. It is further recommended that analysis be conducted to determine whether this model is more appropriate, or whether limited available resources would be better directed to facilitate more community services. <NJ>

It is recommended that the comprehensive review of New Jersey's mental health system, required by the State Comprehensive Mental Health Services Plan Act to 1986, P.L. 99-660, include the issues of planning and service delivery for people with developmental disabilities, and a coordinated response by both mental health and developmental disabilities agencies. <NJ>

It is recommended that the Division of Developmental Disabilities and the Division of Mental Health and Hospitals work group continue to develop ways in which the two agencies can work together on behalf of people with dual diagnosis, and facilitate the elimination of administrative and programmatic barriers. It is further recommended that efforts be made to develop mechanisms for cross training personnel in the two systems, so that mental health professionals receive greater understanding of the developmentally disabled population and personnel serving those with developmental disabilities have access to therapeutic mental health techniques. <NJ>

It is recommended that counseling resources, not necessarily associated with mental health services, be available to individuals with epilepsy or mental retardation to alleviate the stress associated with perceived stigma. <NJ>

It is recommended that the definition/eligibility issues centered on the question of the "primacy" of a present or past psychiatric disorder, which has been the subject of debate within the Division of Developmental Disabilities for more than a year, be promptly resolved, at least on a trial basis. <NJ>

It is recommended that the need for psychiatric treatment for some clients be studied, based on apparent successes achieved with the Division of Developmental Disabilities' clients who at one time exhibited "unacceptable" behavior. <NJ>

It is recommended that at least one mental health center or qualified social agency in each county receive mental health funding to create a clinical staff position to be filled by an individual with experience and interest in serving people with physical disabilities, epilepsy or mental retardation who require mental health services in an accessible environment. < NJ >

It is recommended that the current New Jersey Developmental Disabilities Council project be vigorously pursued and that the results be widely disseminated. The projects will demonstrate an integrated treatment approach that supports the current **placement** of an individual with both a developmental disability and severe mental illness through the addition of needed mental health services. <NJ>

Treat mental health and emotional needs in a preventive, supportive way. <WA>

Adequately fund mental health programs, especially those dealing with prevention and the needs of children. Expand availability of successful programs. <WA>

Some individuals with developmental disabilities also experience mental health problems and are particularly at risk of "falling between the cracks" of the service system. Greater collaboration between developmental disabilities and mental health program is needed to support these individuals in the community. <WV>

TRANSPORTATION: BARRIERS

When respondents in the consumer survey were dissatisfied with transportation services it was because they "didn't receive enough." For example, specialized transportation may be available in the Birmingham area but to utilize those services, an appointment must be made too far in advance to be reasonable and often this service is not available in the evening. <AL>

An individual participating in the public hearings in Huntsville mentioned that there is not "one single public post office that is accessible to the handicapped." While there might be wide parking spaces for "handicapped vans," the space is not wide enough for the van and the lift. <AL>

The most often mentioned barrier to social integration is a lack of transportation services. In addition to the lack of transportation, there are three important reasons why some individuals with developmental disabilities do not take advantage of the services that might be in place (Harris Poll, 1986). First, some people who are dependent on others for mobility may be afraid of getting into a difficult situation and not having someone to help (such as an inability to communicate effectively when requesting directions). Secondly, there is often a real fear of being hurt, becoming sick, or being victimized by crime. Third, the presence of architectural barriers can be challenging. <AL>

When transportation was available (from friends, neighbors or even a public conveyance) often these individuals could not use those options due to architectural barriers. <AL>

The lack of transportation services is often the most obvious barrier for work and social contact. For those people who were not working, slightly less than half mentioned that they had problems getting around in their community. Transportation problems were particularly troublesome for those people who wanted to pursue leisure activities or to participate in non-daily activities (medical appointments, shopping, etc.). <AL>

Only 32% of Arkansas' seventy five counties are covered by a mass transit system. Of the fourteen mass transit systems, eleven are rural. Transportation in the remaining 68% of the counties is generally vendor-provided transportation made possible by service agencies. While the trend toward more integrated options in transportation services is occurring in some large metropolitan and suburban areas in the nation, it does not reflect the reality or trend in a state such as Arkansas which has only three urban mass transit systems and a limited paratransit system in less than one third of the counties in the state. Even in such urban areas as Pulaski, Jefferson and Garland counties, there is only partial paratransit coverage. <AR>

In Arkansas, the limited funding available, the state's refusal to include transportation to day habilitative facilities as a Medicaid covered option, and the federal funding, limits the ability of providers to provide more flexible transit services. The state changed its

Medicaid coverage to specifically exclude coverage for transportation to day habilitative facilities. <AR>

Funding restrictions in some federal Department of Health and Human Services programs limit opportunities for coordination and reduce the number of passenger trips provided by some social service agencies. <AZ>

Insurance liability has been a barrier to meaningful coordination of services among agencies. <AZ>

Transportation is usually not available in the evenings and on weekends and transportation is only provided within the agency's geographic service area. <AZ>

UMTA requires that ADOT coordinate the use of 16(B)(2) vehicles; and also requires recipients of funds to coordinate services across agencies. ADOT has worked to more closely coordinate the activities of the Section 18 Program with those of the Section 16(B)(2) Program. Nevertheless, while progress is being made, coordination in Arizona is not adequate to efficiently serve the population. <AZ>

A mass transit proposal was presented as a referendum to the voters of Maricopa County in March 1989. Had it been approved by voters, the Regional Public Transit Authority would have been authorized to provide an array of services to people with disabilities across the city and county lines. Unfortunately, this referendum was voted down. <AZ>

Agencies only provide transportation to persons who meet their program eligibility criteria, and often only provide transportation for certain activities, such as medical appointments. <AZ>

A major difficulty with most paratransit services is that advanced scheduling is usually required. To maximize the number of people transported on a given trip, providers often require from two days to two weeks of advanced notice. Many individuals relying on this form of transportation have little flexibility and no opportunity to be spontaneous. <CA>

Some paratransit programs limit the types of destinations that qualify for services (e.g., medical appointments, day program participation), and exclude trips for social and/or recreational purposes. Some programs have limits to the number of trips and individual can take in a given month, which eliminates paratransit as the option for people who need to get to and from work on a daily basis. <CA>

Paratransit services vary enormously across the state. Some communities have no van service, and taxis become the only available option. This can be prohibitively expensive to people with developmental disabilities, even when subsidized, and the individuals with wheelchairs may experience access barriers, creating no transportation options. <CA>

Information gathered from key informants and people with developmental disabilities suggests that public transportation is typically underused. Many people are capable of riding such transit, but lack of funding for mobility training or overprotective families/caregivers may prohibit individuals from having this opportunity. <CA>

Many people with developmental disabilities are isolated within the community due to the segregated transportation services, lack of public and/or private transportation, and lack of mobility training. <CA>

Affordable and accessible public transportation is needed for all people, especially those with physical disabilities such as cerebral palsy. <CO>

There is an unawareness among Hispanic families of transportation services that may be available from the service providers. The long distance to specialized services makes it unfeasible for them to try to arrange to use public transportation, if it exists. <CO>

Lift-equipped public transportation is available only in the metro-Denver/Boulder area. Some other areas have paratransit services, but lift-equipped public transportation is not available. <CO>

The Louis Harris study conducted for The Colorado Trust found that eight percent of the population was unable to keep a medical appointment because of lack of adequate transportation. This percentage probably is higher among people with disabilities, especially those who need special accommodations. <CO>

In rural areas, access to services is a major problem. Public transportation is generally nonexistent, and persons with developmental disabilities must depend on transportation provided by agencies such as the schools or community centered boards. Choice is therefore limited to providers and programs which provide transportation. <CO>

The barriers take many forms - legal, regulatory and attitudinal, and their overall effect is the continuation of varying degrees of duplication of service, underutilization of equipment, inefficiency in the use of scarce resources, etc. Some of the major barriers include restrictive passenger eligibility standards; narrow trip purpose limitations; duplicative or independent record-keeping, monitoring, and reporting requirements; and lack of organization willingness to abandon independent operation of social service transportation functions. <CT>

Section "c" of Section 16, developing project selection criteria, is an opening for ConnDOT ("the state agency") to establish policy on full wheelchair accessibility, integrated and regionalized public transportation. ConnDOT has refused to exercise this opportunity. <CT>

Connecticut has no declaration of state policy regarding the right of persons with disabilities to use mass transportation facilities and services. <CT>

Section 16 of the federal Urban Mass Transportation Act (UMT Act) declares it to be the national policy that elderly and persons with disabilities have the same right as other persons to utilize mass transportation facilities and services; that special efforts shall be made in the planning and design of mass transportation facilities and services so that the availability of mass transportation to persons who are elderly or who have disabilities which they can effectively utilize will be assured; and that all federal programs offering assistance in the field of mass transportation should contain provisions implementing this policy. The national policy statement and Connecticut practice are not consistent. The phrase "right...to (use) mass transportation facilities and services" in practice has been limited to making capital and operating assistance available for the creation of separate transportation systems operated by social and human service organizations. <CT>

During those periods when a vehicle is not needed for specific grant-related purposes, it may be used for services to other persons who are elderly or who have a disability. After the needs of these groups have been addressed, the vehicle may be used for transportation of the general public, on a space available basis, if such a use is incidental to the primary purposes of the vehicle and does not interfere with the use of the vehicle by the elderly and persons with disabilities. Sharing rarely occurs. <CT>

ConnDOT evaluation criteria for the selection of 16(b)(2) capital assistance grants includes "cooperation and coordination...with other organizations,...the lack of ...or the inadequacy of accessible transportation must be...demonstrated,...(and) programs which will be available to all elderly and handicapped persons without eligibility restrictions are encouraged..." The ConnDOT application includes a section on "Coordination Efforts" that requests a description of coordination efforts including "purchase of service agreements, interagency agreements or documentation of unsuccessful coordination efforts." In practice, the evaluation criteria and the application elements have not been supported by monitoring to assure implementation. <CT>

In interviews of 288 people with developmental disabilities and parents conducted during 1988 by Connecticut Research Associates for the Developmental Disabilities Council, respondents were largely satisfied with transportation to work and school, but were dissatisfied with transportation for other activities and during leisure time. <CT>

Many youths and adults with developmental disabilities are "transportation disabled," in the sense they have great difficulty learning, reasonably quickly, how to ride public buses safely, at least from home to a job or activity, and back home. Historically, children with developmental disabilities have been bused great distances, beyond their neighborhood schools, to distant sites. Such buses have typically been segregated, transporting only children with disabilities. Heavy reliance on workshops and activity centers, beyond the

school years, has maintained the tradition of door-to-door, segregated transportation for persons with developmental disabilities. <CT>

The DOT 504 regulations are being challenged by those who feel that public transportation services should be available to all citizens. They contend that the separate service provided by paratransit is generally poorly-run, expensive and meets only a small fraction of the transportation needs of the rider with a disability. They feel the paratransit service is inferior to that provided by the public transportation system. <DC>

Efforts to adapt mass transportation for the use of people with disabilities have moved at a slower pace nationally, despite the mandate of Section 504 of the Rehabilitation Act of 1973. This Act prohibits discrimination against people with disabilities in all programs and activities that receive federal financial assistance, including mass transit agencies. <DC>

The most pressing problem within the Delaware Administration for Specialized Transportation system is the delay or failure after a transport request has been made. <DE>

A majority of each county's residents who participated in the study indicate the need for daily and non-daily transportation, as well as leisure-related transportation. Residents of Kent and Sussex [counties] are particularly likely to indicate such needs. A majority of children and adults need transportation to and from daily and non-daily activities. A large proportion of adults (about three-fourths) also need transportation for leisure activities (as do about four in ten children). Transportation for weekday leisure activities is viewed as more critical than is transportation for weekend leisure activities. <DE>

Although new buses have been ordered under the first fleet expansion in Delaware Administration for Specialized Transportation since 1977, the manufacturer custom builds each bus. These specialized buses require nine months for completion and delivery. This means a delay in implementing expanded service. Similarly, the new computer system which has been installed may take several months before it is fully operational. <DE>

Inadequate, costly transportation services were a primary concern of advocates and providers. Individuals with physical handicaps were reported to experience severe difficulties with transportation, often resulting in social isolation. <FL>

Access to affordable transportation is critical to individuals with developmental disabilities being able to be employed. <FL>

Another need is to make transportation available for a variety of work and non-work activities. <GA>

A multimodal approach to transportation is needed which provides that buses or trains used for fixed routes are accessible and that paratransit is made available for those with disabilities which are so severe that they cannot use an accessible mainline transit. <GA>

Strategies need to be developed on how rural communities can increase transportation services to person with disabilities. <GA>

There is a critical need to develop strategies with other state agencies, local governments, private sector operations, and community programs, to expand transportation services. <GA>

There is a need to increase and improve Guam's transportation system to address the needs of individuals with developmental disabilities. The system must be affordable, accessible, safe and available to all, including individuals with blindness, on Guam. <GU>

There is almost no public transportation in the counties of Hawaii, Maui and Kauai. People with developmental disabilities depend upon transportation made available by programs. The counties have limited revenue for the development of a public transportation system and have not aggressively applied for federal funds to assist them. <HI>

Most organizations providing transportation for persons with disabilities offer service to a restricted population using a severely limited number of vehicles. Most restrictions are based on whether or not the person is a participant in the program operated by the agency. In the focus groups conducted statewide, respondents often cited vans sitting for periods of time unused due to program restrictions or lack of trained drivers. <HI>

Of the six full-performance criteria for para-transit services, the City and County of Honolulu are meeting two of the six: eligibility and fares. A review and analysis of an evaluation done in 1988 together with data collected in the focus groups (1989) indicate that the Handi-van system is deficient in: 1) response time, 2) hours/days, 3) establishing priorities, and 4) same area coverage. <HI>

The UMTA and 504 regulations allow a limit of three percent of the average total operating costs to be allocated to meeting the accessibility requirements for a paratransit system. This has been interpreted to mean the above-full-performance criteria is subject to tradeoff against the three percent limit. If satisfying the full-performance criteria results in expenditures beyond the three percent limit, then the service may be excused from satisfying the full performance criteria. The issue of limiting expenditures to three percent, and thereby satisfying federal requirements, is currently the subject of a major dispute in federal courts. <HI>

In a survey done for the Department of Transportation and City and County of Honolulu in 1987, 65 percent of the users of Honolulu Paratransit System indicated their main

complaint was that the vans are not on time. The van may arrive early thereby forcing the rider to leave work immediately or be left behind; or another common occurrence involves situations in which the van arrives late, causing the rider to wait as long as one hour. Consumers have also indicated that they are "punished" if they are late or if a situation occurs in which they were unable to cancel the scheduled pickup. Their "privileges" are revoked for one month. Handi-van is paid whether or not a person "actually" rides. <HI>

The paratransit system is not adequately funded to provide that needed service and if the ridership continues to grow, problems will grow. Over the past six years, Handi-van ridership has increased from 290,252 annual trips to 467,802 annual trips. Handi-van is one of the largest demand response transit systems in the country. At the same time, subsidies were reduced — total annual subsidy was lower in 1987 than in 1986. <HI>

In the survey done in 1987 "rude or unsafe drivers" was the second most common concern expressed by both paratransit users and non-users. This was also raised in the focus groups conducted by the State Planning Council on Developmental Disabilities in 1989. <HI>

Handi-van requires that drivers complete four courses designed to help them in relating to people with disabilities and to improve their driving skills: 1) standard first aid and cardiopulmonary resuscitation; 2) proper handling of people with physical disabilities; 3) proper handling of people with mental disabilities; and 4) driving courses on defensive driving. The Department of Transportation Services, City and County of Honolulu report stated that there is "apparently no requirement, however, that completion of these courses be verified to the Department of Transportation Services." This lack of accountability is inappropriate given Section 27.87(b)(3) of the Federal regulations which clearly states that one of the recipient's obligations is: "ensuring that personnel are trained and supervised so that they operate vehicles and equipment safely and properly and treat handicapped users of the service in a courteous and respectful way." The lack of accountability is also seen in the haphazard reporting to the Department of Transportation Services about drivers' traffic records and no reporting of moving violations issued to Handi-van drivers. Handi-van drivers are often people who have not passed the test to be bus drivers. <HI>

Consumer participants in the focus groups by the State Planning Council on Developmental Disabilities in 1989 indicated that finding appropriate parking stalls is a serious problem and one that would be easily solved. Another concern raised was that some parking stalls are inappropriately placed, i.e., the person has to maneuver through traffic to get out of the car. <HI>

Funding inadequacies were identified by both consumers and professionals as the source of most of these transportation problems. "I'm a job placement specialist," said one woman, "and my clients can go to their jobs on the transit system, but it places real

limitations on putting people in jobs if they have to be picked up by 5:00. But I'm also on the advisory board for the transit system, and there it's a problem because we can't afford the extra time. In order for the bus to run in the evening, someone has to be hired to drive, and you need a certain number of people using it to make it profitable." <IA>

In urban areas consumers voice concerns about when and where transportation services are available, the cost of services, and restrictions on travel depending upon the purpose of the trip. In rural areas, the issue is much simpler — no transportation services are available. As noted in the policy analysis, these distinctions are explicitly allowed by current Urban Mass Transportation policy. <IA>

Of the consumers who have access to transportation services, 41.7% express some level of dissatisfaction with the program, and the concerns they cite are often the direct result of the policy inadequacies discussed above. Limitations in the times services are offered, unreliable scheduling, a lack of transportation to certain destinations, and the screening of transportation service availability on the basis of the purpose of the trip are among the issues identified. Consumers also note the inadequate transportation services may preclude having or keeping a job, a factor that very effectively limits productivity. <IA>

Although a relatively small percentage of consumers have access to an urban mass transportation system, it is a program that aroused lively discussion at all of the forums. Transportation problems are seen as serious barriers to a normal lifestyle for many individuals. Most comments revolve around limited choice: the problems caused by the limited hours that transportation services are available, and inconvenient pick-up times. Inequities between urban and rural areas were also noted in the forums. <IA>

The policy of the Urban Mass Transportation program does not promote independence. The policy provides little support for consumer choice with respect to what services may be obtained, when services are provided, and where transportation is available. The policy also inhibits integration by permitting the waiver of provisions for services for persons with developmental disabilities, if the cost of services will exceed three percent of the total operational budget. <IA>

Persons with developmental disabilities or their representatives who were surveyed confirm that policy inadequacies identified above have indeed resulted in serious problems for persons with developmental disabilities who need transportation services, particularly if they live in rural Iowa. This is seen in the fact that very few consumers — less than 16% — receive transportation services through its program. Seven of every ten consumers interviewed received no transportation services of any kind. Many consumers report that they don't attempt to get transportation services because they know that none is available; if their community has transportation services, they frequently report that no services are available for persons with special transportation needs. <IA>

The policy of the Urban Mass Transportation program emphatically inhibits integration in three of the areas examined. First, the application of different standards for services in urban versus nonurban areas encourages marked service inequities in Iowa. Second, policy that permits the waiving of requirements to provide accessible services if the costs exceed three percent of the budget for mass transit services results in a profound shortage of accessible transportation services for persons with developmental disabilities. Third, policy that calls for accessible services only in areas that have an existing public transportation system results in an almost total lack of transportation services in non-urban areas. It is not surprising to note that Urban Mass Transportation policy does not include integration as an explicitly cited goal. <IA>

There is a serious lack of transportation services to or in rural Idaho communities. All public transit in Idaho is federally funded and operates only within city limit boundaries in the majority of transit areas. If a person with a disability needs to get to a major city for generic services, there is little or no transportation. Idahoans in rural areas are dependent upon shelter home or workshop operators to give them rides. If they live outside a structured facility or program, they may not have an opportunity to get assistance with transportation. <ID>

Within major transit areas, only separate 24-hour advance notice transportation is available for people with disabilities. Fixed routes for buses that are accessible do not exist. <ID>

The Council finds that, in Illinois, citizens with disabilities do not have a statewide system of transportation which offers them the same opportunities as non-disabled citizens. This limits their potential for employment and independent functioning in their communities. <IL>

Groups which make up the "transportation disadvantaged" - people who are elderly, poor or have a disability constitute 24 percent of Indiana's population. This proportion varies by location of the state and by urban/non-urban status. In southern, non-metropolitan areas of Indiana, the rate is highest at 27 percent. <IN>

The formula used for the allocation of state Public Mass Transportation Funds includes both a population factor and utilization factor. As a result there continues to be wide variation from area to area and between grouping of transportation systems because of the weight given for those metropolitan areas already providing service. No factors of need, such as are contained in the Rural America's Center for Transportation study of Indiana's system, are included in the state funding formula. <IN>

Half of Indiana's non-metropolitan counties and 30 percent of its metropolitan counties are unserved by public transportation or taxicabs and are dependent upon the state's specialized transportation providers. Specialized providers, however, are small and highly dependent upon state and federal subsidies for financial support. <IN>

The "civil rights" issue which showed up in the top ten problems concerned the lack of enforcement of local ordinances governing handicapped parking. <IN>

Indiana received about \$9 per capita under the UMTA program in FY 1987 compared with nearly \$13 for the combined area surrounding Indiana and the U.S. average of \$13.25. In short, Indiana received only about 70 percent of the funds it could have if it matched area or U.S. levels. <IN>

Lack of adequate transportation prevents many children from receiving services and isolates families. Parents may not have any way to transport their children to services if agencies do not provide it, especially in rural areas. Even in urban areas, parents express being harried by the need to transport their children from one specialized agency to another for services. <IN>

There is a lack of adequate accessible, affordable and integrated transportation in both urban and rural areas. Of the people interviewed, 20% were dissatisfied with transportation to vocational programs and 35% were dissatisfied with transportation for leisure/recreational purposes. Approximately 20% of people were dissatisfied with transportation to education. <KS>

Although over \$44 million was spent on specialized transportation services, there was and is still a large, unmet need for transportation. <MA>

At least 10% of the population has mobility impairments. Persons who are mobility impaired include those who are pregnant, temporarily disabled (broken and sprained limbs), arthritic, obese, and chronically disabled (heart and respiratory ailments, Parkinson's Disease). In Massachusetts, this represents approximately 583,200 persons who are mobility impaired, and cannot use inaccessible public transportation. <MA>

Transportation has become an increasingly critical issue for persons with disabilities due to the recent trends of community integration and active participation. To facilitate social integration in education, housing employment, political and leisure/recreational activities, full access to public transportation services must be provided without restrictions on hours, trip destinations, eligibility requirements, and advance scheduling. <MA>

Massachusetts Development Disabilities Council's grants in supported employment and community integration have repeatedly documented the lack of accessible public transportation as a barrier. A study conducted by the Boston Center for Independent Living documented that at least 27% of the unemployed population with disabilities identified lack of transportation as the major cause of unemployment. <MA>

Many primary consumers and parents expressed feeling socially isolated as the result of the attitudes of others and inadequate transportation. Without transportation, meeting

others, getting to work and to medical appointments, and having some choices concerning living arrangements are impossible for these individuals. "I could live on my own and not have to go along with the majority in the group home," one young woman said. <MD>

Transportation has for many years been the "hidden" problem affecting virtually all the other areas of the lives of people with disabilities. However, nobody has addressed it as the all-pervasive problem that it is. <MI>

Lack of transportation is a continuing serious barrier to full community integration for people with disabilities. <MI>

Most transportation now provided for handicappers is for very specific purposes, such as educational or vocational programs. All Specialized Services systems fall in this category. These systems operate on rigid schedules. They do not provide transportation needed for health care, community employment, recreation, or any other activity that involves personal choice rather than structured programs. <MI>

Inaccessibility and unavailability of transportation is a serious problem for many people with disabilities who want to work. <MI>

Even when accessible buses are available on regular routes, handicappers face several questions every time they need to get to a specific place at a specific time. Will a lift-equipped bus be running on the route where it is needed at the time it is needed? <MI>

People who cannot get to work, to the voting place, or to meetings of community and advocacy groups cannot exercise their full rights and obligations as citizens. <MI>

Intercity/interstate bus service, the primary mode of public transportation for people in rural areas, is almost completely inaccessible to many people with transportation handicaps. For intercity travel, neither rail nor air transportation provides service that is reliably available and accessible to people with disabilities. <MI>

Air transportation is often inaccessible for handicappers, or else accessibility is so limited that efforts by the air carrier to accommodate the consumer result in negative or even dehumanizing treatment. Air travelers who use wheelchairs and other aids to mobility face a multitude of problems. These range from uncomfortable, dangerous, and dehumanizing boarding procedures to inaccessible restrooms and boarding areas. <MI>

Many people with disabilities need adapted driver training, but face major obstacles to their getting appropriate training. <MI>

Communities face complex issues in establishing and operating public transportation systems. Most capital expenditures (purchasing vehicles, etc.) are covered by state and federal funds. However, communities must fund part of operating costs (fuel,

maintenance, payroll) through a combination of farebox receipts (user fees) and local government subsidies (usually through special mileage). <MI>

People with disabilities should not be kept from using public transportation by inability to pay. Even the fare on fixed-route buses can be a hardship for some handicappers, and the problem is worse for demand-initiated service, in which fares are higher. <MI>

Michigan has good provisions in law for handicapper parking, with stiff fines. Local enforcement of this law is reported to vary greatly across the state and, generally, to be rather lax. <MI>

Few knowledgeable, experienced, handicapper public transportation users have policy or administrative roles in public transportation. <MI>

The drivers or operations on all forms of transportation are not universally well-trained in accommodation and safety for people with disabilities and sensitivity to their individual concerns. People with disabilities at the CRI Forums reported numerous encounters with drivers who did not know how, or did not seem to meet needs of handicappers. <MI>

Transportation services in Minnesota have serious limitations, including: limited service areas, low income limits transit options, limited hours, difficulty in scheduling, existing vehicles are not being used to the greatest extent possible, and coordination among various service providers is not a high priority. <MN>

Most agencies serving persons with developmental disabilities do not receive adequate local, state and federal funds to meet the transportation costs of their clients. In some instances, the lack of funds for transportation limits the number of additional clients who could otherwise be served. <NC>

The lack of available, accessible, dependable and affordable transportation was expressed consistently by consumers in their comments during the survey interviews and by presenters at the public hearings. <NC>

Transportation is a problem for many. Only two cities have public transit systems, therefore, those living outside of Lincoln or Omaha have fewer options available. Mental retardation services provide transportation to some clients being served by community based programs. However, persons with other developmental disabilities do not have this resource. Lincoln and Omaha operate paratransit systems that require advance reservations, have limited hours, and utilize priorities in scheduling trips. Many feel that there must be efforts made to make all buses accessible so that persons can be truly integrated into their communities. <NE>

Modifications of personal vehicles is a costly matter. Wheelchair lifts are very expensive. If families can find an agency to help them with the cost of the lift, there still remains

the expense of the vehicle itself, usually a van. Needless to say, with few public transit options, personal transportation may be the only option, and perhaps, not a viable one for people with limited incomes. <NE>

The unmet need for transportation is critical. Most of the transportation that is available for recreational or leisure pursuits is provided by a consumer's family. <NH>

A new public bus system was introduced in the city of Concord during the past year and none of the buses is able to accommodate riders who use wheelchairs. <NH>

Several service needs can be identified as most important for achieving community membership. Transportation is consistently mentioned as the single greatest need. Two other service needs are of nearly equal importance: companion/advocate/friend strategies, which link people with disabilities to citizen volunteers on a one-to-one basis, and integrated recreation/leisure programs, which assist people with disabilities to gain access to opportunities in the community. Assistance in developing and maintaining self-help or support groups is also frequently mentioned as an important need. All of these needs are currently largely unmet. <NH>

Most county transportation systems were originally designed to meet the needs of senior citizens, primarily between 9 a.m. and 4 p.m.. Many of these systems are now adapted to meet the needs of persons with disabilities attending school or a sheltered workshop. But transportation for shopping, medical treatment and recreation, which are now readily available for senior citizens, remains substantially lacking for people with developmental disabilities. In most counties, competitively employed individuals with disabilities must either drive or live and work adjacent to a public transportation service. <NJ>

Span of service — the range of days and time during which transportation services are available — is an issue that must be examined. <NJ>

In order to improve the delivery of transportation services, we must improve the linkages between existing systems (human service agencies, county paratransit, public transit) and expand the hours and days of services. This expansion is critical if the life needs of people with developmental disabilities are to be met. <NJ>

It is recommended that policies and laws governing transportation for transportation-dependent individuals be reviewed and existing barriers be eliminated. <NJ>

Intercounty services — the integration of transportation service between counties — is an issue that must be examined. <NJ>

Paratransit transit integration — the development of policies and procedures that encourage individuals to use a combination of paratransit and transit modes to reach their destinations — is an issue that must be examined. <NJ>

Dissemination of information — ensuring that individuals not affiliated with human service agency or program have access to transportation information — is an issue that must be examined. <NJ>

New private funding/subsidy sources — the exploration of private funding sources, as well as new application of traditional public and nonprofit agency funding sources, towards subsidizing public and specialized transportation — is an issue that must be examined. <NJ>

Personal transportation options — encourage funding for the appropriate procurement and adaption of personal vehicles for people with disabilities — is an issue that must be examined. <NJ>

There needs to be a focus on shopping and recreational destinations, particularly during the evening and weekends. This is strongly suggested by the overwhelming majority of respondents who currently work, attend school, or go to medical therapy during weekdays and indicate that they are currently unable to reach shopping and recreational destinations. <NJ>

Transportation services are very limited when available. Public transportation is only available in Albuquerque, Santa Fe, and Las Cruces. The rural nature of the state contributes to the challenges of planning and providing transportation to the persons with developmental disabilities. <NM>

The top three needs for adults with developmental disabilities surveyed were: 1) transportation to daily activities, 2) transportation to non-daily activities and 3) transportation to leisure activities. The major barriers to transportation were expense and availability. <NM>

Other surveys and studies indicate schedules and routes of public buses with lifts in metropolitan areas miss populations of persons with disabilities, and paratransit systems are overwhelmed by on-demand calls and have waiting lists. <NV>

Nevada has no public transit system support individuals with disabilities in rural areas. The need for services is reflected in the number of respondents indicating a need for transportation services. <NV>

Senior transportation systems are designated specifically for senior programs such as meals-on-wheels, day activities, and transit of seniors to and from programs and appointment. If senior systems will accommodate a rider with a disability, there is often a cost too expensive for the rider with a disability. <NV>

Survey responses indicate that great numbers of people with visual impairments or severe disabilities are literally cut off from their friends, their community and from services

which are available to them by the lack of accessible transportation. For many, activities which are basic to daily living, such as shopping and banking, are extremely difficult or impossible to accomplish. <NV>

Respondents also noted great difficulty in using transportation which is available due to the non-accommodation of their needs within those systems. They stated that inadequate scheduling, unreliability, location of pick up, lack of means to find your way after you get off and the unrealistic scheduling requirements of specialized systems as prohibiting factors in using existing transportation. <NV>

Conference participants noted that rural areas, both currently and in the future, will have less than adequate transportation for the people with disabilities. <NV>

Participants strongly believed that existing transportation service providers are not aware of the needs of people with disabilities and that systems planning does not reflect input from consumers. <NV>

Being able to get to services by public transportation was a recurrent issue voiced by consumers. People with physical disabilities are frustrated by the lack of accessible transportation. In many areas there is an effort to address these concerns. For example, New York City was recently designated as having the best accessible mass transportation system of any large city in the country. But adapting it to all individuals with developmental disabilities is costly and there is no consensus among people with developmental disabilities, advocates, policymakers, and the business community on the best implementation strategies. Many consumers and advocates are optimistic that the passage of the Americans With Disabilities Act would improve this situation. <NY>

Few public transit systems are accessible to people with physical disabilities and those specialized transportation services (paratransit) that are provided do not usually allow people with disabilities to move freely throughout their community. <OH>

As in all similar states, the non-metropolitan population is not uniformly served by transit systems. <OK>

What is clear from doing this report is that there is a need for an organization or group who will take the responsibility for monitoring on an ongoing basis state-wide availability, efficiency and quality of special transportation services for people with developmental disabilities, as well as the elderly and others who need this type of support. <OK>

Lack of adequate transportation services for people with disabilities in both urban and rural areas and physical barriers for people with mobility limitations. <PR>

Public transportation is of special relevance to persons with disabilities, and Rhode Island spent less per capita than the other two New England urban states: Massachusetts and Connecticut. <RI>

The paratransit systems in existence are loosely monitored and the equipment used is often modified, used equipment. <SC>

Accessible transportation services are sparsely scattered around the state. <SC>

Fares for paratransit services are considerably higher than public transportation fares, yet persons with severe physical disabilities generally have limited incomes and unlimited expenditures required by the nature of their disability. <SC>

Only 1 percent of the projected SSBG expenditures in 1987 were for transportation services in Tennessee. Persons with developmental disabilities and their families reported in public forums held across Tennessee that transportation services for persons with developmental disabilities are scarce, underfunded, and cannot be relied upon in emergencies. <TN>

The lack of available and accessible transportation continues to be a major obstacle blocking people with disabilities from full participation in society. <TX>

At the 1990 Report public forums, transportation was identified as one of the top 10 service needs in the state. At a previous Council forum in September 1988, the lack of accessible, mainline transportation was the most frequently expressed concern of participants. <TX>

A member of the Texas Planning Council recently scheduled a paratransit ride two months in advance to take him to a friend's wedding for whom he had been asked to serve as best man. Much to his dismay, that ride was two hours late, delivering him to the wedding long after the ceremony had ended. <TX>

There is no state law in Texas which requires mass transit authorities to provide full and equal access to transportation systems, including a provision for enforcement, though such legislation is routinely introduced. <TX>

Rural transportation is even more difficult. None of the rural towns in Utah, those off the Wasatch front, have mass transit systems. <UT>

The lack of affordable, accessible, and reliable transportation represents one of the more critical barriers that currently limit the community living options of persons with developmental disabilities. While some individuals in urban areas may complain about the accessibility or reliability of their transportation system, most individuals in the more

rural areas of the commonwealth have no public transportation system available to them at all. <VA>

There is a lack of public transportation at appropriate times and to appropriate places in most areas. Improved access to reliable, accessible and moderately priced transportation would reduce a major barrier to employment in all areas of the state. <VT>

Various human service agencies do not attend to coordinating transportation needs for services; this contributes to a fragmented system which overlooks the potential for use of the few services which are available by various people at a savings in costs. <VT>

There is a statewide need for more physically accessible, life-equipped vans and buses for public transportation. Approximately 24% of respondents to the Consumer Satisfaction Survey (CSS) expressed dissatisfaction with provisions for vehicle modifications in Vermont. <VT>

People with developmental disabilities and their families/caregivers often do not have the resources to purchase the appropriately equipped vehicles to establish private transportation. Costs can range from \$500 for relatively simple control modifications or adaptations to \$35,000 and up for a new, life-equipped automobile or van. <VT>

The UMTA Section 18 program is one of the only sources of support for transportation services in rural areas. However, funding over the past few years has remained relatively low. Although the program is intended to assist rural transportation systems, it receives less than three percent of federal mass transit resources. Estimates show that rural systems serve approximately 39% of the nation's population. <WA>

Specialized services in this state have primarily been provided at the local level and sponsored by a variety of agencies and organizations. In general, large urban areas offer more and better developed specialized transportation services than do rural areas. In fact, most rural areas do not offer such services. However, even when service is available, hours are generally limited. To make it even tougher, businesses offering this service must work under severe contract restrictions and geographic boundaries. <WA>

Many specialized transportation systems — where available — also operate on a Monday through Friday basis with limited hours. Some require reservations at least a day in advance and offer only a limited number of rides per day. Cab companies are usually not accessible to many persons with disabilities. Such rules and regulations can severely restrict both social and business plans. <WA>

Under the UMTA Section 16(b)(2) program, approximately \$600,000 is allocated to Washington State per year. However, the cost of new buses and equipment has risen dramatically and estimates show that nearly twice as much money is needed to provide

adequate services. Many vehicles and related support equipment are old and need to be replaced. The National Association of Transportation Alternatives recently surveyed state programs and found that \$21 million worth of accessible vehicles and related equipment is needed nationwide. This figure is over and above that which could be purchased under the current level funding. <WA>

The UMTA Section 16(b)(2) program has been highly successful in combining dollars from the private sector with federal monies to expand transportation services in areas of demonstrated need. However, federal support for the program has been relatively static for the past several years. <WA>

The reporting procedures used by various transportation programs vary to such an extent that it is difficult to present an overall picture of the services provided in Washington State. <WA>

Present sources of state and federal funding for specialized transportation need to be coordinated at a statewide level. Many providers cope with more than 15 separate service contracts. Coordinated information on funding, simple contractual procedures and less stringent eligibility requirements would encourage businesses to offer improved local services. <WA>

Lack of funding is often the major barrier to establishment and maintenance of accessible, convenient transit systems. <WA>

Rural public transit, where it exists, is sometimes only available at certain times of the day. Some companies shut down service over major holidays and have limited weekend schedules. Long gaps between buses are particularly restrictive for people with disabilities. <WA>

A recent survey of rural community action councils across the state indicated that transportation systems need to be established and existing systems need to be improved. The survey found that lack of coordination between funding and jurisdictional groups (counties and local transit companies) often creates communication problems. As with all communication breakdowns, this slows down the process of effectively addressing rural transportation needs and concerns. Long distances also make it difficult to offer service. <WA>

Inadequate services are particularly critical in rural areas. Many geographically sprawling rural counties have no public transit whatsoever. <WA>

Of the approximately 2,046 transit vehicles statewide, 1,000 of those are owned by Seattle Metro. Only 960 of the total 2,046 are lift equipped. <WA>

Transfers between different services (for example from a bus to a train) is often difficult for people with a disability. <WA>

People with developmental disabilities must confront a confusing array of transportation services in Washington State. The level of service and range of options available varies widely. There are 21 public transit systems, and coordination between the system is limited. In addition, eligibility rules quite often vary between systems. Service gaps are particularly evident when traveling from county to county, city to city, or from urban to rural areas. <WA>

Lack of transportation plays a very significant part in preventing persons with disabilities from participating in local activities as well as securing employment. For many, the inability to travel within the community has resulted in a loss of self-esteem and personal motivation. Some people have been institutionalized because they were unable to see to their own needs due to lack of accessible transportation. <WA>

Many people with disabilities do not have access to the transportation services they need in order to participate in a full range of daily activities. Many people with disabilities must rely on friends and family for rides, or else pay high fares to private transportation companies. Some rely on specialized transportation agencies, although this option is particularly scarce in rural areas. Many times they do not make the trip at all. <WA>

Transportation in the community is not equitably available in all Wisconsin counties. <WI>

Access to events and activities is also critical to integration. Transportation is not a problem unique to people with developmental disabilities in this rural, mountainous state, although there may be particular problems experienced by people unable to use conventional transportation. The Consumer Satisfaction Survey found that people were relatively satisfied with the transportation they did receive, but large percentages indicated unmet needs. <WV>

TRANSPORTATION: RECOMMENDATIONS

Alaska should become a cold weather test site for lifts and other devices essential to making mainstream transportation accessible to people with disabilities. <AK>

Access to safe, dependable, affordable, convenient transportation must be assured through the development and implementation of national and state guidelines and regulations. There must be no delay between the development and implementation of guidelines and regulations. <AL>

Ensure accessible result mass transit services, where available, as well as inexpensive, efficient paratransit services where necessary. Service developers must also consider the proximity of living and working options to available transportation in order to develop options to minimize reliance on provider-owned transportation. <AR>

The Arizona Department of Transportation (ADOT) should continue to explore, in conjunction with the private sector, the implementation of "demand side" innovative projects in urban and rural areas where services exist and a "demand side" approach would be appropriate. Demand-side systems provide the travel subsidy to the person needing transportation, rather than to the provider agency. This makes it possible to take advantage of the various existing transportation services operating in a community, including cooperative neighbors. By simply lowering the cost of travel to users, a range of travel opportunities can be opened up, and existing systems benefit from increased demand. <AZ>

The Arizona Department of Transportation should continue to work in coordination with state, county, and city officials as well as consumers/riders in the expansion of accessible transit services for persons with disabilities for urban and rural areas, including steps to integrate the Section 16(b)(2) and Section 18 programs into a comprehensive, centralized system, and to rewrite transit directories so they are easier to understand. <AZ>

The operation of the Section 16(b)(2) and Section 18 programs should be reorganized according to a regional system, with regions to be determined locally. Within each region, a "centralized model" would be developed in which all persons would be referred to one organization for transportation services. <AZ>

Public transportation services and mobility training in the use of public transportation must be provided to allow people to be as independent as possible within the community. There must be improved accessibility in public transportation. <CA>

Bus driver training must be provided covering the area of disability awareness, civil rights issues and proper/safe equipment operation. <CA>

Support increased availability of integrated, accessible transportation in both urban and rural areas. <CO>

Implement paratransit systems that are regionalized and with flexible, expanded hours of operation. <CT>

Establish public policy, similar to policies that overrule town zoning regarding affordable housing, that requires consortiums, consolidations and intertown cooperation to be linked to vans and funding passed through ConnDOT. <CT>

Establish public policy requiring all new vehicles, mainline 16(b)(2) vans and intrastate coaches, purchased with state or federal funds, to be fully accessible. <CT>

The Council should take the lead role in the development of training and employment opportunities for individuals with developmental disabilities with the Washington Metropolitan Area Transit Authority. <DC>

The Council should enter into an agreement with the Washington Metropolitan Area Transit Authority that would allow for participation in efforts to provide travel training for passengers with developmental disabilities. <DC>

The Council should establish a direct working relationship with Washington Metropolitan Area Transit Authority (WMATA) to insure that the concerns of individuals with developmental disabilities are given major consideration in the planning process. The Council should have a representative on the WMATA's "Elderly and Handicapped Transportation Advisory Committee". The Council also should put into place procedures for monitoring the extent to which WMATA is in compliance with the full performance level as set for thin the federal regulations. <DC>

The most pressing problem within the Delaware Administration for Specialized Transportation (DAST) system is the pickup delay or failure to pickup after a transportation request has been made. Constant review of the service by consumers and advocates is needed in order to assure a system that is responsive to the needs of persons with handicaps. The Advisory Committee to DAST needs to be involved early in needs assessment and in planning of system enhancements. <DE>

Delaware Administration for Specialized Transportation should increase outreach to persons with disabilities. Include involvement of riders in planning routes, level of services, and purchase of transportation equipment. <DE>

Delaware Administration for Specialized Transportation should provide service to those areas currently not being served - rural areas and other areas where a high volume of transportation is not required yet where persons with handicaps still require services. <DE>

Delaware Administration for Specialized Transportation should provide sensitivity training for drivers and all personnel involved in the communication with and transportation of DAST riders. Place more emphasis on the human side of the riders and their **special** needs. <DE>

Delaware Administration for Specialized Transportation should improve and expand its weekday operations in order to provide leisure-related transportation to persons with developmental disabilities who seek this type of service. <DE>

Consumers and community advocates should support and urge passage of House Bill 241 which allows the owners of private property to remove vehicles which are illegally parked in "handicapped" spaces; and House Bill 242, which would increase the fine for violators parking in "handicapped" spaces from \$25 to \$50. <DE>

Conduct a study to fully describe the issues and needs surrounding the claims that individuals with developmental disabilities do not have the transportation required to live, learn, work and play in their communities. Emphasize the use of generic services when at all possible, as opposed to developing segregated transportation services. Submit program and budget requests aimed at resolving identified problems. <FL>

Develop and fund transportation services needed for individuals with developmental disabilities to be employed. Ensure that living in a rural area where transportation services are very limited or non-existent does not prevent an individual with developmental disabilities from being employed. <FL>

Success of local groups on grass roots organizing that led to the creation of accessible transportation should be published and disseminated. <GA>

A directory of companies who do car and van modifications, offer driver's education, and provide financial incentives for purchase or vehicle modification should be published. <GA>

Develop coordinated transportation systems. <GA>

The Council recommendation is to promote and improve the availability and accessibility of transportation services for individuals with developmental disabilities on Guam. <GU>

The Commission on Persons with Disabilities should inventory existing resources and needs for transportation statewide and a county-by-county plan should be developed for the use of all equipment purchased with public funds (including private non-profit agencies, county agencies, and state agencies). The issue of liability coverage should be reviewed and if sharing would increase liability insurance, the state of Hawaii should provide liability coverage. The coordination of all resources should be done to meet the needs of all persons with developmental disabilities. <HI>

All publicly funded transportation services developed in the future must be accessible to persons with disabilities. <HI>

The federal Urban Mass Transportation Administration should adopt and enforce user compliance standards as a condition of public transit systems obtaining and maintaining transit equipment purchased with federal funds. <HI>

Any and all expansion, renovation or equipment replacement in existing public funded or regulated transportation service must be accessible to persons with disabilities. <HI>

The development of a mixed transportation system for persons with developmental disabilities for the counties of Hawaii, Maui and Kauai should be a state priority. <HI>

The Commission on Persons with Disabilities should develop and support legislation to assure adequate funding to provide needed transportation. The State Planning Council on Developmental Disabilities should support these efforts and assure that the needs of persons with developmental disabilities are adequately defined and articulated. <HI>

The State Planning Council on Developmental Disabilities should coordinate efforts with the Commission on Persons with Disabilities and local paratransit providers to improve service to persons with disabilities. The Protection and Advocacy Agency should actively pursue 504 violations. <HI>

The Commission on Persons with Disabilities should develop standards on the maximum length of time it should take per ride on a Handi-van. <HI>

The Commission on Persons with Disabilities should provide technical assistance to the Department of Transportation Services on the development of a training program relevant to the health, safety and comfort of passengers with disabilities. <HI>

The quality of drivers of Handi-van should be improved. In order to attract better drivers, there needs to be a pay increase. Drivers are currently paid \$4 to \$5.25 an hour. <HI>

The county governments should enforce existing regulations on public transit systems, such as designated seating for persons with disabilities. <HI>

The State Planning Council on Developmental Disabilities should support and encourage the Commission on Persons with Disabilities in their efforts to increase the number and appropriateness of handicapped parking stalls, including ticketing of inappropriate users. <HI>

Revise policy to incorporate language responsive to transportation needs associated with work and other productivity-related activities. <IA>

Revise Urban Mass Transportation program policy to explicitly cite integration as a program goal. <IA>

Conduct a study to identify possible models for the delivery of equivalent transportation services to persons with developmental disabilities living in non-urban areas. <IA>

Study the effect of removing the policy waiver that allows elimination of accessible transportation services if the cost exceeds 3% of the program budget. <IA>

Revise policy to eliminate different standards of service for urban and non-urban transportation systems. <IA>

Study the potential benefits to the state of supplementing federal funding for transportation to assist persons with developmental disabilities to become more productive, independent members of the community. <IA>

All public mass transportation services should be required to be fully accessible and operate fixed routes, with curb cuts on regular schedules. The cost for a ride should be the same for all transit consumers. <ID>

The State Department of Transportation should be encouraged in its existing efforts to make fixed-route systems in all transit districts of the state at least partially accessible, while maintaining and expanding para-transit services for people who are unable to use regular transit, by 1999. <IL>

Indiana shall create or expand accessible mainline and para-transit services so that all people with disabilities, including those in rural areas, can travel to any destination of their choice.' <IN>

Indiana shall ensure that insurance costs incurred by para-transit providers do not exceed the costs of non-para-transit providers through insurance reform and/or grants. <IN>

Indiana shall give priority to strengthening and enforcing handicapped parking laws, including private shopping centers, through increasing fines to \$75, towing vehicles, posting notices, and encouraging the development of civilian deputy squads endowed with authority to issue tickets. <IN>

Indiana shall require the installation of sound signals at all intersections to support the independent mobility of people with vision impairments and shall increase signal delays to ensure the safety of people with mobility impairments. <IN>

Indiana shall ensure that all new buses purchased for intra and interstate transportation are equipped with wheelchair lifts. <IN>

Companies who provide transportation services shall adopt, in consultation with state officials, people with disabilities, and accessibility experts, uniform policies to use in adapting services to accommodate people with disabilities. <IN>

Indiana shall provide available, accessible, and affordable public transportation and para-transit systems to ensure that people with disabilities are able to get to and from work. <IN>

Indiana shall develop and provide convenient and affordable paratransit and accessible mainline transportation options to people with disabilities in both rural and urban areas. <IN>

The Louisiana Developmental Disabilities Council should collaborate with the Department of Transportation and Development, the Department of Health and Hospitals, the Department of Social Services, the Department of Labor, and the Office of Elderly Affairs to sponsor a statewide study of public and specialized transportation that would provide comprehensive data on state and local transportation policies and practices, and operating characteristics (availability, accessibility, use), user needs, and costs and develop short and long-term recommendations to increase transportation services and improve, coordinate and maximize the use of existing transportation resources for persons of all ages with disabilities. <LA>

The Division of Mental Retardation/Developmental Disabilities should promote the use of the In-Home and Family Support Program to provide eligible families with the necessary resources for modifying vehicles to accommodate family members in wheelchairs. <LA>

The Developmental Disabilities Council, in conjunction with the Office of Human Service and the State Department of Education should sponsor a statewide conference and technical assistance on: 1) mobility training to provide information on best practices for training persons with developmental disabilities to use public transit services and 2) on organizing and maintaining programs to use volunteers as drivers and escorts in agency transportation programs to increase transportation resources. <LA>

The Department of Transportation and Development should assume a leadership role in Louisiana in developing and increasing alternative specialized, demand-responsive urban and rural transportation services for persons who are elderly, have handicapping conditions, or otherwise need specialized transportation services. <LA>

Continue to fund expanded and ongoing sensitivity training for all staff, including drivers, dispatchers, fare collectors, reservation clerks, etc. Consumers with disabilities should be involved in designing and providing the training. Consumer/user travel training should also be provided. <MA>

The MBTA should continue to expand both the level of service (especially subscription services) and the RIDE into all 78 communities in its service area (currently, the RIDE serves 44 communities). Additionally, the MBTA should continue to implement a policy of full accessibility in its buses, rapid transit (heavy rail), streetcars (light rail) and commuter rail and all associated facilities. The RTAs should continue to expand their accessible fixed route and specialized paratransit services for persons with disabilities. <MA>

Provide adequate resources for the continued implementation and expansion of an accessible public transportation system. The 14 Regional Transit Authorities (RTAs) and the Massachusetts Bay Transportation Authority (MBTA) should be funded at sufficient levels to operationalize a fully accessible mass transit system at all levels, including buses, trains (light rail and commuter rail), airlines, and water (ferry and harbor) transportation. In addition, funding to the Executive Office of Transportation and Construction (EOTC) should be sufficient enough to expand the Mobility Assistance Program (MAP) and the Intercity Bus Capital Assistance Program (IBCAP). <MA>

Develop a multi-modal public transportation system which includes both accessible fixed route and specialized paratransit services. The paratransit system should not be more restrictive (e.g., limited hours, eligibility criteria, limited trip destinations, requirement for advanced scheduling between three and seven days) than the mass public transit system. In addition, the specialized transit services should be expanded to include hours and destinations beyond that of mass public transit. <MA>

Coordinate efforts and combine funds of the human service agencies, RTAs, and MBTA to provide accessible transportation for persons for all ages with mobility impairments. Funding sources should include users (through fares), human service agencies, and local, state and federal government via the RTAs and MBTA. <MA>

Provide accommodations in public transportation systems for persons who with hearing impairments, visually impairments, mental impairments, noncommunicative, and non-English speaking. <MA>

Provide ongoing funds to market accessible services, including updated brochures and maps, to consumer/users. <MA>

Ensure that air travel is accessible to persons with disabilities. Although Logan Airport in Massachusetts has become increasingly more accessible, the FAA does not provide policy or regulation for airlines. The Americans With Disabilities Act also excludes airline policy for persons with disabilities. The FAA should be encouraged to develop regulations for the airlines to promote accessibility and equal treatment on flights. <MA>

The Aging Network transportation services should include all lift-equipped vehicles and should expand to serve persons who have a disability and nonelderly persons who need assistance walking, persons residing in nursing homes, etc. <MA>

, Support innovative approaches to providing accessible public transportation, such as using accessible taxicabs and user ride subsidies, and promoting new technology to improve accessibility. <MA>

Increase private transportation alternatives for persons with disabilities by supporting an expanded MRC vehicle modification program which would assist individuals with the purchase of vehicle to be modified; increase the funding available for modifications; and sponsor research, development, and testing of new adaptive technologies. <MA>

Designate within each local jurisdiction an entity to coordinate all specialized and generic transportation services and funding sources for that county/city. Explore options for the state to create demonstration projects or to provide incentive grants in each region to promote coordination efforts. <MD>

Exable travel vouchers to be valid for trips outside the jurisdiction in which they are issued. Exempt lift-equipped taxis from geographic restrictions. <MD>

Coordinate Medical Assistance transportation funding with funding from other sources to expand transportation availability to more eligible citizens. <MD>

Separate transportation costs from other client and agency costs under the Developmental Disabilities Administration's prospective payment system. <MD>

Employ within the Developmental Disabilities Administration a central office coordinator and designate regional coordinators/monitors to track costs, identify barriers, project future needs statewide and promote interagency coordination of transportation services. <MD>

Administer the Medical Assistance transportation funding program by an agency with expertise in transportation management and operations, such as the Mass Transit Authority. <MD>

Provide accessibility by all small transit systems to people with hearing impairments. <MD>

Make public transit available during hours when people travel to and from work, that is, 6:00 a.m. - 8:00 p.m. <MD>

Create strong incentives by transit operators such as lower fares and travel training, to enable people with disabilities to convert from being para-transit users to using the

mainline system. Offer routinely travel and encouragement by mainline transit providers to their consumers who may feel intimidated by the mainline system, since mainline transit affords critical opportunities for independence, productivity and community integration. <MD>

Encourage transit operators to consider adding a para-transit service where none exists for people who have demonstrated that they are unable to use the mainline service for whatever reasons. <MD>

Provide for 100% accessibility wherever there is a fixed route transportation system. <MD>

The state of Maine should re-assess the availability of transportation for persons with disabilities. A task force, convened by the Department of Transportation, including representatives from state and local agencies, should develop an updated "plan". The plan should result in identification expanded use of federal revenue and recommendations to the governor and legislature for appropriations necessary to provide transportation services. <ME>

Regional Interagency Coordinating Committees (RICCs) and other local advocacy organizations should develop projects to provide volunteer assistance in enforcing handicapper parking. They should develop agreements with local governments to use the increased revenues from fines to improve accessibility of local parking areas, curb-cuts, public buildings, and public transportation. <MI>

The Michigan Department of Transportation should develop a training package by and for handicappers and operators on how to use and operate the system in a nondiscriminatory way. Transportation authorities should provide consumer awareness, sensitivity, and safety training for bus and cab drivers, in order to make each driver an advocate. <MI>

Congress and the President should direct the Federal Aviation Administration to develop a plan to assure that all air carriers understand the rights of handicappers and the available accommodations to make air transport accessible; and material is available to all consumers on their rights to nondiscriminatory treatment and the means to file a complaint. <MI>

Congress should direct the Department of Transportation to develop criteria for universal tiedowns for wheelchairs and require their use in all public transit vehicles. <MI>

The U.S. Department of Transportation, with input from people with disabilities, should investigate the feasibility and cost of adapting bus stops by installing ramps that would enable chair users to enter buses by the regular door. <MI>

The Michigan Department of Education should enforce existing requirements about driver training. Schools should provide adapted driver training and non-discriminatory evaluation programs, to assure that students with disabilities receive the supports they need to learn how to drive. <MI>

The Michigan Department of Transportation (MDOT) should provide incentives and technical assistance to encourage private inter-urban transit providers (buses and trains) to offer accessible transportation between Michigan's cities. Where existing providers cannot meet identified needs for inter-urban transit, MDOT should seek authority and resources to fill the gaps. <MI>

The Michigan Department of Transportation should aggressively pursue increased Urban Mass Transportation Act (UMTA) support for transportation systems in Michigan. Transportation support from UMTA in Michigan should be at least equal to the national average. Just this change would mean an increase in UMTA funding of **43.5%** from our present level. <MI>

The Michigan legislature, with the Michigan Department of Transportation, and handicapper and older citizens' groups, should define the basic transportation services to be available in every county (core services), and develop funding mechanisms and flexible policies to assure provision of core transportation services. <MI>

The Michigan Department of Transportation and the Michigan Developmental Disabilities Council should identify and investigate effective public and private sector models of accessible transportation systems. <MI>

Consumer, parent, advocacy, and professional organizations, should come together with service agencies as a statewide force. This group should strive to bring about changes in public opinion, legislative policy, and consumer participation in transportation administration and advisory boards. Together, they can create new thinking and new solutions to the present situation of transportation inadequacy for handicappers. <MI>

The Council shall assist the Division of Transit, the Coordinating Council on Special Transportation, and the Interagency Committee on Special Transportation with advocating for special transportation which facilitates the independence, productivity, and integration of all people with disabilities. <MO>

Formalize consumer involvement and participation in the planning, implementation and evaluation of accessible public transit services provided by the RTA and MBTA (the Consumer Advisory Committees and the Access Advisory Committee, respectively) through the development of Memoranda of Understanding. <MA>

All transportation plans or programs developed by federal or state government or regional or local transportation authorities should include provisions to make transportation accessible to consumers with all types of disabilities. <MS>

Mississippi should develop a program that will provide vouchers for individuals with developmental disabilities to purchase transportation services in order to work, to receive services, to perform daily activities, or to participate in community activities. <MS>

Need for an increased training in use of transportation systems needs to be emphasized for older children and adults with disabilities. <MT>

The Council recommend that the N.C. Department of Transportation conduct a study in conjunction with the other state departments provide services to persons with developmental disabilities to determine: (1) how much transportation funding each agency is eligible to receive and how much they actually receive; (2) how much each agency is spending on transportation services; (3) how much is needed to provide adequate transportation to those already being served; (4) how much is needed to provide adequate transportation to those waiting to be served; (5) the projected cost of transportation services during the next five years; and (6) innovative methods of funding transportation. <NC>

Transportation providers, public officials and service agencies must address the transportation needs of persons with developmental disabilities in Transportation Development Plans, giving particular emphasis to the needs of individuals in getting to and from work. <NC>

The Council recommends that the U.S. Department of Transportation mandate for all public transportation systems nationwide that any new vehicle purchased must be accessible to persons with physical disabilities and that drivers must be trained to recognize and address the needs of persons with developmental disabilities using public transportation. <NC>

Drivers must be trained to recognize and address the needs of persons with developmental disabilities in using public transportation. <NC>

Persons with disabilities should be included on each county transportation planning board. <NC>

All public transportation must be available and accessible to persons with developmental disabilities. <NC>

Additional state funding for public transit should be applied toward maximizing the use of federal UMTA funds to institute new public transportation services, particularly in North Dakota's largest communities which do not currently operate such services. <ND>

The governor should designate an existing entity or convene a separate task force to obtain broad-based input for developing strategies to address the transportation needs of North Dakota's populations who are elderly or who have handicaps. <ND>

State funding for public transit should supplement and not, replace DHS funding allocated to DD service providers for client transportation costs. <ND>

Preservation and maintenance of North Dakota's state aid program for public transit should become a recurrent legislative priority for advocacy organizations representing elderly persons and persons with disabilities. <ND>

Accessible transportation should become a priority in all communities to insure full participation by all its members. <NE>

Existing public transportation resources serving New Hampshire communities should adopt specific plans and timetables for becoming accessible to riders with disabilities. Accessibility should include the capacity to include riders who use wheelchairs on all vehicles, and the utilization of easily understandable schedules, fares and signs. Transportation authorities should contract with service provider organizations and disability advocacy groups to obtain technical assistance with vehicle and service modifications. <NH>

It is recommended that intercounty services be developed using resources of two or more contiguous counties. <NJ>

It is recommended that services be developed to meet a broader range of destinations during work hours. <NJ>

It is recommended that the availability of group and individual transportation services outside of existing transportation services be increased, particularly during evenings and weekends. <NJ>

It is recommended that support be given to the concept of an integrated fare structure between public transit and paratransit operators. Equity between fares charged on transit and paratransit services could encourage increased use of public transit, coordinated paratransit/transit trips and the creation of a fare transfer between transit and paratransit services. <NJ>

It is recommended that aide/attendant programs be coordinated and expanded to provide more intensive passenger assistance. This could also include reduced fares for any persons providing passenger assistance. <NJ>

It is recommended that every paratransit system have a Telecommunications Device for the Deaf (TDD). <NJ>

It is recommended that all existing and future Independent Living Centers, County Offices on the Disabled and county paratransit agencies be set up as transportation information centers. It is further recommended that New Jersey Transit should take the lead in providing training and information to centers. <NJ>

It is recommended that the availability of travel training, such as that which is presently conducted by New Jersey Transit, be expanded to clients and staff of developmental disability agencies. <NJ>

It is recommended that foundation and other private sector grants be pursued to subsidize transportation services. <NJ>

It is recommended that information concerning sources for technical assistance and grants for personnel vehicle adaptations be disseminated. <NJ>

It is recommended that Casino Revenue Tax funds for transportation be expanded through either an increased tax rate or an increased percentage for the Senior Citizen and Disabled Resident Transportation Assistance Program. <NJ>

It is recommended that state and non-profit human service agencies provide a portion of the subsidy required for expanded paratransit services. <NJ>

Reliable transportation and/or alternative transportation, particularly in rural areas, should be increased. <NV>

The State Divisions of Aging Services, Rehabilitation, and the Urban Mass Transit Authority should consider institution of cooperative planning. From that cooperative planning an agreement could be developed which will insure that existing and proposed systems will recognize and address the transportation needs of riders with disabilities. <NV>

A statewide network of concerned consumers should be established which would advocate for improved transportation services for persons with severe disabilities and improve communication with all transportation entities in order to foster cooperation and ensure nonduplication of planning and service delivery. <NV>

All transportation planning should consider leisure time activities and interests of persons with disabilities. <NV>

Stereotypical attitudes of transportation administrators which skew the priorities established for service provision regarding needs of persons with disabilities should be changed. <NV>

Laws regarding the rights of persons with disabilities in Nevada regarding equal access to transportation should be strictly enforced. <NV>

Existing private transportation systems, i.e., cab companies, who may be experiencing "down time" between peak hours of service, should be contacted to determine if reduced rates might be arranged for consumers with disabilities during these low demand hours. <NV>

All accessible transportation in rural areas should be increased, routes and schedules in metropolitan Las Vegas and Reno and availability of paratransit/on demand services should be increased. <NV>

Volunteer groups currently providing reader and other home services should be encouraged to assess the feasibility of expanding group services to include transportation. <NV>

UTMA Funding should include provision for operational expenditures including costs for liability insurance and include people with disabilities in all planning activities. <NV>

New models of transportation must be developed particularly in rural areas. Examples might include accessible taxis or electric cars with limited licenses. <NY>

Integrated and accessible transportation systems must be required in all urban areas. <NY>

Promote the development of public transportation systems that are accessible to all people with developmental disabilities. <OH>

The non-metropolitan areas of Oklahoma should be targeted with different support services which may include the issuance of vouchers, or cash subsidies, to allow individuals a basic level of transportation services. <OK>

The Council should advocate to ensure the transportation needs of people with developmental disabilities are met by municipal transit authorities of Tulsa and Oklahoma City. Transportation needs of persons with developmental disabilities in non-metropolitan areas will be best met by an effective Family Support Initiative. <OK>

Efforts must be directed toward making all public transportation accessible and equivalent. Transportation should be available to all persons during evening hours, on weekends and for "non-essential" activities such as recreation. <PA>

Individuals should be given transportation vouchers so that problems of crossing county boundaries will no longer exist. <PA>

All public transportation systems must be accessible to all individuals with disabilities. <PA>

It is proposed that the Puerto Rico Public Services Commission shall be responsible for implementing an educational program for bus and taxi drivers on the rights of people with disabilities and to increase community awareness and sensitivity to this population's needs. <PR>

Transportation will be available. <RI>

Transportation sharing between agencies should exist. Persons with employment destinations should be eligible for the same services as are persons with medical destinations. Coordination of services should increase the cost efficiency of these programs. <SC>

The Transit Act which addresses the requirements of compliance to recipients of funds through the Urban Mass Transportation Act needs close monitoring and strict guidelines in the use of funds for services for persons who are elderly or who have a disability. The three percent cap on amounts which can be expended on transportation services (for this population) should be raised. <SC>

A body of professionals, such as the Human Services Coordinating Council, with the inclusion of consumers and private providers, should be formed which would define the transportation needs and develop planning strategies to address the transit requirements of the citizens of South Carolina with disabilities. <SC>

Ride-sharing among agencies should be studied and proposals made outlining strategies to expedite this-program. <SC>

Promote a transportation policy in the state that will ensure appropriate and accessible transportation available to people with disabilities and their families, enabling them to take an active part in society. <SC>

The Texas Planning Council recommends the Texas Legislature establish an interim study committee to make recommendations for developing and improving local transportation options in both urban and rural areas of Texas. <TX>

There must be an expansion of the flex-trans system to serve more people and people with different kinds of disabilities in the urban Wasatch Front area, but there must be creative cooperative approaches that involve local government and maximize the use of vehicles, drivers and routes in rural areas. <UT>

The Virginia Department of Transportation should provide funding to develop and implement an ongoing program of training for users who have disabilities and providers who serve persons with disabilities in public transportation systems. <VA>

The General Assembly should establish and fund a voucher program to allow individuals with developmental disabilities to obtain transportation services needed to work, to receive services, to perform daily activities, or to participate in community activities. <VA>

The General Assembly should require that formal transportation coordination agreements be developed and implemented among local providers of transportation services, especially in rural areas. <VA>

The General Assembly should provide incentive funding for localities to promote purchase of lift-equipped buses and to encourage continuation and expansion of other transit service which promote mobility and independence for Virginians with disabilities. In addition, uniform equipment standards should be required by the Department of Transportation. <VA>

The Department of Transportation should review the recommendations made in each of the Regional Passenger Transportation Development Plans to ensure that the needs of people with disabilities are appropriately addressed in a timely manner. <VT>

Human service agencies must look beyond their own agency and resources for transportation services. Various public and private agencies which provide and/or need transportation for participants must be encouraged to communicate about and coordinate transportation opportunities by pooling resources. Guidelines for transportation options and expenditures must be reevaluated for flexibility and convenience of the consumer. <VT>

Resources must be made available to make all public transportation accessible. <VT>

A statewide commitment to providing appropriate transportation for all persons must be adopted as a high priority by the Department of Transportation. State dollars must support this priority. <VT>

Resources must be made available to assist with the financing and purchase of appropriately equipped vehicles for people with developmental disabilities and their families/caregivers. Such options as low-cost loan programs, tax credits, direct grants, and assistance through Vocational Rehabilitation should be established and/or expanded upon and publicized widely. <VT>

Local jurisdictional groups should collaborate to maximize both federal matching funds and service coordination. Transportation elements of specific federal and state programs should be combined. <WA>

Access to transportation and information should be a simple affair. For example, a local agency could have a 24-hour access line and have information on all local transportation resources. They should be able to match a customer with the appropriate service and be accessible to those who have hearing or speech impairments. <WA>

Private and public sector coordination should be promoted. Funding for ongoing research and development of transportation services is also needed. <WA>

Funding levels should be appropriate to support transportation services needed by people with disabilities. <WA>

Transit authorities, local elected officials, legislators, state agencies, and the public should be made aware of the transportation needs of people with disabilities. Local communities must face the negative economic impact produced by a lack of accessible public transportation. <WA>

All transportation system employees should be trained and encouraged to practice good consumer relations. Such programs should include a strong focus on serving people with disabilities. <WA>

Transportation policies should reflect consideration for the needs of people with developmental disabilities regarding the right to privacy and the ability to travel. <WA>

Uniform standards for reduced rates and special services should be established and given statewide recognition. <WA>

Where gaps exist, local systems should develop new services to provide for after hour and intercity transportation. <WA>

Terminals, transfer centers and other transportation facilities should be accessible. <WA>

Transportation options need to be developed that are at least as frequent and convenient as those offered to the general public. <WA>

People with disabilities should be actively involved in local land use planning and design of appropriate transportation services to ensure that decisions such as site selection for social services are made with transportation needs in mind. <WA>

People with developmental disabilities and their advocates should have an active role in defining the need for, and the selection of, transportation equipment. They should also be involved in program development for employee training. <WA>

Increase funding levels for the State Transportation Assistance Program for Counties (s.85.21, Wise. Stats.) 40% by the end of 1990. <WI>

CIVIL RIGHTS: BARRIERS

Multiple States

Section 504 sets out the process that determines if unlawful discrimination has occurred, but misperceptions about people with developmental disabilities erode the effectiveness of the law. <CA,MT,UT>

There is a lack of enforcement of the federal equal opportunity laws such as Section 504 by the Department of Justice, especially at the local level, which is a major barrier to independence, productivity, and integration into the community for people with developmental disabilities. <CA,ID,LA,MT,OH,TN,UT,WY>

Through the years, judicial decisions by the lower federal courts and the Supreme Court have undercut the effectiveness of Section 504. <CA,MT,WY>

Despite the enactment of Section 504 of the Rehabilitation Act, discrimination has yet to be tackled in the private sector or at the state level. <CA,ID,LA,MT,WY>

Rights and protections need to be brought into balance. While some people with developmental disabilities may not become self-sufficient due to the nature or severity of their disability and may need protection and/or assistance in some life areas, others will reach independence. <ID,IN,LA,MT,UT,WA,WY>

While society has a proper role to play in protecting its vulnerable citizens, the critical issue is how to do so without stripping away the essence of that person's humanity or overly restricting individual autonomy. <IN,LA,MT,UT,WY>

One of the most critical barriers to achieving autonomy and control over one's life is society's general misunderstanding of the ability of people with developmental disabilities and erroneous assumptions that they lack the capacity for responsible decision making. Presumptions are too often made in law and practice that if an individual needs assistance in one area of decision making, such as financial planning, that individual must also require assistance in making other types of decisions, such as where to live or how to vote. <ID,IN,MT,UT,WY>

One of the most critical barriers to civil rights is the denial of basic due process rights based on a person's disability. Substantive due process may be broadly defined as the Constitutional guarantee that no person shall be arbitrarily deprived of his life, liberty or property. Yet many state laws affecting people with disabilities paint with a broad brush and label all people with disabilities far too similarly. People with developmental disabilities are denied due process rights on a regular basis when state laws assign certain characteristics to individuals because they have a disability. <ID,MT,UT,WA,WY>

There are informal ways of denying rights to individuals with developmental disabilities. Families may create an atmosphere where the person with a disability is treated in a childlike manner and not encouraged to decide for him/herself what life activities should be pursued. This can be as great a barrier to independence as any state or federally sanctioned activity. <MT,TN,UT,WY>

Major barriers to civil rights enforcement for people with developmental disabilities are the lack of advocates and attorneys who can help to secure their civil rights. Access to attorneys or advocates for persons in institutions has been a major barrier to the protection of civil rights for persons with developmental disabilities. The issue faced by most Protection and Advocacy agencies is the insufficiency of their resources. <HI,IN,LA,MT,WY>

Major barriers to civil rights enforcement for people with developmental disabilities and the lack of advocates and attorneys who can help to secure their civil rights. <NM,OH>

Protection and Advocacy agencies have had difficulty in gaining access to records in institutions as well as to the clients. Notice is required, sometimes as much as 24 hours in advance, before an attorney can visit his/her client in an institution. <LA,MT,WY>

Although voting is a fundamental responsibility of American citizens, many people with physical and mental developmental disabilities do not vote, due to barriers to their participation. <ID,OH,TN,UT,WY>

Such limitations, usually set by the institution, create barriers to effective advocacy and can act as barriers to uncovering abuse and neglect in institutions. Where it is difficult to gain access to a client, it becomes even harder to gain access to potential clients. While federal statutes provide for access to attorneys in general, they do not always adequately address the issue of the reality of access. <MT,WY>

Although much progress has been made, many polling places are still not accessible by objective standards. <IN,MT,OH,TN,UT,WY>

The issue of voting rights for state and local elections has not been addressed in any federal legislation. <IN,MT,TN,UT,WY>

People with developmental disabilities are not always aware of their rights and avenues for legal redress and there is a lack of outreach and education in the area of civil rights, particularly the ability to inform people with disabilities that they have a right to enforce their rights and seek redress against those very individuals and agencies providing the education and advice. At times, a proper understanding of civil rights will place people with developmental disabilities at odds with their advocates, families and/or guardians, who then have a conflict of interest. <IN,LA,MT,UT,WY>

The Voter Accessibility for the Elderly and Handicapped Act (P.L. 98-435) encourages citizen participation while also promoting integration into the community by enabling **persons** with disabilities to access polling places. The **effectiveness** of the **statute**, however, is somewhat diminished by its weak enforcement provisions. <MT,UT,WY>

Forty states prohibit certain classes of people with mental disabilities from voting. <MT,WY>

There is a lack of data available in the area of civil rights for people with developmental disabilities. <ID,LA,MT,WY>

In many areas of legal representation, conflicts of interest arise regarding the issue of attorney loyalty. This is a particularly problematic area when the client with developmental disabilities has cognitive limitations or communication difficulties. Attorneys must be clear that it is the person with the disability, and not a third party who may be paying the attorneys' fees, who is being represented. <ID,LA,MT,UT,WY>

There is a lack of outreach to underserved minority groups and limitations to making full use of recent advocacy legislation for persons with disabilities. <IN,LA,MT,UT,WY>

79% of Americans with disabilities report not being familiar with Section 504 antidiscrimination provisions. <IN,MT,UT,WY>

People with developmental disabilities have been denied basic human and legal rights and have been discriminated against for no other reason than that they have a disability. The discrimination experienced by people with developmental disabilities has been one of the most lasting barriers to their integration into the community and acceptance by society. Despite the fact that federal and state statutes and regulations have provided incremental gains, they have been insufficient to counter discrimination against people with disabilities. <CA,HI,IN,LA,MT,UT,WA>

Individual States

Due primarily to the existence of their individual disabilities, tens of thousands of Alabamians experience poverty, segregation, the denial of mental, emotional and physical support, and the unjust denial of basic human rights. <AL>

Existing laws intended to protect Alabama citizens with disabilities are frequently inadequate, ignored, minimally implemented, or inconsistently enforced. <AL>

Despite the progress made since Governor George Wallace became a highly visible member of the disabled population, discrimination continues to severely limit all people with disabilities in every major life area including accessibility, communication, economics, education, employment, housing, insurance, recreation, and transportation. <AL>

It has been found that parents and consumers often are unaware of their rights and how to effectively safeguard their rights. The Council and the Protection and Advocacy System have identified the training of advocates and families to be an important need across the state. <AZ>

A statewide survey was conducted by the Governor's Council and the State Association for Retarded Citizens in 1989 for the purpose of determining the effectiveness of the Human Rights Committees (HRCs). The results indicated that there are many inconsistencies among districts with regard to their involvement, management and training of HRC members. The survey also showed a lack of consistency across districts in the selection, orientation training and roles and responsibilities of the HRCs. This limits the effectiveness of the HRCs to assure the rights of individuals with developmental disabilities. <AZ>

Discrimination from society as a whole persists, creating serious barriers to physical and social integration. <CA>

Individual rights to religious freedom and practice are sometimes violated because transportation from residential programs is not available to assist them in practicing their religion. <CA>

The need for statutory recognition and remedy of discrimination of any type regarding people with disabilities, so that they are assisted in achieving full citizenship. <CO>

Most election commissions in Colorado have made provisions for persons with disabilities to obtain assistance in voting. However, although all polling places are nominally physically accessible, in many cases this means that a person who uses a wheelchair must use a service entrance to gain access to the voting area. The state does not provide interpreters for people with deafness at polling places nor are ballots routinely printed in Braille. People in need of these accommodations must arrange for them on their own. Legislation has periodically been introduced to address this issue, but has been defeated; the lack of funds to implement the changes has been cited as the barrier by state legislators. <CO>

Today, there are about 43 million Americans who have one or more physical or mental disabilities. Far too many have been victims of discrimination that have denied them an equal chance to lead productive lives and to fully develop their potential. <DC>

Under the "Home Rule" Act (P.L. 93-198) Congress delegated to the District Government the authority, functions and powers of a state, with some important exceptions. Congress has retained the authority to review legislation passed by the City Council and may use the process of appropriating the federal payment to enforce changes in policy and programs. Revenue-raising authority is circumscribed by federal law in that the District is prohibited from enacting a non-resident income tax. The courts are part of the federal

system and the District's prosecutor is the U.S. Attorney. These exceptions can and do act as impediments to the enactment of civil rights legislation for all of the residents of the District of Columbia. <DC>

The civil rights of children, adolescents, and adults with disabilities are restricted daily by segregated education and work settings. <ID>

One of the most critical barriers to civil rights is the denial of basic due process based on a person's disability. There is a lack of outreach and education in the area of civil rights due process. <ID>

The discrimination experienced by people with developmental disabilities has been one of the most lasting barriers to their integration into the community and acceptance by society. <ID>

While Idaho does not prohibit people with mental retardation from voting, the state also does not encourage or educate service providers about the voting opportunities available to people with disabilities. <ID>

In Idaho, 853 or 100% of the polling places were accessible for people with disabilities in 1988. However, 11 of those polling places (13%) have been ruled exempt. <ID>

Children with mild disabilities are many times excluded from the full range of available services. This exclusion from services is a subtle form of discrimination. <ID>

All people must have knowledge of these rights and the opportunity and free will to protest and be heard if these rights are denied. The right to make these choices and take action is the very core of a person's independence, integration and self-determination. Yet, with some current attitudes, beliefs and policies about Idahoans with a disability, these rights are difficult to exercise. There are only certain places you can live to receive residential services. There are only certain places you can work to receive state support and assistance. There are only certain schools or classrooms you can attend to receive training or instruction.<ID>

Under the Civil Rights for Institutionalized Persons Act (CRIPA), it is unclear whether Protection and Advocacy agencies have a right to initiate actions. It was generally assumed that the Department of Justice had enforcement authority; but, in the face of serious inaction on the part of DO J, P&As are eager to pick up the mantle and intervene. <MT>

Every Idahoan has and exercises personal rights and freedoms. These rights and freedoms for Idahoans with a disability must include easy access to stores, shops, sidewalks, telephone service, voting booths/polling places, government buildings, recreational facilities, parks, resorts, buses and airplanes. For a person with a disability in Idaho,

however, the vision can be faint and distant. Many of these have been ignored or abused because accommodation is costly, inconvenient or infrequently requested. <ID>

Federally funded Protection and Advocacy agencies (P&As) like Idaho's CO-AD have insufficient resources to handle all complaints. <ID>

Idaho lacks enough legal advocates to protect the rights of people with disabilities. People with developmental disabilities are not always aware of their rights and avenues for legal redress. <ID>

Families may create an atmosphere in which the person is treated in a childlike manner and not encouraged to decide for him/herself what life activities should be pursued. <IN>

A critical barrier to civil rights is the denial of basic due process based on a person's disability. Many laws affecting people with disabilities paint with a broad brush and label all people with disabilities far too similarly. People with disabilities are denied due process rights on a regular basis when laws assign certain characteristics to individuals because they have a disability. <IN>

In hearings conducted throughout the state of Indiana on this "1990 Report," Council staff heard strong testimony from consumers concerning physical and communications accessibility to community services. The testimony emphasized that Indiana should enforce the laws it has regarding accessibility (e.g., P.L. 44 and state laws regarding design or construction) and make a code book available to builders, architects, and designers and suggestions for appropriate compliance. <IN>

In many areas of legal representation, conflict of interest arises regarding the issue of attorney loyalty. This is a particularly problematic area when the client with developmental disabilities has cognitive limitations or communication difficulties. Attorneys must be clear that it is the person with the disability, and not a third party who may be paying the attorneys' fees, who is being represented. <LA>

There is a great lack of data available in the area of civil rights for people with developmental disabilities. <LA>

Discrimination is a major obstacle to achieving the society's goals of equal opportunity and full participation of individuals with disabilities. The deprivation of an opportunity because of someone's disability is the antithesis of equal opportunity. The pervasiveness and severity of discrimination against people with disabilities is well-documented. <MA>

The Massachusetts Commission Against Discrimination is charged to investigate allegations of discrimination based on disability and other criteria, and monitors government compliance with federal and state affirmative action guidelines. The number of complaints rose from 1,990 in 1984 to 3,000 in 1985, and continues to increase. State

funding for this agency has diminished in the last two years despite desperate complaints about the agency's inability to meet its mandate. The average processing time for discrimination cases had already risen from 307 to 375 days and will rise even more. The Commission has been given limited resources to accomplish its mandate, and cannot do its job. <MA>

The legal services needs of people with disabilities are not being met. Between 1980 and 1986 in Massachusetts, the number of Legal Services attorneys declined thirty percent while simultaneously caseloads increased from 34,000 to 50,000 cases. Legal Services funding is 34% lower than at the beginning of the Reagan Administration in 1980. The Massachusetts Legal Assistance Corporation reports that 85% of the civil legal needs of the poor, including people with disabilities, are unmet. <MA>

The Rehabilitation Act was amended in 1973 to include Section 504, the first civil rights legislation to guarantee equal opportunity. However, the Department of Justice does not enforce this law, particularly at the local level. Each federal agency is responsible for enforcing Section 504 in its own programs through its own Office for Civil Rights. Increased levels of enforcement are needed throughout the federal system. But the limited protection offered by Section 504 only covers activities related to the federal government. <MA>

The present Protection and Advocacy Programs for Developmental Disabilities and Mental Illness do not have sufficient resources to represent all the legal needs of people with disabilities. <MA>

The inaccessibility of public buildings and bathrooms continues to be a major barrier for people with disabilities. <MA>

The use of certain painful treatments (aversives) to affect the behavior of persons with autism and other developmental disabilities has been met with outrage by consumers and advocates. Much debate has been heard in the community about the effectiveness of such treatments and of other more positive approaches. Lack of planning and poor resource allocation has meant that available alternatives for families do not always exist. <MA>

Americans with disabilities have the right to choose where and with whom they live, work, and socialize. Because of their special needs, they often encounter physical, social, financial, and attitudinal barriers to exercising their rights and getting their needs met. <MI>

People with disabilities do not have the same legal protection against discrimination that other groups (e.g., minorities, women) have. <MI>

Citizens with disabilities face discrimination in all sectors of their lives, in spite of laws intended to protect against discrimination. <MI>

Handicappers who are also members of minority groups face double-edged discrimination: (1) because of their minority status and (2) because of their handicapping characteristic. Despite the good faith efforts of mainstream advocacy groups, minority group members with disabilities and their families have little active participation in many advocacy groups. <MI>

Agencies designated to investigate alleged violations of rights and access often do not have enough staff to help handicappers adequately. <MI>

Lack of accessible environments at work, in residences, in transportation, and elsewhere in the community still make it difficult for handicappers to participate in the community at large. <MI>

The public does not perceive citizens with disabilities as potential voters or as a valid voting group. As a result, citizens with disabilities seldom receive training in their rights and responsibilities as citizens. <MI>

All adult citizens have the right to vote, regardless of type of disability. However, polling places often are not prepared to meet the individual needs of all voters with differing disability characteristics. <MI>

Many state laws have negative consequences for the person with developmental disabilities affecting voting rights and the exercise of other rights such as commitment to institutions, adjudication of competency, or appointment of guardians. <MT>

Under the Civil Rights for Institutionalized Persons Act (CRIPA), it is unclear whether Protection and Advocacy agencies have a right to initiate actions. It was generally assumed that the Department of Justice had enforcement authority; but, in the face of serious inaction on the part of DOJ, P&As are eager to pick up the mantle and intervene. <MT>

Data from the consumer survey and public hearings indicate that many individuals with developmental disabilities and their families are not aware of their civil rights or don't know where to begin looking for services to meet perceived needs. <NC>

Discriminatory practices persist in areas of employment, housing, and education. Many people with developmental disabilities who experience such discrimination have little recourse. They may not have the resources, either personal or financial, to pursue the matter. In some situations, people may not even recognize that their rights have been violated and that they have a right to protection under the law. This need for education and training is ongoing. <NE>

For persons with physical limitations, accessibility is often cited as major problem. The current system permits local communities to opt to enforce accessibility standards. Although they must follow the some minimum standards as the State Fire Marshall, enforcement may not be consistent. If persons with developmental disabilities are to achieve true integration within their communities, accessibility is essential. <NE>

There are many more needs and requests than there are P&A staff to meet these needs. DADD faces the normal case load demands of a very populated state as well as being involved in outreach to community groups, and legislative activity. They have also undertaken systems change by filing suit on behalf of named "individuals" on the waiting list for community residential services. <NJ>

People with developmental disabilities do not have adequate procedural safeguards to protect their rights in decisions regarding guardianship, residential placement, medical treatment and other matters that affect their lives. <NM>

Despite the protections of state and federal laws, people with developmental disabilities continue to experience discrimination in housing, education and employment. <NM>

People with developmental disabilities are not always aware of their rights. <NM>

There is a lack of outreach and education about civil rights, particularly to those persons with developmental disabilities. <NM>

Because consumers are not fully informed and aware of services and of their legal and/or civil rights, they are not accessing appropriate, needed resources. <NV>

Although inadequacy of informational provision to consumers has been noted in other sections, it bears repeating here as it is a strongly held concern of all survey and conference participants that many persons with disabilities do not avail themselves of their rights because they are not aware of them. <NV>

Participants believe that although increasing legal and civil rights are being afforded to people with severe disabilities, those provisions are not being fully implemented and enforced. This is particularly true in housing, physical accessibility and the right to be treated, rehabilitated and educated in the least restrictive environment. <NV>

Participants additionally expressed the concern that lack of knowledge by professionals in the area of legal and civil rights creates further negative impact on the problem. <NV>

Participants strongly held that there is great need for well coordinated disability rights advocacy in several areas: transition from school to work; the right to a safe environment; the right to job training and advancement; access to technology; the right of deaf persons

to interpreters at all public meetings; and the right of persons with visual impairments to easily access alternative media. <NV>

The Civil Rights of Institutionalized Persons Act (CRIPA), passed in 1980, empowers the Department of Justice to initiate action to protect the constitutional and federal rights of people in institutions, among them persons with developmental disabilities. There has been an apparent lack of resolve on the part of the Department of Justice to take the necessary legal action to implement the protections available under CRIPA. <OH>

Currently, except for the assistance provided by the Ohio Legal Rights Service, formal supports are not usually available to enable people with disabilities to make informed choices and advocate for the protection of their rights. While guardianship is needed for many people with developmental disabilities, especially those with severe mental handicaps, there is a fear that we will rely on the courts to appoint more and more guardians rather than fund the support services that would facilitate people with developmental disabilities in advocating for themselves. <OH>

Although voting is a fundamental responsibility of all American citizens, many adults with developmental disabilities do not vote, often due to societal barriers to their participation. Although much progress has been made, many polling places are still not accessible to people with physical disabilities. <OH>

Major barriers to civil rights enforcement for people with developmental disabilities, including those in institutions, are created by the lack of advocates and attorneys who can help to secure their civil rights. <TN>

People with developmental disabilities are discriminated against because of their disabilities. <TN>

The State of Texas has no comprehensive legislation to protect people with disabilities from discrimination in the areas of architectural accessibility, employment, public services, public accommodations, communications and transportation, such as that which has been proposed at a federal level by the Americans With Disabilities Act. <TX>

The federal definition of disability is needed for two reasons. First, Texas has never had one definition of "disability" that is applied throughout state law. Different laws apply different definitions, excluding some people from protection under some programs, although the same people may be eligible under other programs. Second, in 1987 the Texas Supreme Court interpreted one state law definition of "handicap" in such a way as to protect only a very limited group of people with severe disabilities — those who are "impaired to the point that they might not be able to participate in the social or economic life of the state, achieve independence or become gainfully employed." This state definition does not protect from discrimination those people with disability who are or could be gainfully employed or those who are able to live independently. <TX>

Chapter 21 of the Human Resources Code prohibits discrimination against people with disabilities; however, it offers no provisions for enforcement and contains no specific requirements that reasonable accommodations be made. A variety of other laws also address discrimination in one way or another but authority for enforcement is piecemeal and rests with a variety of state agencies. <TX>

Only approximately 20% of the state's counties have architectural barrier requirements attached to privately financed public facilities and areas. Some categories of private and public accommodations are not required to adhere to the Architectural Barriers Law. Restaurants and hotels are not included in the list. Also, the University of Texas System is excluded from the law. <TX>

The State Purchasing and General Services Commission is currently responsible for carrying out the provisions of the state architectural barriers law. The commission can refer all facilities covered by this law that are in compliance to the Attorney General. However, in the 18 years that this law has been in existence, not one facility has been referred. The part of the agency budget that administers this section of Title 20 has experienced budget cuts that limit the ability of the commission to carry out plan checks or monitor or enforce the architectural requirements. <TX>

Incompetence has become synonymous with the absence of citizenship. For example, Utah's Constitution says: "No mentally incompetent person.../unless restored to civil rights shall be permitted...". And the blank is filled in with such privileges as voting. This subtlety unfortunately translates into leaving people with mental retardation, and others, without rights. <UT>

The critical issues are the need for information and advocacy that enable people to exercise their rights; personal choice and the dignity of risk; the application of comparable standards for living; least restrictive environments; access to services and opportunities; and, fair and equitable treatment with adaptive advantages. <UT>

People with disabilities often are denied their civil rights due to a lack of information and advocacy in gaining access to participation in the community. <UT>

Utah has experienced another problem with legalizing rights for people with disabilities in their judicial system. Even though the paperwork may be in place and the laws enacted, if judges are not educated to the implications of discriminatory practices against people with disabilities, enforcement will never be implemented. <UT>

According to the Legal Center, the biggest deterrent to civil rights for people with disabilities is that people view "rights" as something that interferes with the individual's well-being and the smooth delivery of services. In a community which values authority, it is difficult to implement a system of self-assertion and it is therefore difficult to get plaintiffs to follow through even when complaints are made. <UT>

Another matter that has been of concern is the absence of public guardianship for people with disabilities who need legal guardians and have none. These are people who are without representation in circumstances requiring medical decisions, deinstitutionalization, and financial matters. In some cases, agencies are assuming the responsibilities for guardianship without legal support. This is especially a problem when decisions have to do with the administration of psychotropic medications. The extent of these illegalities taking place is not known. <UT>

Utah needs criminal statutes for the offender with mental retardation. It is still true that if a judge finds a defendant incompetent at the point of adjudication, he or she can commit the offender to the USTS indefinitely without adjudication. <UT>

The Washington Protection and Advocacy System is inadequately funded. Both individual and legal advocacy are needed statewide. Although the federal government provides a base level of program support, the state should augment those monies to insure quality service in both institutions and communities on a statewide basis. <WA>

There is a great unmet need for formal, individual advocacy services across the state. The Washington State P&A System (WPAS) is underfunded. The state, through the Division of Developmental Disabilities (DDD), funds advocates at each institution. Similar support is not provided to local communities. With the amount of federal funds available, WPAS is unable to strategically place adequately paid, trained advocates around the state to provide formal, individual advocacy services. <WA>

The availability of free legal representation in civil cases is severely limited. In addition, the Washington Protection and Advocacy System is severely underfunded. The system will be hard pressed to meet new federal mandates and provide individual advocacy at the local level. At the same time, to adequately do its job, the legal system will need state funds in addition to those provided by the federal government. <WA>

There is a lack of outreach to underserved minority groups and limitations to making full use of recent advocacy legislation for persons with disabilities. <WA>

If any person is to exercise their individual rights, they must know that those rights belong to them. People are not always aware of the avenues for legal redress. The 1987 Harris Poll reported that 79 percent of Americans with developmental disabilities report not being familiar with Section 504, the anti-discrimination provisions. Nationally, there is a lack of outreach and education in this area, particularly when it comes to informing people that they have a right to seek redress against those very individuals and agencies which provide them with education, support and advice. In other words, you can buck the system. <WA>

Another major barrier to civil rights enforcement is the lack of dollars to pay for attorneys and legal services. Most protection and advocacy agencies are underfunded.

This is also true for legal service cooperations which cannot meet the demand for legal services for the poor. <WA>

Society generally misunderstands the abilities of people with developmental disabilities and underrates their capacity for responsible decision making. Too often, it is assumed that if a person needs help in one area of decision making, he or she is incapable of making decisions in all areas of their life. <WA>

Data available from the state Human Rights Commission is difficult to analyze because it does not break out into disability categories. In other words, it is impossible to determine just how many of the complaints have been made on the basis of discrimination against a person with a developmental disability as opposed to other disabilities. <WA>

By law, citizens of the state of Washington with disabilities have full protection of their civil and human rights. But, in reality, these statutes are rarely employed by the developmental disabilities community. There are many reasons, but the most pivotal issue is this: people with developmental disabilities are just now moving into the mainstream of American life. Many do not even know it is illegal to discriminate on the basis of disability. <WA>

In the state of Washington, the availability of legal protection and advocacy services is limited. There is an apparent inability of the federal Offices for Civil Rights and the state Human Rights Commission to respond to complaints. This is a major barrier to enforcement. It is also unclear whether people with disabilities and their families are aware that their access to federal and state programs are protected by law. <WA>

There is a lack of enforcement of federal equal opportunity laws by the Department of Justice. <WA>

Discrimination continues and constitutes one of the greatest barriers to full acceptance of people with disabilities into the fabric of American life. While it is true that over the past 20 years federal and state legislation in this country has done a great deal to provide measurable gains, those gains have been insufficient to counter deep-seeded, societal discrimination and fear. <WA>

In Wyoming any resident who is 18 and registered to vote may do so unless he or she is felon whose rights have not been restored or unless she or he has been adjudicated as mentally incompetent. This may affect some individuals with developmental disabilities who have guardians. <WY>

CIVIL RIGHTS: RECOMMENDATIONS

Multiple States

The state should adopt a State Bill of Rights or Equal Rights Amendments for Persons with Disabilities to state constitutions. The state can ensure that state laws include strong nondiscrimination provisions and enforcement provisions. <ID,LA,MT,WY>

The Americans With Disabilities Act should be enacted during the 101st Congress as the main vehicle to secure and enforce nondiscrimination in the private sector and in state government activities. <AK,HI,ID,LA,MT,OH,TN,WA,WY>

Surveys of state laws should be done in each state to identify those laws that impede the independence, productivity, and integration of persons with developmental disabilities. <ID,LA,MS,MT,WY>

The American Bar Association should review the professional Code of Responsibility concerning such representative and develop guidelines for attorneys in the disability field to eliminate issues of conflict of interest, such that their interests are guided solely by the interests of their client. <LA,MT,OH>

Encouragement must be offered through recruitment efforts to those attorneys and local bar associations to join the disability rights movement. <MT,OH>

CRIPA's enforcement authority needs to be expanded so that P&As may initiate suits on their own. <ID,LA,MT,NM>

Governments at all levels should discard the presumption that there is a relationship between a developmental disability and the decision making capacity to vote. <LA,MT,WA>

A policy of affirmative action should be developed and implemented for people with developmental disabilities living in institutions regarding voter registration and voting. <LA,MT>

Beyond access to services and supports, exercising civil rights requires receiving those supports. Access to a waiting list does not advance the vision of full citizenship for people with developmental disabilities. Thus, expanding entitlements to Medicaid Reform efforts under consideration in the 101st Congress must be accomplished, <LA,MT,WY>

It should be the policy and practice of state and local governments that assistance will be available and accessible on a nonpartisan basis for those requiring it to exercise voting

rights. Voter registration should be made as easy as possible for all potential voters. <LA,MT>

Individual States

The state must be accessible to all Alabamians, including those who have developmental disabilities. Barriers, whether attitudinal or physical, must be removed. <AL>

Advocacy Services, Inc., the federally-funded Protection and Advocacy Agency (P&A), should take a vigorous interest in promoting the goals of federal legislation to ensure integrated services for students and adults. For instance, parents and consumers need increased help in the IEP process when they are denied least restrictive educational placements and when unconstitutional zoning laws seek to bar community programs. The P&A should also seek an increased role in monitoring educational and other services for which regular federal and state reviews are available. <AR>

Rules and operating procedures practiced by the DDD service system must be uniform throughout the state and consistent with the laws designed to assure the rights of persons with a developmental disability. <AZ>

A greater emphasis should be placed by the Protection and Advocacy (P&A) unit of the Center for Law on the training of advocates and guardians to know their rights and to know how to secure services and protections within the community systems. <AZ>

The Center for Law should continue its efforts to coordinate with the Arizona Department of Education, the Association for Retarded Citizens, and other groups which also provide advocacy training. <AZ>

The statewide Human Rights Committees should be authorized to provide full oversight to assure that there is satisfactory closure on all human rights issues and unusual incident reports in the community service system. The members must be trained and well informed representatives of the community. Human rights committees must have the authority to pursue their investigation as vigorously as they deem necessary. <AZ>

More emphasis should be placed by the Center for Law's Protection and Advocacy unit on providing individual legal assistance. <AZ>

The rights of people with developmental disabilities to protection from discrimination, full access to community life, and the ability to function in the least restrictive environment must be more strongly enforced. This includes provisions in Section-504 of the Rehabilitation Act as well as other protection in federal and state law. <CA>

The provisions of the American With Disabilities Act (ADA), when enacted at the federal level, should be implemented and enforced in California. <CA>

Advocate increased enforcement of existing non-discrimination statutes. <CO>

Support federal Americans With Disabilities legislation. <CO>

Establish protected class status in state statute for people with disabilities, consistent with treatment of women and minorities. <CO>

The Council should marshall all of the resources available in support of federal and local legislation to secure and enforce non-discrimination in the private and public sector. <DC>

The Council should spearhead local and join national efforts to protect the rights of people with AIDS/HIV who also have a developmental disability. <DC>

The Council should establish procedures for ongoing dialogue between the courts, legal profession and health care professionals for the purpose of clarifying issues related to individuals with developmental disabilities, with developmental delay, and crack and abandoned babies. <DC>

Procedures should be put into place by the Council for monitoring the extent which service delivery systems are in compliance with existing mandates, law and regulations. <DC>

Increase efforts of inform all individuals with disabilities, their caregivers and advocates of the legal rights of individuals with developmental disabilities. <FL>

Increase efforts to ensure that all persons with developmental disabilities, their caregivers and advocates have access to counsel, regardless of their ability to pay for such services. <FL>

Advocate for passage of the Americans With Disabilities Act. <GA>

Increase public education on civil rights legislation. Civil rights legislation should be reviewed to determine how well provisions are being implemented. Successful techniques on how to implement civil rights legislation should also be disseminated through local workshops. <GA>

Enforce and educate people about Georgia's access code, Section 504, and the Fair Housing Act; enforce the code requiring accessible voting sites and polling places and assist with transportation to the polls and with the use of the voting machines. <GA>

The Council recommendation is to increase public awareness of accessibility issues for individuals with disabilities on Guam. <GU>

Public policy should be formulated that puts the burden of proof on the public service, not the person with a disability. <ID>

State funding should be provided to establish and support an advocacy institute to provide information and teach persons about their disability rights. <ID>

Funds shall be allocated for the development and implementation of state-wide non-aversive behavior management technical assistance and training. <IN>

Indiana shall enforce all laws pertaining to accessibility (e.g., PL 44, A.N.S.I. codes at the state level) and provide clearly defined codes to builders, architects, interior designers, etc. <IN>

Indiana shall provide greater enforcement of voter accessibility at the polling place, including transportation to and from the voting precinct when necessary. <IN>

In the development and enforcement of accessibility standards, consideration shall be given to the safety and convenience of the user. <IN>

Businesses who serve the public should be encouraged to seek input from the disability community on accessibility issues. <IN>

Indiana shall designate disability specialists whose job is to review plans and inspect new construction and public buildings to enforce accessibility standards. <IN>

Indiana shall mandate that public meetings be held in accessible buildings and that interpreter services be provided on request. <IN>

Comprehensive civil rights legislation for people with disabilities should be enacted to eliminate bias in housing, employment and public services. <IN>

Indiana shall develop and enforce policies to assure that people with sensory, physical, or intellectual disabilities have full and easy access to all buildings, programs, political processes, and other activities in the community. <IN>

Indiana shall adopt a policy which promotes the dignity and value of people with disabilities in all written, printed, and pictorial language. <IN>

The Office of Human Services should fund the Advocacy Center for the Elderly and Disabled Legal Capacity program statewide. <LA>

The Advocacy Center for the Elderly and Disabled, in coordination with the Council and other advocacy groups, should develop a strategy to increase public awareness of the rights of persons with developmental disabilities. <LA>

The Council and the Advocacy Center for the Elderly and Disabled should assist advocacy and parent groups with self-advocacy training programs and help promote new self-advocacy groups. <LA>

The Americans With Disabilities Act should be enacted during the 101st Congress as the main vehicle to secure and enforce nondiscrimination in the private sector and in state government activities. <LA>

The Advocacy Center for the Elderly and Disabled (ACED) should continue to monitor enforcement of state and federal laws related to persons with disabilities. Congress should increase the funding for Protection and Advocacy Agencies so they will have adequate resources to address this activity. <LA>

Often attitudinal barriers on the part of people without disabilities affect everyday life for people with disabilities. Public awareness and understanding must be addressed to replace fear and negative attitudes. <MA>

Enact the Americans With Disabilities Act and zealously enforce it and all other disability laws and protections. <MA>

A major voter registration drive should be launched to register and support every person with a disability in Massachusetts to vote, participate in the electoral process and know how to lobby for their interests with their legislators. <MA>

The state-wide renovation of all inaccessible public facilities, buildings and recreation areas should be financed through a public bond authorization program. <MA>

The use of certain painful treatments (aversives) to control the behavior of persons with severe autism and other developmental disabilities should be banned through the passage of House 5469. <MA>

The State legislature should: (a) pass the Housing Bill of Rights for People with Disabilities Act; (b) create an AIDS anti-discrimination statute; (c) add provisions regarding "disability" and "age" to the new state Civil Rights statute; and (d) change present state mental health hospital "voluntary" and "involuntary" admission standards to create a genuine voluntary standard with an advocate ombudsperson present at every admission. <MA>

The Massachusetts legislature must provide fiscal resources to enable the Massachusetts Commission Against Discrimination to enforce the present laws and regulations existing to protect the rights of people with disabilities. A strong partnership should exist between the Massachusetts Commission Against Discrimination, State Office of Affirmative Action, Office of Handicapped Affairs and Architectural Access Board to keep abreast and increase coordination of their efforts. <MA>

The Americans With Disabilities Act should be enacted by Congress with strong requirements and tough enforcement powers. <MA>

Federal and state civil rights laws protecting persons with disabilities, such as Section 504 of the U.S. Rehabilitation Act, the Education and the Handicapped Act and Massachusetts Constitutional Article CXIV prohibiting discrimination against persons with handicaps, should be vigorously enforced by the U.S. Department of Justice, the Offices for Civil Rights in federal agencies, the Massachusetts Commission Against Discrimination, and all other appropriate authorities. <MA>

An independent entity should be given the responsibility for oversight to ensure the protection of all rights for all people with disabilities, both within state agency programs and their vendors' programs. It should have the capacity to work with the state agencies and go "outside" or "above" them when needed, to: (1) investigate allegations of human rights violations and enforce findings; (2) provide independent hearing officers and decision-makers separate from the agencies and programs they review and make judgments about; (3) initiate investigations of all abuse complaints and ensure the provision of protective services (a function on behalf of some adults with disabilities by the Disabled Persons Protection Commission); (4) assure the quality of state services; and (5) offer ombudspersons and/or client advocates to act on the individuals' behalf when they interface with the state system. <MA>

Federal agencies should develop new and expanded initiatives to publicize the requirements of current federal laws that prohibit discrimination against persons with disabilities, and to inform individuals with disabilities of their rights under such laws. The U.S. Justice Department should appoint an overseer for the rights of persons with disabilities, as the department needs to more clearly see disability discrimination as a civil rights issue. <MA>

Administer state contracts for legal services for people with disabilities through a single, neutral agency. Award all contracts for legal services for people with disabilities for periods of three years in recognition of the time and expense required in the contract preparation and negotiation and the limited resources available. <MD>

Continue and expand training and consultation provided by the Maryland Legal Services Corporation and Legal Aid to increase the expertise of the private bar in serving people with significant disabilities. <MD>

Provide more funding of legal resources. <MD>

Increase emphasis by the University of Baltimore and the University of Maryland Law Schools on issues affecting people with disabilities and on sensitivity training needed to be responsive to individuals with significant disabilities. <MD>

Continue emphasis by the Maryland Legal Services Corporation and the private bar association on the need for pro bono work on behalf of people with developmental disabilities. <MD>

The State of Maine must assure that all children with developmental disabilities in state custody will have an effective means of rights protection. State policy must also reflect the right, responsibility and obligation of case managers to actively and aggressively advocate for the rights of children with developmental disabilities in state custody. <ME>

A task force or oversight commission should be established, sponsored by the DD Council, the Maine Human Rights Commission, the Protection and Advocacy Agency, the Maine Independent Living Center, the Bureau of Rehabilitation - Sec. 504 Compliance Office and other appropriate entities. The Task Force should be charged with: identifying public buildings and programs and private places of public accommodation that fail to meet accessibility standards, taking such action as shall be necessary to bring noncomplying entities into compliance with existing requirements; identifying gaps in current mandates and developing and advocating for any necessary legislation; and assuring publicity for the effort and encouraging voluntary compliance. <ME>

The Maine State Legislature should adopt, as a reference point for public policy and funding, a Bill of Rights for persons with developmental disabilities and their families. <ME>

Through Executive Order or Legislative Resolve, state agencies should review their statutes, regulations, and other relevant public policy documents to assure appropriate reference to persons with developmental disabilities. Reference should be stated as "persons with developmental disabilities" rather than such stigmatizing terms as "the mentally retarded" or "the mentally ill". <ME>

The Americans with Disabilities Act which dramatically expands federal protection against discrimination based on handicapping conditions. <ME>

Departments of state government should adopt and apply guiding principles based on full citizenship, community inclusion, and participation. State departments also must work with others to communicate to communities the substance and benefits of community inclusion and participation for people with disabilities in communities. <MI>

Congress should pass and the President sign, without weakening amendments, the Americans With Disabilities Act, and assure direct prompt, full implementation. <MI>

The Michigan Developmental Disabilities Council should develop and launch the Michigan Full Citizenship Initiative (MFCI). MFCI will stress full inclusion and participation in the community as the major outcome of this 1990 Report; support people with disabilities in their efforts to communicate the need for, and benefits of, inclusive communities that

value diversity; help people with disabilities to articulate both the barriers to and the vision of participation in inclusive communities, and to develop understanding of the issues and concerns they share with one another; and advocate for a chance to choose, for people with disabilities in Michigan. <MI>

The governor should direct, and the legislature should fund, expansion of the role and functions of the Barrier Free Design Division of the Bureau of Construction, Michigan Department of Labor. <MI>

The Michigan Developmental Disabilities Council, with other advocacy groups, should work to assure that appropriate agencies have adequate funding to assure civil rights protection for citizens with developmental disabilities. <MI>

The Michigan Legislature should pass S.B. 368 and H.B. 4764, the proposed amendments to P.A. 220 of 1976, the Michigan Handicapper Civil Rights Act, to clarify definitions and accommodations. <MI>

The Michigan Developmental Disabilities Council should stimulate and enable formation of local community barrier free design Advisory Committees with handicapper and aging representation. <MI>

All state agencies should complete implementation of Governor Blanchard's Executive Directive 1987-1 on the accessibility of public services, programs, and activities. <MI>

The Michigan Commission on Handicapper Concerns and the Division of Deaf and Deafened should work cooperatively with the state legislature to introduce a bill that would require that every hospital, fire department, ambulance service, and police department in the state, and all public agencies and their contractees must be accessible by Telecommunications Devices for the Deaf (TDDs); all public agencies and organizations must use and publicize the availability of their TDDs; and all public agencies and organizations must develop a method to identify and pay signing interpreters for people with hearing impairments. <MI>

All human service agencies and disability advocacy groups should adopt policies requiring that any communications of their organizations will use People First language ("people with "or" handicappers"). <MI>

The Michigan Developmental Disabilities Council, with the League of Woman Voters, the Bureau of Elections, political parties, and interested others, should develop and plan to assure that all citizens have full access to the polls. <MI>

The Michigan Commission on Handicapper Concerns should carry out a project to give the barrier free symbol a single, universally understood, user-friendly definition. <MI>

The Michigan Legislature should fund the accessibility recommendations by requiring that all buildings that are not accessible pay a tax surcharge on property every year until corrected. Income from the surcharge could also be used to establish and administer a revolving loan fund that property owners could use to help finance accessibility modifications. <MI>

Efforts must be extended to assure that the rights of elderly Mississippians with disabilities are protected in such areas as abuse, competency hearings, powers of attorney, protection of entitlement and guardianship. <MS>

Services to persons with disabilities in Mississippi consistent with individual dignity should be provided when necessary to protect from abuse, neglect, and exploitation. <MS>

All callers who inform CARE-LINE that they have a developmental disability or that they are calling about a person with a developmental disability must be given information about how to contact the Governor's Advocacy Council for Persons with Disabilities in order to obtain information about their civil rights. <NC>

Consistent enforcement of accessibility standards across the state should be assured. <NE>

Nebraska should consider adopting a State Bill of Rights for persons with disabilities to ensure that state laws include strong nondiscrimination and enforcement provisions. <NE>

Legal services need to be available for persons with developmental disabilities when their civil rights are in questions. <NE>

Organizations responsible for safeguarding and advocating on behalf of the rights of citizens with disabilities should cooperate in the conduct of ongoing outreach and informational activities to inform service consumers about their rights, about advocacy strategies and processes, and about the availability of protective services. <NH>

It is recommended that the Americans With Disabilities Act be enacted at the earliest feasible opportunity. <NJ>

It is recommended that the New Jersey Developmental Disabilities Council's Committee on Advocacy meet with officials from the Division on Civil Rights to discuss the pattern and practice of cases that the division reviews, as these cases may reflect issues particularly pertinent to people with developmental disabilities, and to ascertain to what extent, if any, the Americans With Disabilities Act extends mandates beyond present New Jersey law. <NJ>

It is recommended that continuing education be offered to building inspectors, construction officials and architects on practical ways to achieve accessibility in practice. <NJ>

It is recommended that during the gubernatorial transition, an effort be made to secure a basic public commitment from the new governor to the principle that, as a matter of public policy in this state, people with disabilities should not themselves bear the major part of any burden of achieving equal access to social institutions. <NJ>

The concept of "best interest of the child" must remain the overriding principle so children have a right to an advocate, when necessary, protect their best interest. Society must be ready to assist children when their best interests are not realized. <NM>

Enforcement authority of the Civil Rights of Institutionalized Persons Act's should be expanded so that Protection and Advocacy agencies may initiate their own suits. <NM>

The Americans With Disabilities Act should be enacted during the next Congress to secure and enforce the civil rights of persons with developmental disabilities in both the private sector and in state government. <NM>

Instate statutory legal and civil rights for Nevadans with disabilities should be established through legislation. <NV>

The right to a least restrictive environment related to education, housing, and transportation must be implemented within, policies of all providers of services to Nevadans with disabilities. <NV>

Congress should act immediately to pass, without weakening amendments, the Americans With Disabilities Act. <NV>

All families, professionals and providers of services must actively address discrimination practices against people with developmental disabilities and their families. This includes all areas of community services such as housing, employment, health and dental care, transportation, recreation and education. <NY>

Greater efforts must be made to inform and educate people with developmental disabilities and legal, medical, educational and social service professionals regarding legal rights, especially informed consent issues. <OH>

The funding allocation for protective services for adults with developmental disabilities should be significantly increased. The source of this funding should be shifted to a state agency that is not directly involved in service delivery to persons with developmental disabilities. In addition, a mechanism for the provision of protective services for adults with mental illness should be developed. <OH>

Government at all levels should reject the presumption that people have a diminished capacity to vote simply because they have a developmental disability. A policy of

affirmative action should be implemented for people with developmental disabilities, especially for those living in institutions, regarding voter registration and voting. <OH>

All existing statutes and regulations protecting the rights of people with developmental disabilities should be rigorously enforced. <OH>

The rights and safety of persons receiving services will be safeguarded. Human rights councils — consumer controlled and independent of the grantor and grantee — are necessary to monitor agencies, but the responsiveness of the criminal justice system also needs to be improved. <RI>

There is a lack of outreach in consumer rights education for persons with disabilities. Seldom do consumers with developmental disabilities know their rights as individuals. Provision for full education and exercise of the civil rights of persons with disabilities needs to be addressed. <SC>

Tennessee should adopt a Bill of Rights for Persons with Disabilities. Tennessee should ensure that all relevant state laws include strong nondiscrimination and enforcement provisions. <TN>

A survey of Tennessee laws should be completed in order to identify those laws that impede the independence, productivity, and integration into the community of persons with developmental disabilities. <TN>

Service agencies should be required to inform their clients of their rights, of steps in the appeals process, of due process procedures, and of advocacy agencies during each meeting with clients to discuss the client's program, living accommodations, and services. <TN>

The Texas Planning Council recommends the Texas Legislature amend those law requiring architectural accessibility and laws that prohibit discrimination against people with disabilities in employment, public services, public accommodations, communications and transportation by expanding the coverage of such laws and strengthening the monitoring and enforcement provisions of such laws. <TX>

The Council concluded that the federal definition of disability should be adopted in Texas. That definition reads 'individual with handicaps' means any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment." 29 U.S. Code, Section 706(8)(B) <TX>

The Council also recommends that existing state legislation be amended to ensure there are minimum due process protections in state programs. Each agency should provide applicants or recipients an opportunity to appeal the denial, suspension, reduction or

termination of assistance or services, and include reasonable written notice and an opportunity for a hearing. <TX>

State statutes should be amended to ensure private right of action, including acceptable penalties, attorney fees and court cost recovery provisions. Currently in Texas, the winning side can only recover attorney's fees if there is a statutory authorization. The damages provision also should be changed to increase the minimum amount of damages from \$100 to \$500. <TX>

The Council's recommendations regarding access include stronger legislative action to eliminate architectural barriers. <UT>

The DDPC (through the "Advocacy Council") should continue to examine both the formal and informal advocacy system in this state. It should seek to re-design the "system" so there are clearly defined areas of responsibility. <WA>

Agencies and organizations compiling data on advocacy activities should develop a common data gathering system. The data gathered should be compiled by the DDPC and used in its planning and systems advocacy. This data should be made available to the public. <WA>

The DDPC should convene a quarterly "Advocacy Council" to provide linkage between advocacy groups statewide. <WA>

All volunteer advocates must be trained. <WA>

Washington Protection and Advocacy System should continue its strong focus on individual advocacy at the local level. Advocates should serve county or multi-county areas and should be hired by the Washington State P&A System (WPAS). WPAS professional advocates should have some kind of certification. <WA>

The state should provide funding for individual advocacy in both the community and in institutions. Washington Protection and Advocacy System federal funding should be used to augment individual advocacy and to provide legal advocacy services. <WA>

Individual advocacy provided formally and informally through advocacy organizations should link with Washington Protection and Advocacy System to share information. Technical assistance and support for the less formal service should be provided by WPAS. <WA>

The legal and advocacy communities must monitor those agencies and departments responsible for ensuring that laws and regulations are obeyed. <WA>

With full legal protection in hand, self-advocacy movements need to be encouraged in every state and territory. <WA>

The civil and human rights of people with developmental disabilities in the state of Washington are fully protected by law. We are fortunate as those protections do not always extend to the federal level. It is, therefore, essential that the Americans With Disabilities Act become law. <WA>

When civil rights are denied, greater use should be made of existing state statutes and of the Human Rights Commission. People with disabilities and their advocates are largely unaware of the resources available to them. The Human Rights Commission should also be more receptive to serving people with disabilities. The perception continues to exist that the Commission serves only ethnic minorities and women. <WA>

It should be the policy and practice of all levels of government to provide needed assistance and accessible voting facilities on a nonpartisan basis for those with special needs. <WA>

Government should assist all citizens in understanding their civil rights and the responsibility citizens within local communities have to be mutually supportive of one another. <WA>

The state of Wisconsin should publicly declare that what Wisconsin must do for its citizens with disabilities is to provide no more nor no less than the long-established rights which people without disabilities enjoy. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the same basic rights guaranteed by the Constitution of the United States and the state of Wisconsin. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to be respected and treated with dignity by their fellow citizens. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the full privileges and responsibilities associated with the status of citizenship. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to vote and otherwise participate in the political process. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to have opportunities to make informed choices in

all aspects of their lives, including the choice to assume risks and have the chance to experience success or failure. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to move about freely in their communities, and to take part in any aspect of community life they choose. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to enjoy the opportunity to associate freely with other people within the community. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to be physically safe, have affordable and comprehensive health care, and be free from all forms of abuse or exploitation. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to enjoy the experiences and benefits of family life and meaningful relationships. <WI>

Wisconsin should ensure that state law sets forth basic fundamental guarantees that all citizens of Wisconsin share the right to utilize any publicly-funded services, facilities or transportation. <WI>

Wyoming should assure that all people are provided the supports/assistance they need to vote. <WY>

EMPOWERMENT: BARRIERS

Multiple States

Individuals with developmental disabilities and their family members are frequently ignored in the monitoring process, rather than empowered. The wishes and plans of the person with developmental disabilities are all too often considered peripheral to monitoring, rather than its heart. <AZ,ID,LA,MT,NJ,UT>

Individual States

Most people who experience disabilities want to make choices about how they live their lives. Some program personnel view consumers, parents and guardians as incapable of making decisions. <AK>

While many national news and entertainment programs are closed captioned, only one Alaskan television station provides closed captioned local news and few Alaskan specials are captioned. <AK>

Most people who experience disabilities want to make choices about how they live their lives. Some program personnel view consumers, parents and guardians as incapable of making decisions. <AK>

In Arkansas, the most powerful political constituencies at present appear to be those representing the providers of community services and the state's Human Development Centers. The community providers in particular are well-organized, well-financed, have well-established information networks and long-standing alliances with politically powerful individuals. Parents groups in general are less well-organized with the exception of those who advocate for the Human Development Center system, who benefit from the organization of the institutional superintendents the staff. <AK>

One concern for adults with developmental disabilities is protecting their right to develop independence outside the family home when that is their choice. The problem is created when the family unit has become dependent upon the funding provided to the person for services. This can be an issue in a state where many people are economically deprived. <AR>

Though the People First conference was a powerful experience, concerns arose over the patronizing manner in which some advisors were treating self-advocates, a problem that has persisted within People First of Arkansas since its inception. <AR>

People with developmental disabilities often cannot make personal choices and do not have the opportunity for privacy, either alone or with another person. <CA>

Most individuals with developmental disabilities have little power or decision-making authority over the services they receive. <CA>

Staff of the Center on Deafness feel that there is a lack of awareness of rights among deafness, which also prevents their becoming active in the political arena. <CO>

Improving consumer and family participation in choices affecting services should be a top priority for all programs. Data supporting this conclusion can be found under the individual program analyses. One could not listen to the comments and stories at the public forums without sensing the intense struggle that consumers and parents sometimes face when their individual needs do not fit conveniently into the service structure. <IA>

Physical accessibility to recreational facilities, community stores, performing arts, residential sites, vocational settings, school buildings, voting places, and religious organizations is not uniformly available. <KS>

State regulations tend to discourage consumer and family participation on boards and commissions essential in shaping public policy. <ME>

Consumers feel they have little control over the organization and delivery of services and support most affecting their lives. <ME>

Consumers and their families feel overall that they do not have adequate knowledge of resources available or assistance in making informed choices. Furthermore, they deeply resent being categorized, referred, and then denied service. <ME>

While growing up, many people with disabilities have not had opportunities to participate in student and community organizations to develop and practice skills in leadership and speaking for themselves. <MI>

Various disability organizations and projects in Michigan have sponsored self-advocacy and leadership training for people with disabilities. However, training usually consists of one time or short term events with little follow-up or support in practical application. <MI>

People with disabilities need a focus for coming together across disability categories. <MI>

Many organizations, even those that advocate for people with disabilities, have not yet fully incorporated an empowerment model into their work. The medical model or a developmental ("readiness") model is still embedded in much of the services system. These models continue to influence professionals, family members, advocates, and organizations. <MI>

People with disabilities often have little control over their own lives. In many cases, the ordinary decisions that affect how they live are made by agencies, guardians, family members, or others. <MI>

People with disabilities are seldom asked to participate on boards of voluntary organizations, advocacy groups, or on local and state commissions. When they do participate, some report that they do not receive significant assignments or encouragement for active participation. <MI>

Most organized handicapper groups have limited revenues. <MI>

There is no widely disseminated, easily accessible, or comprehensive listing of services, and of alternative approaches to service delivery, available to Minnesotans with developmental disabilities. As a result, individuals must rely on the knowledge and judgments of those with whom they are in contact to get such information. There are serious gaps in knowledge about what services are available, and to whom those services are available. <MN>

Training which would give people with disabilities the ability to act on their own behalf, known as consumer empowerment or self-advocacy, is needed across the state. <MO>

A major barrier in self advocacy programs is transportation regarding the employment of people with disabilities to staff these programs and the participation of self-advocates in programs. <NJ>

Lack of funding is a barrier. Advocacy groups do not grow without people to help the group get off the ground. It is not now possible to provide even minimal support services to help groups reach a point where they can run on their own without depending on staff. <NJ>

Individuals with developmental disabilities and parents frequently reported that when they do participate in meetings, case reviews or other planning efforts, they feel intimidated by the professionals. They feel they are the "experts" in knowing what they would need or like to see happen, but this knowledge is not often accepted or utilized by professionals who "feel they know what is the best." <NY>

Both parents and individuals with developmental disabilities believe that the state must continue to seek new ways of providing services that are more responsive to their needs. They want policymakers and professionals not only to listen to them, but to also take actions based on what they are saying. They want to be viewed as equal partners, not just as recipients of services. Individuals with developmental disabilities feel that integration into the community also means integrating them into the policy making process. <NY>

In the past few years, NYS and local voluntary agencies have made a concerted effort to promote "consumer input" by including consumer representatives or Planning Boards, Councils and other types of advisory groups. While opportunities to be included have been offered, many consumers feel that their voices are often unheard and unheeded. This lack of real involvement often places them in adversarial roles. <NY>

State agencies and service providers have disseminated a considerable amount of literature and utilized a variety of audio-visual and media approaches to provide information to people. Despite these efforts, many individuals, parents and professionals report they do not have ready access to the information they need when they need it most. <NY>

Adults with developmental disabilities want information that will enable them to make their own choices about the supports they need. <NY>

The current system is predominantly based around a "unit of service" organization (i.e. the "slot" system). Respondents, as well as participants in the Public Forums, expressed concerns that the "slot" system is inflexible and does not encourage the empowerment of individuals to make choices for themselves. <OR>

Consumers and families felt there was a basic inequity in the way information is disseminated about how the system works and what is available. <OR>

Many individuals and families are unaware of the benefits or of the availability of services for people with disabilities, and do not participate fully in the decision-making processes. <TN>

A significant concern currently confronting the issue of living in the community is the lack of a strong consumer-based orientation to the planning and delivery of services for persons with developmental disabilities. The traditional orientation is typified by the consistent use of the term "client" to refer to individuals who receive services. Current funding mechanisms for the service delivery system provide the individual with few or no choices regarding service options, since funds are provided to agencies and programs rather than to the individuals themselves. Individuals with developmental disabilities must either agree to participate in the program or services offered, or to receive no services at all. The essential problem is the lack of real choices for persons with developmental disabilities. <VA>

Quality assurance programs and methods of evaluating program effectiveness was identified as an area in which consumerism is needed. Specifically, there is need to assure program quality from the perspective of the consumer, not the provider or the funding agency. <VA>

There is a lack of participation by individuals with disabilities on governing boards of most state and community agencies that provide services/support. Representation by individuals

with disabilities on these boards was identified as a critical need for promoting consumerism within the disability field. <VA>

While children and their parents are generally satisfied with their current service and family environments, this satisfaction often cloaks dependence, a potential barrier of importance to future life satisfaction. <VA>

Virginia's commitment to the independence of persons with developmental disabilities is often limited by the vested interests of primary caregivers and service delivery systems. <VA>

The need for more emphasis on personally directed services and program flexibility so services providers can deliver services based upon individual needs. <VT>

In many situations there is not enough opportunity for people with disabilities to participate in choosing services and making decisions. <VT>

People with disabilities and their families often assume a "client" mentality and do not pursue a vision of independence, productivity, and integration. <VT>

DVR offers personal care services through federally-funded Centers for Independent Living. This program has shown again and again that appropriate assistance enables individuals with severe disabilities to gain independence as well as become more involved in the community. Unfortunately, continual funding shortages restrict the number of people who can be served under this model. <WA>

Both society and individual families can create an atmosphere in which people with disabilities are treated in ways that de-emphasize their natural abilities. This attitude allows others to discount people with differences and creates what is probably the greatest barrier of all. Research shows that growing numbers of people with developmental disabilities are making good life choices for themselves...a fact not often acknowledged by society. <WA>

Families need advocates who can assist them in getting what they need immediately and ~ then — teach them how to get it for themselves. Ideally they in turn will assist other families. This is how informal support networks are born. But for some people with disabilities the story takes on an interesting twist. Many adults who now live in the community grew up in institutions where they were not allowed to have a voice, to make choices about their lives, or to ask questions. People must be informed about their rights and encouraged to be their own advocates. Self-advocacy organizations such as People First help those with disabilities find their voices and assert their power. <WA>

People with developmental disabilities must be empowered to personally exercise their entire spectrum of civil and human rights. As a back-up, there must be a strong individual

and class advocacy component to ensure those legal rights are protected. Data from the Consumer Satisfaction Survey indicates that people with developmental disabilities felt advocacy was second on their list of priority issues. <WA>

EMPOWERMENT: RECOMMENDATIONS

Family member/consumer-professional relationships must be increased and strengthened. This will require training programs for both family members/consumers and professionals and will necessitate attentive listening on the part of policy makers and service providers. <AL>

Emphasize advocacy services that empower and support consumers and their families in their quest for high quality, stable community supports based on individual needs and preferences. <AR>

Enhance the role of consumers and family members in planning services. <AR>

Provide instruction to school-aged children in the area of self-advocacy so that they are aware of their rights, and offer tangible organizational support to self-advocate groups. <AR>

Recognize the right and capability of consumers to actively participate in the decisions that affect their lives. Persons with disabilities, the primary consumers in the service system, must have the opportunity for a meaningful role in choosing and evaluating the services they receive. This can be accomplished through consumer participation in policy making bodies, monitoring activities and task forces that have major impact on the shape of services. <AR>

The Council should seek an increased role for primary consumers both in its membership and among the recipients of its financial support. Specific areas of need include statewide technical assistance to present self-advocacy training to individuals with disabilities and their advisors, and also to educate parents, providers and the general public to remove stereotypes that foster overprotection and unnecessarily limit personal choice. <AR>

More training must be provided to enable people with developmental disabilities to advocate for themselves and protect their rights to services and community access. This should also include training for individuals, families and support groups to understand and utilize due process protections. <CA>

Support development of a consumer-directed service delivery system through incorporation and implementation of values related to consumer empowerment in state agency enabling statutes, operating principles, rules and regulations, and perhaps other avenues as well. <CO>

Advocate membership for persons with developmental disabilities on all service provider boards of directors. <CO>

The Council should put into place a mechanism for actively involving consumers in the planning and decision-making process on issues which affect their lifestyles. <DC>

The Council should put into place procedures for conducting forums with service providers and consumers. These regularly scheduled forums would be geared toward education, advocacy and obtaining direct input from the constituent individuals with developmental disabilities. <DC>

Allow and facilitate the ability of individuals and their families to make choices about their present and future lives. <FL>

The state legislature should reallocate existing resources to services which emphasize individual supports and self-direction. All programs for persons with developmental disabilities that receive public funding must include an integration component within the next two years. <HI>

The state legislature should make funds available to expand and improve a peer advocacy program. <HI>

Enhance the effectiveness of every state serving persons with developmental disabilities through policy that requires consumer membership on all policy-making boards for these agencies, and that gives these consumers a decisive role in determining policy, rules and procedures. <IA>

People with developmental disabilities and their families should be educated in advocacy, decision-making, and problem-solving skills, and included in the development, implementation, and monitoring of all programs and services which affect their lives. <IL>

State and local agencies should work together to develop a program for people with developmental disabilities, including severe mental illness, to assist consumers and their families in making choices of where to live, where to work, what daily activities to pursue, and other choices made by people who do not have disabilities. <IL>

Indiana shall require that community and state agencies include consumers in the planning, implementation, and evaluation of new and current programs and in outreach to people not receiving services. <IN>

Indiana shall adopt a policy which emphasizes community-based individual services that allow people with disabilities, their families, and advocates to decide the goals of the services and the way services are delivered. <IN>

Indiana shall ensure that adults with disabilities control the expenditure of their allocated funds with minimal state or agency involvement. <IN>

Indiana shall ensure that people with disabilities, family members, and advocates have equal representation on all agency board receiving state and/or federal funds to provide disability-related services. <IN>

Indiana shall seek out qualified ombudsmen among people with disabilities to speak to schools, groups, and organizations and to serve as positive role models. <IN>

Indiana shall encourage people with disabilities to seek elected offices and to serve on local, regional, and state policy-making boards and commissions. <IN>

Indiana shall conduct a public awareness campaign which will promote the dignity and value of all people with disabilities. <IN>

Indiana shall promote the development of a network of self advocacy organizations. <IN>

The State Developmental Disabilities Council should sponsor training for parents and consumers to educate them concerning their rights, responsibilities, services available and how to access services. <LA>

Train persons with disabilities in self-advocacy, self-empowerment and independent living skills so that they can express their own preferences, based on their own desires, needs, wants, goals and dreams. <MA>

Listen to people with disabilities and what they say really makes sense for them: the overall message is (1) flexibility to support people in homes, schools, job sites, etc., and (2) full accessibility and reasonable accommodation in transportation, public buildings, housing, and employment. <MA>

Refine funding mechanisms to allow development of individualized services which assume that no consumer is required to receive services that the consumer does not choose or need. <MD>

The governor and legislature should support legislation to amend Title 5 MRSA to provide per diem and reimbursement for all relevant expenses enabling consumers and family members to participate on boards, commissions, and committees. Furthermore, it should be declared state policy (through executive order), that similar reimbursement shall be routine and allowable costs for all advisory and related groups convened by various state agencies, and entitles receiving state and federal funds. <ME>

Through executive order, a mechanism for the appropriate involvement of persons with developmental disabilities and their families in the development or expansion of services should be established. The mechanism should provide for integral involvement that may build upon, but goes beyond that required by the Administrative Practices Act rule-making process. The views of parents and consumers should be reflected in both formal and

informal activities of state agencies that impact upon the lives of persons with developmental disabilities and their families. <ME>

Convene a Blaine House Conference for persons with disabilities. The focus could be on model programs in Maine and the nation,, and what collective resource, policy, and regulatory actions need to be taken. The "Blaine House" Conference should result from regional conferences allowing for maximum consumer and parent participation, the results of which shall be the focus of the "Blaine House" Conference. <ME>

A significant focus on persons involved in the treatment of people with developmental disabilities should be empowering consumers by helping them understand and make use of their right to determine unacceptable physical contact. Such training for providers as may be necessary to enable them to carry out this responsibility must be provided. <ME>

The Michigan Developmental Disabilities Council and other statewide consumer advocacy organizations should sponsor the first annual Congress of Persons with Disabilities in the Spring/Summer of 1990 (The Event). The Event should include a march to establish a presence in the state capitol and to publicize a public policy agenda for people with disabilities. It will provide an opportunity to educate and to advocate for the concerns of people with a wide range of disabilities from across the state. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations and service providers should conduct training for "significant others" (parents, providers, etc.) of people with disabilities in support for self-advocacy, empowerment, and disability rights. <MI>

Local organizations should establish "mentoring" programs for people with disabilities. The programs should emphasize community integration, using models such as "Active People" and "Circles of Friends." State and local organizations should more explicitly emphasize informal recruitment networks, to remind and encourage people with disabilities to bring along a friend to activities. <MI>

The Michigan Developmental Disabilities Council should support development and production of a statewide newsletter by persons with disabilities. This can include creative arts, self-advocacy, self-help information, services and rights information, letters to the editor, sports and fitness. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations should encourage and support self-advocacy training programs. They should set a joint target that, each year, at least 10 percent of people with developmental disabilities in Michigan will be trained in advocacy and self-advocacy. Training should include follow-up and self-evaluation of effectiveness gained one year after training. <MI>

The Michigan Developmental Disabilities Council and the Michigan Commission on Handicapper Concerns should carry out the Northern Michigan Consumer Education and Rights Training Project. The project includes six training sessions in the Upper Peninsula and the northern part of the Lower Peninsula of Michigan. Training will emphasize subject areas identified as highest priority by people who are likely to attend. <MI>

The Michigan Developmental Disabilities Council should increase the percentage of Regional Interagency Coordinating Committees (RICCs) that meet the 50 percent consumer participation requirement. All RICCs should hold meetings in accessible meeting places in accessible buildings. RICCs should increase primary consumer participation and opportunities to gain experience through providing leadership. <MI>

The Michigan Developmental Disabilities Council and other advocacy organizations should support local coalitions and political action groups on community integration and access, in at least the 30 Regional Interagency Coordination Committees (RICC) communities. The long-term goal should be to have a large number of politically active people with disabilities within five years. <MI>

The Michigan Departments of Education, Mental Health, Social Services, Public Health, and Labor, and other state departments with relevant programs, should increase consumer participation in policy and program development by requiring all contract agencies providing services to people with disabilities to have representation and participation on their boards of directors by people with disabilities; increasing the percentage of their own paid staff who have disabilities; developing a mandate that defines the consumer's role and responsibilities, and methods for consumers to direct and evaluate their own service plans and outcomes; and developing training programs for professionals and agency staff, focused on the philosophy of normalization and on enabling independence, productivity and integration into the community, and making this training a requirement for employment. <MI>

The Human Services Cabinet Council should initiate and coordinate Michigan Rehabilitation Services, the Department of Social Service, and the Department of Mental Health, along with people with disabilities and their advocates, in setting up a collaborative pilot program, to enable people with developmental disabilities to purchase the services they need in the way they prefer to purchase them. <MI>

The Michigan Commission on Handicapper Concerns should continue carrying out their plan to improve the image of people with disabilities as portrayed by the media. <MI>

In developing new program initiatives, the Departments of Mental Health, Social Services, Public Health, and Education should include family and consumer education as a basic part of these programs. The departments should coordinate these initiatives with each other and with parent advocacy organizations. <MI>

Regional Interagency Coordinating Committees (RICCs) and other advocacy organizations should encourage and enable local chapters to build local, consumer-driven coalitions that would identify a lead agency/person to coordinate local information services; and develop local dissemination plans for information services. <MI>

All public education should positively portray the abilities of persons with developmental disabilities. <MO>

All agencies and professionals should use "people-first language" (i.e., "persons with developmental disabilities") that emphasizes capabilities and recognizes similarities to the general population. <MO>

The Divisions of MR/DD and CPS should adopt the recommendations of the Council which outline strategies for increasing minority involvement in the service system. <MO>

All agencies, including those which are not specific to developmental disabilities, should provide opportunities for people with disabilities and their families, especially minorities, to become more involved in the planning, development and monitoring of programs and services. <MO>

The Council and the SACCPS should begin to implement mechanisms to train families and individuals in the areas of empowerment, advocacy and networking. <MO>

Consumers and their families should receive more training on self-advocacy techniques. <MS>

Promotion of self-advocacy by all public agencies is recommended to allow continuous consumer participation in decisions concerning the planning and implementation of services for individuals with disabilities. <MS>

Consent by persons with disabilities for medical procedures, behavior programs, financial decisions and sexual activity should be studied and addressed in a more systematic, comprehensive and clearly delineated manner. <MT>

Services for adults should be consumer centered. Persons with disabilities or their guardians must be acknowledged as the central decision makers. Service planning must include representatives of these using that particular service. <NE>

Services for children must be family-centered with the recognition by providers that families are in control. Families and individuals with developmental disabilities must be included in all levels of service provision including the planning of these services. <NE>

Involve families and consumers in the design, implementation and monitoring of family support systems and statewide planning for programs that touch the lives of people with

developmental disabilities in order to strengthen the family's role as primary provider of care and support to younger people. <NM>

Consumer directed materials and training should be developed and implemented focused on interagency resources, emerging rehabilitative technology, research and technique, disability rights and entitlements. Presentations should include trainers with disabilities who can address issues related to sensitivity and stereotyping. Similar training should be implemented for service providing professionals. <NV>

Self advocacy training should be established focused on service availability, and how to access those services. Particular attention should be given to providing such advocacy training to young consumers and their parents. <NV>

Clear delineation of roles and responsibilities of consumers in obtaining services should be established in each state agency. <NV>

Attitudinal training along with information on pertinent laws and regulations must be provided to service providers so that they will understand the value of promoting opportunities for individuals to make choices. <NY>

If individuals with developmental disabilities are to have real choices, real opportunities, and participate as full partners in the community, information about community resources, entitlements and rights that is clear, concise, and timely is essential. <NY>

Consumer and self-advocacy groups that have as their mission empowering consumers and their families should be supported. Their activities should include training programs that have a policy and public education orientation as well as training in citizenship roles and responsibilities. <NY>

Consumers must be provided with information and skill development in order to become effective partners with professionals in planning and developing services and support at the local, state, and federal level. <NY>

Consumers' membership on planning and advisory boards must be expanded and strengthened. Recruitment and training efforts must be extended to include a broad representation of different disability groups and individuals with developmental disabilities. <NY>

Multi-agency public education efforts should be promoted to reach a greater number of consumers. <NY>

Orientation programs at the local level of consumers on issues regarding entitlements, rights, resources, and eligibility requirements should be promoted. <NY>

Information that is available to other citizens with special needs should also be available to people with developmental disabilities. For example, elderly people with developmental disabilities should receiving training, awareness programs, support groups, and opportunities for social contacts in order to effectively deal with physical, emotional, social and financial changes and stresses that result from the aging process. <NY>

People with developmental disabilities and their families must be included in state efforts to increase resources and assistance in targeted areas. Examples include the Economic Development Campaigns, community schools or other neighborhood-based strategies. <NY>

Effective strategies must be developed to ensure that people with disabilities are offered real options and have a powerful role in the planning, implementing and monitoring of their housing and support services. Service models, such as a voucher system, which would allow people with disabilities more control over where they live and who provides the needed support services, should be investigated. <OH>

Supports and programs for individuals with developmental disabilities should promote maximum consumer control and direction, including a reformation of the crisis driven orientation which fosters dependency. <OR>

Information networks should be established that promote the flow of data to and from consumers. <OR>

All programs providing services to those with developmental disabilities will ensure that all decisions for services are made by the individual with disabilities and/or his or her family. <RI>

The service system will be consumer controlled through vouchers and through majority membership on the boards of all agencies serving individuals with developmental disabilities. <RI>

Establish a formal network in South Carolina that will serve to empower people with disabilities and their families to obtain the services through appropriate advocacy, peer support, and other activities and create a mechanism within state agencies for empowering consumers. <SC>

Government emphasis must shift to one of developing policies which focus on input from persons with disabilities. Persons with disabilities should be "enabled" to determine their own futures. <SC>

A formal network should be established in South Carolina that will serve and empower people with disabilities and their families to obtain the services they need through

appropriate advocacy, peer support, and other activities. A mechanism should exist in all state agencies for empowering consumer. <SC>

Programs supporting self-advocacy organizations should be developed with a component providing formal training in self-assertion. <SC>

The Texas Planning Council recommends the Texas Legislature amend state statutes and the Sunset Act to require and strengthen participation of people with developmental disabilities and their families or guardians in planning and evaluating agency services, including membership on boards and advisory committees. <TX>

The Governor should promote and monitor self-advocacy and consumer empowerment in all public agencies by requiring through an executive order that there be continuous consumer participation in decisions concerning the planning and implementation of services for individuals with disabilities. <VA>

On a statewide basis, people with disabilities and their families should be encouraged to participate in the decision-making process to determine how funds are allocated. <WA>

Expand distribution of the DDPC sponsored news magazine, Habilitation News. This magazine has an emphasis on advocacy, empowerment, outreach and integration. Current circulation is 17,000, targeted circulation is 60,000. <WA>

What is needed is a new partnership between consumers and professionals in which professionals support, rather than direct, the decision making of the people they serve. For children, this means honoring the preferences of the family. For adults, it means respecting their right to make choices to the maximum extent they are able. <WV>

Self-advocacy training is one strategy for helping consumers gain a greater voice in the individual and public policy decisions that affect them. <WV>

If the ultimate goal is for consumers to speak for themselves, then training and support are needed, especially for adults, with disabilities to assume this role. <WV>

Parents need to be supported as the primary decision-makers for their families. Individuals with disabilities and their families should also be playing active roles in local, state and national decisions that affect people with developmental disabilities. <WV>

PEOPLE WHO ARE UNSERVED AND UNDERSERVED: BARRIERS

Another area of confusion is that some services, especially special education, are entitlement programs. Once a child finishes school, the state is no longer required to provide services. <AK>

The range of services people who experience disabilities in Alaska receive is largely dependent on where they live. People living in the state's rural areas often must leave family and culture hundreds of miles behind to move to urban areas for services they need. <AK>

Young adults who finish high school often wait years before finding residential support for employment through community programs. <AK>

There is currently no systematic method of dealing with the DMHDD waiting list. People who are new to the list, but in crisis, are often the first to find placements. Residents of nursing homes and Harborview who are on the waiting list are often not considered for placements in community based programs. Likewise, people who live in community settings and who are ready to move to less restrictive settings are often unable to find appropriate placements. <AK>

There are major unmet service needs in the state for persons with severe disabilities. <AL>

Regulations governing the access of services are frequently inflexible. <AL>

Another critical concern relates to the massive numbers of persons who are on waiting lists. Throughout the state public hearings and discrimination hearings, persons with disabilities and/or their advocates commented on the difficulties they had obtaining services and the frustration of being placed on a waiting list. A waiting list implied to these people that the services or programs they wanted would be available soon. One brother commented that his family had been waiting for over ten years for residential services designed to serve the specialized needs of his brother who has a severe mental illness. This problem is pervasive in all areas but particularly evident in the education, vocational and residential domains. <AL>

Services to individuals with closed head injuries and their families are extremely limited, particularly in regard to community living arrangements. <AL>

One of the first and most significant findings of this study is that there is a state-wide lack of usage of the federal definition of developmental disabilities. Major groups of people who meet the federal definition of developmental disability are excluded from services on the basis of not meeting the eligibility requirements of service delivery programs. The most common exclusionary criterion is the requirement that the person

have mental retardation. Examples of groups of people frequently ineligible for services are those who have physical disabilities, such as cerebral palsy, but who are not cognitively impaired; children with autism; and people who had traumatic brain injuries before the age of 22. <AL>

Alabama continues to operate with mental retardation as the focus for developmental disability programs. Although this is not a behavior unique to our state, it is a behavior not justifiable on the basis of population needs. Historically, fundamental changes in human services in Alabama have resulted from federal litigation. Not only would it be right in terms of caring for the citizens of Alabama, but it would be financially advisable to move ahead to broaden and strengthen services for the presently unserved, underserved and inappropriately served. <AL>

There is frequently a discrepancy between the types of clients agencies say they will serve, and the clients they actually accept, with those being served meeting much more stringent eligibility requirements than publicized. <AL>

Waiting lists become more prolific and extensive as Alabamians with cognitive, sensory (particularly deaf/blindness), physical, and emotional disorders exit public school settings and find fewer services to meet their adult needs. <AL>

An examination of the types of services available across the state in the Policy Analysis Study revealed that many of the services needed by its citizenry were available, but limited, at selected locations. Yet obtaining these services often meant having to travel long distances (2 to 3 hours per day) in agency vehicles. <AL>

Cooperative arrangements with mental health service agencies are of primary importance in helping people in the community. This is an area where Arkansas needs improvement in order to effectively serve people with challenging behaviors. <AR>

The potential demand for services far outstrips supply in Arkansas as in most states. <AR>

People with severe medical and physical problems should be offered all community options. The Medicaid Waiver and small ICFs/MR should provide new options for community services. However, the system must be capable of providing the necessary funding to meet the people's complex medical needs. A funding crisis can occur quickly where medical care and treatment is a daily necessity. The system must not fail the families by leaving them the responsibility of mounting medical bills when medicaid won't pay for care. <AR>

Approximately 177 individuals are currently on the waiting list of Human Development Centers in Arkansas. Approximately 135 individuals are currently on the waiting list of individualized programs. Newly elected of the Community Provider Association, Ruth

Castleberry, estimates that over 700 individuals are currently on the waiting list for traditional community services. <AR>

According to estimates based on a 1986 study of the Human Services Research Institute, there are approximately 40,000 individuals with disabilities in Arkansas who would likely fall under the federal definition of developmental disabilities who are currently not receiving identified services. <AR>

Arizona's definition of developmental disabilities used by the Division of Developmental Disabilities (DDD) to determine eligibility for state services is more restrictive than the federal definition. In general, the following groups of individuals are included in the federal definition, yet excluded in the state services definition: people with sensory impairments, physical impairments (including spinal injuries), chronic mental or emotional illnesses and those whose disability began between age 18 and age 22. These people are not being served because they do not fit into the state service definition. <AZ>

There needs to be better accessibility to Medicaid offices on the 20 reservations. The isolation of most Indian families and the limited income gives little opportunity for them to seek eligibility in an off-reservation office. <AZ>

Though there are 3,000 American Indian persons receiving long term care, there are 700 persons identified as needing this care who are unable to get serviced. <AZ>

Financial support available through the general Medicaid program should cover people with developmental disabilities whether or not they are at risk of institutionalization. <AZ>

Ethnic minority parents and advocates have indicated a number of barriers to services including: 1) lack of information about available services, 2) lack of language-appropriate informational materials, 3) lack of bilingual/bicultural personnel, 4) lack of culturally responsive service models, and 5) inadequate or inappropriate outreach methods. <CA>

Like many other states, California is experiencing a rapidly accelerating incidence of newborns exposed prenatally to illicit drugs and alcohol. In many communities the rate of exposure is estimated to be between 15 percent and 25 percent or more of births. Infants exposed prenatally to drugs have problems which significantly impact the service delivery system in California in both fiscal and human terms. It is estimated that 30-40 percent of infants of cocaine-addicted mothers are born prematurely, with intrauterine growth retardation and neurological damage. Current clinical and longitudinal follow-up data point toward worrisome continuing developmental, and emotional, language and behavioral problems, and subsequent learning problems, which put these children at very high risk for subsequent educational and social failure. <CA>

Because of the four-year gap in age of onset (period between ages 18 and 22), and the fact that many categories of disability are determined to fall outside of the state definition of developmental disability, there are many individuals who meet the federal definition and could be individuals who meet the federal definition and could be considered underserved or unserved within the state service system. Primary examples are individuals with traumatic system. Primary examples are individuals with traumatic brain injury occurring between the ages of 18 and 22, individuals with chronic mental illness resulting from childhood neurological disorders, individuals with special syndromes (such as Prader-Willi) or health conditions who may not meet regional center eligibility criteria because they are too high functioning in cognitive skills, and individuals could fall into the functional or "fifth category" of eligibility under the state definition, but are often denied services by the regional centers because they are borderline in terms of having conditions similar to mental retardation, or because their IQ score is too high. <CA>

There is a large group of individuals with physical disabilities which is excluded from the state definition of developmental disability, but which could be included under the federal definition. <CA>

Gaps in eligibility for services also arise from the complexity of the developmental services system at both the state and local level in California. There are many state and local agencies which provide services to individuals meeting either the state and/or federal definition of developmental disability state and local service agencies frequently develop policies which conflict rather than complement each other. Programs provided by the various service agencies may have specific eligibility criteria which are inflexible and which leave out certain groups within the population with developmental disabilities for reason such as functional ability, age of onset, type of disability, etc. This complexity and fragmentation within the service system makes it inherently difficult for people with developmental disabilities and their families to access the services they need. <CA>

There remains a built-in conflict of interest between providing entitled services to a growing population and having a fixed budget. <CA>

California is ethnically diverse with rapid growth occurring among certain ethnic populations, specifically Hispanic and Asian. At present, about one out of every four residents is Hispanic, and a significant portion of this population speaks Spanish when at home. It is estimated that 23 percent of Californians speak a non-English language when at home, compared with 10 percent nationally. Language and cultural barriers have a significant impact on services to people with developmental disabilities. <CA>

People with mental retardation, cerebral palsy, epilepsy and autism are included in the state definition for eligibility purposes. The state definition also includes handicapping conditions found to be closely related to mental retardation or to require treatment. This "other" category has been identified by numerous organizations and individuals as a serious violation of entitlement rights. Advocates such as Protection and Advocacy,

Inc. (PAI) believe that regional centers frequently deny eligibility to individuals meeting this fifth category including individuals who have been denied services and who have conditions such as attention deficit disorders, Prader-Willi syndrome, birth injury , brain damage as a result of head trauma and pervasive developmental disorders. Although the individuals have been found eligible at administrative hearings, regional centers continue to routinely find persons with these and other conditions similar to mental retardation ineligible for services. The result of these consistently successful hearing decisions has not had the effect of modifying existing policy. <CA>

Another group which has experienced extensive problems with eligibility for services in California is individuals with epilepsy. Epilepsy is specified as a category eligible for regional center services within the state definition. Based upon the HSRI population estimates contained in this chapter, individuals with epilepsy could represent as much as 21% of the potential regional center clientele. Yet June 1989 regional center client evaluation report data demonstrates that only 1,475 individuals with epilepsy are being served by regional centers. This represents 1.6% of the regional center caseloads and 3.5% of the estimated number of individuals with epilepsy eligible and needing services. Therefore, it is the conclusion of testimony provided by the Epilepsy Foundation of America and its California affiliate chapters that epilepsy "may well be the largest underserved group within the state." <CA>

Based on public comment from parents and professionals, along with the experiences of Protection and Advocacy, Inc., individuals with IQ scores of 70 or higher are often found ineligible by regional centers, regardless of whether these individuals have functional disorders or needs similar to mental retardation. One example of this occurs sometimes with individuals who have Prader-Willi syndrome. While these people may score higher than 70 on an IQ test, they may function at levels below individuals with substantially lower IQs. Whether or not one is verbal has a strong influence on how well one will do on an IQ test. <CA>

Serious community placement problems exist for people with dual diagnoses. Group homes are either licensed for people with developmental disabilities or for people with mental illness, leaving little room for specialized programs to serve people with both disabilities. There are very limited options for day programs specialized to meet this unique group of people. Professionals are not adequately trained to serve individuals with dual diagnoses, which often creates further difficulties for the individual with a dual diagnosis. <CA>

While these populations who meet the federal but not the state definition of developmental disability may be receiving services from some generic sources at the federal, state and local levels, they do not have access to the regional center system of assessment, case management and referral services. This makes it much more difficult for them to access needed services, especially in a system as large and complex as we have in California. <CA>

The major unmet needs of persons with visual impairments and blindness were reported to be: lack of accessible transportation which often prevents employment and ability to access needed services; training in independent living and vocational skills - availability of these services for persons with blindness and visual impairments is limited outside the major cities; and public school staff who work with children who have multiple handicaps often have received their training ten to fifteen years ago. Due to their lack of training in current techniques and concepts of working with students with multiple handicaps, staff may not be able to serve these children appropriately. <CO>

The differing perspectives of the three groups of adults with hearing impairments make it difficult to state with certainty that the same needs exist across all people within the deaf community, since there is little agreement amongst themselves about their need for services from the human services system. <CO>

Although some specialized services are generally available in the urban areas, in rural areas the services may not meet the special needs of some persons with cerebral palsy. <CO>

The need for a focal point for organized, comprehensive service delivery (or a "service system") for people with developmental disabilities who do not have cognitive impairments. <CO>

Among the most critical needs for persons with traumatic brain injury are re-training programs leading to jobs, follow-along supportive services, family counseling, long-term residential program, and financial supports. There is also a need for more prevention activities, including public education. <CO>

In the Asian culture, grandparents fill a critical gap nowadays. They often rear their grandchildren while the parents are working. However, many of these older persons cannot drive, and so they don't take the children out of the home. This reinforces the social isolation of children with disabilities. <CO>

In addition to transportation and employment services, there is a need for greater public awareness and social support networks, as well as recreational opportunities for people with spina bifida using wheelchairs. <CO>

Parents and families indicated that they felt that none of the state agencies consistently provides appropriate services statewide, and few programs exist which are geared specifically to the unique needs of people with autism. <CO>

Staff of the Center identified several problem areas affecting persons with cerebral palsy, including: the need for increased funding for transition services; a lack of wheelchair-accessible transportation; a lack of specialized residential services; a need

for community integrated recreational and social opportunities; and an insufficient amount of supported employment opportunities for people with severe disabilities. <CO>

Access to services can also be unintentionally denied to persons who have difficulty in reading and understanding written instruction. <CO>

Since the deinstitutionalization and least restrictive environment emphasis in Colorado over the past five to ten years, a greater variety of settings have been utilized to serve people with dual sensory handicaps and other multiple disabilities. As a result of these efforts, often service providers are asked to accommodate these individuals without adequate staff training and with limited financial resources. <CO>

About eighty percent of the state's population lives along the Front Range. Many persons living outside this area experience great difficulty in obtaining medical, educational, and social services due to transportation problems and a lack of resources in the local community. It has been found that there is chronic scarcity of trained professionals to provide diagnostic services, as well as occupational, physical, and speech therapies. With a small population base to draw from, it is often impossible to develop services needed by only a few people. <CO>

Many persons with developmental disabilities, who do not have cognitive impairments live with families or relatives and are isolated because of their inability to get around in the community. Some of these people would unquestionably benefit from living in a more independent setting if accessible housing and personal care attendant and therapy services were available. <CO>

The negative effect of the federal and state governments' lack of initiatives for minorities in recent years has become more apparent as time goes by. The result has been decreased access to culturally and linguistically appropriate services as well as a lack of visibility of minority issues. <CO>

Interpreters and Spanish-speaking staff persons are needed. <CO>

Other needs identified by families were; 1) more sensitivity and awareness on the part of the general population of the special problems of people with cerebral palsy; 2) more services for the multiply handicapped, many of whom have a combination of disabilities that cannot be adequately addressed in existing programs; 3) a need for guardianship and other arrangements as the parents get older; and 4) the lack of adequate coordination between various state systems and agencies, such as the those in the specialized developmental disabilities system and those in the generic system. <CO>

It is believed that the cultural bias in certain commonly used assessment tools affects Hispanics adversely and leads to inappropriate placements in programs. <CO>

The low prevalence of autism hampers the development of highly specialized services for people with autism in each area of the state. Few staff are currently able to work effectively with people with autism, and the need for staff training is great. <CO>

There are a number of discrete conditions which might be considered to be low incidence developmental disabilities. Among these are Tourette's syndrome, fragile X, dystonia, multiple sclerosis, muscular dystrophy, tuberous sclerosis, Prader-Willi, juvenile arthritis, juvenile diabetes, Tay-Sachs, and cystic fibrosis. Each one of these low incidence disabilities poses special problems and requires highly individualized treatment. As with other developmental disabilities, there is a great need for transportation and mobility aids, public acceptance, residential, vocational and employment services, supportive services, and adequate medical and mental health treatment. <CO>

Attendees at a conference agreed that some of the most pressing needs for older persons with developmental disabilities were activities suited to their age and interests, provisions for retirement, residential and vocational services, and guardianship services. <CO>

Lack of training of medical and service agency personnel in epilepsy hampers their effectiveness with these people. <CO>

A high proportion of persons of Hispanic origin have low income. This leads to a "survival" life-style with no money left for services for their children with disabilities. They often delay accessing services because they do not have financial resources. They seek emergency help rather than develop an ongoing relationship with service providers, which further hinders their ability to access appropriate services. <CO>

Parents believe that people with autism remain unidentified within the service system because they are unable to obtain case management services in many areas of the state. If an applicant does not fit into the current array of available services, he or she is likely to be determined ineligible for services and thus may not even be placed on the waiting list. <CO>

It appears that the low rate of participation of Asians with developmental disabilities in existing programs is due to cultural factors as family denial and acceptance of handicapping conditions, language barriers, staff attitudes, and lack of resources to develop and expand culturally appropriate services for this population. <CO>

One of the biggest challenges facing many people with Hispanic background is access to education and training which will enable them to obtain well-paying jobs. The same factors that make it difficult for many Hispanics who do not have disabilities to succeed make it nearly impossible for Hispanics with developmental disabilities to do so; i.e., culturally and linguistically appropriate services are not generally available from agencies

in the developmental disabilities system, and Hispanic agencies do not have special expertise in serving persons with developmental disabilities. <CO>

Although it is the policy of all agencies in the state's developmental disabilities service delivery system not to discriminate on the basis of any intrinsic characteristics of persons in need of services, some advocates have felt that due to cultural and language barriers in particular, minorities may not be appropriately served by existing programs and services. Even though, in some cases, a high number of minorities are served by an agency, staff are primarily non-minority; there appears to be a lack of commitment of seeking out and hiring minority staff. <CO>

Colorado has a registry of persons with deaf /blindness; however, the registry information relets a voluntary process with little incentive for identification and referral. Another factor compounding this ineffective registry process is the limited use of deaf/blindness as a primary handicapping condition from birth through adulthood. These problems may contribute to an understatement of the number of persons with the dual sensory handicaps of deafness and blindness. <CO>

Although the specialized developmental disability service delivery system has identified a need to "do something" about elderly persons with developmental disabilities for a number of years, funding has not been available to develop programs for their special populations. However, with the overall aging of the population, it can be expected that many more persons with developmental disabilities will be living to an older age. Therefore, increasing attention must be given to developing appropriate programs for these people when they retire from vocational programs, as well as finding ways to successfully integrate them into other community activities. <CO>

Various studies have indicated that a larger proportion of minorities, especially children, may be at risk of having developmental disabilities or developmental delays due to their families' low income, lack of access to adequate prenatal and other types of medical care, and other factors unrelated to ethnicity or race per se. <CO>

Hispanic families feel that providers staff lack sensitivity to the minority culture. <CO>

Members of the Colorado Association for Autistic Persons indicate that the most critical needs now are: respite care and residential programs for children and adults; crisis intervention and family support services within all age groups; and appropriate community work and recreational programs for adults. They identified the general lack of understanding about autism and the lack of funds to address special needs as the most significant current barriers to service at this time. <CO>

In addition to the cultural barriers experienced by other minorities, the structural, jurisdictional, and political problems created by the separate service systems impede the

participation of Native Americans with developmental disabilities in the state's service delivery system. <CO>

Those who do not have intellectual deficits such as mental retardation but who have physical, sensory, and neurological impairments that would fall under the federal definition of developmental disabilities are among the most consistently unserved and underserved. <CO>

Among the most important needs identified for the Asian population with developmental disabilities is the need to change the attitude of the staff in provider agencies. They do not appear to be interested in including parents of Asian children with developmental disabilities in decision-making, nor engaging interpreters for Individual Habilitation Plan (IHP) and Individual Education Plan (IEP) staffings. <CO>

Other needs cited to increased access to programs for consumers with physical handicaps were: transportation; access to all types of public and private buildings, including voting sites and higher education facilities; curb cuts and other mobility aids; personal care attendant services; jobs which focus on the functional ability of the consumer, such as special accommodations at the work site and arranging flexible hours; and health insurance coverage and financial assistance for medical devices and adaptive equipment. <CO>

There is a waiting list for services of the Division for Developmental Disabilities. Even if persons with other developmental disabilities desired services from the Division for Developmental Disabilities, because the Division has historically been oriented to providing care over a person's entire life span, few openings become available for those who need shorter-term services from the Division. Because these persons have never been served by the Division, they would be placed at the bottom of the waiting list, and serving them would be a low priority. <CO>

Although staff of the Denver Indian Center programs indicated that they did not have difficulty obtaining services for their populations with developmental disabilities, they felt that they need more information on specific specialized services that might be available. In addition, they identified the need for more jobs, funding, and membership on various community organizations as needs of the Native American population in general. <CO>

There is lack of information for Hispanic families about services available, and the information that is provided is frequently inadequate. <CO>

Connecticut does not have a mandate to serve all people with developmental disabilities. <CT>

The Division of Mental Retardation (DMR) intake system is the entry to DMR's residential and day programs. Intake must limit admissions because of limited program capacity. <DE>

Consumers, caregivers, providers and advocates lack knowledge about the programs and services which are available for individuals with developmental disabilities. <FL>

As is true for most states, Hawaii does not provide comprehensive services to people with developmental disabilities who do not have mental retardation. Thus, those whose developmental disabilities are the result of physical or emotional impairments are especially underserved. Our developmental disabilities system is "mental retardation" oriented. It is based upon an older developmental disabilities definition where other conditions are supposed to be "closely related to mental retardation" and require treatment or services similar to those required for people with mental retardation. <HI>

The results of the consumer survey, public forums, and (for some programs) the policy analyses indicate major variations in the quality, quantity, and availability of services in Iowa, depending upon where one lives. This complex issue is made even more complicated by the manner in which Iowa funds services, for in our state the county of residence is often a crucial determinant of what services a person or family will have access to. Consumers frequently note that certain types of services are available "in the next county," but not in their county. The presence of county-to-county inequities in service is also clearly seen in some of the programs whose policies are reviewed in the policy analyses. For example, program policy makes the community support program a local county option. <IA>

An even more basic and pervasive difference in the level of services can be seen when urban-rural distinctions are analyzed. Rural consumers repeatedly mention the lack of basic services in their areas. Examples of service inequities across urban and rural areas can be found in nearly every program. <IA>

The causes of inadequate services are many. Persons with developmental disabilities may be underserved because they live in rural areas where services aren't available. Even when services are available, people may not be served due to eligibility requirements (based on age of onset, income level, place of residence, and a variety of factors other than need). Even when services are available, and eligibility requirements are satisfied, a person may not be able to get services because the waiting list is two to five years long. In other words, the presence of a service program in a community does not mean that the service will be available to the consumers. <IA>

The most fundamental finding, however, of the policy analyses, consumer survey, and public forums is that almost all Iowans with developmental disabilities are underserved. <IA>

Within the policy of every program are restrictions that prevent a service from truly responding to the individual's strengths and needs — limitations on age, place of residence, income, number of program participants, level of disability, age of onset, type of disability, medical concerns or the lack of medical concerns, low levels of financial support, conflicting eligibility requirements, lack of interagency coordination, inadequate levels of service, lack of qualified staff, funding patterns that force institutionalization — the list goes on and on. <IA>

Eligibility criteria are cited by many consumers and families as the reason they are unserved or underserved by a particular program. The limitations on who qualifies as having a developmental disability provide one example of this. Persons who develop a disability after their twenty-second birthday may deal with the same functional limitations as persons with onset of disability prior to age twenty-two, and yet they are categorically denied services targeted to persons with developmental disabilities. <IA>

Financial eligibility limits for programs are mentioned by many consumers and families as being unrealistic and a major block to much needed services. <IA>

Idahoans with a disability are discovering they must live in or near a city in order to receive effective, or ample service or assistance. There is a major service system delivery gap in rural areas. Of 44 Idaho counties only 16 have a state developmental disability service office. Approximately 14 counties receive workshop or CSE services. <ID>

People who are aging and have a developmental disability are sometimes considered to be in "double jeopardy" In a society that values youth and intellectual ability, seniors with developmental disabilities are victims of ageism, or a societal bias against the elderly as well as handicapism, a bias against those with disabilities. <ID>

The needs of a person with a developmental disability/mental retardation and mental illness are often clouded by the interaction of the developmental disability and the psychiatric disorder. Cognitive limitations, different developmental outcomes, and limitations of lifestyle imposed by the care system can often lead to the presentation of symptoms of psychiatric disorders in ways different from those we are accustomed to seeing in the general population. A major need of an individual with mental retardation and mental illness is treatment for their mental illness and, concurrently, integration of that treatment into their place of residence, place of work and their peer group. <ID>

The consensus among Idaho professionals in the field of developmental disabilities is that Idaho minorities with disabilities fare much worse in the service delivery system than do whites. The services necessary to bridge cultural and language barriers have not been adequately addressed by programs which serve people with developmental disabilities in Idaho. <ID>

The major finding of the Illinois 1990 report to congress is that persons with all types of developmental disabilities are underserved in Illinois. Information has come from consumers, families, and service providers to demonstrate that people with severe or multiple disabilities and people from groups which are culturally and linguistically in a minority in American society are less well served than other people with developmental disabilities in this state. Yet few individuals from any group with developmental disabilities receive services sufficient to assure their independence, productivity, and integration into the community. <IL>

The definition of "developmental disabilities" differs among federal agencies and between the federal government and the state government. It differs too between several of the major state agencies which serve consumers. Often people with severe mental illness and sometimes people with disabilities other than mental retardation are excluded by definition from service. <IL>

According to the information in the Consumer Satisfaction Survey, eight out of ten people with developmental disabilities live with their families or on their own in homes in the community. Yet most of these consumers and their families indicated in the Report that they were underserved. <IL>

Illinois citizens with all sorts of developmental disabilities, from all sorts of cultural/linguistic backgrounds, from all different regions of the state, are receiving less than the optimum array of services which would assist them to achieve independence, productivity, and community integration. <IL>

The study indicates that the amount of services currently available needs to be tripled to meet the currently expressed needs, and may need to be increased even more to meet real needs not yet articulated. Of 95 specific services included in the interview, half were being received by fewer than 6 percent of persons living in households and 9 percent living in institutions. <KY>

When necessary services are not available in the community where a person lives, the persons's options are limited. The number and type of services identified as necessary and their availability vary greatly in different regions of the commonwealth. <KY>

The study found indications that access to services is based on knowledge of services or the administrative and political process of obtaining services, and not necessarily on need. People cannot access services they do not know exist. Greater dissemination of information, along with additional services will provide options and increase equity. <KY>

The study indicates that services currently are inequitably distributed, so that persons with mental or emotional illness as the primary diagnosis for developmental disability receive over half of the services needed, while persons with mental retardation as the primary diagnosis receive one-fifth of the services needed. <KY>

In 1983, the Louisiana legislature enacted legislation which expanded the individuals to receive services from the Office of Mental Retardation to include persons with (other) developmental disabilities (Act 659 of 1983). Since enactment of the legislation, the Louisiana State Planning Council on Developmental Disabilities has advocated that services be expanded to persons with other developmental disabilities. While some progress has been made, in general persons with developmental disabilities (other than mental retardation) remain unserved or underserved. <LA>

Persons with very challenging self-injurious or destructive behaviors continue to be sent to out-of-state or expensive private schools or special programs, or committed to psychiatric hospitals. We have long-standing concerns with the use of painful aversives at certain facilities. The number of persons with serious behavioral after-effects of head injuries grows dramatically by the year. <MA>

An adult has severe epilepsy or multiple sclerosis and needs supported, staff housing. If her diagnosis were chronic mental illness, mental retardation, blindness or deafness then DMH,DMR,MCB or MCDHH (respectively) would acknowledge her need and try to help. No agency, however is legally obligated to serve people with many other equally severe disabilities. <MA>

Massachusetts spends approximately \$3 billion a year on programs and services to help persons with disabilities. The 35 state agencies serving this population together have some 350 "points of entry" to state-sponsored programs and apply 71 different definitions of eligibility criteria for various disability services. Despite this expenditure and profusion of agencies and programs, however, many go without the kinds of help they need. <MA>

Despite an impressive array of programs and services, few individuals or agencies can quickly and reliably learn about all possible resources. <MA>

Inequities exist between "class clients," who have a legal entitlement to life-long services from the state, and all others. <MA>

Inequities exist among the four major groups of Department of Mental Retardation clients; from most to least favored in terms of resources available to them, these groups are: (1) class clients in facilities (approx. 3000), (2) class clients in community (approx. 3200), (3) non-class clients in community services (approx. 11,000) and (4) persons eligible and waiting but not currently receiving services (approx. 6000). Persons with all ranges of disabilities may be found anywhere in these four categories. Persons in state schools are older as a group, but are not necessarily more significantly disabled. Budget cuts fall disproportionately on groups (3) and (4) but group (2) is hurt by general weaknesses in the overall community system, which is underfunded and overregulated. <MA>

Service cuts fall particularly heavily on children who are abused and neglected who may have (or develop) disabilities. In FY 1989, the number of children reported abused or neglected rose to an all-time high of 65,775. <MA>

The needs of People of Color with disabilities are often overlooked, especially in a budget cutting climate. Not surprisingly, People of Color have been historically underserved by a service system created for a white middle class constituency. When culturally sensitive services are created for them, these services are often the first to be cut. Massachusetts, a state with an increasingly multi-cultural fabric, must make all of its services more responsive to the needs of a culturally diverse population. <MA>

One major reason that people are "left out" of our system is a lack of resources in the system, including capacity to plan, expertise/specialized skills or knowledge, physical sites, leadership and "political will." <MA>

When resources are lacking, the person with a disability is told by the state agency representative, "You're eligible for our services but we have no money so we can't provide the services." Eligible persons are on waiting lists, cut from existing programs, "backlogged" in some inappropriate (typically institutional) setting. <MA>

Populations who even in good times never enjoyed their "fair share" of disability services - notably, cultural and linguistic minorities, persons in inner cities and rural areas - are disproportionately hurt when resources shrink. <MA>

A major reason why people are left out of our system is a lack of governmental responsibility. When no agency is mandated to help certain persons with severe disabilities and the needs related to their disabilities, the seeker is told: "You're not eligible for what we offer. You have the 'wrong' diagnosis or type of disability." Or: "It's too severe or too mild." Or: "The need you express doesn't match the type of service we can offer..." Bottom line: "Sorry, but you fall between the cracks." The two major categories of "left-outs" are: people whose "disability label" doesn't match the target population mandate of the state's categorical disability agencies, and people who are getting one type of service that meet some of their needs, but no one is responsible for addressing needs in other parts of their lives. <MA>

Accessibility to programs and facilities remains a major concern. <ME>

Children at risk of or having developmental disabilities and their families are still too often not served or underserved. <ME>

Persons with developmental disabilities and their families are often unable to choose among needed services. This is true for services needed by the individual, i.e., services are just not available, or, if available, are offered by only one provider or in a manner in appropriate to identified need. <ME>

The current services system generally serves clientele by income or disabilityspecific criteria. Overall personal and family need, participation, and choice are not dominant factors. <ME>

People with severe physical disabilities who do not qualify for many services, especially those whose disabilities are relatively newly identified (such as traumatic brain injury or the late effects of polio) are not able to get the supports they need. <MI>

Women with disabilities endure additional inequities in earnings and education, compared to men with disabilities. Differences in opportunities for men and women in the general population are reflected and intensified for women with disabilities by patterns of interventions by services agencies. <MI>

People with late effects of polio at the CRI Forums reported extreme difficulty getting information about their condition and finding knowledgeable physicians. This population also has a broad range of other unmet needs. <MI>

People with traumatic brain injury may have unmet needs years after the injury. They face eligibility barriers to receiving mental health and education services, based on their age at the time of injury. <MI>

Advocacy and services outreach efforts in Michigan and nationally often fail to reach people with disabilities who are members of minority groups. <MI>

Some Community Mental Health Boards serve only people with mental retardation. <MI>

Michigan families with members who have high health care needs report eligibility criteria that create barriers to fuller use of the Model Home and Community-Based Services Waivers. <MI>

Waivers are not available to families who have insurance that covers hospital but not in-home care. It is not always possible to show immediate short term cost savings. The waiver requirement of "otherwise needing Intermediate Care Facility/Mental Retardation (ICF/MR) care" is a problem because of Michigan's progressive policy of not approving admission for children into state institutions or nursing homes. <MI>

Services which enhance the independence, integration and productivity of people with developmental disabilities are currently unavailable to the following individuals: people who are living in congregate facilities; young people who are attending special schools; adults who are currently attending congregate, segregated day programs; and adults who are currently involved with case managers who because of their case loads and lack of training are unable to provide the service they are mandated to provide. In other words, these individuals are receiving services that do not enhance independence, integration and productivity. These individuals are, therefore, underserved and unserved. <MN>

One way to define underserved is "those individuals who are currently receiving services, but whose needs are not being met by those services." Using this definition, we can identify two major groups who are underserved: those who are living, learning, or working in environments which congregate and segregate them, and who are not actively assisted in being present and participating in the community; those who are being supported to be merely present in the community, but are not being supported to develop and sustain relationships with typical citizens and to participate in the life of the community. <MN>

The cap on payments, as stated in the HCB waiver application, often excludes persons with severe needs who cost more to serve than the "average." Current providers may screen applicants in order to serve only those persons they can afford to serve. <MN>

Minnesota does not have a centralized waiting list that provides an accurate estimate of need based on functional limitations or urgency of need; any waiting list data reported by providers contains duplicated numbers. <MN>

We believe there are many Minnesotans with developmental disabilities, or families, who are not aware of available services, and of services for which they might be eligible. <MN>

There are clear indications that members of the following groups or communities receive less or far less service than others: people with epilepsy, cerebral palsy, autism, and head trauma; people who require personal assistance; people who live in rural areas, and/or areas outside the seven-county metropolitan area; and members of specific ethnic groups. <MN>

Generic services and programs are often linked to two problems relating to knowledge. First, providers of a generic service may not view it as applicable to people with disabilities. As a result, they do not advertise the service to such individuals, or think about them when services are developed or implemented. Second, lay people and professionals do not view the generic service as available or appropriate for people with developmental disabilities or their families. As a result, they do not approach the program or service. As a consequence, individuals do not refer themselves to services, nor are they referred by professionals. <MN>

The number of persons waiting for services in the state has risen from 364 in July of 1980 to 1066 in December of 1988. The 1988 figure represents 439 (41%) individuals currently receiving no services and 627 enrolled in developmental disabilities services but identified as in need of more appropriate services. The growth of the number of persons on waiting lists is partially a function of the maturing of the system, with improved methods of identifying persons in need and communicating the availability of service to them. More importantly, the rise in the number of persons waiting for services reflects the inability of the system to provide funding for services needed to address the demand. <MT>

Waiting lists for community-based services (e.g., transitional services for young adults graduating high school, Specialized Family Care, respite, adult supported living services) are long and growing. Over 790 Montanans with developmental disabilities need services that are currently not available in sufficient numbers. <MT>

The North Dakota Department of Human Services determines eligibility for many DD services primarily on the basis of mental retardation. As a result, many individuals with developmental disabilities who do not have a primary or a secondary diagnosis of mental retardation are not eligible to receive DD services. Respite care is but one example of services that are difficult for with developmental disabilities other than mental retardation persons to access. Such selective targeting of DD services by DHS is contrary to North Dakota's statutory definition of developmental disability. <ND>

In expanding community services for the without mental retardation DD population consideration should be given to utilizing the state's existing delivery system essentially consisting of private, non-profit service provider corporations. <ND>

In order to respond to the federal Court order issued in the ARC lawsuit against the state of North Dakota, the legislature since 1981 has directed a substantial share of state fiscal resources toward community as well as institutional services for persons with mental retardation. As the state continues to remain economically depressed, fiscal resources to maintain such services at existing levels have become more and more difficult to secure. Despite the scarcity of fiscal resources, most state policymakers recognize the need to develop and maintain community-based services for DD populations other than people with mental retardation such as people with chronic mental illness (CMI) and severe physical disabilities. <ND>

Information from organizations such as community housing authorities and the Department of Employment Security indicates that a great deal of effort is required to insure that people with developmental disabilities are taking full advantage of the services of these organizations. <NH>

Individuals for whom coordination of services is particularly important include those who are elderly and have a developmental disability and those who are labelled both developmentally disabled and mentally ill. The Developmental Disabilities Council is required to recommend to the Congress the most appropriate state agency or agencies to be designated as responsible for the provision and coordination of services to persons with developmental disabilities who belong to such subpopulations. The primary responsibility for coordination of services to New Hampshire citizens with developmental disabilities must rest with the Division of Mental Health and Developmental Services. <NH>

Waiver services are based on certification that an individual requires an ICF level of care. Such certification is jeopardized when a person (a) becomes independent and

productive, or (b) becomes older and wishes to retire from a structured daily activity. <NH>

With respect to responsibility for the "provision and coordination" of services to persons with developmental disabilities who are traditionally "underserved", we must first make clear that the "underserved" include many persons with mental retardation with or without multiple handicaps as well as many other children and adults with autism, cerebral palsy, epilepsy, spina bifida, head injury, spinal cord injury and other disabling conditions. <NJ>

Some people with autism, cerebral palsy, epilepsy and other "non-traditional" conditions and their advocates are not satisfied with the extent of diversification and specialization to their specific needs represented in the DD menu of community service. <NJ>

The waiting list for community based living arrangements to be provided by DDD now exceeds 2,000 exclusive of persons now in institutions and not counting individuals who have applied but have not yet been evaluated for eligibility. Of recent applicants for DDD services who have neither mental retardation nor autism, 905 have been evaluated for eligibility and found eligible; some are being served in non-residential programs, but the majority of recent applicants who need residential services are waiting, regardless of diagnosis. The crisis is especially acute for aging parents who have cared for a son or daughter at home over many years. <NJ>

The "redirection" from the former Division of Mental Retardation to a new Division of Developmental Disabilities greatly increased the numbers of eligible individuals. Funding, however, has not matched the demand for services. As a result, services have not extended to the population of people with developmental disabilities who do not also have mental retardation. According to the consumer satisfaction survey, 21 percent of those surveyed identified "in-home respite care" as a "critical, primary" need, while eight percent cited "child day care" and 15 percent cited "homemaker services" as strong to critical needs. <NJ>

The ability of service providers to meet specialized needs of families may vary according to the disability involved. A service may be able to meet the needs of a family with a 3-year old girl who has Down syndrome, but the same service may be inappropriate for a family with a 17-year old boy with autism. <NJ>

Some children may be medically fragile, may need technology or may need medical supports 24 hours a day. Many programs, including day care, early intervention, preschools and elementary schools, are not prepared to provide the needed services. <NJ>

In 1987, 28 percent of the individuals served by the Division of Developmental Disabilities were on waiting lists of alternative living arrangements or day programs. Approximately

2,000 students with developmental disabilities leave the school system each year and become eligible for adult services. Serving this number of potential clients requires a doubling of the Division of Developmental Disabilities' case management capacity. <NJ>

A main concern of our committee in the small amount of progress that has been made by the Division of Developmental Disabilities in serving individuals other than those with mental retardation. The change has been essentially in name only. <NJ>

A man with developmental disabilities in Albuquerque was shot and killed by his terminally ill father. The Albuquerque Journal reported that he was despondent because there would be nowhere for his son to receive care after he was gone. Five hundred twenty five people are currently on waiting lists for community services. <NM>

Aging parents express concern over the future of their adult children and the shortage of available placements and supports. They often need assistance in allowing their children to develop independence. The lack of transportation limits access to services, especially in rural areas of the state. <NM>

Supported employment is only available to the non mental health/mental retardation population with developmental disabilities because the Council has provided the follow-up support required by the Rehabilitation Services Administration to access those services. Even so, services are limited to ten job coaches to serve all persons with severe disabilities in the state. <NV>

Nevada has not chosen to exclude any disability fitting their already exclusive federal definition (of developmental disability). The reasons for the Nevada Council's long established inclusionary policy are many, but two are paramount: (1) resources available in Nevada for mental health and mental retardation are currently well above \$68,000,000.00, three times the amount available for all other disabilities in the state including alcohol and drug abuse; and (2) resources available to assist other disability populations, who have disabilities so severe that they fall under the federal definition, are so limited as to be almost non-existent. <NV>

There are no long term care group homes for this non mental health/mental retardation population, only one 13 bed residential facility (privately funded), no transitional living homes or supervised apartments, no work activity or sheltered centers, no respite care, and no family preservation funding. All these services are available in Nevada to persons with mental health mental/retardation disabilities, inadequate certainly, but existent. <NV>

There is a growing number of children with severe or complex medical whose parents are unable to find facilities that can provide the services they need. There is a serious shortage of appropriately trained personnel, especially for in-home services.

Parents of these children also feel that insufficient pay to these personnel limits access to these services. <NY>

Unserved or underserved populations include people who are denied services because of eligibility requirements. For example, a person whose traumatic brain damage occurred at the age of 20 years is not eligible for services from OMRDD. <NY>

Unserved or underserved populations include people who are eligible for services but the service does not exist in their area. For example, people with multiple, complex disabilities such as people who are medically fragile, technology dependent or deaf and blind have difficulty locating qualified staff or programs. <NY>

Unserved or underserved populations include people who are unaware of what services there are and their rights to these services. For example, recent immigrants and new parents who have not had previous contact with the service system do not know how to find out about existing services. <NY>

Unserved or underserved populations include people who lose services due to time limited funding and benefits as a result of federal and state fiscal disincentives. For example, people who are receiving services funded by a state or federal grant, or individuals who will lose their personal Supplemental Security Income benefits if they become competitively employed. <NY>

Our society continues to discriminate against minorities; children with a developmental disability living in minority families are subject to dual discrimination. <OH>

Interviews with key informants and the results of the qualitative case studies convincingly establishes that a de facto practice of eligibility determination in Oregon adds an additional layer of complexity to this issue. The eligibility issue for most people is not "functional versus categorical" but mental retardation versus any other label. Officially, individuals with cerebral palsy, epilepsy, or autism are currently eligible for developmental disability services in this state. In practice, the term "developmental disability" is operationally synonymous with "mental retardation." With few exceptions, an IQ score of 69 or lower seems to be the crucial determining factor in whether or not individuals receive services. Conversely, some human service agencies outside the Developmental Disability Program Office exclude individuals from their system if they have a "DD" label. <OR>

Many of the report respondents believed the basic orientation of the service system was one of crisis intervention. The crisis management orientation was thought to politicize the service system, and contribute to inflating the needs of individuals in order to gain services, or exacerbating very real problems by the delays in services until the "crisis" occurs. <OR>

Another significant finding of the report was the identification of people with severe physical handicaps who are also mentally alert as an underserved group. This population includes persons with head and spinal cord injuries, muscular dystrophy, and cerebral palsy. The group of persons who are dually diagnosed (mentally retarded and mentally ill) were also found to be underserved. These two groups have special and unique needs, and no one agency is designated to serve their needs and coordinate their services. <SC>

Perhaps even more critical is the fact that if persons with highly complex needs are to be served in the most desired settings, current funding levels pose substantial barriers to assuring the availability of high quality, effective services. <SD>

The fact that some disabilities are low incidence creates special problems for a predominantly rural, sparsely populated state such as South Dakota in building the specialized program capacities needed to effectively serve such persons. <SD>

The lack of community-based programs organized and funded to address the needs of persons with complex, multiple disabilities in community-based settings has led to a de facto policy of continuing to utilize highly restrictive institutional settings as the "safety net" placement for such persons. The lack of such community-based programs was often cited as a reason why the state should expect to maintain a capacity of approximately 300 institutional beds over the mid-to-long term. <SD>

While the low incidence of certain disabilities contributes to this service delivery problem, potentially a more important reason is that the technology of service delivery — either in a community-based or institutional settings — appears not to have evolved to the point where well-defined, validated approaches to service delivery have been defined to meet the needs of many of these populations. <SD>

The lack of clear lines of accountability, jurisdictional issues, funding shortfalls within Bureau of Indian Affairs programs, cultural differences, and a host of other factors were cited as barriers to the establishment of an effective system of services to Native Americans with developmental disabilities in South Dakota. <SD>

The lack of community-based programs designed to serve persons with low-incidence disabilities, serious behavior disorders, or persons with multiple disabilities was viewed as significantly contributing to the ongoing need for institutional admissions. Redfield and Custer State Hospital (and, to a lesser extent, the Human Services Center at Yankton) are fulfilling a "safety net" function which would not be necessary if appropriate resources were available in the community. <SD>

There seems to be little doubt that Native Americans with developmental disabilities represent the service population facing the greatest difficulties in obtaining needed services. <SD>

There are broad, serious gaps in services to families and children in South Dakota. <SD>

Parents who are better educated, more experienced, or more aggressive in seeking services are both more likely to receive services, and more likely to be aware of needed services which are not available in Tennessee. <TN>

Persons in rural areas of Tennessee receive fewer services than those in urban areas. <TN>

Even for those persons with developmental disabilities who identify a responsible agency or program, limitations in the scope or flexibility of the program may create problems for families. <TN>

There are large numbers of people with developmental disabilities, primarily adults, who do not have statutory access to services. There is no state agency responsible for providing residential and home and community-based services to people meeting the federal and state definition of developmental disabilities. <TX>

The second issue was identified primarily as a funding issue. The TDMHMR has statutory responsibility for providing these services to people with mental retardation and mental illness, but only to those who qualify as part of the Department's priority population. <TX>

The Texas Planning Council concluded that most people with developmental disabilities fall into the category of being traditionally underserved in Texas. One part of the underserved population includes whole groups of people with developmental disabilities who do not have a diagnosis of mental retardation, including but not limited to people with cerebral palsy, spina bifida, epilepsy, head injuries, autism, deaf-blindness, chronic health conditions, and many other rare conditions and combinations of disabilities. The underserved population also includes people with mental retardation and mental illness who have never been placed in an institution or on the waiting list for institutional placement, and people with autism who have had limited access to MHMR system services. <TX>

For every dollar it receives from the federal government, Texas sends \$1.59 to Washington, while New York sends \$.75 and Montana sends \$.59. Medicaid is the major program which accounts for this disparity. Less than 29% of all Texans living in poverty are covered by the state Medicaid program. <TX>

Many families who have children or adult children with developmental disabilities living in the home need services. However, because they work they generally have incomes which exceed the income eligibility criteria of state assistance programs. <TX>

Some people expressed frustration about being unable to receive services for their family member solely because of their income, even when there was no doubt about the need for services. As one mother stated "Whom are they hurting, the able or the disabled? The disabled is the one being denied and not receiving services, and not benefiting to learn self skills and putting the caretaker in bad health and bad backs to struggle to take care of the disabled." <TX>

People who do not speak English, including people who are deaf, have a tremendous amount of difficulty in getting accurate information about services and receiving services. <TX>

The Council continually receives information about the difficulties families and individuals with developmental disabilities have in gaining access to services. The Texas Department of Health (TDH) 1990 Report policy analysis study confirmed that people in Texas are facing barriers to services because of the variety of state and federal criteria used to determine eligibility, and the fragmentation of the Texas service system. <TX>

The inability to access service in rural remote areas of the state is due to several factors: a) lack of professionals living in or willing to locate in rural areas; b) lack of a sufficient number of users to maintain program viability; and c) distance to service centers being costly in time and transportation. <UT>

Many adult service programs become limited by eligibility definitions that are tied to funding sources and thereby deny services based upon arbitrary definitions rather than client needs. <UT>

Virginia differs from the federal government and numerous other states in its application of the federal definition of developmental disability. No major service program in Virginia has adopted or attempted to incorporate the federal definition of developmental disabilities into its basic eligibility criteria. The lack of reliance upon the federal definition of developmental disabilities has far-reaching ramifications for service delivery in the Commonwealth. Individuals with cerebral palsy, epilepsy, traumatic brain injuries, autism, orthopedic impairments, severe learning disabilities, and many other disabilities are unable to access much needed case management, housing and residential support services, personal assistance, family support services, and other services because no state agency has a legislative mandate to provide these services. As a result, persons with developmental disabilities who do not have either mental retardation or mental illness comprise the largest group of unserved and underserved individuals in the state. <VA>

Not all individuals with developmental disabilities in Virginia have equal access to needed services. Availability of critical services varies widely from community to community. <VA>

A number of existing state programs also are presently underutilized by individuals with developmental disabilities. Varying eligibility definitions make it impossible to determine the precise number of individuals with developmental disabilities receiving service through the 56 programs. However, it is clear that persons with developmental disabilities are underrepresented in programs such as the Job Training Partnership Act, Centers for Independent Living, and Vocational Education. Social Security provisions designed to remove disincentives to employment, including Section 1619 (a) and (b) and Plan for Achieving Self-Support, are only minimally utilized as are Medicaid options such as the Ventilator Dependent Services, Personal Care Services, and Optional Services programs. <VA>

Many important specialized programs, where they exist, are underfunded, lack trained personnel, and are not supported by the service system at large. Examples of constituencies who are significantly unserved or underserved are persons with autism, persons with traumatic brain injury, and persons with physical disabilities. <VA>

Virginia's service delivery system often fails to target its resources with appropriate differentiation across disability groups. Virginia's service system is set up to provide different services for different disabilities. Unfortunately, it often fails to provide the services that are needed. When asked why they were not receiving needed services, a common response by consumers was "not eligible by type or degree of disability." <VA>

In many instances, rural areas of Virginia face particularly acute shortages. Lack of accessible transportation services in many areas makes even obtaining necessary medical care a formidable challenge for many persons with developmental disabilities. Many programs, such as the Centers for Independent Living, are not available to individuals in many parts of the state. <VA>

Policymakers in Virginia have not adequately acknowledged and addressed the discrepancies and inequities that exist among the publicly-supported opportunities made available to various populations with disabilities. This situation affects, but is certainly not limited to, individuals with developmental disabilities. <VA>

Virginia has made a commitment to provide emergency treatment services needed by persons with mental health, mental retardation, and substance abuse conditions, and to promote the development of a full range of appropriate "core services" for them, including prevention and early intervention, case management, day support/vocational, and residential. However, Virginia has not made a comparable policy and resource commitment to provide "core services" for persons with developmental disabilities who have severe sensory and/or physical impairments. <VA>

There is also a lack of coordinated and comprehensive planning being conducted for constituencies with sensory and/or physical disabilities. <VA>

Many persons with developmental disabilities are also not able to obtain appropriate vocational habilitation/rehabilitation services, independent living rehabilitation services, or other needed assistance from the Department of Rehabilitative Services (DRS) or local Independent Living Centers (ILCs). This is because of both eligibility limitations and funding/manpower limitations. <VA>

The Division of Developmental Disabilities (DDD), Department of Social and Health Services (DSHS) has long lists of people waiting for services. There are over 1,100 waiting for some kind of residential support and over 2,500 in need of supported employment or other day programs, a number which increases by 250 every year. There are children in need of early intervention services, and finally, over 400 applications by families for respite services are rejected each month. <WA>

The flaw in the federal Medicaid definition of developmental disability is that it is categorical. As a result, some people will not be receiving the supports and services they need. Moreover, it is not required that states use this definition for Title XIX, except in the instance of OBRA nursing home diversions. So (even to the extent that some people might be eligible for services from medicaid) the state may elect not to make them eligible. States may use their own definition for eligibility for Medicaid services. Washington State takes this approach. <WA>

The categorical nature of the state definition of developmental disability rather than inclusive. For example, persons with traumatic brain injuries, cystic fibrosis, narcolepsy, tuberous sclerosis, and numerous other disabling conditions are ineligible for services from the state agency responsible for services to persons with developmental disabilities; that is, unless they also happen to have one of the disabilities included in the definition. All of this, of course, does not take into consideration their need for support services. <WA>

Nearly every task force expressed concern over the categorical nature of the Washington State definition of developmental disabilities. Members argue that it ultimately results in discrimination against persons with disabilities who are not included in the definition because (while their support needs may be identical to those individuals included in the definition) they do not receive the services they need. Not only is the categorical nature of the state's definition an issue, but also the fact that several different definitions of developmental disabilities apply depending on the circumstance. <WA>

In order to enter this country, immigrants with developmental disabilities are required to post a bond as an affirmation that they will not become dependent upon public assistance programs. However, the United States Department of Immigration and Naturalization Service indicates that utilization of public services such as those provided to people with disabilities does not constitute a breach of contract. It is, however, reasonable to assume that the difficulty some people have in immigrating would make

them particularly hesitant to use services even if they were told such an exception was permissible. <WA>

It seems obvious that the developmental disabilities community at large has little exposure to minority cultures. At best it has been unresponsive — and at worst insensitive to — minority peoples. <WA>

In a 1985 report by the Minority Executive Director's Coalition for the Division of Developmental Disabilities' specific gaps and barriers in the service system as they related to non-English speaking persons were addressed. The report cited problems with outreach, intake, case management, services, and administration. <WA>

Minorities with disabilities get a triple whammy from the dominant culture: minority status, poverty status, and disabled. That is a very powerful set of negatives to attach to any one. These negative perceptions put minorities of disability at the front of the line for discrimination in all areas of life. <WA>

Persons with severe disabilities are frequently at risk of being excluded from the community service system due to the intensity of their needs. <WV>

Over 200 people are on a waiting list for the Waiver Program, about three-quarters of whom are under age twenty-three and residing with their natural families. <WV>

The provision of services in low population areas and across miles is problematic. Even solutions such as regional centers have problems addressing issues like transportation and personal assistance services. <WY>

Wyoming has no provision for waiving parental income in extending Medicaid eligibility to children with developmental disabilities who remain in their family home. <WY>

UNSERVED AND UNDERSERVED GROUPS: RECOMMENDATIONS

The Division of Mental Health and Developmental Disabilities should develop a method for dealing with the waiting list which includes a process which provides a systematic method of access to services for. first time consumers of services, people in crisis, those in programs looking for other settings, and people currently residing at Harborview Developmental Center and in nursing homes. <AK>

The Division of Mental Health and Developmental Disabilities should change the state definition of developmental disability to the functional definition to be consistent with current federal legislation. <AK>

State-wide use of the federal definition of developmental disabilities should be implemented immediately by all service providing agencies. A developmental disability cannot be used as an excluding criterion by tax-supported programs. <AL>

Specific attention must be paid to the offering of programs to meet the needs of consumers and their primary caregivers at all transition stages. <AL>

The Council must be responsive to the full definition of developmental disabilities. <AL>

Conduct an annual independent needs assessment of persons on the community services waiting list so that a useful profile is established a guide to service planning and delivery. The efficient planning and development of services to meet the future demand represented by persons on the waiting list and others requires a more detailed understanding of their specific support needs. In addition to those on the waiting list for services, it is important to anticipate other sources of future demand such as persons with disabilities living with elderly family members who will require assistance when the family can no longer provide support. <AR>

Establish a separate office within the Division of Developmental Services (DDS) to address the needs of persons with developmental disabilities who are traditionally underserved. There is a tendency within the field to equate developmental disabilities solely with mental retardation, with a consequent under emphasis on services for persons with related conditions and disabilities attributable to physical impairment or dual mental impairments. The situation of a separate office within the DDS would serve to highlight and meet the needs of these individuals while minimizing the increased costs of administration and would also preserve a unified management system for DD services. <AR>

DDD must develop an adequate number of providers for long term care services in all areas of the state. It should make all efforts possible to simplify "paperwork" requirements, which may be deterring potential providers from participating. Providers should be paid promptly. <AZ>

The denials of eligibility by the state Medicaid program based on status of disability must be studied. If the Pre-Admission Screening (PAS) instrument used for determining eligibility for long term care is not reliable, DDD must request a change in the instrument. Those excluded due to their level of disabilities must be reevaluated and assisted with the appeals process. Those found ineligible due to their financial status must be assisted with the appeals process. <AZ>

According to state statute (ARS36-203), the DDD and the Arizona State Hospital shall develop appropriate plans, to be implemented by DDD, to transition persons with both developmental disabilities and mental illnesses to more appropriate settings, with adequate funds to provide the services that are required by these individuals. Transition plans should include provision for a current medical assessment to be completed, which will include a complete psychological evaluation by a competent psychiatrist. Plans must also provide for each person to be assigned to one psychiatrist, rather than being treated by a "pool of psychiatrists." <AZ>

The Office of Behavioral Health should establish communication linkages with DDD for the purpose of establishing interagency agreements to provide services to meet the needs of individuals who are "dually diagnosed" with a combination of developmental disabilities and severe, chronic behavior disorders and their families. <AZ>

The application of eligibility standards through the regional center assessment process must be reviewed to ensure fairness and consistency in eligibility on a state-defined groups with primary disabilities other than mental retardation. <CA>

A statewide program includes state and local administrative agencies as well as professionals, families and primary consumers to that all perspectives on the definition of "quality of life" are represented. <CA>

The process for determining eligibility for services under the state definition must be carefully examined to ensure fairness in application and assessment procedures. This applies to regional center services as well as special education and health services. <CA>

Attention should first be given to the provision of services needed by groups which fall within the state definition of developmental disability. Until the state defined population is fully served in the areas of case management, specialized and generic services, it would be presumptive to propose the legal explanation of the state developmental services system to cover populations qualifying under the federal but not state definition. <CA>

Unmet service needs should be uniformly documented and addressed through a comprehensive resource development planning process. Resource development must adequately and appropriately respond to the growth needs of the service system. <CA>

There is a need to better coordinate generic services for federally but not state defined individuals with developmental disabilities, including those with brain injury and mental health needs. The Council therefore encourages improvements in interagency collaboration among relevant state agencies in the identification of service needs and provision of services to those individuals. <CA>

More appropriate program models are needed for people with dual diagnoses, as well as stronger working relationships among local agencies and a commitment to cross-training of providers in both the developmental disabilities and mental health fields. <CA>

Establish statutory authority and funding for expansion and augmentation of service delivery statewide for people with developmental disabilities who do not have cognitive impairments. <CO>

Actively support development of a coalition of specific disability advocates and associations to create an organized constituency for people with developmental disabilities who do not have mental retardation. <CO>

Change the eligibility criteria used by the Division for Developmental Disabilities to conform to the state statute or change the state statute to conform to the eligibility criteria. <CO>

Advocate raising or eliminating the "before 22" age restriction in the federal and state definitions in order to serve all people having a level of functioning and needs similar to those currently targeted in existing statute. <CO>

Assess the needs of elderly persons with developmental disabilities. This is an unidentified population. <DE>

Provide supplemental financial resources, on a pilot basis, so that care plans for persons with physical disabilities can be tailored to the needs of the individual. <DE>

Continue and expand public awareness activities designed to educate the public about the abilities and needs of individual with specific handicapping conditions, i.e., mental retardation, cerebral palsy, spina bifida and epilepsy, as well as those individuals with multiple handicapping conditions. <FL>

The Council recommendation is to provide for a full range of culturally relevant and accessible services for individuals with disabilities through a coordinated system of public and private service providers. <GU>

All state agencies providing services to people with developmental disabilities should have written agreements assuring cooperation and access to services as determined by the

respective lead agency/program, including but not limited to the Division of Vocational Rehabilitation and Department of Education. <HI>

All persons having a developmental disability attributable to mental retardation, physical impairments, a combination of mental illness and mental retardation, or a combination of physical and mental impairments should be eligible for services provided to people with developmental disabilities. <HI>

Hawaii state and county governments should use the Uniform Federal Accessibility Standards when approving building permits. <HI>

The Department of Health's Developmental Disabilities Division should institute an "adult find" program to identify adults with developmental disabilities who need and have not been receiving services. <HI>

Conduct a study to determine what agency should be responsible for services for persons who are currently unserved or underserved. <IA>

Amend state policy so that persons with developmental disabilities are provided by law with appropriate services. <IA>

Study the development of alternative models at the federal level for service funding and delivery that would provide equivalent services to persons with developmental disabilities who live in rural areas. <IA>

Indiana shall place more emphasis on providing year-round, life-long, integrated community services to people with severe disabilities, including aging people with developmental disabilities. <IN>

Indiana shall apply for a Medicaid waiver to provide home and community-based care services and supports to children with severe disabilities and serious chronic illnesses. <IN>

Indiana shall adopt a functional definition of developmental disabilities. <IN>

The state should support planning efforts of the various agencies and work with them to determine expansion opportunities relative to the unused capacity, licensing, and available funding. <KS>

MRI (contractor) recommends that the state follow up with agencies to ascertain why the gap between current operating, licensed, and maximum capacity exists. The total capacity of the service delivery system in the state should be known prior to formulating plans for facility and program expansion. <KS>

Individuals with developmental disabilities and their families should have options available in their local area so they may choose the services most appropriate for the individual's needs. These options include, but are not limited to, intermediate care facilities for mental retardation and developmental disabilities, independent living support, family support, adult day programming, and supported employment. <KY>

Legislative Action for Disabled Persons should request the Governor, the Department of Health and Hospitals, and the Department of Social Services to conduct a study to determine minority group involvement in the delivery and use of vocational, residential, and support services and to make recommendations to increase minority involvement in planning and service delivery. <LA>

The solution in our view is not to dismantle the existing system but to supplement it selectively to ensure that people are not denied or left out. In addition, it is critical for government to have the structure and information it needs to play its larger policy, planning and resource development role. <MA>

Outreach to all cultural and linguistic minorities is needed, to ascertain (a) what services and supports persons of various cultural backgrounds need, (b) how such services and supports should be delivered, and (c) where appropriate, to inform persons of currently available services and supports. <MA>

All publicly assisted programs must reach out to un- and under-served populations, e.g. minorities, persons with low-incidence conditions, homeless persons; state agencies should employ bilingual specialists to help them shape their services to be culturally appropriate. <MA>

It is important that funds follow consumers, and in general, not be limited to individuals who are deinstitutionalized. <MD>

Access to services for persons with severe handicaps, including persons with autism, must be increased. <MD>

The Michigan Developmental Disabilities Council should continue to support and participate in an interagency task force to address minority under-representation in the services system and advocacy network. The task force will develop strategies to increase minority handicapper participation in planning and delivering services. <MI>

The Michigan Developmental Disabilities Council should periodically hold forums around the state to secure information about progress in carrying out the recommendations in this report, and to assess opportunities for access and community integration for people whose developmental disabilities may be newly identified. <MI>

The Michigan Developmental Disabilities Council should evaluate the outcomes of its Level IIA grants to Regional Interagency Coordinating Committees (RICCs) in order to identify promising strategies for including members of racial and cultural minorities in advocacy networks and for obtaining their participation and contributions. <MI>

The governor should direct the Human Services Cabinet, with the Michigan Women's Commission, the Michigan Developmental Disabilities Council, and the Michigan Commission on Handicapper Concerns, to develop and carry out focused priorities for service delivery agencies' policy, staff training, and outreach activities that address gender equity. <MI>

The governor should direct that the Human Services Cabinet develop and carry out a comprehensive state policy to address the services needs of people with disabilities and their families. The policy should assure attention to the needs of people with severe physical disabilities who do not qualify for mental health services. <MI>

The governor should direct that the Human Services Cabinet develop and carry out a comprehensive state policy to address the services needs of people with disabilities and their families. The policy should assure attention to the needs of people with severe physical disabilities who do not qualify for mental health services. In developing the policy, the Human Services Cabinet should, based on this report, review the role and function of all state agencies to determine the extent to which they are effectively serving people with severe disabilities. It should develop a timetable to carry out the recommendations of this report, including the recommendation of the State Board of Education Blue Ribbon Task Force on Rehabilitation. <MI>

The governor should direct the Human Services Cabinet to coordinate, and the directors of the Departments of Education, Mental Health, Social Services, and Public Health, in consultation with people with disabilities, to develop and establish an interagency agreement and action plan to remove obstacles and to assure that appropriate, needed programs and supports are available for all people with disabilities and their families, regardless of category or diagnosis. <MI>

The Michigan Developmental Disabilities council, with a coalition of human service and advocacy groups and agencies interested in minority concerns should study under-representation by members of minority groups in typical service settings; provide recommendations to the Governor for correcting identified inequities for enabling Michigan to become a model for the country; and urge Congress to provide a national policy and a new program that improves outreach to minority group members and their families, enhances delivery of services for minority professionals. <MI>

The Michigan Department of Mental Health should implement its policy that all public mental health services are to be provided for all people who meet the Michigan Mental

Health Code definition of developmental disabilities, including those who do not have mental retardation. <MI>

There are two broad approaches to the definitional issue which would ensure, either along or in combination, the inclusion of greater numbers of persons with developmental disabilities: a definition based on any disability listed as eligible for Social Security Disability Insurance, and/or a definition based on need for support or limitation in activity. <MN>

The Council should assist other advocacy groups in planning for services for persons who experience sudden onset disabilities after the age of 18. <MO>

The Division of MR/DD should adopt the broader functional definition recommended by the Council Definition Task Force. <MO>

An array of individualized, integrated, community-based services and supports (e.g., transportation, information, education, etc.) should be developed and maintained by all agencies with a special focus on rural areas. <MO>

New specialized programs and services should be developed, financed, and implemented to meet the needs of Mississippi's unserved/underserved population of persons with developmental disabilities. <MS>

Within the Mississippi Planning Council on Developmental Disabilities, a special task force for people with severe mental illness and physical disabilities should be established to assure that gaps in services for this population are eliminated. <MS>

A substantial number of Mississippians remain unable to obtain needed care. The limited funding and associated staffing restrictions of the state's public facilities for mental health and retardation services have not permitted service to all who seek care. Concurrently, the high cost and limited third-party coverage of private sector mental health services denies access to all but the wealthy or persons with exceptional health insurance coverage. Therefore, the state should examine new ways to provide proper mental health and retardation services for people with disabilities. <MS>

DD advocacy groups and organizations should actively support and assist DHS efforts to secure any increased legislative appropriations that may be necessary to accommodate expansion of services for the DD population without mental retardation. <ND>

DHS should discontinue its selective targeting of DD services, particularly services for adults, toward persons with mental retardation and instead should begin to determine client eligibility for services on the basis of the state's statutory definition of developmental disability contained in Chapter 25-01.2-1 of the North Dakota Century Code. <ND>

Advocates for DD persons should emphasize preservation of existing levels of funding to support the level of community-based services for persons with mental retardation called for by the federal court order. Advocacy to support creation of new or expansion of existing community-based DD services should focus on allocation of resources not already dedicated for services to persons with disabilities. <ND>

In developing an ongoing state funding base to maintain community-based services for DD persons other than persons with mental retardation within an environment of fiscal restraint, North Dakota policy makers should resist the temptation to appropriate funds from allocations previously committed to supporting ongoing community services for people with mental retardation. <ND>

Services should be able to accommodate persons with high needs including behavioral problems and medical fragility. <NE>

Statewide relay services for people with deafness need to be established so that they may be assured equal access to community services and the independence and safety afforded all able-bodied people through telecommunications. <NV>

Full range service delivery to individuals with head injuries, with provisions for families and individuals with no third party funding available to them, should be made a priority of all service agencies in Nevada. All services must include cognitive and behavioral components. <NV>

Existing services leading to employment and higher education should recognize and address the full potential of people with chronic illness, consumers and their families should be involved in planning these services. <NV>

Adults with developmental disabilities living at home or coming out of institutions must have the same right to service. <NY>

Ohio should seek to expand entitlement for services for people with developmental disabilities. The need for such entitlements is clearly evidenced by the long waiting lists for vital residential and day program services. <OH>

The adoption of a state statute which defines "developmental disabilities" according to the federal definition and uses functional descriptions rather than clinical diagnosis. <OK>

Services and programs should gradually shift towards a functional eligibility approach. Eligibility should be universal for all who need services. <OR>

What is needed is a legislatively empowered body charged with the interests of the physical disability community. <PA>

All organizations receiving public money (federal, state, or local) will make their programs, activities, benefits, jobs, or other opportunities available to all persons with disabilities. These programs, activities, benefits, or other opportunities must be equal to those afforded others, as effective as those provided to others, and the same as those provided to others. <RI>

Expand the capacity of the service system to accommodate the increased demand being felt by agencies to provide early intervention services, school to work programs, and community residential services. <SC>

Establish a formal interagency coalition among the primary agencies that provide services to people who have severe physical disabilities and are mentally alert, in order that responsibility is established to ensure that these persons receive the necessary services. This coalition would include the Department of Vocational Rehabilitation, the Department of Mental Retardation, and the Department of Health and Environmental Control. A lead agency would be designated to coordinate budget requests and service planning. Service responsibility will be contingent upon the availability of funding. <SC>

Establish a formal interagency coalition among the primary agencies that provide services to people with head injuries in order that responsibility is established to ensure that these people receive necessary services. This coalition would include the Department of Vocational Rehabilitation, Department of Education and the Department of Health and Environmental Control. A lead agency would be designated to coordinate budget requests and service planning. Service responsibility will be contingent upon the availability of funding. <SC>

State officials should pilot community-based programs designed to serve the needs of persons with a dual diagnosis of mental retardation and mental illness. To assist in the design and initial operation of such programs, the SPCDD should earmark funds for this purpose. <SD>

South Dakotans should develop services to ensure improved responsiveness to persons with special needs. <SD>

The Texas Planning Council recommends the Texas Legislature direct state agencies to eliminate financial status as a criterion for eligibility for services for individuals and families of people with developmental disabilities. Eligibility for public services should be based upon evidence for a functional need for services, and fees for services should be based on ability to pay, up to the actual cost of services. <TX>

The Texas Planning Council recommends the Texas Legislature amend the Texas Sunset Act to add review of programs accessibility issues. All agencies should be reviewed to determine whether they should be responsible for preparing and implementing procedures which assure access to programs for a person who does not speak English or who has a

physical or mental disability; and offering flexible and alternate hours of operation to ensure reasonable access to services after 5:00 p.m. and on weekends. <TX>

The Texas Planning Council recommends the Legislative Budget Board develop budget instructions to require state agencies to establish and annually update the number of individuals requesting services as need indicators for submissions of legislative appropriations requests. <TX>

The Texas Planning Council recommends the Health and Human Services Coordinating Council develop consistent definitions of services and eligibility criteria for state and federally-assisted programs in Texas. <TX>

The Council recommends that the eligibility definitions for people with disabilities is broadened to approach the DRS and Special Education definitions in all agencies and find other means of controlling spending than narrowing eligibility. This would allow the system to provide services based upon the needs of the individuals and appropriate services to meet that need. <UT>

The General Assembly should formally determine and enforce the ability and responsibility of all existing state and federally-assisted agencies and programs to accommodate persons with developmental disabilities with appropriate services and supports. This may require formal interagency agreements initiated and enforced by the Secretary of Health and Human Resources and other cabinet Secretaries. <VA>

The Secretary of Health and Human Resources and the Board for Rights of the Disabled should identify and address through the plan of cooperation the service needs of constituencies with developmental disabilities who are currently unserved/underserved. <VA>

The recommendation made by the task force is that Washington State should implement the definition used in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146). <WA>

Develop programs to holistically address the needs of children and families who must deal with the effects of multiple disabilities. <WA>

Address such issues such as funding, licensing and cross responsibilities when it comes to dealing with children who have multiple disabilities. <WA>

The Washington Protection and Advocacy Agency should seek funding to develop outreach to minority communities. <WA>

The DDPC should develop and fund educational materials addressing attitudes about disability, family and community as those issues relate to minority cultures. This information should be available to service providers, planners and advocates. <WA>

The Developmental Disabilities Planning Council (DDPC) should outreach on a consistent basis to people who are known and trusted within local minority communities. They would provide an important communications link as well as facilitate education programs sensitive to the particular needs of each group. <WA>

Seek funding for Spanish and Asian language editions of the DDPC sponsored news magazine, "Habilitation News." <WA>

Budget requests should target funds to develop services sensitive to cultural differences. Training of department and contractor personnel around cultural issues would be an important step. <WA>

The Department of Social and Health Services should form a comprehensive task force made up of all human service departments and representatives from ethnic minority groups. Observations and recommendations concerning ethnic issues have application not only in the developmental disabilities system, but in all human services administered by this state. <WA>

The federal government should fund research which will identify various minority cultural attitudes about sickness, wellness, and disabilities which can provide baseline information to the states. This information will assist in the development of culturally sensitive services. <WA>

The United States Immigration and Natural Service policies toward people with disabilities must be examined and redefined. Current policies are based on dominant cultural assumption, bias, and unfamiliarity with the abilities of people with special needs. <WA>

Wisconsin should incorporate into state law a five-year policy goal that ensures the availability of quality, accessible services for persons with developmental disabilities throughout all parts of the State of Wisconsin, including a minimum level of services and service quality in each and every county (based on statewide standards). <WI>

Review current state eligibility for services, and assess whether any changes should be made. <WI>

The Consumer Satisfaction Survey sample was too small to conduct any comparative analysis of satisfaction by racial group, however, it is recommended that this issue receive further examination in the future. <WV>

It is recommended that information be collected and examined regarding the representation of people with severe disabilities among agencies providing community-based services. <WV>

EFFECTIVENESS: BARRIERS

Multiple States

Most of the federal programs which currently finance supports were included in the administration's "flexible freeze" group in its FY 1990 federal budget request, including Supported Employment State Grants, Independent Living State Grants and Centers, the Social Services Block Grant, Children with Special Health Care Needs/Maternal and Child Health Block Grant, the Alcohol, Drug Abuse and Mental Health Block Grant, Title IV-B Child Welfare Services, the Foster Grandparent Program, Technology-Related Services, the Foster Grandparent Program, Technology-Related Assistance Grants, Temporary Child Care and Crisis Nurseries Grants, and the Early Infant Intervention Program (special education). No funding is proposed for the Special Recreation Grant Program. <CA,FL,IN,MT,TN,UT>

A related issue is the bias in many publicly-supported programs toward funding services in facilities and institutions, but not in homes and communities. <IN,MT,UT,WY>

The Home and Community-Based (HCB) services waiver cannot be used to provide individually-oriented services to all who need them because total costs of individual waivers cannot exceed the Medicaid funds that would have been expended had these people been in an ICF/MR, and states must document that those being served would otherwise have been institutionalized. In addition, waiver support is potentially unstable because it is a federal demonstration program, is applied for at state option, and because individual waivers are time-limited. <ID,LA,MT,TN,UT>

The Home and Community-Based (HCB) services waiver cannot be used to provide individually-oriented services to all who need them because total costs of individual waivers cannot exceed the Medicaid funds that would have been expended had these people been in an ICF/MR, and states must document that those being served would otherwise have been institutionalized. <ID,MA>

Individual States

Many programs still focus on making the person fit the program rather than the program fit the person. People are often relegated to services that are more intensive and restrictive than is necessary, limiting a person's ability to be as independent and as integrated in the community as possible. Families feel strongly that programs do not meet their individual needs. <AK>

The Division of Mental Health and Developmental Disabilities should immediately begin an evaluation period for standards developed during FY89 for services funded by the division. The state and service providers have an opportunity to work together to

implement standards that will protect consumers. The evaluation period should include on-site monitoring by the division. <AK>

Further questioning regarding educational services revealed that many people are so grateful to finally be receiving anything that they do not want to jeopardize what they have by complaining. This fear of reprisal was also found in regard to other major tax-supported state agencies such as Crippled Children's Service. <AL>

While community-based programs are known to promote integration, independence, and productivity of people who have developmental disabilities more than institutional programs, Alabama continues to go against the national trend of putting more resources into community programs. <AL>

A vast majority of people with disabilities want to be productive to the full extent of their capabilities, want to earn income and pay taxes, want to function in the mainstream of society, and want to be free from the unnecessary dependence produced by society's attitudinal and architectural barriers. <AL>

The prospect of Medicaid reform at the federal level, the ultimate outcome of the dispute with the federal Health Care Financing Administration and the decision of the Baldrige v. Clinton lawsuit, will have a substantial bearing on the extent of services which can be delivered and the type and extent of case management which can be provided in Arkansas. <AR>

One of Arkansas's most formidable obstacles to the cultivation of a quality community service system is its current lack of system infrastructure. Arkansas has urgent needs in the areas of staff development, quality assurance, case management and appropriate interagency cooperative agreements. <AR>

The ICF/MR option can limit long-term flexibility of service delivery by locking providers into a specific service mode, regardless of whether consumer need and preference dictate its continuance. Consumers should be guaranteed their choice of services, including waiver services. <AR>

The key variable which must be known before reliable projections of service demand can be made in Arkansas for strategic planning purposes is a stated policy defining: what burden a family is expected to bear in supporting dependent(s) with mental retardation and other developmental disabilities before the state or, by default, the service community feels compelled to step in, and whether the state will continue to favor the same service patterns thus engendering additional demand for these services, or whether the state wishes to alter the service patterns and related demand. <AR>

Arizona should seek additional waivers and/or funding to eliminate the further development of a "dual system." <AZ>

The move to community-based services is placing stress on the state's monitoring and licensing process, resulting in too many provider homes operating on provisional licenses or operating at a lower level of quality. The DES/DDD inability to maintain a consistent and efficient provider payment system has forced providers to cut back and lower their standards of operations. This has placed undue economic stress on a fragile community system. <AZ>

The present system does not encourage friendships between people with developmental disabilities and those without. Group homes have only people with disabilities living in them. Day programs segregate individuals from the community. Work enclaves disabilities as "different". All people need friends, but making friends is much more difficult when one has a disability and must fight the barriers to integration. <CA>

Ideally, services should be planned to meet the needs of the individual. In reality, they frequently are planned based upon the programs and resources available. <CA>

The service system is complex and there are many transition points throughout an individual's life when they are transferring from one part of the system to another, and when services should be designed to meet the special needs for that particular stage of their life. It is frequently at these transition points when the system fails to respond to those needs, or when there is serious lack of continuity in individual service plans. <CA>

The need for individualized, culturally appropriate, and empowering service orientation and delivery. <CO>

One area which is especially troublesome in the double message which is given to persons with developmental disabilities, exhorting them to integrate on the one hand, but not have children on the other hand. <CO>

We cannot afford the disability industry. The disability industries and the public policies that support them have created a problem. If families want to care for people in their homes, or educate them in neighborhood schools, all the economics are against them, because they are competing with the powerful disability industry. The disability industry needs deficiency. Disability is of great value to an economy that sees people as a deficient, incompetent group in need of professional service. <CT>

Seven out of 10 service providers agreed that some programs deliberately or inadvertently exclude people with developmental disabilities who could be potentially integrated into the community. <DC>

Almost no written policy information and very little discussion with agency representatives, other than those who administer or receive support from Developmental Services or the Developmental Disabilities Planning Council, indicated that current federal/state supported programs which provide service for individuals with developmental

disabilities embrace a comprehensive vision or are destined to promote independence, productivity and social integration. Many agencies address one or two of the desired outcomes with little attention to the others. The primary approach is to focus on development of service slots with a single agency or program can provide to address the basic needs, residential/living placement, education or work for the group of people identified as developmentally disabled. <FL>

The reasons for such failures are debatable, but generally seem to be due to a combination of causes which include: a) inadequate resources; b) poor coordination among agencies and among professional disciplines; c) lack of knowledge or technology; and d) inadequate advocacy. <HI>

We do not have a system which reflect the goals of independence, productivity and integration for persons with developmental disabilities. The services are built on an institutional facilities model, without regard for the differences, competencies and strengths of individuals. <HI>

The "institutional bias" of the present Medicaid policies is not congruent with contemporary views of people with disabilities living and receiving the necessary services in the community. <HI>

While the philosophy of service is shifting to give more decision-making power to consumers and family members, it is clear from the policy analysis, the consumer survey and the public forums that this philosophy is translated only weakly into practice. Across all the programs reviewed, the average rating on the promotion of independence—which has been defined as the extent to which persons with developmental disabilities exert control and choice over their lives—was only 14%. Productivity ratings and community integration ratings, on the other hand, had cross-program averages of 65% and 45%. <IA>

In Public Law 100-146, consumer success in accomplishing these three goals is cited as the measure by which program effectiveness is to be evaluated. In too many of the policies that guide crucial services, these components are not even cited as program goals. In some programs, policy clearly inhibits their achievement. <IA>

Throughout the policy analysis, language was encountered that is both archaic and demeaning. Terminology that makes consumers the passive recipients of services is not only inaccurate, but subtly damaging. Persons with developmental disabilities use services, they don't receive them. Policy that contains inappropriate language reinforces negative stereotypes and perpetuates paternalistic attitudes. A sensitivity toward accurate, appropriate language is needed in policy, procedures, and rules at all levels. <IA>

There is a need for an overall shift in thinking from facility-based services to a "facility-free" system of supports. "Personal futures" or lifestyle planning (O'Brien, 1987) has been used to help groups of people create a positive future vision for the life of a

specific person with a disability. To accomplish this, public attitudes need to recognize the significance of this approach in the quality of life for people with developmental disabilities and the viability of this approach for people with challenging and severe disabilities. <ID>

The Council finds that, in Illinois, citizens with developmental disabilities value the importance of independence, productivity, and integration within their communities. In reality, they seem to be minimally independent, productive, and integrated. Illinois must make a firm commitment to improving services if citizens are to achieve what they value so much. <IL>

Few human services programs have adequate evaluation measures built into them. <IL>

There are, in Illinois, 7 state agencies which have major responsibilities and 6 state agencies which have minor responsibilities in funding, administering, licensing, and monitoring services for people with developmental disabilities. The Council finds that all these state agencies have gaps which range from troublesome to critical in their service delivery. These gaps are in the areas of: access: knowledge of where to go for service, eligibility requirements for service, outreach to unserved populations, cultural, linguistic, or physical barriers to service; training: hiring trained staff, upgrading state agency staff training, training contract agency staff (especially to work with people with severe or multiple disabilities); program: lack of interagency coordination which leads to either service gaps or duplication of efforts, lack of long-range planning, lack of coordination between regional staff and local service providers, lack of resources; and accountability: lack of standardized information as to what individuals are being served, lack of information on how federal and state funds are spent, lack of monitoring of local agencies' provision of service, lack of evaluation of service effectiveness. <IL>

There is a substantial need for training and awareness at every level if the human service system in Illinois on integrating people with developmental disabilities. <IL>

From the highest levels of state and local government to frontline workers in community social service agencies, a profound lack of knowledge exists about how to integrate people with developmental disabilities in the generic services offered by the state for its citizens. This situation results in long waiting lists for services at provider agencies which do serve people with particular disabilities. It also results in a severe underutilization of generic human services - those services which people without disabilities use - by people with developmental disabilities. <IL>

Independence among Illinois consumers is relatively low. Among adults who responded to the Consumer Survey, 73% did not choose where they live. Out of all the consumers, only 30% choose what to do every day or from which community agency to receive service. <IL>

The most limiting practice in traditional services has been to separate people with developmental disabilities from the rest of society. Specialized needs were met behind closed doors, beyond which friends, family and the rest of the community were not allowed. This practice allowed society to forget that people with developmental disabilities existed as part of society, making it easier to deprive and deny them. Public policy and the programs it supports have put these negative practices into action, affecting thousands of lives. <LA>

Public policy that allows for no decision making on the part of the person affected, that provides only one type of service that should meet all people's needs, and that continues to brand people with developmental disabilities as less than full citizens has solidified society's worst prejudices. <LA>

Sometimes a person is getting a service, but it's the wrong service. Unlike with the "left-outs", the state typically knows exactly who these individuals are, frequently has them in state custody, and often spends large amounts of money on them. Public resources are wasted and personal options lost when a person gets the wrong service. <MA>

Significant numbers are receiving inappropriate services. There is a failure to allocate resources flexibly so that dollars can "follow the client" or otherwise be used creatively to carry out social values such as client preferences and cost-effectiveness. Some of the rigidities of funding streams can be blamed on federal requirements; many, however, could be eliminated or at least moderated at the state level. This systems-level failure of tying money to "slots" or "beds" or "facilities," often causes "backup" in restrictive, expensive programs, leaving people in them who could do better (often, at much less net cost) with personalized supports in their own homes or in less formalized arrangements. <MA>

Even though the problems and needs of the individuals and groups involved are well-known and/or predictable, and the solutions conceptually not difficult, planning failure continues at both the individual and systems level. <MA>

There is a need to create external, professional, objective monitors to ensure that state agencies directly responsible for the provision of services to a particular population do so in a manner that provides adequate safeguards to its consumers. The key to any monitors' effectiveness is their independence from the agencies providing services. <MA>

The Office of Human Rights (OHR) has been eliminated from the Department of Mental Health (DMH) because of budget cuts, at a time when the budget crisis has forced major cutbacks in services. Consequently, consumers and advocates are concerned about respect for consumers' rights, lack of treatment, fewer treatment options, and already overcrowded and overtaxed facilities. <MA>

The service system in the Developmental Disabilities Administration is bottle-necked. This system needs to include more options for persons with more severe disabilities. <MD>

The state needs to consider how to make time available to reassess the current system and how to restructure existing agencies without penalty. The state needs to address the issue of reasonable size for a community-based program. Many agencies are forced to increase their size to handle financial pressures. <MD>

On the average, consumers had received eighteen services; and most were satisfied with the services they had received. Many consumers, however, were dissatisfied with services. The majority of those dissatisfied were either not receiving enough of a particular service, or felt that the service was not suited to their individual needs. <MD>

The access and eligibility regulations are inadequate to meet the needs of people with developmental disabilities who are homeless and others who reside with aging caregivers. <MD>

The Development Disabilities Administration must break service monopolies in those areas where the operate to provide freedom to choice to consumers. Contracts should be awarded in a fair and equitable manner to enhance the number of service options and providers available to consumers. <MD>

Many state and federal statutes/regulations contain language reinforcing disability and devaluing persons. <ME>

Individual and system advocacy efforts have not kept pace with consumer need and program complexity. <ME>

Institutional crises and funding patterns often drive new initiatives and resource allocation. These detract from long range development of a balanced and community/family oriented system of care and support. <ME>

State and federal financing of community programs, by regulations and level of support, provide powerful disincentives for expansion and result in services inappropriate to the individual constituent needs. <ME>

The specific findings are not meant to portray Maine as patently uncaring or incompetent in public policy. Maine is a leader in addressing many of the need areas identified. Maine and the nation are attempting to reverse a 200 year old policy of ignoring, institutionalizing, pitying, stigmatizing, and taking advantage of persons with disabilities. In so doing we have neglected a wellspring of growth, sharing, and giving. This will take time and careful consideration as we continue to articulate a public policy emphasizing abilities and potential. The Maine Developmental Disabilities Council welcomes this challenge. We present our recommendations in this spirit. <ME>

Many people with disabilities (and their friends, relatives, and advocates) report difficulty obtaining information and advice. They are interested in learning more about services, rights, entitlements, and ways to negotiate the services system. <MI>

Too many federal programs intended to benefit people with disabilities include institutional bias. Many have provisions that restrict choice and risk taking, or conflict with beneficiaries' ability to increase their independence, productivity, and integration in the community. States need federal leadership and incentives to help strengthen supports and build inclusive communities. <MI>

People with disabilities are made to feel unwelcome, are unable to participate in, or are excluded from too many of the ordinary activities of community life. <MI>

Many ordinary community activities happen in places where people with some kinds of disabilities cannot go, or cannot go without making strenuous efforts just to get there. <MI>

Most people with disabilities live in more restricted, isolated ways than others in many life areas. <MI>

Traditional services have used a medical/developmental model, which emphasizes "treatment" and teaching skills in a "normal" developmental sequence, rather than an empowerment model, which emphasizes the supports an individual needs to control his or own life. <MI>

Even programs that do focus on independence and integration sometimes try to mold the handicapper into the existing environment. This approach misses opportunities to help modify the environment to accommodate the handicapper. <MI>

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Lack of funds to meet individual needs can encourage services in restricted settings. Current funding structures do not encourage serving underserved or unserved persons as HCB resources are allocated on a "first come, first served basis." <MN>

People with developmental disabilities and their families expressed a need for legal services, particularly with regard to planning for long-term care. Parents feel an urgent need to plan ahead in the event that they become unable to provide the necessary care. <NC>

Services for persons with developmental disabilities are costly. Whether they reside in institutions or communities, persons with severe physical impairments, complex medical

needs, or behavioral problems require high staff ratios which may include 24-hour supervision. Although these individuals represent only a small portion of those with developmental disabilities, the complexity of their care can create serious problems for families and providers. The demand of their care may require services to rearrange scarce staff resources leaving programs understaffed. Lack of adequate human resources is a problem facing most providers. In many instances low salaries and lack of opportunities for career progression result in high staff turn-over. Efforts must be made to arrange the system in a more responsive way. <NE>

The average number of services received by individuals with developmental disabilities and their families is twenty-one. There is no significant difference in this number either by category of disability or age. When one considers what it must mean to interact with twenty-one different services, even taking into account that a single agency may provide several services, it is evident why many families experience frustration and report fragmented services. These services may have different eligibility criteria as well as varying availability depending on where an individual lives. All of these factors complicate the service system. <NE>

Survey data indicates that most persons with developmental disabilities are living in the community. Measures of integration such as attendance at movies, sports events, etc. and frequency of visits to supermarkets, restaurants, and churches or synagogues etc., are equal or better than national averages on these measures; however, other responses indicate that true integration may not be occurring. When asked if they had any friends/acquaintances whom they saw regularly who did not have a disability, 41% of those with mental retardation and 65% of those with emotional disabilities answered "no". (Persons with physical impairments [15%] and sensory impairments [17%] fared better on this question.) It would seem that many persons with severe disabilities are living in their communities but are not part of their communities. <NE>

The current system of services is closely tied to the need to secure Medicaid waiver funds. Federal funding inevitably brings with it federal regulation and the concomitant weakening of home rule. But Medicaid as a source of funding for developmental services is problematic because no matter how creatively it is used, Medicaid is a funding source for medical services. Developmental disability is not a medical condition. A conflict is inevitable between the aspirations of people with developmental disabilities toward independence, productivity and integration and the orientation of the Medicaid system towards medical treatment. This leads to a host of problems for waiver recipients. <NH>

The use of segregated school facilities should be reduced. <NM>

"The medically oriented ICF/MR model is inappropriate for many people with developmental disabilities. Even when the "level of care" is technically correct, regulations do not promote independence, productivity, and integration. New Mexico does not restrict the growth of ICFs/MRs." <NM>

These factors, combined with the fact that no agency in the state except the DD Council, utilizes the federal definition to track client services or participation in education, make it a difficult task to evaluate services provided to the DD population and to distinguish their needs from those of the larger population of people who have chronic, life limiting, severe disabilities. Therefore, this report reflects the needs and issues of all Nevadans with severe disabilities with regard to their independence, productivity, integration and care. <NV>

Definitions of developmental disabilities make it difficult to collect information. The varying definitions of developmental disabilities in NYS cause problems in accessing services and collecting data. The State Mental Hygiene law employs a definition that relies on "labels" (categorical approach), and requires that the disability occur before the age of 18. There are two federal definitions, which several agencies use, that look of individuals with chronic functional "deficits" acquired before age 22. For example, the SED has a definition of "handicapping conditions" as mandated in federal law P.L. 94-142, as applied to children up to age 21. As a result, it is difficult to gather reliable information on service needs. Additionally, there is no process for systematic and coordinated data collection between federal and state agencies. Generic service providers who do not have specific mandates for serving persons with developmental disabilities are not collecting data which identifies this population. Data are only collected on those already receiving services, making it difficult to determine and project service needs for the un/underserved. <NY>

There is still unequal access to services. Obtaining access to appropriate services was cited as one of the major problems encountered by individuals and families. Consumers have stated that individuals who are vocal or know how to negotiate the system seem to be able to obtain supports. But many people who are poor or are minorities are often beset with social barriers, language differences, financial distress, and multiple family problems that limit and affect their abilities to obtain supports. <NY>

Individuals and their families often have multiple needs requiring them to interact with a variety of agencies. They describe the hardships imposed on them in having first to seek our resources and then to deal with numerous personnel located in different settings. They see the system as fragmented and unresponsive. <NY>

The needs of individuals with developmental disabilities and their families change over time. For example, the brother or sister of a person with disabilities may need counseling in their adolescent years, but later may need legal assistance to carry out guardianship roles. <NY>

The current service system, although providing an extensive array of services, still has too few options for people. The long waiting lists for residential alternatives are creating family crises. Some are forced to accept what is offered, whether or not it best suits their needs, at the risk of losing their place on the waiting list. <NY>

The lack of commitment and creativity is more of a problem than the lack of funding. People with developmental disabilities want New York State and the federal government to complete the unfinished business of affording them the same protection and opportunities to participate in a society enjoyed by non-disabled citizens. There are other ways to accomplish this besides job spending more state and federal dollars. <NY>

Consumers and families believe we could save money by giving individuals what they need — not what others think they want. Parents of children leaving the education system feel that money invested during the school years is lost when these individuals are forced into idleness due to lack of programs for adults. The long waiting lists are creating crisis situations which sometimes cost more to resolve than would providing appropriate supports. <NY>

Because only an estimated 50,000 Oklahomans are people with developmental disabilities, many people in our state of 3.1 million have never even met or had a neighbor with a development disability — let alone hired them in an employment situation, or had them as a guest for dinner in their home. <OK>

The understanding of the special needs of a person with developmental disability is fraught with misconceptions that are the products of an ignorance without malice, but an ignorance nonetheless. The most limiting practice in traditional services has been to separate people with developmental disabilities from the rest of society. Being defined as different required those persons so defined to be hidden; having special needs required, in effect, meeting those needs behind closed doors, beyond which friends, family and the rest of the community were not allowed. Many view this as the most debilitating practice for it allowed society to ignore them, making it easier to deprive and deny them." <OK>

There is a common conviction throughout the disability community that Berkowitz' assessment is the correct one: there is no unified, coherent, effective policy directing responses to the needs and abilities of disabled people. Many of the conventional programs currently in place are thought to pose major problems for their intended recipients that all too often outweigh the benefits. The two systems of support — need-based and work-based — currently tend to each counteract the good intentions of each other. Income support programs provide disincentives to supported employment programs. Formal supports seem often to overwhelm a person's informal supports and resources, creating isolated "clients" rather than integrated citizens. <OR>

Over the past ten years, a broad critique of social policy — including disability policy — has begun to emerge that challenges some of the basic assumptions that have governed our system of social welfare for most of this century. Perhaps the sharpest critique of disability policy in America is the simple observation that there is no such thing. Berkowitz (1987) has succinctly described this perspective: "America has no disability policy. It maintains a set of disparate programs, many emanating from policies designed for other groups, that work at cross-purposes." <OR>

Definition of people with disabilities is being created by non-disabled people. People with disabilities need to be included (some would say in charge of) this effort. <PA>

The development of services in South Dakota has proceeded at a rapid pace over the past several years. This development has relied on what might be termed "conventional" approaches to service delivery, particularly with respect to adults with developmental disabilities. The state (like other states), however, is being challenged to adopt new strategies for the provision of services, strategies that may not fit comfortably with existing modalities for delivering services. New service delivery strategies, such as supported employment and family support services, pose challenges to more conventional approaches. Yet it seems clear that many of these strategies offer greater opportunities for the state to fulfill its overall service delivery goals; namely normalization, integration, and increased self-reliance for persons with developmental disabilities. <SD>

The critical challenge facing South Dakota is how to build upon the solid foundation of commitment to serving persons with developmental disabilities in order to construct a service delivery system that is capable of reliably, efficiently, and effectively meeting the needs of such persons in the best way possible. <SD>

In South Dakota, service delivery to persons with developmental disabilities is at a crossroads. A good community-based service delivery system has been stretched to the limits of its capacity. The question is what new steps must be undertaken to advance service delivery to an even higher plane without placing a sound system under unbearable stress. Addressing this absolutely critical problem requires all sectors of the service delivery system to come together to engage in a forthright dialogue concerning the future of services to persons with developmental disabilities in South Dakota. <SD>

In discussing this issue during site interviews, it seemed clear that key system actors are not hostile to long-range planning but that the capacity to develop such plans is severely limited in South Dakota. This limitation, in part, reflects the lack of staff resources among the principal administering agencies. In addition, the fact that responsibility for service delivery is scattered among so many state agencies militates against comprehensive planning. While the development of such a plan may fall within the purview of the SPCDD, the Council has only very limited capability to undertake such a planning effort. <SD>

One concern expressed by state officials, provider agencies, and other interested parties involve how well South Dakota is able to plan for the future of service delivery. Currently, South Dakota does not have a long-range, strategic plan for services to persons with developmental disabilities that has gained the acceptance of all major sectors concerned with service delivery. <SD>

The state's HCB waiver renewal request envisioned further expanding the role of the HCB waiver program by converting existing community-based ICFs/MRs to waiver funding and

also expanding the scope of the program to serve persons currently inappropriately placed in nursing facilities as well as to meet expected additional demand for community-based services. The hostile reception accorded the waiver application has raised significant concerns among ODDMH/DSS officials regarding the feasibility of achieving these objectives through the HCB waiver program or whether other alternative sources of financing should be examined. The renewal request recently approved by HCFA stops short of meeting the objectives of ODDMH officials. <SD>

A number of adjustment training center directors were very blunt in singling out deficiencies in ODDMH program administration as an emerging issue in South Dakota. ODDMH staff were characterized as becoming "increasingly bureaucratic." Questions were raised concerning the competency of the staff to dictate program changes to provider agencies. The directors of some agencies felt that the role of ODDMH staff should be defined as technical assistance rather than as regulatory or contract enforcement. <SD>

The problems expressed concerning ODDMH parallel similar concerns voiced by provider agencies in other states. While such problems are indicative of serious issues that bear additional scrutiny, they also represent a natural byproduct of vendor/buyer relationships. In many states, the rapid rate of growth in community-based services has resulted in increased levels of stress throughout service delivery systems. Furthermore, expectations placed upon both state MR/DD agencies and service agencies alike have increased, partly in response to a growing demand for governmental accountability and higher quality of services, but also as a result of the infusion of Medicaid financing, accompanied by federal administrative requirements, into community-based service delivery systems. Rarely do either the managerial resources of state administrative agencies or provider organizations increase at a sufficient pace to meet this rising tide of expectations. In this environment, increased demands breed widespread system stress and a growing sense of the divergence of state and community provider agency objectives. <SD>

The concerns expressed in South Dakota with regard to the lack of emphasis on supportive services also reflect growing reservations about the "institutionalization" of community-based service delivery. The question that seems to be emerging is whether client needs must be regulated by the relatively limited set of community-based programs that presently exist or whether services should be put into place that accommodate such needs in a wide variety of ways and in various settings. <SD>

While South Dakota has built a significant community-based service capacity, the present array of services available to adults with developmental disabilities is strongly oriented toward congregate programming. <SD>

The state has paid a price for its highly effective, aggressive efforts to maximize federal funding to support services to its citizens with developmental disabilities. Nationwide, South Dakota stands out as a state that has taken extensive advantage of federal funding opportunities as a means of fueling expansion of its service delivery system. The price

that has been paid is to lock service delivery into modes that are increasingly recognized as less capable of achieving overarching system goals. <SD>

In several areas, it is not clear that the present organization of service delivery in South Dakota promotes effective programming on behalf of persons with developmental disabilities. <SD>

Centering the delivery of adult services in South Dakota on the adjustment training centers clearly has served the best interests of all concerned over the past several years. At the same time, however, it may be necessary to re-examine basic relationships between the ATCs and ODDMH. <SD>

Based on the public input received by the Council, home and community-based services, including residential services and habilitative services, are the greatest service needs of families and individuals with developmental disabilities. <TX>

Working parents of children or adult children with developmental disabilities living in the home are particularly hard pressed to routinely miss work in order to go to appointments. Some families reported the conflict was so serious between the needs of their family member and the demands of work that parents had to decide to run the risk of losing their jobs in order to gain access to services for their relative. <TX>

In order for local agencies to address individual program accessibility issues when they arise, state agencies must have procedures and financial resources in place in advance for the immediate need for special assistance. Often the local service provider does not have the authority to make exceptions to established procedures or to allocate funding for people needing interpreters or other special assistance. <TX>

The major findings are of gaps in service, exclusionary eligibility requirements, and a complex system. None of these problems should be attributed to the agencies, per se, or the administrators, but rather to the patchwork fashion in which programs, mandates, authorities and regulatory control have been created. <UT>

If we are going to include people with disabilities and the elderly and allow them to fully participate in the community, it will require more than government intervention. It will require a commitment on the part of all of us to develop a "circle of friends" (Perske, 1989) made up of community members that will enable people with disabilities to full integration and full participation. As one consumer in the public hearing observed: "We as a society go zipping along and leave a lot of folks behind; we've got to stop, pick them up and take them along with us." <UT>

One other frequently expressed frustration remains, that is, the inability to access a little help without reducing the family income to poverty status or below. While the argument may be made, quite appropriately, that taxpayer assistance should be available only to

those who are unable to purchase the needed service themselves, a contrary argument may also be made. For example, under the Medicaid system, a child with developmental disabilities living at home is ineligible for Medicaid care under Medicaid if his family's income is "excessive" (defined as \$516 per month for three people). However, if the child is placed in an institution, Medicaid assumes the cost of care after the first 30 days of residence. <UT>

Another major finding from the public meetings, underscores the need for increased program flexibility. Repeatedly, the individuality of need was presented. Frequently, the need was created by circumstances unique to the family and was outside any service provided by any agency. Typically, the service need was less costly to the taxpayer than institutionalization. <UT>

Consumers with developmental disabilities are dissatisfied with sitting on the sidelines of life. They want the services and supports that will allow them to be active and integrated members of their communities. Consumers give high satisfaction ratings to all services aimed at increasing their community participation. Concurrently, they indicate a high level of need for services and supports such as community living assistance or training, self-help or support groups, and community support services. Virginia has not moved rapidly enough to implement the concept of least restrictive environment as a guiding principle of its service delivery system and relies much too heavily on program alternatives that are neither appropriate nor cost effective. The mission statements of most state agencies reflect the concept of least restrictive environment as a way to enhance, productivity, and integration of individuals with developmental disabilities. However, the general assembly, major state agencies, and many local programs continue to dedicate massive resources to service alternatives that are often overly restrictive and segregated. <VA>

Less costly, proven service alternatives such as family support programs, personal assistance services, educational programs based in regular schools, and supported employment remain grossly underfunded. Large, facility-based programs persist as key components of the Commonwealth's residential services (ICF/MR), educational (special centers for children with severe disabilities) and vocational (sheltered workshop) service delivery network. <VA>

There are inconsistencies among the initiatives undertaken by major state agencies. For instance, currently DMHMRSAS is proposing to close admission of children to state operated residential facilities, while the Department of Education is considering significant expansion of a residential educational facility for children with various severe or multiple disabilities. Many consumers remain isolated and limited in their involvement in "real world" roles and environments. <VA>

Lack of sufficient and appropriate human services in Virginia and interagency limitations. <VA>

Rules and regulations in federal and state programs that foster dependency must be eliminated. People with disabilities and their families must be given the opportunities and encouragement to embrace the spirit of community and full citizenship. Community connectedness must be encouraged and taught, if necessary. <VT>

Program eligibility guidelines frequently contribute to dependence instead of independence. For example, between October 1, 1987, and September 30, 1988, almost four times as many federal dollars were spent on institutional and facility based services for people with developmental disabilities than was spent for community based services and supports to individuals and families. <VT>

Lack of public awareness about disabilities and people with disabilities. <VT>

There are many training opportunities available for parent advocates. Training for professional advocates, however, is not as readily available. It is important for professional advocates to have well developed negotiation skills and members of the Advocacy Task Force felt this could be attained through a formalized training program. Such a program is not currently available within the disability advocacy community. <WA>

Trying to fit people into categories has never worked, yet that's still the approach most service systems take. Categorization can also result in unnecessary treatment. For example, if a child with behavior problems is labeled as having mental health problems simply in order to qualify for treatment, he or she does not receive the help he or she really needs. The negative connotations associated with such categorical placement can also prevent a child from getting the assistance needed. <WA>

In most non-English speaking cultural groups, a person with a disability is sheltered within the family unit. They are not usually encouraged to achieve the level of independence they may be capable of if given the opportunity. Because of this, the concepts of normalization, independence, and most certainly integration are not particularly valued goals for many ethnic minority cultures. Other kinds of cultural differences come into play. For example in many Native American cultures, disability is not seen as a sickness, so the disability doesn't become something that has to be "fixed." If a person is physically ill, then help will be sought, but disability alone is not seen as an illness. Native Americans do not stigmatize disabilities. <WA>

Wisconsin could be making a stronger commitment to the use of Medicaid waivers for community-based services. <WI>

Decisions made at local, state and federal levels often perpetuate the segregation and dependence of people with disabilities. Consumers, individually and collectively, have an important role to play in educating decision-makers about their needs and preferences. <WV>

The funds that are now being spent on services for people with developmental disabilities are being invested primarily in segregated settings. The small percentage of funding allocated for integrated alternatives is striking. Only 14% of vocational funding and 11% of residential funding are presently directed to integrated services. <WV>

EFFECTIVENESS: RECOMMENDATIONS

Multiple States

Public awareness should be heightened regarding the need for appropriate expectations of individuals with disabilities, since only behaviors that are expected can be achieved. <ID,LA,MT,WY>

Individual States

Service agencies need to be aware of their changing role of being a facilitator and helper rather than a decision maker and director. <AK>

The Department of Health and Social Services should pursue Medicaid options and waivers that will provide community alternatives to institutional care for people who experience disabilities. Options that may have positive impacts on people who experience disabilities are case management, extending categorically needy eligibility to all qualifying children with disabilities, "home and community based" waivers and "model" waivers. The purpose of a waiver is to provide Medicaid funded community based alternatives to institutional care. The federal government will pay 50% of the costs of approved programs. <AK>

The Department of Mental Health/Mental Retardation has both a Policy Advisory Committee and a Clinical Advisory Committee. These committees should be activated, with reorganization if necessary, and the expertise of the members taken advantage of. <AL>

Those people who are elected or appointed to serve in national, state, or local bodies must become knowledgeable and sensitized about developmental disabilities and must extend their activities to include responsibilities to this important portion of the citizenry. <AL>

The Council and the programs of the Council should have greater visibility in Alabama. Reasons for the maintenance of the predominance of an institutional-based state program should be examined carefully and modifications made as appropriate to take advantage of state and national expertise and expand community-based services. <AL>

Expand direct service options that promote community integration, independence and productivity for persons with developmental disabilities. <AR>

Build on the Mission and Goals Management Plan developed by the Department of Human Services to coordinate services among different agencies. In addition, develop formal cooperative agreements between agencies around specific needs, such as high school transition services and early intervention. It is essential that there be a consistent vision to guide the development and provision of services among the various offices that are

involved, including the Department of Economic and Medical Services which handles Medicaid issues. <AR>

Build a systems infrastructure capable of supporting, enhancing and monitoring the services that are provided. <AR>

It is essential that the Council view both its own mission statement and the 1990 Report as living documents that may serve as tool for regular guidance and evaluation. It is critical as well as the Council use its resources in ways that will advance the goals and values it espouses to the maximum extent possible. <AR>

The Council should establish a means for facilitating communication between all those who are committed to systems change. A periodic newsletter dedicated to documenting the course of change is highly advised. <AR>

Make efficient and effective use of resources already available, such as the existing community provider system and the Human Development Centers. <AR>

Develop a plan for implementation of the recommendations contained in the 1990 Report. <AR>

The Council must be prepared to assume a leadership role to actively advocate for progressive change in the disability services system. <AR>

Decisions regarding services through the Arizona Long Term Care System must be based on what the individual needs; choice among service options should be given consideration. The need to match federal Title XIX dollars must not result in insufficient funding for persons who are not eligible for Title XIX. <AZ>

The Long Term Care state statute, as well as the waiver and State Medicaid and DDD rules, should be reviewed to determine what options are available. The following should be considered at minimum; including services in preparation for vocational opportunities and other options in the Title XIX waiver; increasing and improving habilitation services; assuring that the IPP determines the number of hours of therapy a person will receive, rather than an arbitrary number of hours being provided; provision for maintaining eligibility for DDD funded therapy services for persons whose families choose to pay privately for additional therapy; and the "bundling" of funding for long term care and acute care services. <AZ>

Programs must be designed to serve all students in the least restrictive environment, in accordance with the student's identified needs. The Council proposes that integrated placement be available wherever it is appropriate. <AZ>

More case management procedures which address these transition points, particularly in the areas of early intervention, school-to-work transition, and aging. <CA>

Actively support development of a coalition of specific disability advocates and associations to create an organized constituency for people with developmental disabilities who do not have mental retardation. <CO>

Promote service provision in integrated settings in all areas of the state and at all age levels. <CO>

Medicaid reform legislation must strike a balance between state and federal regulatory roles in order to assure quality but not hamper providers and states from being flexible and increasing the creative options to provide supports to persons in family, home and community services. Such standards must focus on service outcomes tied to independence, productivity and integration. <CT>

Connecticut's congressional delegation must support Medicaid reform. <CT>

All state human service agencies, particularly funding sources for community services, should adopt the following principles for evaluating community service grants and contracts: concrete material improvement in the lives of people; encourage and reinforce community life; individual and group empowerment; effectively promote self-reliance; spin-off wider results beyond the "project" itself; efficient and of a manageable scale at the small community level; and channel funds through real partnerships with local groups, especially at the neighborhood level of communities. <CT>

All state human service agencies, particularly funding sources for community services, should assess the degree to which their budgets, including their contracts/grants for community services, are contributing to, or moving away from, supporting dependency and isolation of people. <CT>

All state human service agencies, particularly funding sources for community services, should require values-based training as part of their inservice training and continuing education for their staff and contractors. <CT>

Medicaid reform must make eligibility for family, home and community services available to persons with disabilities without meeting the test of institutional need or at risk of same. Most people with severe disabilities do not require 24-hour supervised facility-based services. Eligibility for new Medicaid entitlement authority must be tied to the person's severity of disability. <CT>

Medicaid reform legislation must require the state to engage in a comprehensive planning process with required public hearings in order to shape a five year plan of expanded

family, home and community services. Such planning must mandate a maintenance of the state's current level of funding in services. <CT>

Medicaid reform legislation must make federal funding for family, home and community services stable, permanent, open and accessible, remove the institutional bias, and provide a financial incentive to states to expand family, home and community services. <CT>

Procedures and guidelines should be established and adhered to for selecting and replacing inactive Council members; such procedures and guidelines should, however, be consistent with the intent of the Mayor's Order 88-3. <DC>

Adequate full time permanent professional and support personnel should be selected and assigned specific duties in the office of the executive director of the Council. <DC>

A full time executive director should be appointed to provide administrative and program support to the Council. <DC>

There should be an ombudsman position established, with adequate staffing, within the Council. The Ombudsman's Unit would: enjoy the freedom to function external to government bureaucracies, hold a continuing full-time position (s), focus its efforts on housing and other life areas of individuals with developmental disabilities, and establish direct and effective relationships with advocacy groups and constituents. <DC>

Monitoring and accountability procedures should be planned and operationalized for all developmental disability health care providers and related service delivery providers to insure to the greatest extent feasible that: (1) "mini-institutions" are not being created, (2) staffing is adequate and qualified, (3) case management is appropriate and effective and (4) persons with developmental disabilities are being accorded dignity and respect. <DC>

A compendium should be developed and widely disseminated which states in clear and precise terms current and potential laws which affect independence, productivity and integration of persons with developmental disabilities. <DC>

Assess the degree to which Medicaid regulations deny community-based assistance to qualified recipients with mental retardation or related conditions; and support legislation along the lines of H.R. 854 which would increase federal Medicaid outlays. Support removal of strong financial incentives for expensive institutional service. <DE>

Support the Consortium for Citizens with Disabilities' Task Force on Medicaid Long Term Care to endorse the federal Energy and Commerce Committee's request for new entitlement authority necessary to make carefully targeted improvements in Medicaid coverage and benefits. <DE>

Conduct public awareness activities for the general public and training for providers which emphasizes the availability and appropriateness of generic community-based services for individuals with developmental disabilities. <FL>

Conduct follow-up studies to determine the status and perceptions of individuals while receiving services and after having exited the service system. Ensure that such studies determine individuals' levels of independence, productivity and social integration, including their use of generic resources. Initiate action plans, as needed, to assist the individuals and to improve the service delivery system. <FL>

Revise Florida Statutes and Administrative Rules to reflect the federal functional definition of developmental disabilities. <FL>

Efforts to obtain federal discretionary funds and the support to the private sector should be increased. <FL>

Engage in systematic discussion with major agency/program administrators to determine which, if any, specific policies, procedures or resource allocations can be altered to improve opportunities for individuals with developmental disabilities to achieve independence, productivity and social integration and how they can be coordinated with other programs and services to provide individuals with real lives. Artificial barriers created by organizational structure and structure of the budget should be removed. <FL>

Provide training and public information which builds awareness and vision, throughout the service system and the state at large, that the desired outcomes for individuals with developmental disabilities are independence, productivity and social integration. The services provided must be the appropriate type, intensity, and duration to enable them to achieve these goals. <FL>

The primary focus for policy and resources development should be obtaining and coordinating resources to meet the individual needs of each Floridian with developmental disabilities. Fine tuning of one or several of the existing federal/state supported programs will not result in significant improvement in the desired outcomes of independence, productivity and social integration of individuals and developmental disabilities. <FL>

The Council recommendation is to expand and improve long-term care services to individuals with developmental disabilities. <GU>

All state agencies providing services to children and adults with developmental disabilities should develop regional administrative units for the delivery of services. <HI>

The State Planning Council on Developmental Disabilities should develop an "action" plan to advocate for integration of people with developmental disabilities in generic programs. <HI>

Congress should pass Medicaid reform to remove its institutional bias and provide a financial incentive to states to expand family, home, and community services. Medicaid reform should mandate waiving the deeming of parental income for eligibility for family support services. The Department of Health, Department of Human Services, and the State Planning Council on Developmental Disabilities should actively support the passage of such legislation. <HI>

The Department of Health should assume the administrative responsibility for assuring plans for the development, implementation and maintenance of an infrastructure for improving services for the developmentally disabled population with developmental disabilities with federal funding sources through the Medicaid program. <HI>

Revise federal Medicaid policy to require Medicaid funding to be used to support services that are integrated and community-based. <IA>

Revise Medicaid policy to make home and community-based services the preferred option, rather than a waiver program. <IA>

Seek increased funding to support this home-and community-based mode of service delivery. <IA>

Require that the rules and regulations used to implement policy operationalize the consumer-centered goals of independence, productivity, and integration. <IA>

Amend all state policy for programs that affect persons with developmental disabilities, requiring policy to cite independence, productivity, and integration as program goals, to mandate their implementation, and to systematically evaluate their effectiveness. <IA>

Within federal programs, establish the specific outcomes of independence, productivity, and integration as program goals, while allowing the states flexibility in designing programs intended to achieve these outcomes. At the same time, establish specific measures of effectiveness against which to evaluate state performance. <IA>

Require appropriate language in all state policy and administrative materials; for example, "Residential Care Facilities for the Mentally Retarded" would become "Residential Care Facilities for Persons with Mental Retardation." <IA>

Re-evaluate in depth the ways in which policy determination of eligibility has an impact upon the effectiveness of programs. <IA>

Eliminate policy that serves to prohibit or inhibit community-based services. <IA>

Develop models for alternative, community-based services whose policies require ongoing evaluation of the program's effectiveness in improving the outcomes of independence, productivity, and integration. <IA>

Enhance program effectiveness through policy that requires consumer and family input into all phases of the design of service plans, so that services truly "fit" the consumer, and not vice versa. <IA>

Require the use of appropriate language in federal policy and administrative materials that affect programs for persons with developmental disabilities; a timely example is the recent change from the Senate "Subcommittee for the Handicapped" to the Senate "Subcommittee on Disability Policy." <IA>

Enhance the effectiveness of every federal agency serving persons with developmental disabilities through policy that requires consumer membership on all policy-making boards for these agencies, and that gives these consumers a decisive role in determining policy, rules, and procedures. <IA>

Resources must be shifted from institutional and facility-based care to individual and family supports that are tailored to meet the needs and choices of the individual with developmental disabilities. <ID>

All state, county and city public buildings should be modified for full accessibility and participation by Idahoans with a disability. <ID>

All programs - educational, employment, housing, social service, transportation, health, mental health, legal, and recreation - in which people without disabilities participate should be integrated to allow people with disabilities to live, work, and play alongside people who are not disabled. <IL>

The major recommendation from the Illinois 1990 report to congress is that the service system be changed so that all people with developmental disabilities and their families have the choice to live, work, and socialize in the community with people who do not have a disability. <IL>

Publicly funded programs serving people with developmental disabilities, including severe mental illness, should be evaluated annually on program effectiveness in: increasing independence, productivity, and community integration; level of consumer involvement in the development and implementation of the program; outreach efforts toward underserved groups, including but not limited to members of low-incidence disability groups and racial/ethnic minority groups, people with multiple or severe disabilities, and/or people who live in rural areas. <IL>

Indiana shall authorize flexible and creative funding and program options (including, but not limited to, a Medicaid waiver and the CHOICE program) to provide home-based services and support. <IN>

Indiana shall support and work for the passage of local, state, and federal legislation and policies which promote independence, productivity, and community integration of people with disabilities. <IN>

Medicaid funds should be redirected to provide an array of family support home, and community-based services, and regulations should be changed to increase access for children and to mandate the inclusion of SSI recipients. <IN>

Indiana as a state government shall develop policies and rules to ensure that it serves as a model and a leader in the foregoing recommendations. <IN>

Indiana shall expand community support services for people with disabilities and their families and reduce its emphasis on state-operated and state-funded institutional programs. <IN>

Indiana shall insure that people with disabilities are provided opportunities in mainstream environments that enable them to develop social, independent living, and self advocacy skills. <IN>

Indiana shall develop a comprehensive plan designed to integrate people with disabilities into mainstream society. <IN>

Reallocate our public fiscal resources to encourage flexible service delivery in the home, school, job site, and local community, and to discourage use of restrictive, costly institutional settings unless clinically required. <MA>

Reverse the "institutional bias" in the federal Medicaid program for persons with mental retardation and developmental retardation and developmental disabilities, via reforms proposed by Senator John Chafee of Rhode Island in (U.S.) Senate 384. <MA>

Simplify paperwork for, and provide training, quality assurance, funding and other system supports to, the state's struggling purchase-of-service community system. <MA>

We call for: (1) Medicaid reform so that community services are the norm and institutional services the limited option (U.S. Senate 384), and (2) Department of Mental Retardation to focus consent decree compliance on meeting client needs where they will be best met, rather than on physical plants. <MA>

Enact Senate Bill 384 (filed by Senator Chafee of Rhode Island) to redirect needed federal Medicaid dollars to where the vast majority of beneficiaries with mental

retardation/developmental disabilities live. Of the 15,000 persons served by Massachusetts Department of Mental Retardation, only some 3,000 reside in large state institutions. Yet Mental Retardation's \$600 million plus budget is spent for this one-fifth of its clientele. Others receive no services. Much of this is because Medicaid reimburses us for the institutional but not the community services. It should be just the other way around! <MA>

Achieve greater consumer responsiveness by reconfiguring the Developmental Disabilities Administration service system to individually adapted services and supports rather than preconceived "slots." <MD>

Ensure varied approaches to serving persons with the most severe disabilities so that neither their productive abilities nor their human needs for personal and social relationships are overlooked. <MD>

Accelerate flexibility of the service system supported by increasing flexibility in funding procedures. <MD>

Develop individualized service/support planning processes that encourage individuals to reach toward their potential based on their abilities and choices instead of on assessments of services needed to compensate for limitations. <MD>

Remove barriers to movement between more or less intensive services and supports as individual circumstances of consumers change. <MD>

Foster effectiveness of locally-based, private non-profit organizations because of their critical roles in responding to the evolving lifelong needs of persons with developmental disabilities and their families. <MD>

The governor's "State of the State" message to the legislature and the people of Maine should clearly reflect the Administration's high priority on persons with developmental disabilities and their families. Specific statements addressing the administration's vision for people with developmental disabilities and those actions necessary to achieve the vision should be an integral part of the "State of the State" and budget messages. <ME>

Congress and the president should re-examine current efforts to reduce the federal deficit. With the states, they should identify means to readjust funding priorities to restore support for state and local programs. Programs that enable people with developmental disabilities to function independently and productively in inclusive communities should receive special attention. <MI>

Congress should enact, and the president sign, the Medicaid Home and Community Quality Services Act of 1989. The Act should pass without provisions that would limit redirection of funds. Neither should it penalize Michigan's progressive programs to improve

independence, productivity, and integration in the community for people with disabilities. <MI>

In 1991, the Michigan legislature should convene a bipartisan joint committee to review progress toward improving opportunities for independence, integration, and productivity for people with developmental disabilities, supporting their full participation in their communities. <MI>

The governor should direct, and the legislature should fund, the Developmental Disabilities Institute at Wayne State University as the University Affiliated Program in Michigan, to provide leadership in developing a Michigan Institute for Persons with Disabilities. <MI>

The Michigan Developmental Disabilities Council should develop strategies to prove the cost-effectiveness of enabling independence, as compared with the efficiencies of group-based care. <MI>

Congress should pass, and the president should implement, significant Medicaid reform legislation that will encourage people with disabilities who are trying to live independent, integrated, productive lives in the community, by providing funding for the supports they need. <MI>

Support appointment of qualified advocates and people with disabilities to high ranking positions in the Department of Health and Human Services. <MI>

Performance contracting to improve individual outcomes: allocate funds based on achieving outcomes for the individual, rather than simply providing a service or support. <MN>

The governor and legislature should reconsider the major overriding policies which relate to services for people with developmental disabilities. <MO>

The state of Missouri should adopt policies which require that services provided by all state agencies embrace the philosophical values of the principles of normalization and least restrictive environment in developing integrated services, provided at the community level, and include specific services designed to support and preserve the option of family care for individuals with disabilities. The governor and the legislative leadership should establish an executive/legislative review process with the directors of the Departments of Elementary and Secondary Education (DESE), Mental Health (DMH), Social Services (DSS) and Health (DOH) for the purpose of creating specified action plans to implement this recommendation. (MO)

It is recommended that we continue to develop a continuum of developmental disabilities services that are located in communities on a regional basis. Such a continuum would allow an individual to be given the most appropriate, as well as least restrictive service in or

near the home community. The ultimate goal is one in which all Mississippians with developmental disabilities will have ready access to needed services. <MS>

Mississippi's special education and rehabilitation programs should be designed in such a way that by the time a student is of high school age, he/she will be able to live successfully in an independent living apartment with only minimum supervision. <MS>

Medicaid restrictions on the financing of home and community-based supports must be lifted in ways that stimulate their expanded availability to people with developmental disabilities regardless of the nature of the developmental disability. <MS>

A great need exists for system development which will employ state-of-the-art computer technology and artificial intelligence applications to harness the enormous wealth of information from national sources and efficiently utilize it in combination with the information generated in applied settings to achieve maximum benefit for consumers. <MT>

To counter lack of transition planning due to current agency-specific mandates, "Individual Life Plans" should be developed with an advocacy perspective. <NC>

A coherent policy with regard to services for people with developmental disabilities should be developed at the national level and should be reflected in all federal, state and local funding. Such a policy should acknowledge that people with developmental disabilities have life-long special needs which involve more than one service agency. The function of policy should be to maximize opportunities for this population and to eliminate contradictory mandates among various service agencies. <NC>

The Governor's Advocacy Council for Persons with Disabilities should convene an inter-organizational task force to develop creative solutions for planning for long-term care which would not add significant costs to the social service system. <NC>

North Dakota's legislature, executive agencies and private business sector should continue to pursue cooperative economic development strategies to diversify and expand the state's economic base in order to create and retain new, quality jobs for the entire North Dakota labor force. <ND>

Integration into the community must be a goal for both the person and the community. Both will benefit from this relationship. Starting with young children, community leaders must take concrete steps to ensure that activities and services are open to all. Such a simple thing as making sure that a meeting site is accessible can begin to sensitize individuals to the issues that may discourage full participation in the community by all citizens. <NE>

The Council should continue its exploration of alternative administrative mechanisms. At present, the Council must comply with all state rules and procedures applicable to multi-million dollar agencies. While procedural controls are necessary, there may be more efficient ways for the Council to conduct its business. <NH>

The Council should provide more frequent opportunities for consumers, service providers and interested citizens to express their needs, strengths and ideas to improve services. Monthly meetings in different locations around the state would be ideal. <NH>

Institutional placement should be made only if appropriate services could not be provided in less expansive and intrusive settings. If necessary, resources should be transferred to less restrictive settings, along with clients to achieve this goal. <NM>

The state should utilize federal resources (including ICF/MR and Medicaid Waiver) to provide less expensive and less intrusive programs. <NM>

The federal government should review policies to assure that states do not have an incentive to place persons in more expensive and restrictive settings than are appropriate for their needs. <NM>

Fully implement planning and priorities listed in the New Mexico Developmental Disabilities Community Services Act of 1984. <NM>

Current New Mexico state laws should be surveyed to identify those laws which may inhibit the independence, productivity, and integration of persons with developmental disabilities. <NM>

The DDPC must focus on areas of issues of greatest need as expressed by consumers when developing its plans and priorities. <NY>

Individuals with developmental disabilities must have the same access to services that are available to all citizens. Examples include child care options and retirement opportunities including retirement planning and pensions. <NY>

Existing services must be redesigned to meet individual needs and to focus primarily on supporting and using the skills and competencies that people with developmental disabilities have rather than on the disability itself. At the same time, thought must be given to how to expand services and to meet current urgent needs. <NY>

The same array of choices available to others in the community must also be available and accessible to people with developmental disabilities. <NY>

The DDPC should develop ongoing strategies for involving people with developmental disabilities and their families in measuring the impact of its efforts to promote integration, productivity, and independence. <NY>

The DDPC should continue to promote effective and equal partnerships with consumers and families in the development of impact measures and in the actual measurement of the usefulness of various components of the service system. <NY>

We must change the way we think about the role of individuals with developmental disabilities and service providers in the planning and development of supports and services in the community. Both of these groups can contribute to this process in more effective ways. <NY>

Re-evaluate the role of the County Boards of MR/DD with an eye to redirecting their efforts toward identification and coordination of services, and away from emphasis on direct provision of services. Utilize the County Boards as a "resource" rather than a direct service provider. <OH>

We must develop a flexible, responsive system of services and funding to support people with developmental disabilities. For example, increasing the funding to the Medicaid waiver and Supported Living programs must be a top priority. <OH>

The Council should initiate dialogue with the Oklahoma Congressional delegation concerning the Americans With Disabilities Act and SB 384, the Medicaid Home and Community Quality Services Act of 1989, and promote efforts to increase public awareness of the issues related to this proposed legislation. <OK>

Oklahoma should continue public support and implementation of the Multi-Year Plan for Developmental Disabilities adopted by the Human Services Commission. <OK>

The goal of a statewide community education and awareness plan will not be achieved immediately, but it must begin today. An informed and motivated public in Oklahoma is crucial in order to assist persons with developmental disabilities to attain independence, productivity and integration into every community in the state of Oklahoma. <OK>

Historically in Oklahoma, various disability groups have gone alone or in small delegations to the State Capitol or to Washington to lobby for legislation and policies that affect their interest group. Largely this has been ineffective. This report proposes that a statewide advocacy organization be formed which will include persons, family members, advocates and care providers who will band together. This group should pursue policies and programs that positively affect the lives of all Oklahomans with disabilities. The overarching goal should be to develop an ongoing dialogue with state legislators, the Congressional Delegation, and municipal leaders so that they are informed on issues and concerns of

persons with developmental disabilities. The OPC/DD is the appropriate agency to make this goal a reality in 1990. <OK>

Referral and advocacy functions of the Centers for Independent Living should be strengthened by their state sponsor, the Office of Vocational Rehabilitation in the Department of Labor and Industry. <PA>

The unique character of Centers for Independent Living, and their specific need for funding should not be lost, and their line item status should be restored. <PA>

A decentralized, locally driven service system can best meet the individual and highly specific needs of persons with disabilities. The new agency should have local private or public agencies that can provide easy access for consumers and can be the actual service hubs or brokers. <PA>

The new home in state government must be sufficiently powerful to: influence the budgetary process, be able to shape services offered through generic departments (e.g., education, aging) so that they accommodate the needs of persons with disabilities, and be able to withstand changes in administration or political climate. Power in government is often best accomplished by the administration of significant funding streams or well established programs. <PA>

The most progressive service philosophies governing programs geared to citizens with disabilities often run counter to those governing traditional or long established systems. This new home in government must have sufficient independence from existing bureaucracies to be able to put its service philosophy in action. <PA>

Whichever option is chosen, in order to be truly reflective of the needs of persons with disabilities, the program must be controlled by people with disabilities themselves. If this is accomplished through an advisory board, the advisory board must be comprised of and selected by people with disabilities. <PA>

To strengthen and expand services and to erase the attitudinal barriers that often block the attempts by citizens with disabilities to achieve independence, integration and productivity, the home in state government must have high visibility to both the general public and to state governmental bodies. <PA>

If this new program is subsumed under an existing structure, or if existing programs are brought under its umbrella, it is important that these other agencies have service principles and philosophies that are compatible with those of persons with disabilities. <PA>

Wherever the home in state government lies, it is crucial that it be given statutory authority to influence the provision of services to persons with disabilities and other

agencies, so that they are indeed responsive to and reflective of the unique needs of persons with disabilities. <PA>

The Developmental Disabilities Program should promote research and development of new diagnostic and intervention strategies. <PR>

The effectiveness of services will be guaranteed. A consumer driven system (with vouchers) needs two mechanisms to guarantee effectiveness: full and accurate information about services (prepared by an independent organization similar to Consumers' Reports) and procedures that deny licensure to agencies providing ineffective services. Both mechanisms will be consumer controlled. <RI>

The objectives of all programs providing services to persons with disabilities will be independence, productivity, and integration into the community. <RI>

Statutory and fiscal policy should not work against community based services and family support programs. <SC>

Develop and implement programs throughout the state that will heighten all citizens' awareness and sensitivity of disability issues. <SC>

The major recommendation is that all parties join together in a concerted, highly focused effort to define a common set of overarching service system goals and objectives. Based on that framework, a comprehensive strategic plan should be developed that will guide future system development. This plan should identify the key barriers to achieving a community-based service system capable of meeting the needs of any person with developmental disabilities. It also should pinpoint the steps necessary to realize such a system. <SD>

Key system actors in South Dakota should be convened to oversee the development of a long-term system plan designed to guide actions to improve services on behalf of persons with developmental disabilities over the next three to five years. <SD>

Tennessee should promote a strong public awareness program to heighten awareness regarding the need for appropriate expectations for individuals with developmental disabilities and to develop a central source of information about services for persons with developmental disabilities. <TN>

The Texas Planning Council recommends the Texas legislature increase funding and expand the array of residential and home and community-based services and options for people with developmental disabilities. <TX>

Fund Home and Community Based Services as optional Medicaid services without the need for waivers. <UT>

The General Assembly should require the Department of Medical Assistance Services to work collaboratively with appropriate state and local agencies to determine the feasibility of expanding the scope and increasing the individuals eligible to participate in all aspects of the Medicaid program, particularly to increase opportunities for community-based habilitation/rehabilitation services needed by persons with developmental disabilities. <VA>

The Act recognizes that opportunities which allow for taking chances, for learning, for succeeding and failing are vital parts of life. Public policy must promote these opportunities by eliminating barriers that falsely limit the potential of people with developmental disabilities. <VT>

The Intermediate Care Facility/Mental Retardation Program and the Home and community-Based Services Waiver for community services and long-term care should be pulled from the Title XIX Program. They should be re-examined to review service needs which are separate from, or in addition to, healthcare needs. <WA>

A new entitlement program should be formed to provide nonhealth-related services. This would operate in conjunction with the Title XIX Program. Individual states would provide community services in lieu of institutional and nursing home care without current medical restraints. <WA>

Public relations campaigns should be created to educate all members of the community about developmental disabilities. Until old fears and misconceptions about what people with disabilities are or are not capable of doing are laid to rest, the struggle for full acceptance into the community will continue. <WA>

Integrate children with special needs into generic systems and community activities as much as possible. This involves personnel preparation as well as resource and support issues. <WA>

Senior citizens should be given the opportunity to learn more about the needs of people with developmental disabilities. Programs offering this type of information would assist in counteracting the social stigmas attached to people with disabilities. <WA>

The state of Wisconsin should publicly declare its commitment to the 100,000 citizens of Wisconsin who have developmental disabilities and who may need publicly-funded support services in order to become independent, productive, and integrated members of their communities. Wisconsin should incorporate into state law the national goals of independence, productivity, and integration for people with developmental disabilities which are identified and defined in the federal Developmental Disabilities Act. <WI>

The state of Wisconsin should adopt a statewide policy which clarifies its broad expectations for the community and the publicly-funded service systems as they pertain to the lives of people with developmental disabilities. <WI>

Expand the use of the Home and Community Based Services Waivers both in the numbers of people served by the program and in the amount, type, and extent of services provided to each individual. <WI>

Support federal Medicaid reform efforts that provide for the extended use of Medicaid for community-based services (e.g., the Chafee bill). <WI>

Encourage the state to use all options for community-based waivers, and have DHSS indicate which waivers are not being used and the rationale for not pursuing them. <WI>

FUNDING: BARRIERS

Although lack of availability of funds is often cited as the reason for not providing service, we in Alabama tend to cite this more often than is appropriate. For example, Alabama roughly spends about \$30 to receive \$70 of federal funds for service. Yet we do not take advantage of this opportunity to multiply our resources. <AL>

There is a lack of funding to develop and maintain needed services. <AL>

As great as the increase appears to be in funds for community services to the MR/DD population, Alabama has not compared well with national figures that indicated that overall spending for community services has increased over threefold nationally. While 21 states have passed the point at which community service expenditures have surpassed those for large institutional programs, Alabama continues to spend a disproportionate share for the latter. <AL>

Arkansas, because of its favorable Medicaid match rate, will be tempted to develop only those programs that are Medicaid-reimbursable. In fact, there is a real need for increased general revenue funding precisely because many of the services needed are not eligible for Medicaid matching funds. <AR>

The rate methodology used to determine payment to community based service providers needs to be examined. <AZ>

Within the past five (5) years, the state of Arizona went to a sealed competitive bid Request For Proposals (RFP) process. While this appears appropriate relative to road construction and the like, it is not the most appropriate method of contracting for human services. Agencies contracted to provide "people" services need long-term commitments. Most of the community agencies in the Arizona service system were started at the local level. Families are most comfortable in the assurance of the continuity of service being provided by an agency they are familiar with. <AZ>

Purchase of service contracts need the flexibility to meet the multiple needs identified, particularly in small rural communities where age and disability needs are diverse. <AZ>

Arizona has committed the state to bring the Arizona Training Program at Coolidge facility up to Title XIX ICF/MR compliance levels. This has not occurred, and state dollars which could have been utilized for community services have been diverted to this institutional program. The Council has taken a position that state funds should not be diverted to deal with institutional certification issues. Such diversion of funds is in conflict with the goals of independence, productivity, and integration. <AZ>

The Medicaid HCB Waiver program was expected to assist the state to meet the growing financial burden of care for people with disabilities who are elderly and poor. The federal

share of the cost of service and the quality of services required has caused increases in the cost of care for those eligible for Medicaid. The entitlement for service by those eligible gives them priority for the state's limited dollars. The available funds for those people with developmental disabilities who are not eligible for Medicaid are getting smaller and smaller. This is creating a "dual system" that is hurting many people. The need to use state dollars to match Title XIX has reduced the availability of funding for non-Title XIX services. <AZ>

Arizona has had a structural deficit for several years due to an over-dependence on the sales tax in its revenue base. For several years, revenues have not been sufficient to fund the state's budget; and cuts have had to be made in mid-year. A special committee has prepared a report for the legislature recommending solutions. However, no action has been taken to date. All agencies have faced reduced budgets or very limited increases at a time when the state's population has grown at a rate that exceeds the national average. <AZ>

Sealed and competitive bids have the potential of undermining the trust and security that families place in a particular agency to provide services to their son/daughter. Award of contracts for "people" services should not be made on the basis of "lowest bid". The process precludes potential contractors from assisting in program development with the funding agency prior to the development of RFP. This creates an unnecessary barrier in the Governor's Council attempts to develop innovative ideas and develop projects to implement them by excluding from the "idea generation" phase those who may have much to contribute. <AZ>

The Court ruled in 1985 that when funding resources are exhausted, the legislature has the responsibility to either provide additional appropriations or reduce the entitlement. The decision rendered former regional center budget control practices illegal. Despite this ruling regional center resources are still limited and some individuals do not receive needed services because of funding limitations. <CA>

By California state law, the budget must be balanced without deficits. In addition, a cap has been placed on state spending through public initiative — the Gann Limit. Revenues determine how much funding is available for services and programs, but revenues have not increased as fast as the growth in demand for services. <CA>

With California's population of people with developmental disabilities growing, new funds are needed to start new programs, particularly residential programs. While there is approximately \$5 million per year available for new program development through the Program Development Fund, this barely scratches the surface of community development needed to serve Californians with developmental disabilities. In FY 1988-89 the regional centers submitted resource development plans to cover anticipated growth in excess of \$18.2 million statewide. However, only \$4.5 million was actually funded. <CA>

California's state government operates with a budget of nearly \$40 billion annually, but even at that amount, a number of program demands are presently creating serious fiscal pressures. State and local health care programs for indigents have been unable to meet the demand for these services in recent years, and the idea of providing some form of insurance coverage is receiving greater attention; the prison inmate population is increasing faster than the state's ability to house them, with an estimated \$1.6 billion needed to build additional prisons in the next five years; more people are enrolling in higher education, creating demand for new facilities; state transportation funds are nowhere near the level needed to cover the projected expenditures outlined in the state's plan for transportation improvements. <CA>

Entitlement programs such as Aid to Families with Dependent Children (AFDC), Supplemental Security Income/State Supplementary Program (SSI/SSP), Medical, and Developmental Services, account for a substantial portion of the state's General Fund budget. Seventy percent of the General Fund is controlled by entitlement programs and other policies placed in statute or in the state constitution. These programs are also growing faster than the state's constitutional appropriations limit. As one can envision, there is a conflict between a philosophy of a balanced budget without tax increases and service entitlements in rapidly growing areas. <CA>

With long waiting lists for residential and vocational services funded by the Division for Developmental Disabilities, in many cases there are no options; when a vacancy occurs in a particular program, the person most in need is moved into it. There may be a poor match between the program and the person's needs, which can result in crises and stress on consumers, families, and staff. <CO>

Coupled with this set of conditions was a decrease in federal spending, not only for housing, but for other social programs. <DC>

The cost of operating human service programs in the District of Columbia has increased dramatically over the last two fiscal years. This is particularly true for homeless shelters, Medicaid and foster care. <DC>

Nine out of 10 service providers contended that funding formulas do not promote the expansion of service and that discretionary grants could be used more efficiently and effectively for persons with developmental disabilities. <DC>

The reality that sufficient funds are not being made available to meet the needs of Florida's individuals with developmental disabilities cannot be avoided. The long waiting list for services and the gaps in service availability by geographic area are evidence that extraordinary measures should be used to advocate for additional funding. <FL>

The private non-profit sector has been weakened in the past decade due to serious cut-backs in federal funding for human services. As government has decreased funding, the nonprofit sector has had to reduce its service provisions. <GA>

Hawaii's public funding of developmental disabilities services, through state and federal dollars, is the weakest in the nation. According to information recently compiled by researchers at the University of Illinois/Chicago's University Affiliated Program for FY 1987-88, Hawaii ranked 50th among the states in terms of its relative overall level of financial support for mental retardation/developmental disabilities (MR/DD) services. The same study shows that Hawaii's level of public funding for MR/DD services has deteriorated over the past 12 years. <HI>

While the program policy analysis did not deal explicitly with the issue of funding, serious concerns with elements of the Iowa funding system emerged in the public forums. These concerns are related to the ways in which services are delivered and perceived by consumers and families. One area noted in the public forums is the special Iowa balance of federal, state and county funding of services. As one provider comments, "Counties continue to be responsible for individuals with mental retardation and often accept responsibility for individuals with developmental disabilities. Between federal, county and client dollars, the majority of the individuals costs are being paid, but the state continues to avoid commitment to community-based programs. A better partnership must be established. <IA>

Having the county of legal settlement responsible for service costs can throw consumers into a service limbo and restrict access to appropriate services, as well as cause problems for individuals or families who move from one county to another. One mother explained. "We moved to Iowa three years ago, in November, and my son graduated from high school the next May. Evidently you have to be a resident of the county for one year, and not receive any community based service, before you can get county funds. So he has been here for two years now. He got switched to state funding and now he can't move from state to county funding unless he drops out of all programming for a year to meet the county of legal settlement requirements...He has to sit home for a year, literally, no funding or anything. <IA>

Another issue related to funding concerns involves the recruiting, training and retention of qualified staff when wages are so low. In the public forums, a number of people mentioned the problem of low direct care staff wages and the impact this has on services. Some of these comments were directed at Medicaid reimbursement rates for services like attendant care. Other comments focused on wages for group home staff. <IA>

Due to lack of funds to serve current clients, few state agencies have active outreach programs for people with developmental disabilities. <IL>

Funding for people with developmental disabilities is not flowing to where most of these citizens and their families live - in the community. <IL>

Illinois services for people with developmental disabilities and their families are seriously underfunded by both the federal and state governments. <IL>

Kansas is not supporting services for the population of people with developmental disabilities. The increase in total state and federal commitments to developmental disabilities services in Kansas is relatively small when compared to expenditures increase in five nearby states. Comparison states have experienced an increase in spending per \$1000 of wealth in the population while Kansas has had a decrease from \$3.02 in FY 1977 to \$2.71 in 1988. <KS>

Louisiana has suffered severe fiscal problems over the past three years due to the collapse of world oil prices. There have been major cuts in social services which has resulted in a reduction of the number of individuals being served and the loss of experienced staff. It is expected that this situation will continue. <LA>

More money is needed to finance services for persons with developmental disabilities other than mental retardation. <MD>

Salaries for direct staff must be increased. Even though agencies may receive supplemental funding, this does not always get passed through to direct service staff. The salaries and benefits earned by direct service staff working for private non-profit agencies should equal the salaries and benefits of personnel working in similar state positions. <MD>

Limited resources is a big issue, especially in the rural areas. It is difficult to recruit providers in rural areas because of the level of funding available to provide services. <MD>

Adequate compensation, salary enhancements for direct service staff serving persons with severe and profound handicaps, is required to develop services to meet the needs of this population. <MD>

Significant opportunities for increased federal financial participation are not being realized. <ME>

The Developmental Disabilities Council is underfunded and cannot fully meet all its statutory mandates. <ME>

State agency funding crisis and disbursement patterns have, in some areas, negated legislative mandate and intent of appropriations. Services to persons in critical need are being reduced. <ME>

The existing network of federal and state funding of services to persons with disabilities is inadequate. Existing unmet needs data indicates a 25-40% shortfall. Full funding of basic federal support grants has reduced (because of inflation) actual resources by an estimated 20% over four years. <ME>

Critical community based services such as transportation, supported employment, transition support for high school graduating youth, recreation, and independent living are not receiving funding commensurate with current future need. <ME>

Proposed state budget cuts sometimes cause added hardship for people with disabilities and their families. People with disabilities often get the support they need from public programs funded through state departments and private, nonprofit community agencies. For example, cuts in Adult Foster Care Licensing staff can slow development of community living arrangement for adults who cannot live on their own. The proposal to reduce the Family Support Subsidy for FY 1989 undermined families' confidence in the State's commitment to help with care for family members with severe disabilities. <MI>

In the face of decreasing revenues, human services programs are receiving a shrinking proportion of Michigan's available state revenues. Michigan needs seriously to reassess and realign budget priorities, especially the fiscal emphasis placed on the state's prison system in recent years. <MI>

Despite Michigan's recovery from the fiscal crisis of the early 1980s, state revenues are restricted by the transformation of Michigan's economy from a manufacturing to a service base, federal cutbacks; and the increasing cost to state revenues of tax breaks. <MI>

Michigan gets a good return on dollars invested in federal grant programs. However, of the four areas of federal expenditures in states, this is the one that is declining. State agencies have identified several areas in which the state could be taking advantage of additional available federal funds. <MI>

Federal deficit-reduction measures are failing to accomplish their stated objective. They are, however, allowing federal budget priorities to shift in a way that supports the defense establishment at the expense of programs needed by people. <MI>

Governors and states face managing state programs and services while the federal government abdicates its role in human services and education. Federal legislation establishes new requirements, for example, in environmental protection, welfare reform, and nursing home reform. These changes respond to important needs, affecting the nation's quality of life. However, the president and congress have not made available the financial resources to carry out the new mandates. <MI>

Programs that focus on independence and integration often have limited resources. <MI>

Individuals receiving waiver services cannot simultaneously receive funding from another source. Agencies dependent on a projected level of waiver funding may be reluctant to allow a person to take advantage of services from other funding sources, such as Division of Vocational Rehabilitation sponsorship. <NH>

Perhaps even fundamentally obvious is that both systems are drastically underfunded. Authorization is not allocation, and this country's disability systems are fraught with examples of policies declared, programs established, but services undelivered because of a seemingly undeniable failure to adequately fund them. <OR>

Many of the consumers and their families who were interviewed did not know budget figures; they only knew that there were no residential programs available, no jobs, no respite, no transportation, and no recreation programs. <OR>

The key informants interviewed for the Policy Analysis Report identified funding issues as a major problem. Some characterized funding issues as the whole system being underfunded, resulting in problems with program monitoring and quality control. Others spoke of the impact of inadequate funding in relation to how it affects community service providers: the need for more providers; low wages; high staff turnover; and insufficient cost of living increases. <OR>

Funding issues contribute to another common concern: there is a visible resentment in the community at the perceived double standard of support for people with developmental disabilities depending on whether they have recently come out of the Fairview Training Center or not. Respondents from all the research strands complained that recently deinstitutionalized individuals receive a much higher level of funds for services than consumers already in the community. <OR>

With respect to community-based services, present funding levels have resulted in community provider agencies holding wage rates for line staff at relatively low levels. As a consequence, the adjustment training centers experience very high rates of employee turnover (in the range of 30-40 percent annually). This high rate of turnover significantly detracts from the effectiveness of service delivery by making it very difficult to maintain continuity of care and sustain family-like living arrangements. In addition, low wages heighten the difficulty of recruiting trained professionals to fill key positions. <SD>

Another overarching concern facing the state is the adequacy of funding services for persons with developmental disabilities. During on-site interviews, the adequacy of current funding levels clearly emerged as a critical system-wide concern. Providers, for example, expressed frustration at having to meet a rising level of expectations regarding the quality of services without commensurate increases in basic funding levels. <SD>

Present funding levels for community-based services make it next to impossible to serve persons with highly complex needs in community programs and facilities. As a

consequence, South Dakota continues to rely on institutionally-based services to meet the needs of many such persons. Persons interviewed pointed in particular to services to offenders, persons who are dually diagnosed, and highly medically-involved individuals as especially problematic given current funding levels. <SD>

The most frequently mentioned problem during interviews was the perceived inadequacy of funding for community-based services furnished to persons with developmental disabilities. Concerns about the adequacy of funding were expressed not only by service provider agencies but also by state officials, advocates and parents. <SD>

Particularly among the adjustment training center directors, there is growing concern that present funding levels do not support the quality of services needed to continue to meet ACDD standards. Provider agencies strongly question whether state funding has kept pace with state expectations regarding the quality and scope of services. <SD>

Despite having succeeded in recent years in gaining executive and legislative support for increased funding levels, hardly anyone expressed strong confidence that perceived weaknesses in funding levels would be corrected in the near-term. Many individuals commented that, over the next few years, they expected funding for services to persons with developmental disabilities to be governed by a "zero-sum" paradigm wherein increases in funding for community services would have to be financed through decreases in funding for institutional services. Real growth in total funding was viewed unlikely. <SD>

This perception of the inadequacy of funding levels is a growing and increasingly troublesome theme in nearly every state. Concerns about the adequacy of funding are increasing the level of tension in service delivery systems; more and more, deep concerns are being expressed about the ongoing stability and effectiveness of service delivery on behalf of persons with developmental disabilities in the face of federal cutbacks in the level of domestic assistance and shifting budgetary priorities at the state and local levels. <SD>

It was noted that the heavy reliance on Medicaid funding of community-based services in South Dakota creates a bias toward the provision of services in more restrictive settings. <SD>

Another issue is the broadly-shared concern that the present funding mechanisms employed by ODDMH do not promote the placement of persons in the least restrictive setting possible. <SD>

A number of persons interviewed raised specific issues concerning ODDMH rate setting and reimbursement policies apart from the broader issue of the adequacy of funding. <SD>

Issues concerning funding methodologies and their influence on shaping the direction of service delivery are receiving heightened attention in most states. The growing

complexity of community-based services, the increasing reliance on Medicaid funding with its inherent restrictions on the types of services that may be funded and how reimbursement is structured, and changing expectations governing service delivery are combining to lead key system actors in many states to reexamine the effectiveness and appropriateness of current rate setting and reimbursement methodologies. <SD>

While the reservations about reliance on Medicaid funding expressed by all parties in South Dakota are valid and should be seriously considered, the state's options in terms of seeking alternative financing sources are limited. For example, other Medicaid financing options for specialized DD services have significant drawbacks, not the least of which is the difficulty in supporting provision of services in what are viewed as the least restrictive, more integrated settings. On the other hand, it seems clear that the withdrawal of a significant share of the present level of Medicaid support for community-based services in South Dakota would result in a major service delivery system crisis. <SD>

Provider agencies are expressing increased reservations about the degree of the state's reliance on Medicaid funding in general and waiver funding in particular. These agencies are extremely concerned that this high level of reliance increases the service delivery system's vulnerability to changes in federal policies; in addition, provider agencies question whether funding levels have kept pace with the increased requirements that have accompanied expanded use of Medicaid financing in South Dakota. <SD>

The problems encountered by South Dakota in renewing its HCB waiver program parallel some of the same difficulties experienced recently by other states. Objectives within HCFA to curtail further expansion of HCB waiver programs have resulted in a proliferation of requirements on the states to demonstrate the effectiveness of waiver programs and a concurrent trend on the part of HCFA to "micromanage" state HCB waiver programs. Hence, despite prior federal and state assessments regarding the effectiveness of the HCB program, significant problems may be encountered when seeking to continue or expand a waiver program. Many of the issues raised by HCFA officials with regard to South Dakota's request for renewal reflected this increasingly adversarial negotiating environment. <SD>

Most of the agency personnel interviewed cited a lack of funding as the greatest single factor limiting independence, productivity and integration of people with developmental disabilities. <TX>

There are waiting lists for HCB Waiver Services because of limited state funds to provide the match for federal financial participation and the limit on the number served under the waiver. In Utah, DSH could serve more people than they do but are limited to the current numbers because of the requirement of documenting "cold beds" for every person served. <UT>

The state doesn't maximize Medicaid collections. We should be able to collect about eight million dollars based upon the number of clients that are Medicaid eligible and we collect only four to six million each year. Red-tape and rigorous waiver regulations tend to limit participation. <UT>

To relatively poor states such as Utah, federal funding for programs is a virtual financial necessity with federal monies supporting state tax revenues. With federal funding comes federal program management with its attendant problems. The congress, appropriately, seeks to establish a rational service standard, both for program quality and service eligibilities. Establishing the national standard, however, means the imposition of regulatory requirements that may or may not meet the particular state's needs and, in fact, may mitigate against the most needed or effective service delivery. <UT>

This situation underscores the contradictory nature of the service system. The children could be served at a minimal cost to the family, although considerable cost to taxpayers, if the child were institutionalized, but little or no taxpayer funds are available to assist the family while the child is at home. <UT>

The capacity of many local programs is in large part dependent on the amount of local government funding which can be accessed to supplement federal and state funds, which in and of themselves are greatly insufficient to address the present need. This problem has become more serious in the last several years as federal funds have significantly decreased as a percentage of agency budgets. For example, significant decreases in federal contributions have forced agencies such as the Department of Social Services to reduce or eliminate programs once targeted toward individuals with developmental disabilities. In other state agencies (e.g. DRS, DMHMRSAS) level federal funding has compelled the general assembly to fund a significantly larger share of agency budgets with state appropriations. <VA>

Despite the fact that it is both cost effective and humane to provide services to persons with disabilities that will increase their productivity, independence, and integration into community life, it is difficult to generate significant new revenue and resources to increase and establish new human services. There is also heavy competition for public funding among various disability populations and other disadvantaged groups. <VA>

The need for increased dollars to enable us to move beyond crisis management in programs/services. <VT>

Another downside to the Title XX Social Services Block Grant program is that people with disabilities and their families have little choice as to how these limited funds are spent. <WA>

The potential benefits of the HCB Waiver are limited by a "cost-neutrality" requirement. This prevents states from using funds to finance home and community-based supports for

those who need them. To qualify for the HCB Waiver, each state must demonstrate that without the waiver, it would require an increased level of ICF/MR. The state must also be able to ensure matching state dollars to do so. Washington State is not able to expand ICF/MR bed slots to achieve this. The result is a ceiling on HCB funding which restricts expansion of services and creates long waiting lists. <WA>

Over the last ten years, the Washington State budget for Residential Habilitation Centers (RHCs) has grown from about \$40 million to just over \$100 million. The budget for all other developmental disability services has grown from \$10 million to just over \$80 million. Yet during this same ten year period, the population of RHCs has been reduced while people using other more independent services has grown by almost half. As a result of these population changes, the current waiver programs cannot address the rapidly expanding waiting lists nor do the existing regulations allow for a natural expansion of services. <WA>

People with disabilities are often prevented from attaining their potential because programs focusing on independence and integration are typically underfunded. Many people cannot access them because of stringent eligibility standards. <WA>

Funding inequities affect every aspect of life for people with special needs. Lack of money also promotes competition among special interest groups for dwindling resources. To compound the problem, funding sources are usually rigid and inflexible in their eligibility criteria. <WA>

West Virginia's total spending was only 56% of the national average, and its investment in community-based services was only 44% of the average. The state ranked 46th in the nation on total spending for services for people with developmental disabilities. <WV>

There are currently many inequities between counties on the types and amounts of services provided to people with developmental disabilities. Funding of basic community services has been inadequate and, as a result, many people with developmental disabilities are being placed on waiting lists for essential services. <WI>

The current funding level for community-based services is severely lacking in meeting the needs of West Virginia citizens with developmental disabilities. Analyses of waiting lists, consumer survey responses, and unfulfilled court orders and federal mandates found large numbers of people in need of early intervention, family support, employment services and living arrangements. <WV>

FUNDING: RECOMMENDATIONS

Alabama should enlarge upon the programs which take advantage of financial incentives as long as the programs also fit within the priorities established by the state. <AL>

Examining the priorities of the state, it should be possible to allocate a better use of currently existing funds. As the community of consumers, individuals who have developmental disabilities, their families, and others who are interested in persons who have disabilities marshal their resources, it should be possible to obtain the needed resources. <AL>

State dollars must be expanded to fund programs for individuals from all categories of developmental disabilities. The existence of one responsible agency or a trans-agency team will facilitate the co-mingling of funds which will make it possible for Alabama to take optimal advantage of funding matching opportunities. <AL>

The issue of rate-setting is complex but central to improving community services, and various strategies are being evaluated around the country. It is important that the state conduct an in-depth examination of this issue in order to determine the best approach for Arkansas. <AR>

Fund people, not facilities. Move away from a slot system toward a funding mechanism that de-emphasizes rigid rate structures and encourages the creation of flexible supports according to individual need. Federal and state funding systems and regulations should be coordinated and integrated to facilitate the funding of people rather than facilities. This would allow consumers to receive a flexible array of services appropriate to need at different points in time. <AR>

Explore and develop creative means of financing new community initiatives, utilizing Medicaid funding as much as possible but without having this resource dictate the substance and direction of services. It is essential for system development, particularly in the area of Medicaid financing, to occur within the context of a clear set of goals and objectives reflective of a consistent vision of services. As in other area, Arkansas must look to the future and the shift in federal policy toward noninstitutional approaches. <AR>

DDD should assess what funding is required to serve persons who have both a developmental disability and a severe behavioral problem and identify all potential funding sources, including Title XIX. <AZ>

The DDD and RSA representatives on the Governor's Council should include information on issues and allocation of Social Services Block Grant funds in their regular budgeting reports to the Council to enable the Council to provide input to the Department of

Economic Security (DES) when appropriate; and an analysis of the Title XX Social Services Block Grant (SSBG) allocation process should be conducted to explore the feasibility of allocating more funding to direct services by streamlining the administrative and planning functions associated with allocation of SSBG dollars. <AZ>

DDD must continue to re-evaluate the factors and rules used to establish reimbursement rates to service providers to assure they reflect actual costs and support the goals of promoting integration, independence, and productivity. <AZ>

There must be adequate financing of services. More attention must be given to utilizing current resources, fiscal as well as in-kind, from both public and private sources, in a more effective manner. This includes the development and maintenance of a well-trained, stable direct care workforce in community based programs. This approach will require more flexibility within the state bureaucracy and the encouragement of state agencies to coordinate and share resources in ways which will more effectively tailor programs to meet the needs of the individual with developmental disabilities. <CA>

Given the endorsement by Coloradans for making changes in basic service systems in the state, the governor and legislature should enact policy changes that will result in provision of needed human services, rather than refusing to increase taxes. Another way to pay for services is to increase the operating efficiency of government and state-funded services. <CO>

In order to assure quality and stability in the community, Medicaid reform legislation must include a more explicit definition of "reasonable and adequate" including prevailing wages, fringe benefits and other operating costs as well as special rates to cover the extra costs of "downsizing" a large facility and "start-up" of new services. <CT>

There should be established within the Council either a unit, or procedures for contractual arrangements, that would have the exclusive responsibility for identifying existing and potential federal and foundation funding sources. This unit or contractor would develop concept papers, write and implement proposals which would insure to the benefit of persons with developmental disabilities and their families. <DC>

By 1992, the Hawaii State Legislature should allocate additional funds to provide services to people with developmental disabilities. Funding allocations should stipulate that programs incorporate the goals of independence, productivity and integration into the community. <HI>

The Hawaii State Legislature should stipulate that services provided to people with developmental disabilities through contracted services with state agencies should not be less than the amount necessary to provide the service. The contracts should reflect "pay equity" with state workers. <HI>

The Department of Health should develop a plan by July 1, 1991, for the programs and facilities usage to Waimano Training School and Hospital, and present Waimano funding should be allocated to community services with a significant percentage allocated toward family support services. <HI>

The state of Hawaii should plan and allocate resources for the necessary service supports, including transportation, personal care attendants, and case management. <HI>

Funds "saved" by maximizing Medicaid through reimbursement and/or matching funds should remain with the program rather than going to the General Fund. <HI>

Study the effects of funding levels upon the ability of community-based programs to recruit, train, pay, and retain qualified staff. <IA>

Expand the Mental Health/Mental Retardation Services Fund to include services for persons with developmental disabilities, and increase the level of funding. <IA>

Study the extent of county-to-county variations in the funding and delivery of services in Iowa, and determine whether alternative service delivery models exist that could provide equality of services regardless of county of residence. <IA>

Provide increased funding to all federally-funded programs to more effectively support requirements for the dissemination of information about each program. <IA>

One of the primary goals for provision of independent living services in Idaho should be a conscious shift of funding from facilities to individuals. Along with this substantial increases in state fiscal participation and utilization of partially federally funded services is necessary. <ID>

The federal and state service system should be changed so that funds are allocated directly to individuals with developmental disabilities and their families so that they can choose which services to purchase. <IL>

Priority in the state and federal budgets should be given to all initiatives by State and federal agencies, especially services under the Community-Integrated Living Arrangements Act, which provide individualized residential, employment, and leisure options for people with developmental disabilities, including severe mental illness, to live independent, productive, and integrated lives in the community. <IL>

Community-based facilities and programs are much more cost-effective. Increased funding is required for these facilities and programs to (1) meet current needs of the unserved population and those on waiting lists and (2) to assist them in responding to the accelerating demand for services as persons move from state institutions to their facilities and programs. <KS>

MRI (contractor) recommends that increased funding be provided by the state of Kansas to support community-based services and programs for the population of people with developmental disabilities to meet the increasing demand for service, to reduce the impact of inflation, and to provide the most cost-effective programs. <KS>

We recommend that the commonwealth of Kentucky increase its funding for developmental disabilities by \$13.7 million per year for the next ten years until its annual commitment to persons with developmental disabilities has tripled. <KY>

Invest early and generously in essential social supports. Services and programs that make people healthy, families intact, kids educated and hopeful, neighborhoods and workplaces safe, and the environment clean yield excellent returns in preventing or reducing the incidence, severity, or cost of disability and illness, and anti-social conduct. <MA>

Build a dependable, broad-based, fairly-supported revenue base, to "enlarge the pie." The DD Council has declared our support for the proposals of the Tax Equity Alliance of Massachusetts (TEAM). This requires great political courage during an era of anti-government passions, but is an essential duty of our elected representatives. <MA>

Stop the state budget cuts! An existing service means a lot to the people getting it or waiting for it. It should not be ended or trimmed unless and until something better is available. Savings from cuts in "people-support" services are usually illusory: the problem surfaces later, and worsens. <MA>

Invest in children: they and their mothers are the new poor. Ten years ago, 24.5 million Americans were living below the poverty guidelines, the U.S. Census Bureau reports. Last year, 32 million Americans were officially poor. The poverty rate for children under 18 continues to be higher than that of any other age group. Pay particular attention to the needs of minority families. More than third of all children under 6 in Boston are poor or near poor; three in four Latino children in Boston are poor or near poor. <MA>

Devise programs to encourage people with private resources to contribute them, and/or combine them with public resources, to create and enlarge new programs. Ensure, however, that people with private means are not favored over those without private means in the distribution of publicly-supported "people" services. <MA>

The state can and should do much more to access and use present Medicaid options for community services and private resources, including client trust funds and voluntary contributions to services. <MA>

Guard more prudently the public trust. People with disabilities and other taxpayers are enraged at what we must pay for the HUD and pentagon scandals, the savings and loan bail-out, and certain defense expenditures. <MA>

When money is needed for legitimate activities, raise it in a progressive way. <MA>

Pay your fair share for programs you create. For P.L. 94-142, special education, 40% federal support was promised: 9% federal support is actually delivered to the states. Federal funds for the WIC Program and housing, to name only two programs, have been slashed. It is hard for states to plan and deliver services under these conditions. <MA>

Fund more basic research to learn about causes, cures, treatment, and ameliorations of disabilities and diseases; support assistive technologies. <MA>

Support the reform of the ailing state funded purchase-of-service system for the delivery of community-based human services, especially via (a) adequate funding for staff and other components ensuring quality, and (b) simplified administrative requirements, as recommended by A&F's Office of Purchased Services. <MA>

Stimulate initiatives to expand local funding of services in addition to state funding. Include local governments in service planning and decision making in order to encourage their participation. <MD>

Adopt a plan to respond to needs of all persons waiting for community services. Assure that large scale service models to achieve "economies of scale" are not contemplated in any plan, but rather that services will be designed to enable individual exercise of abilities and choices. <MD>

Assure quality of services by raising existing base funding of operating organizations to adequate levels, including direct service staff salaries, while continuing service expansion in response to persons on the waiting list. <MD>

Provide enough funding for persons leaving institutions to permit services of the intensity necessary for successful community experience and enable purchase of services in a variety and choice of setting, including the consumer's own home, family home, and other living arrangements. <MD>

Increase funding levels for direct service staff of community programs in order to shore up the state's community service system, and assure that residential alternatives are supported in all Maryland communities. <MD>

Seek an enactment of the federal Medicaid Home and Community Quality Services Act (S.384), to assure that a broad array of services are available to support both persons leaving institutions and those who have not been institutionalized. <MD>

The Executive Department or the Legislature should establish a "Blue Ribbon Commission" to analyze the current system of financing services for persons with developmental disabilities. <ME>

Assure continued and expanded federal support for State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies and University Affiliated Programs. <ME>

We recommend increases in federal block grant and related programs which have been relatively flat funded for the past several years and, in effect reduced through inflation, including the Social Services Block Grant (Title XX of the Social Security Act) the Alcohol, Drug Abuse and Mental Health Services Block Grant, the Maternal and Child Health Block Grant (Title of the Social Security Act), the Urban Mass Transportation Act (Section 9, 16(6)(2), 18), Vocational Rehabilitation (Title I and Title VII, Title VI Part C), housing (HUD, FmHA, FHA), and education (P.L. 94-142, P.L. 99-457, P.L. 89-313). <ME>

An "Office of Resource Development" should be established within the Interdepartmental Council - "Children's Policy Committee". The "Office of Resource Development" should be jointly funded by the four departments (requiring legislative approval and potentially utilizing revenue generated by cost savings, resulting from administrative efficiencies and increased Medicaid, AFDC-FC and Title IV E usage). <ME>

The proposed Office of Resource Development should be charged with: coordination and maximization of federal and third party reimbursement and use of the existing resources, including technical assistance to local communities and organizations; planning and development of community-based care and treatment options for clients needing services with particular focus on services supporting family based care; coordination of funding for these options via single contracts, reporting, audits and accountability assurances; with participation from the provider, consumer, and advocacy community, act as a focal point for sharing information relation to current federal trends, bills before Congress, etc.; and act as a Maine consortium advocating for all persons with disabilities in critical matters pending at federal executive and congressional levels. <ME>

The governor should continue to work with the Michigan congressional delegation and others to address outdated formulae for distribution of federal funds to the states. <MI>

The Coalition for the Public Trust, and other groups committed to investments in people, should continue to examine the Tax Expenditure budget. They also should continue to educate policymakers and taxpayers about the costs and outcomes of this part of the state budget. <MI>

The governor and the legislature should develop policies and procedures on tax breaks, or tax expenditures, to assure that the state budget includes only those tax expenditures that accomplish a public purpose for which a direct appropriation would be made; benefit groups whose activities strengthen and emphasize public sector responsibilities; effectively accomplish that public purpose at the lowest cost without harmful unintended outcomes, and accomplish the purpose better than would alternatives, such as direct expenditure or regulation; all tax expenditures have sunset provisions, to assure their annual review by

the legislature; and each tax expenditure is classified by its public purpose and is annually reviewed by the legislature for continuation. <MI>

The governor, human services agencies, and advocacy groups should assure active outreach to groups of people who may be under-counted for the 1990 Census, so that population-based funding formulae do not under-represent Michigan's needs. <MI>

The Michigan Developmental Disabilities Council and other advocacy groups should continue their commitment to supporting increases in state revenues. They should continue working with others to help taxpayers understand the costs of providing needed human services. <MI>

The Michigan Department of Management and Budget should design the state budget to avoid using federal revenues and restricted revenues intended for program improvement and expansion to displace or supplant state funds. <MI>

The governor, the legislature, and the Michigan Department of Management and Budget should adopt and apply principles for designing the state budget to allow full use of available federal funds. Full appropriation of available Vocational Rehabilitation funds, and necessary match, should receive special attention. <MI>

The governor and the legislature should carry out the State Independent Living Council's proposal to require a Disability Impact Statement for any proposal to cut a Human Services budget. The Disability Impact Statement should detail the numbers of people affected and the potential negative impact on the quality of life for people with disabilities and their families. <MI>

The governor and the legislature should carefully re-evaluate state policies and budget priorities for programs dealing with prison expansion and capital outlay. This should include consideration of the long term effects of bricks-and-mortar investments at the expense of effective community corrections programs, early intervention and support programs, and other human services and education activities. <MI>

The Missouri Planning Council for Developmental Disabilities (MPC) should establish a consortium of various advocacy groups to pursue increased funding for services for people with developmental disabilities. <MO>

Campaigns for passage of mill tax levies for local funding for both developmental and mental illness services should be encouraged in all counties who currently do not have these levies. <MO>

The Mississippi Legislature should provide permanent funding to significantly expand and make uniformly available supported employment services, independent living services, and rehabilitation technology services. <MS>

Serious consideration should be given to shifting the current federal funding for non-medical services for people with disabilities out of the Medicaid program into a more appropriate program. Alternatives to medical funding that should be considered or utilized in combination include (a) funding services such as housing assistance and transportation through specialized programs or affirmative policies for the inclusion of people with developmental disabilities within the generic administrative agencies responsible for these services, (b) increasing Supplemental Security Income payments to a level sufficient to allow recipients to purchase needed support services, or (c) funding state developmental service agencies under the auspices of a non-medical federal program such as the Administration on Developmental Disabilities. <NH>

Increase federal funding for the Social Services Block Grant and other discretionary programs. Maintain state flexibility in the use of the funds to meet state needs. <NM>

New Mexico should increase its participation in grant, entitlement, and optional federal programs. Administrative, financial and other barriers to participation should be addressed by policy makers. <NM>

If reduction in institutional populations have an adverse impact on the economy of any area of the state, the governor should direct the Department of Economic Development and Tourism, the Department of Labor and other resources of state government to find alternate uses for facilities, provide assistance for any employee who is adversely affected and take other steps to minimize the impact on the economy. <NM>

New Mexico should expand the use of federal grants for Centers for Independent Living. <NM>

Change the current approach to funding services for children with disabilities to maximize flexibility and assure that the needed array of supports can be developed on the basis of the specific needs of the child and family and also allow for funding to "follow" the child. <OH>

Funding for basic services should be increased; "slot" differentials should be equalized; and funding for services should shift from Fairview Training Center to the community. <OR>

It is proposed that the Puerto Rico Central Office for Personnel Administration shall be responsible for studying means to provide incentives and better remuneration for government employees working with people with disabilities. <PR>

We are aware that additional funding is required by the different agencies to carry out these recommendations. <PR>

The service system will be based on vouchers: individuals with developmental disabilities or their families (when necessary) will have complete control over choosing and purchasing services. All those who meet the functional definition of developmental disabilities will be eligible to receive these vouchers. Consumers will establish and oversee the policies for allocating vouchers. <RI>

All programs providing services to those with developmental disabilities will use all funding for services to finance vouchers given to consumers, and will not directly provide services with agency staff. <RI>

If the service system based on vouchers is to work, individuals with developmental disabilities or their families (when necessary) need an organization to assist them in choosing services. This organization will be independent, community (local) based, and controlled by consumers. It will respond quickly and with respect. Though these organizations will be local, and they will be related to each other, sharing information and cooperating better to provide services. <RI>

With regard to funding for community-based services in South Dakota, we recommend that state officials, service providers, and other interested parties initiate a concerted, focused effort to analyze current problems and prepare a detailed plan to overcome such impediments to progress. Longer term state officials and other interested parties should examine alternative means of funding community-based services. <SD>

The state administering agencies in South Dakota need to receive increased resources if they are to perform effectively. <SD>

The Texas Planning Council recommends the Texas Legislature maximize the receipt of federal funds, particularly Medicaid, in improving health and human services. <TX>

The general assembly should provide permanent funding to significantly expand and make uniformly available supported employment services, independent living services, and rehabilitation engineering/assistive technology services. The administration and implementation of these services should be coordinated among DRS, CILs, DMHMRSAS, CSBs, and other appropriate state and local agencies. <VA>

The general assembly should provide sufficient funding and allocate appropriate manpower to enable significant growth in the human services system in Virginia. New specialized services and supports must be developed, financed, implemented, and monitored to meet the needs of Virginia's unserved/underserved population of persons with developmental disabilities. This may be accomplished both by expansion/modification of existing and traditional programs to accommodate persons with a variety of types of disabilities, and by creation of new appropriate programs and services needed by these constituencies. <VA>

The Title XX Social Services Block Grant should be restored to its original funding level. <WA>

Government should create incentives and make money available to facilitate the blending of all formal systems, the private sector and informal community resources. <WA>

Government should create incentives and make money available to facilitate the blending of all formal systems, the private sector and informal community resources. <WA>

Federal and state funding programs that serve children should be increased dramatically. As a result, services would be stable and dependable. <WA>

Wisconsin should incorporate into state law a policy statement that declares Wisconsin's commitment to eliminate the past and present realities of funding discrimination which penalizes families for keeping their child with disabilities at home. <WI>

The state of Wisconsin should adopt a statewide policy which clarifies Wisconsin's commitment to provide the necessary funding to enable people with developmental disabilities anywhere in the state to exercise their basic rights as citizens, and affirms that all citizens should have equal protection of their rights and, consequently, declares that needed funding for services to people with developmental disabilities will be allocated in fair, just, and equitable ways throughout the state, based on the individual service needs of people. <WI>

Wisconsin should incorporate into state law a policy commitment to establish equity in the funding of community and institution programs which serve people with developmental disabilities by ensuring that community programs will have at least as much federal and state funding support as will institution programs. <WI>

Wisconsin should incorporate into state law a five year policy goal to provide the state and other funding necessary to eliminate all waiting lists for basic and necessary developmental disabilities services in Wisconsin. <WI>

Wisconsin should incorporate into state law policy changes requiring the restructuring of community aids into eight categorical funding allocations based on specific human service needs and consequently improving accountability to the governor, legislature, and the general public. <WI>

Create an adequate and stable funding structure for community services that supports full community participation by people with developmental disabilities, including increasing accountability in the system for funding and providing basic community services such as early intervention, individual service coordination, community living arrangements, training for independent living, vocational and day services, respite care and other family supports, counseling, transportation, et al.; restructuring community aids funding into eight distinct

target group allocations; working to eliminate all waiting lists for community services; and ensuring equitable funding to all counties for community services. <WT>

Increase the per diem rates for Community Integration Program (CIP) IA and CIP IB to the maximum allowable levels under federal law. <WT>

HUMAN RESOURCES: BARRIERS

Just as public pressure is building in favor of ensuring that person with disabilities and their families receive the supports they need, there is concern throughout the nation that the supply of labor will not be able to keep pace with an expanding economy. Providing human services is a labor intensive endeavor where numerous positions offer only modest compensation. If the field is to expand its capacity to serve persons with disabilities and their families, it will need to learn to compete for its share of potential workers. Moreover, it will need to develop service design patterns and staff development strategies to match the type and amount that can be attracted. <AR>

Additional staff training is needed in all areas, but there is insufficient funding for training, especially for; ongoing case manager training, group home staff training, and specialized training for staff who work with medically at risk individuals. <AZ>

Problems in obtaining and maintaining a sufficient number of qualified personnel to meet the needs of individuals with developmental disabilities of all ages is of concern. Specific personnel areas which need attention include job coaches, family support specialists (social workers), behavior management specialists, residential training staff, and speech/language, occupational, physical, and recreational therapists. <FL>

State agencies report major problems in recruiting staff trained to work with people with developmental disabilities and trained in a particular discipline, such as law, medicine, mental health, or substance abuse. <IL>

Current budget allocations permit few community service providers to pay salaries which are sufficient to attract and keep staff who have received higher levels of training in working with special populations. <IL>

Few state agencies have procedures to train the staff of the agencies to whom they give grants to provide services for people with developmental disabilities. The most frequently cited training need among community providers was for information on current services; there are insufficient mechanisms to provide information to service providers about state agency services available to the providers' clients. <IL>

Two major barriers to service were found to exist in the state service delivery system: lack of trained, qualified staff at both the state and community levels and lack of quality assurance in programs serving people with developmental disabilities, including severe mental illness, and their families. <IL>

Staff vacancies, frequent turnover, and the resultant necessity to choose personnel with less than optimal qualifications results in serious shortages in direct service and professional staff availability and preparedness. <ME>

An organized incentive-based strategy for recruitment, education, training, and retention of qualified staff is noticeably lacking in both public and private sectors. <ME>

There is now sharp disparity between cost of living adjustments available to staff in state-funded community-based programs and state employees performing similar functions. This exacerbates the problem of staff retention and recruitment at the community level. <ME>

Well-trained staff are necessary to provide stable community and institutional residential services of high quality. Lack of qualified employees and high employee turnover rates have been identified as problems. <NC>

Because housing, recreation and transportation officials and professionals are not fully informed of the needs, abilities and limitations of people with disabilities, they fail to design accommodations which are suitable to those needs. <NV>

There is no cross-disciplinary professional training at the most critical level of learning, the college experience. Such training is essential to appropriate and effective technological intervention, as these are the professionals who will assist in planning the future and life quality of people with disabilities. <NV>

Individuals with disabilities want to be recognized as "people first", and want to have the same opportunities that are available to others for making life choices or following preferences and interests. Many will need information, skill training and supports in order to make appropriate choices and feel that service providers should more fully embrace the intent and spirit of the laws and regulations that ensure their rights. Individuals believe that this mainly involves a change in the attitudes of service providers. <NY>

Professionals want more information about laws and regulations, community resources, newly identified syndromes, and successful approaches. Their concern is that the information be presented in a manner that is not overwhelming. <NY>

Consumers have been aware of workforce issues for some time. In many parts of the state, they cannot locate certified therapists, such as trained nurses, bilingual professionals, behavioral specialists, those with knowledge of sign language, visual consultants, or adaptive equipment specialists. They have seen first-hand the staff shortages and high turnover rates in residential, day programs, and home care, and believe this has a negative effect on the quality of programs. <NY>

The state colleges and universities currently sponsor professional training in special education and speech/physical/occupational therapy. Expansion of these programs is subject to available funding within a fiscally stressed system of higher education. There is no public program of inducements (loan forgiveness, scholarships, etc.) to encourage the migration of graduates to underserved areas. <OK>

The establishment of a University Affiliated Program would provide a federally funded program located within an institution of higher education whose mission is to provide interdisciplinary training of professionals and paraprofessionals who serve persons with developmental disabilities. This program would provide a critical resource to Oklahoma in providing professional education and training to personnel serving persons with developmental disabilities. <OK>

Many parents and several professionals felt that professionals needed more information about how to relate to families of adults with disabilities. <OR>

Need to increase professional and other services providers' knowledge regarding autism and other developmental disabilities. <PR>

One major concern is the education, pre-service and in-service training of professionals working with people with developmental disabilities. In Puerto Rico there is not a curriculum or training program to prepare the professionals and allied health professionals that work with this population. <PR>

There is a need for the evaluation and modification to the curriculums to keep them up to date with changing knowledge. Training experiences must be provided out of the classroom. <PR>

The availability and maintenance of trained personnel is emerging as a significant issue in the provision of community-based services in South Dakota. Provider agencies, state officials, and advocates all expressed deep concerns regarding the effects that low wages and high rates of staff turnover are having on the quality, effectiveness, and stability of services to persons with developmental disabilities. <SD>

Serious limitations were noted in the ability of most direct service agencies to recruit and retain professional specialists. Nearly all such agencies noted substantial difficulty in hiring physical therapists. Locating and retaining psychologists and psychiatrists also is very difficult. In the more rural areas of South Dakota, including the Indian reservations, these problems are extremely serious. Clearly, the fact that South Dakota is predominantly a rural state contributes to these problems. In addition, state universities are not able to offer degrees in many key specialty areas. <SD>

The state's difficulties in recruiting professional specialists in key areas represent a barrier to meeting the needs of persons with certain disabilities. <SD>

High turnover and manpower shortages in key specialties are impediments to continued expansion of community-based DD services. Few states are able to avoid the problems stemming from national manpower shortages in professional disciplines such as physical therapy, occupational therapy, nursing, and certain medical specialties. <SD>

Families in Texas repeatedly expressed dissatisfaction with individual professionals who provided services to them or to their family member with disabilities. Frequently the problem was due to a lack of training and sensitivity regarding disabilities. Many families stated that they had traumatic experiences at the hands of professionals who were uninformed. <TX>

Professionals stated they felt unprepared to deal with many of the problems people with disabilities and their families encountered. They stated their training was often limited to skills needed to perform certain tasks such as teaching or meeting medical needs. Sometimes the training was specific to one type of disability and did not include any information on other disabilities. They expressed a need for continuing education programs and better postsecondary educational programs. <TX>

There is an increasing "professionalism" of the services provided to individuals with disabilities, resulting in a system that doesn't recognize the value of supports provided by the family. <WI>

Direct service workers who are working in the community are not receiving adequate pay and benefits. <WI>

HUMAN RESOURCES: RECOMMENDATIONS

Alabama is fortunate to have a number of individuals living within its boundaries who are making significant contributions to the field of developmental disabilities and who are recognized nationally and internationally as leaders in the field. We should find ways to take greater advantage of their expertise. <AL>

Money must be funneled into the pre-, in-service, and specialized training of personnel, including the broad range of personnel in the medical, social, and educational fields as well as primary caregivers. Resources should be made available for enlarging and strengthening academic programs. Additional resources should be channeled into the recruitment and retention of personnel. <AL>

Investigate the issue of labor resources in order to know that planned service arrays will be ones that can be adequately and competently staffed in the years to come. The possibility of worker certification should be explored. <AR>

Develop a statewide staff training plan to ensure that community program employees' skills match the services they need to provide. Higher education must also play a role in developing personnel preparation programs that will meet the future leadership needs of the DD system. <AR>

Increase training opportunities for professionals about persons with developmental disabilities. For agencies that have case management functions, existing pre-service and in-service training programs should include components on sensitivity and how to work effectively with persons with developmental disabilities. <GA>

The University Affiliated Program should provide quality, ongoing staff training and support to agencies providing services to persons with developmental disabilities to enhance the integration and independence component(s). <HI>

Students entering training for occupational or physical therapy, speech/language therapy, communication disorders, special education and other related developmental disability professions should have some of their college costs covered if they make a commitment to stay in Idaho to provide services. <ID>

All human service professionals and staff should be encouraged, on an ongoing basis, to learn about working with people with developmental disabilities. <IL>

Federal and state funding should be expanded or redirected to allow state agencies and community agencies which serve people with developmental disabilities, including severe mental illness, to recruit and retain high-caliber staff and to provide ongoing in-service training. Such training should include material to further sensitize staff to cultural differences among the people with whom they work. <IL>

Indiana shall develop and promote higher standards for personnel serving people with disabilities and provide more training and financial incentives to attract and retain these persons. <IN>

MRI (contractor) recommends that the state gather additional information on the wage/salary ranges for employees in the agencies and programs serving people with developmental disabilities. The relationship of salaries to staffing problems and the subsequent underutilization of some facilities should be documented. <KS>

The Department of Health and Hospitals should require agencies serving persons with developmental disabilities to arrange for their direct care staff to attend sexuality training to that the staff can provide training in sexuality. <LA>

The Office of Human Services should explore mechanisms to provide adequate training and compensation to direct care personnel serving individuals with developmental disabilities. <LA>

The Administration on Developmental Disabilities should fund the University Affiliated Programs to develop a statewide interagency planning initiative on personnel preparation. <LA>

Strengthen and sustain locally-based private, non-profit organizations as the key sources of service delivery and the capacity to recruit, train and supervise a pool of personnel available to support persons with development disabilities for an extended or lifelong duration as needed. <MD>

Institute training programs for Developmental Disabilities Administration personnel at all levels of the system to install in practice the values inherent in supporting persons based upon their choices and abilities. <MD>

The proposed plan for personnel development should establish a University Affiliated Program (UAP). The establishment of the UAP, via a grant application by the University System and securing other necessary state and federal funds, should be accomplished through a collaborative process. The disabilities community must be an integral part of the process, assuring the development of a UAP responsive to the needs of families and individuals with developmental disabilities. <ME>

The Interdepartmental Council, with the leadership of the Department of Educational and Cultural Services, should develop a comprehensive plan for personnel development utilizing the combined resources of Council members to attract and train needed professionals in human services (not limited to education). <ME>

Comprehensive education efforts should include an orientation for professionals in the service system to assist them in providing supports to individuals with developmental disabilities, to their family members, and to communities. <MS>

Training for professional personnel, such as health and mental health professionals, should include courses on working with individuals with developmental disabilities. <MS>

An innovative staff development system should be developed for future service providers of persons with severe disabilities. <NE>

Educational qualifications and the availability of pre-service and in-service training programs for human service professionals should be enhanced at all levels of personnel statewide. Salary incentives and career opportunities to encourage and reward staff for the attainment of post-secondary degrees should be an integral part of provider agency personnel policies. Greater efforts should be placed on developing arrangements between human service agencies and post-secondary educational institutions for internships, remitted tuition and flexible scheduling of time. Regulatory requirements for staff training should be carefully monitored and enforced through the quality assurance activities. <NH>

The university system should institute a course of study to train professionals and para-professionals in providing independent living skills and other rehabilitation teaching to people with disabilities and their families. <NV>

Management practices that support the workforce, such as job redesign, increased employee decision making, providing daycare and other benefits, advanced training and educational opportunities, must be expanded. <NY>

Initiatives to utilize and reimburse friends, relatives, neighbors or other community sources in providing supports for parents and individuals with developmental disabilities must be supported. Informal supports should be used first before more costly specialized services. <NY>

Creative approaches to recruiting people with and without disabilities into the human service field must be designed and implemented. Training and adequate compensation must be provided. <NY>

Attention must be given to recruiting, training, and nurturing service providers and paying them a wage that reflects the worth of the job they do for people with disabilities. <OH>

The Office of the Governor, in cooperation with the Oklahoma State Regents of Higher Education, should ensure the continued multi-university cooperation necessary to secure permanent federal funding for a UAP. <OK>

It is proposed that the University of Puerto Rico shall be the leader in curriculum development and the implementation of interdisciplinary pre-service and in-service training programs for providers of services to the population of people with developmental disabilities. <PR>

Emphasis must be placed on strengthening existing programs as well as developing new service models in order to facilitate the vision of a better developmental disabilities system. Concerted efforts are needed to expand and enhance the training of professionals who service this system utilizing in this process such entities as the University Affiliated Programs and the Commission on Higher Education. <SC>

The Texas Planning Council recommends the Texas Legislature require a course in disability issues which encompasses the values of independence, productivity and integration in the delivery of services as a requirement for licensing and/or certification and continuing education credits of professionals involved in planning, evaluation or delivery of services to people with developmental disabilities. This would include, but not be limited to training of physicians, dentists, nurses, allied health professionals, lawyers, teachers, psychologists and social workers. <TX>

The general assembly should require and provide funding for a statewide system of personnel support which includes in-service training and programmatic technical assistance for professionals and paraprofessionals who participate in the public/private developmental disabilities service delivery network. <VA>

The Virginia Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of interdisciplinary pre-service training to prepare professionals and paraprofessionals to deal with the assessment, training, and other service delivery needs of persons with developmental disabilities. <VA>

Service providers must be well oriented and trained to provide only what the person with a disability wants and in a manner that values that person as an individual. <VT>

Provide adequate pay and benefits to direct service workers (e.g., personal care attendants, job coaches, group home staff, etc.) who are working in the community. <WI>

QUALITY: BARRIERS

Programs can meet requirements of licensure, such as ICF-MR and ACDD accreditation regulations, without providing quality services. Monitoring of quality of life issues is critical. <AR>

Services should be "driven" by the person's needs, rather than by funding sources. <AZ>

With the exception of the volunteer ARC parent monitoring, there is no quality assurance system which does not receive state or federal funding in place for services provided by DDD. There are no checks and balances. Yearly licensing of residential settings is an internal process and day programs have no formal review process. Overall, quality control and assurance procedures appear to be very weak and/or ineffective in Arizona. There is a critical need for reliable external safeguards. <AZ>

Eight out of 10 providers agreed that individual plans focus too much on what is available than the needs of persons with developmental disabilities. <DC>

It is clear from comments in the public forums that specific administrative efforts could make the regulations affecting quality control and compliance procedures more relevant to actual service goals that help individuals become more integrated, productive members of their communities. As one forum participant notes, "I'm a parent and...I feel a drawback in the group homes is that there is so much red tape and paperwork that it robs staff of time for teaching independent living skills...I think it's better to invest our money in hiring good personnel to work with people than to be spending it on paperwork." <IA>

There must be a switch away from service process to service outcome to effectively evaluate and manage the services a person receives. <ID>

Information is needed on organization, recruitment, training, public reporting and effects of alternatives, citizen/consumer monitoring systems for community program sites. <MO>

The low self-concept of the consumers may be an indicator that the services they are receiving do not necessarily meet their needs and interests. <PR>

Although the results of the study show that a majority of consumers are satisfied with the services they are receiving, this may be biased, as many persons do not express what they really feel because are afraid of losing the services they are receiving if they complain. <PR>

Most diagnostic and assessment tests are adapted from the United States and they have not been validated with the Puerto Rican population, nor are there norms for our population. <PR>

Virginia makes few efforts to systematically evaluate the effectiveness and efficiency of services and supports provided to individuals with developmental disabilities. Despite efforts of the Board for Rights of the Disabled, opportunities for consumers and families to express satisfaction and concern with the services they receive are rarely provided.

<VA>

QUALITY: RECOMMENDATIONS

For the first time the state has a separate staff position on quality assurance in the Division of Developmental Services (DDS). The focus of this individual's effort should be three-fold: ensure minimal compliance with existing licensing standards; focus on enhancement of service quality; and develop a multi-faceted quality assurance system that includes components for consumer/family monitoring, and an increased systems-wide monitoring presence by the Protection and Advocacy agency, Advocacy Services, Inc. <AR>

Quality of services provided to individuals with developmental disabilities must be established through consistent program standards which are effectively monitored. The standards must be developed to reflect the principles of independence, productivity and integration into the community to the fullest extent possible. <CA>

Funding mechanisms must cover provider costs in meeting the established quality standards. <CA>

The State Planning Council on Developmental Disabilities should be designated and funded to establish a quality assurance unit responsible for evaluating existing standards, establishing new standards and monitoring services for people with developmental disabilities. The standards developed will be on a systems basis. <HI>

Indiana shall restructure services so that residential and community day programs are designed to be flexible and to meet people's changing needs. <IN>

MRI (contractor) recommends that the state identify in which regions placements from state institutions should be made and attempt to place persons in or closest to their homes or their counties of origin. MRI recommends that the Kansas Association of Rehabilitation Facilities (KARF) work with the state to monitor community placements. <KS>

If accreditation is required for licensing in the future, the state should provide additional resources, including additional financial support, in order for existing agencies to achieve accreditation. <KS>

Encourage voluntary citizen monitoring of service quality as a means for consumers, community members, and families to promote the most consumer responsive services. <MD>

Identify an objective third party who can receive completed evaluations from individuals, families, and advocates regarding the quality of assessment, planning and implementation. Have the third party create regular reports on the system's quality, and report findings to state agencies, services, and advocacy organizations. <MN>

Have consumers and families use simple, but powerful, checklists to monitor and evaluate services. <MN>

Friends and family as monitors: ensure that there are people who are close to the individual (rather than paid to be) involved in the regular monitoring and evaluation of plan implementation. <MN>

As a supplement to its internal quality assurance activities, the Division of Mental Health and Developmental Services should work towards the establishment of (a) empowered consumer monitoring of service quality for all services funded by the Division, and (b) an ongoing peer review system for Area Agencies. <NH>

Institutions should seek accreditation by nationally recognized bodies(i.e., Commission on Accreditation of Rehabilitation Facilities, Joint Commission on Accreditation of Hospitals. <NM>

State and federal grant programs must include funds for evaluation and requirements that consumer satisfaction and impact on independence, productivity and integration be major components of any evaluation. <NY>

The impact of services must be measured largely by whether or nor the service meets the needs of people with developmental disabilities and their families. Better ways of measuring this impact in terms of independence, integration, and productivity must be found. <NY>

An ongoing system of consumer satisfaction evaluation should be established. The system should be individually focused to supplement program evaluations, and should include quantitative as well as qualitative assessments. <OR>

The results of the study show that consumers are apparently satisfied with the services they receive from private as well as public providers. As a result, private organizations should be considered as potential service providers. <PR>

In all programs receiving public money, consumer councils or another independent evaluation system will be developed and used to evaluate programs and ensure protection of human rights. <RI>

The general assembly should establish and make uniformly available throughout the state a quality assurance system that is independent from agencies which directly fund/provide services, that actively involves consumers with developmental disabilities and their families, and which evaluates programs and services with criteria of individual outcomes relating to independence, productivity, and community integration. <VA>

Local agencies should receive supportive consultation that encourages them to evaluate their programs without the outcomes being tied to program funding. <WV>

A combination of strategies is needed to ensure the provision of quality services that are consistent with the goals of independence, productivity and integration. One of these is a planning and evaluation system that establishes clear goals, allocates funding in a manner consistent with those goals, and measures program outcomes to determine the extent to which the goals have been met. <WV>

DATA COLLECTION: BARRIERS

Multiple States

There are no recent national data on the way the HCB Waiver program is being used by the states nor any separation of data on expenditures for people in state-sponsored residential care programs versus those for people living in their own homes, despite the critical need for information on the potential of this approach in financing such supports. <LA,MT,UT,WY>

Individual States

Planning for a "service system" is impossible with current methods of data collection. Information collected by individual programs about the people they serve is generally not comparable across programs. The majority of people probably use more than one service at a time but it is currently not possible to determine how people use the "system" to meet their needs. <AK>

There is no common method of collecting information on clients and services used by people who experience disabilities. Some programs have long standing computerized information systems while many others are still using paper systems that make analysis of service information difficult and time consuming. <AK>

Due to improper, incomplete, or outdated classifications and definitions of disability, inappropriate or unavailable testing of children and adults, and the failure to identify a large segment of the elderly population with disabilities, a vast number of people with severely disabling conditions are not included in the figures representing the population with disabilities. Clearly, this definitional dilemma should be an initial effort in addressing the needs of individuals with developmental disabilities in the 1990s. <AL>

There is a general lack of definitive information about the needs of Blacks with developmental disabilities. However, it is known that many Blacks with developmental disabilities are low income, have not completed school or vocational training programs, and in general are considered disadvantaged. It was reported the greatest need are for culturally appropriate services to enable them to compete effectively for jobs, family support services, and information on services available. <CO>

Although data are available from the Division for Developmental Disabilities, data on enrollment of minorities with developmental disabilities are unavailable for other agencies. <CO>

Good data on the number of people who have multiple disabilities and the true extent of disability per the federal definition are unavailable. <CO>

A review and analysis of state and federal program data has certain inherent limitations. First, the developmental disability definition is problematic. There was virtually no data on information maintained according to the federal developmental disability definition. The procedures to "fit" existing data into the definition were difficult at best and simply did not provide a complete story. Second, the data provided by most state programs is woefully inadequate to respond to the important issue of how effectively services are promoting independence, productivity, and integration within the community. <GA>

One area for which there is not a chapter, but which did surface repeatedly as a difficult issue, was the lack of available and useful data. While our consumer surveys, public forums and focus group input provided us with a data bank previously unavailable in Idaho, the preparation of this report reminded us once again of the gaps in information created by a range of different reporting systems driven by different needs. In all fairness to state and local agencies, much of the data collected is in response to federal funding requirements, which may or may not have relevance to local or state data needs. To the extent, however, that this report points out information for which data is soft, difficult to retrieve or non-existent, we hope that changes in policy and practice will reflect an effort to alter current methods of information gathering and dissemination. <ID>

Federal funding formulas which are based on state population sometimes underestimate the number of residents with developmental disabilities who potentially might be served in particular geographical areas. This may lead to underfunding of services. <IL>

Many human service state agencies have no record of how many people with developmental disabilities are being served, if any at all, by them. <IL>

Current reporting methods do not identify clients in such a manner that an accurate enumeration of the total population with developmental disabilities in the state proved to be possible at this time. Only program data use is possible which results in duplicated counts. <KS>

MRI (contractor) found that annual client data are not routinely maintained by a number of the agencies surveyed. <KS>

Sufficient data are not maintained to permit an accurate analysis of costs and fees on all programs. <KS>

As a result of the project, more extensive data are now available. However, statistically accurate estimates of future need are not possible at this time, based on the MRI survey, because of lack of consistent data collection at some agencies. It is impossible to project from the current information available (from either KRIS or HSRI data) what the ACTUAL need may be for services in specific counties. <KS>

Various state studies have been undertaken to estimate the number of people served and expenditures, but rarely do these studies focus on outcomes such as changes in independence, productivity, and integration. Nor do these studies provide an accurate estimate of need based on type of disability. <MN>

While collecting data from the various state agencies for the "1990 Report", the Council staff and contractors found that it was difficult to identify the number of persons with developmental disabilities served by each agency. <NC>

There is no reliable way to document how services changed the lives of people. The DDCPC's Consumer Survey provided information on people's levels of satisfaction with the services they are now receiving, but did not provide information on how the quality of life of individuals and families was changed by these services. Traditional surveys usually focus on what people feel they need, at that point in time, based on what is available. They do not take into account people's total lives or their changing needs. <NY>

When policy analysis and program development actions are encouraged by federal funds and programs, obtaining state specific information is extremely difficult. <OK>

This issue overlaps with all other concerns, yet it was raised separately by respondents in all the reports and by participants in the public forums. Underlying many of the opinions and experiences in the reports seemed to be a basic desire for more information. This gap of information is far from being restricted to consumers and families. Some of the most serious information needs seemed to be that of professionals. <OR>

There is concern among the institutions serving the population with developmental disabilities regarding the lack of reliable statistics. This is necessary for the planning and implementation of services for this population. <PR>

Information presently available does not appear to support the development of any firm conclusions regarding client outcomes. <SD>

There is currently very limited accurate documentation concerning the numbers, characteristics, and unmet service needs of Virginians with developmental disabilities. The lack of such information has resulted in insufficient planning and advocacy to expand services. Since many persons with developmental disabilities do not currently have an active local agency at either the state or local level, no formal effort is being made to develop a centralized data base on the size and nature of the population with developmental disabilities and the extent to which service needs are met or unmet. <VA>

DATA COLLECTION: RECOMMENDATIONS

The state should require that all new agency information systems use a common system of generating consumer identifiers. This will greatly enhance the state's ability to compare information across programs. <AK>

Alabama is in a unique situation with the recent awarding of \$20 million from Civitan International to the University of Alabama at Birmingham for the development of an international center devoted to research in developmental disabilities. This money which will be given over a period of years can be used for leveraging other monies. Alabama and the nation must take advantage of the opportunity to proceed with focused efforts to gain and disseminate knowledge related to developmental disabilities. <AL>

A top priority must be given to research in the field of developmental disabilities. There is a dearth of information as to the efficacy of intervention approaches. Factual data in this arena will assist in the procurement of third party support for assessments, treatments, and provision of technology. <AL>

Improve management information system. Ensure that management information systems include data elements which provide for the identification of individuals with developmental disabilities and develop cross agency and inter-office methods for aggregation of service and budget and expenditure data by type of service. <FL>

Encourage the maintenance of complete data on consumers' complaints. Encourage agencies which are responsible for handling consumer complaints to maintain data on the number and type of individuals with developmental disabilities who contact them, the nature of the complaint, and resolution of the complaint. <FL>

MRI (contractor) recommends that the state allocate sufficient resources to ensure the completion and maintenance of a comprehensive data collection and information system. To facilitate this effort, reporting requirements for agencies should be enforced by the state for licensure to ensure a continuing flow of accurate information. <KS>

Agencies reporting on the KRIS system should require that each client served or who applies for services have a Social Security number. KRIS personnel, in turn, should develop a method for unduplicating client and waiting list counts utilizing these Social Security numbers. <KS>

Additional follow-up on data collection with the nonparticipating agencies should be undertaken to inquire which counties they serve and in which counties their facilities are located in order to provide a true picture of where all the facilities are located and actual service areas. <KS>

MRI (contractor) recommends that agencies that do not already do so maintain records on how many clients they serve each year and that the state maintain aggregate data on a year-to-date basis through the KRIS system. <KS>

MRI (contractor) recommends that the state (SRS and KRIS) give consideration to providing computer hardware and training for those agencies currently unable to provide consistent information on clients and programs. <KS>

In order to provide useful information relating to costs and fees, MRI(contractor) recommends that SRS, utilizing KRIS and other appropriate sources, record, analyze, and provide costs and fees data on all programs. <KS>

Agencies need to develop mechanisms for tracking and monitoring the ethnicity of their clients, for purposes of program planning and educating staff. This must be done in such a way that it respects clients' rights. <MA>

Secure linkages between the databases of the Developmental Disabilities Administration and the still developing early-intervention database (under P.L. 99-457), schools, Division of Vocational Rehabilitation, and local health departments for appropriate planning. However, assure that design of data systems does not label children and adults with developmental disabilities in a manner which diminishes expectations of their own abilities to choose goals and develop toward unrestricted potentials. <MD>

Reports on federal expenditures should be expanded to provide additional information on how supports are financed and the availability of supports to people with developmental disabilities. This information should be complemented by consumer-based research on the relationship between supports and the ability to reach greater independence, productivity and community integration, building on the Mississippi Developmental Disabilities Council 1990 Report. <MS>

Further analysis of the prevalence of substance abuse or alcoholism among persons with developmental disabilities is necessary, with more funding and efforts applied to prevention and treatment. <MT>

The Council recommends that an in-depth analysis of the services provided by at least two state agencies be conducted each year, beginning in January 1991. <NC>

The Council recommends that the divisions with the Department of Human Resources work with the Council to develop a consistent system of collecting and reporting data on services utilized by persons with development disabilities by January 1, 1991 and other state departments work with the Council to implement the data collection and reporting system developed by the Department of Human Resources beginning no later than July 1, 1992. <NC>

As part of the effort to secure support for sufficient legislative appropriations for prenatal care under Medicaid, DHS, in cooperation with the Health Department's Maternal and Child Health Division, should attempt to prepare a comparative cost analysis for presentation to the state's policymakers. Ideally, this analysis should compare the substantial costs of providing neonatal and ongoing health care for premature and with birth defects children with the relatively low cost of providing the prenatal care that would prevent many of these premature and defective births. <ND>

Data collection at the local and state level should be improved. Mandatory collection and reporting of appropriate data may help to ensure that more individuals receive such services. <NM>

Information which is collected by a number of state and/or federal agencies about the same and similar issues related to people with developmental disabilities must be collected in a consistent format. <NY>

New ways of collecting and using information about the preferences and needs of people with developmental disabilities must be developed. People with developmental disabilities, their families, and providers must be equal partners in the planning of this information collection. <NY>

Fund an in-depth fiscal analysis. Government funding is needed to determine with certainty the number of persons presently eligible for and in need of services, as well as those individuals that are presently underserved who require expanded services. A fiscal analysis could project the costs of these services and could assist in making recommendations of how present funding streams can be reorganized and expanded to meet the identified needs. <PA>

All programs providing services to those with developmental disabilities will use the functional definition in consumer records and agency reporting. <RI>

Programs should require the collection of client-specific data to better facilitate the analysis of statistics relating to persons with developmental disabilities. <SC>

In order to provide key system actors and policymakers with vital information regarding the performance of state programs serving persons with developmental disabilities, it is recommended that ODDMH initiate steps to develop and implement a management information system which focuses on the collection of outcome data. <SD>

The Texas Planning Council recommends the Texas Legislature monitor and enforce Rider 114 in the 1989 Appropriations Act which requires 13 state agencies to report certain data elements using uniform geographic boundaries. <TX>

The Utah Department of Health should immediately implement the steps necessary to make the Utah Registry for the Handicapped functional. <UT>

The general assembly should require all state and local agencies which receive public funds to establish and maintain waiting lists of people requesting services who are not being served or who desire additional services to provide data for planning, evaluation, and program development activities. <VA>

The general assembly should require and provide funding for a coordinated statewide data base on disability to be established and maintained. This base of information must include extensive data about the characteristics and service needs of persons with disabilities, detailed information about relevant programs and services provided by state and local agencies, and employment information. <VA>

Policymakers and program designers should fully utilize available needs assessments, surveys, and program evaluation data. Resources should be directed at eliminating information gaps and all information should be easily accessible and shared with all appropriate organizations. <VT>

COORDINATION: BARRIERS

Because there are multiple health care systems in the state, coordination is a major issue and the possibility of people falling through the cracks between systems is a continuing concern. <AK>

The Alaska DMHDD uses a categorical definition of developmental disability. The Infant Learning Program, Special Education, Handicapped Children's Program, and Medicaid use a wide range of definitions to determine eligibility for services. <AK>

There is great disparity in eligibility criteria for programs serving people who experience disabilities. As a person ages, the services and supports they can receive change. A child is eligible for medical services that are not available to adults. Adults do not have access to the therapy services that children receive as part of special education. <AK>

While it is common and appropriate for state agencies to work together to expand expertise and services, there are frequently artificial, administrative problems in Alabama. These problems sometimes interfere with contractual arrangements between agencies and should be reduced or eliminated. <AL>

Details of the findings are mixed but when brought together give a picture of uncoordinated activity. Numerous agencies, tax supported and voluntary, purport to meet selected needs of people who have developmental disabilities. The resulting service delivery system is a fragmented one. <AL>

Findings highlight the need for increased interagency collaboration. While agencies are aware of this need, there are often legal barriers or disincentives, such as insurance liability or a lack of interagency agreements, to interagency cooperation. The onus for investigating specific barriers rests with planners at both the state and federal level. <AL>

Cooperation and communication between and among agencies is ineffective in removing obstacles to services or in eliminating discrimination. Regulations governing the access or services are frequently inflexible. <AL>

The program planning process in Arizona's service system occurs at several levels: statewide, regional, county or local. The varying levels at which the planning process is conducted may increase the difficulty in coordination of planning efforts across programs. <AZ>

Many programs which serve people with developmental disabilities use neither the state nor the federal definition of developmental disabilities. Each program's target population is defined by its own legislation. For instance, Special Education's definitions of handicapping conditions covers the broadest range of disabilities of all the programs.

Another example is that the Rehabilitation Service Administration's (RSA's) legislation defines "severely disabled" as an individual who has a severe physical or mental disability which seriously limits one or more, rather than three functional capacities. <AZ>

There is need to coordinate long term care services with existing tribal services. There is concern that the Medicaid system and the Bureau of Indian Affairs system will run parallel services. <AZ>

Each service division in the State of Arizona reported a need for better coordination with other service delivery systems. Many gaps that were identified could be filled if all elements of the service system did planning and problem solving together. <AZ>

The problem of cooperation and coordination among providers, regional centers and the Department of Developmental Services has been identified through the public input process. <CA>

Eight out of 10 service providers said that intra-agency/organization coordination is not at a high enough level. <DC>

Providers and advocates expressed concerns about the lack of coordination between multiple program and service providers. Problems in coordination were cited as limiting access and creating conflicts. A case manager representing a single program is not able to effectively assist individuals in obtaining needed services in a coordinated fashion. <FL>

Lack of a single point of accountability to ensure that individuals who are developmentally disabled receive adequate, comprehensive habilitation which is designed to assist them in attaining independence, productivity and social integration. Habilitation continues to be provided piecemeal and results in a fragmented, short-sighted view of an individual's potential for progress. Each agency, program, budget entity, etc., attends as best it can to its "part" of the individual. Coordinated, effective collaborative efforts are few and often conflicts occur which are not in the best interest of the consumer. <FL>

Consumers, caregivers, providers and advocates struggle to ensure that individuals with developmental disabilities meet the eligibility criteria of the myriad of program/services which they need and individuals may be "misabeled" to secure needed service. <FL>

Another system-wide concern identified by survey and forum participants is the lack of coordination among the various service providers. The application processes for many programs duplicate one another, and consumers wonder why they must provide the same information over and over again; why can't providers share information? Specific areas of complaint focus on duplication, conflicting regulations, long time lags between establishing eligibility and having access to services, and the difficulties of working with more than one program when services aren't coordinated and providers aren't

communicating. <IA>

Because programs are administered at different levels, consumers must often contact service representatives at the county, state and sometimes federal levels to find the answers to their questions, or to present required information. <IA>

Service providers indicated they were 2:1 in favor of a unified Department of Developmental Disabilities. This was partly because of constant problems they were experiencing with lack of interagency coordination, leading to duplication of effort between state agencies and gaps in service. <IL>

There is a continued need for state and local agencies to link together more so that services are implemented to the advantage of the person with a disability. For example, the medical community needs to collaborate more with the vocational rehabilitation sector. Case management systems may need to be strengthened to accomplish this. <IN>

Despite an Executive Office of Human Services, numerous state service agencies, advocacy-oriented state agencies such as the Office of Handicapped Affairs and Mass. Developmental Disabilities Council, the Governor's Office of Human Resources, and many other bodies, there is no clear, consistent place or process for setting state policy on key disability matters. <MA>

Consistent public policy and resource focus is uneven across many state agencies. Their current services and new initiatives are critical to persons with developmental disabilities. <ME>

Maine's developmental disabilities community, the university system, and other institutes of higher education have yet to fully realize their collaborative potential. <ME>

Disparity in services among counties is another major concern. Most services available to persons with developmental disabilities are state administered but locally controlled. Because of local control and the differing amounts of money provided by local government, services for persons with developmental disabilities vary greatly in quantity and quality among counties. <NC>

Concerns are magnified by limited information exchange. Individuals with developmental disabilities and their families are experiencing great difficulty in identifying and accessing services resources. Service providers are having difficulty, particularly with limited funds, identifying effective methods for reaching potential clients. <NC>

Current agency-specific mandates regarding case management result in poor transition planning and frequently allow persons with developmental disabilities to "fall through the cracks." <NC>

No comprehensive written plan exists for DD services administered by the Department of

Human Services. With no such plan in place, DD service providers and consumer and advocacy organizations encounter a great deal of difficulty in trying to anticipate DHS policy changes and service delivery initiatives relative to developmental disabilities. The absence of a written plan invites arbitrary policy change by DHS and little or no input from providers or consumers and inhibits the ability to evaluate the state's progress toward achieving an optimal community-based DD service system. <ND>

The structure of the service system that individuals with developmental disabilities and their families must access creates problems with coordination of services. One commonly cited problem is the lack of clear roles and responsibility for the entities, and families may be unsure who is in charge. To a certain extent money is control and as local schools come to rely on special education money from the state and regional programs on Medicaid Waiver funds, conflicts arise regarding the matter of control. <NE>

Even other Divisions within the Department of Health and Human Services whose activities are clearly relevant to, for example, children with special needs or adults incapacitated by a developmental disability, do not keep data or have any provisions for accommodation of their services for people with developmental disabilities. Such a system contains great potential for gaps, overlaps and confusion. <NH>

The large variety of different geographic divisions of the state is a source of unending confusion to people who need services. The twelve geographical subdivisions within developmental services, referred to sometimes as "areas" and sometimes as "regions," do not match either county boundaries or the geographic boundaries of other state departments or other divisions within the same department. The same individual may be in seven or more different "regions" at the same time, depending upon the agencies with which he or she has contact. To coordinate services, representatives of each of the organizations involved must deal with a confusing array of different offices of the other organizations. <NH>

Current agreements exist between the Department of Health and Human Services and the Department of Education regarding services to children with developmental disabilities, and between the Bureau of Community Developmental Services and Division of Vocational Rehabilitation regarding supported employment. Information from consumers indicates that neither agreement is meeting its intent. <NH>

Over ten years ago the original pilot program for deinstitutionalization of the residents of what was then known as the Laconia State School was evaluated and the results reported to the legislature (Provider's Management Inc., 1979). The report highlighted the importance of interagency agreements for comprehensive service delivery and recommended establishment of an "Interagency Task Force on Community Services to the Developmentally Disabled" with the responsibility to develop interagency agreements. Since that time the number of different agencies affecting people with developmental disabilities and the system of community services has grown far more complex. The need

for workable interagency agreements is greater than ever. <NH>

The diverse nature of the state has resulted in a service delivery system for persons with developmental disabilities and their families which is fragmented and contains significant gaps. Access to services is largely dependent on the age of the individual and the area of the state in which he or she resides. Services (except for public education) which are intended to enhance integration, independence and productivity, are, for the most part, not accessible to the majority of people with developmental disabilities. <NM>

A fragmented services system and the lack of an integrated case management system are significant barriers for people with developmental disabilities. Lack of availability made case management services the sixth ranked need by all respondents to the Consumer Satisfaction Survey. <NM>

Providing employment services for persons with developmental disabilities requires a great degree of cooperation among state agencies, service providers and the general public. Resources are divided among a number of public agencies. Community agencies have only a limited ability to create jobs and must work closely with employers in the public and private sectors to meet the need for competent and dependable workers. <NM>

Because educators and rehabilitation personnel are not aware of the rights of clients with disabilities and of inter-agency resources, they often fail to provide appropriate referral and service information. <NV>

Individuals and their families often have multiple needs requiring them to interact with a variety of agencies. They describe the hardships imposed on them in having first to seek our resources and then to deal with numerous personnel located in different settings. They see the system as fragmented and unresponsive. <NY>

This issue is critical in the daily living of persons with developmental disabilities. The absence of a uniform definition of developmental disability creates confusion and misunderstanding, which in turn, creates barriers to services. The importance is related to federal and state coordination, planning and implementation of initiatives supporting people with developmental disabilities. The federal government has been increasingly proactive in establishing programs and funds to provide for people with developmental disabilities. In that regard the federal government has adopted a uniform definition of "developmental disabilities." State agencies will have varying definitions of "disabled" depending upon the purpose and clientele of that agency. <OK>

Several informants thought the developmental disability service system had become overly bureaucratized and politicized. Many attributed this perceived politicization to inadequate communication among state agencies, and between state and county agencies. <OR>

Although there has been genuine interest and efforts in the development and

implementation of programs for people with developmental disabilities, each agency is working on its own without the necessary coordination. Coordination is a must for the successful implementation of such programs. <PR>

South Dakota's present system of delivering services to such persons is less the product of careful planning than the result of relatively independent development of specialized service delivery networks that have evolved to meet particular needs or been established in response to federal mandates or funding opportunities. South Dakota is not unique in this respect; similar historical patterns are evident in other states where the delivery of MR/DD services is spread out among a variety of state and local agencies, as well as public and private service providers. Inevitably, under these circumstances, service delivery is affected by a variety of points of view concerning program objectives. In some cases, duplication, inefficiency, and even unhealthy competition among the various systems are the result. While "coordination" is an often stated objective in managing services to persons with developmental disabilities, in practice it is very difficult to achieve that objective effectively. <SD>

A number of individuals who were interviewed cited shortcomings in interagency coordination of services as a major weakness. In the area of vocational services, for example, it was noted that services managed by ODDMH and those overseen by DVR are not well coordinated. As a consequence, strategies for enhancing employment opportunities for persons with developmental disabilities have not been effectively structured. Similarly, the rapid growth of education cooperatives within the special education system is viewed by some as potentially duplicative of services and programs offered by the adjustment training centers. Significant coordination problems were cited as reducing the effectiveness of early childhood programs in the state. <SD>

The level of collaboration among the state agencies, particularly in the development of joint program initiatives, appears to be weak in South Dakota. <SD>

It appears that the level of interagency cooperation and collaboration at the local level in South Dakota is mixed. It is apparent that there is tension among some local agencies. One area in which there is considerable tension is the relationship between adjustment training centers and educational cooperatives in many areas of the state. <SD>

The state has not seized upon changes in federal policies as opportunities to improve the coordination of programs in key areas. More specifically, the state's responses to the planning and service coordination provisions of the Rehabilitation Act Amendments of 1986 and the new Part H of the Education of the Handicapped Act have been particularly weak. <SD>

One service provider stated there could be a good working relationship between the state and private providers if the current atmosphere were more conducive to the private sector. He reported problems with inconsistent and frequent rule changes; dilatory

practices in paying providers for services which has resulted in cash flow problems and the need to charge higher prices to compensate for those additional costs; a lack of accountability by public agencies; excessive monitoring; and the failure of state agencies to adopt good business practices. <TX>

The patchwork nature of federal and state legislation creates immediate barriers to developing consistent definitions of services and eligibility criteria. At the state agency level, there are at least 17 state agencies responsible for planning, operating and accounting for health and human services programs. Because each agency is independent, there is a tendency to develop programs in a patchwork and uncoordinated manner. When programs with similar goals are developed by separate state agencies, the potential for differences in eligibility criteria and gaps in services is increased. <TX>

State policymakers have only a vague and general understanding of the health and human services system, there are countless differences between programs with similar goals, and the public is totally confused about how to access the system. Individual families see no logic in the gaps in eligibility criteria and geographic availability of services. <TX>

Utah's system is no less and no more complex than that of any of the other states. However, professionals operating in the field typically are unaware of all resources available to persons with disabilities, never mind being knowledgeable of service eligibility requirements. For parents of a child with a developmental disability, the service is an unending maze or obstacle course which must be traveled. <UT>

Congress has shown, in the passage of the House Medicaid Reform Bill, a troubling tendency to Congressional micro-management with extensive program management requirements established statutorily. The extensive requirements severely limit the usefulness of the program for the states. Such requirements increase program rigidity and bias, and exacerbate program gaps and complexities. <UT>

Another need for individual and family support that was identified in the public meetings was for service system information and referral. The complexity of the system makes guidance and assistance in service access a critical need, one that is being inadequately met in many areas of the state. <UT>

Interagency program collaboration and coordination of client services are difficult to achieve because of variations in specific mandates, administrative structure and operations, limited target populations, funding restrictions, and other constraining "turf" issues. The lack of formal case management for most persons with developmental disabilities impedes their accessing services across multiple agencies and programs. <VA>

State agencies and many other services do not necessarily have common service regions. For example, a person living in Hardwick may receive mental health services in St. Johnsbury and welfare services in Morrisville. These services are 35 miles apart and the

two agencies have very little opportunity to work together due to the geographic boundaries and structure of the service system. There tends to be a regional model, but it is not functionally complete because of the number of situations where service regions overlap inconsistently. The resulting problems are confusion over where services should be accessed and a lack of coordination among the services in different regions. <VT>

Persons with developmental disabilities may work with several service providers in pursuit of ways to have a variety of needs met. Staff changes and lack of communication among agencies, confusion over service boundaries and roles and a lack of a planned case management system have interfered with interagency cooperation. Fifty three percent (53%) of the respondents of the Consumer Satisfaction Survey (CSS) expressed a need for case management services. <VT>

It is not always clear to people with developmental disabilities or their families what services are available and what the eligibility criteria may be or whom to contact for information about services. <VT>

There currently exist a great many formal and informal cooperative agreements for service provisions. These agreements are not all being implemented in the true spirit of a caring community. Part of the problem with cooperative agreements is that they are negotiated at the top levels of government or organizations and are not based on the input and concerns of those receiving the services or providing those services at the local level. <VT>

Information and referral is a large part of the service that the Washington Protection and Advocacy System provides. There is, however, currently no central point to collect and distribute program information in this state. <WA>

Who pays for what...that question often sets up a pitched battle with families caught in the middle. For example, when children of military families need therapy, it's up for grabs as to who will pay. Will it be Children's Coordinated Services? Medicaid? Champus? Should those receiving the service have to sort all this out by themselves? <WA>

Various programs differ on how they define "poverty level." This drastically affects availability and consistency of services. <WA>

Bringing together services and resources is a case management function, but the fact is there are not enough case managers to do the job. Expanded case management services are often cited by persons with disabilities as the area that needs the most improvement. <WA>

A centralized, computerized system to provide up-to-date information and referral on current programs and benefits could be of immeasurable use to recipients. This resource

has been requested by people statewide. <WA>

Government programs need to be simplified and coordinated so they are more "user friendly." Quite often, it is difficult to see how programs logically connect to each other. In addition to coordination, some standardization of regulations used in various programs would help decrease conflicts and improve utilization of benefits. <WA>

COORDINATION: RECOMMENDATIONS

Agencies need to consider the organization of their services, and how this can sometimes lead to delays in service and repetitive eligibility processes, from a consumer point of view. <AK>

Networking among federal and state tax supported agencies and voluntary agencies should be capitalized on and enlarged. <AL>

There must be clarification of eligibility criteria for the various programs available in the state. <AL>

Given that people will be served through different divisions of DHS, coordination of services becomes even more important to ensure that services are provided as needed. The DHS Mission and Goals Statement should serve as a resource for unifying direction for all division within DHS and as the basis for all interagency agreements. <AR>

The Council should seek out ways in which its efforts may complement those of other agencies where this is possible. Specific issues identified in these recommendations in which the Council might take a leadership role include infrastructure issues such as quality assurance and staff development, public awareness and improved communications with families. Similarly, the Council should investigate ways where the private sector can also be mobilized. In this regard, employers and health insurers carry great potential for assisting families who provide care at home. <AR>

Develop a consistent approach to disability throughout the Department of Human Services that stresses coordinated effort directed at expanding community-centered service options. <AR>

The existing Interagency Coordinating Council (ICC) interagency agreement should assure, at minimum, the development of: an expanded definition to include children who with developmental delay; a coordinated, integrated automated tracking system; involvement of the family; and development of effective models for case management. Further, the agreement must continue past the analysis stage to the design and implementation stages. The ICC must involve all relevant state agencies, as well as other relevant entities in the private sector, e.g. Pilot Parents, private health care providers, etc. <AZ>

The Interagency Coordinating Council (ICC) should continue its efforts to coordinate and participate in the development of a coordinated, integrated automated tracking system and an automated central directory of resources. This must be coordinated with all agencies who have established or are developing resource directories and information and referral systems. <AZ>

Communication should be established between the Governor's Council and the Arizona Department of Transportation Transit Advisory Committee. <AZ>

Examine the administration of services to persons with disabilities, with particular attention to the elimination of fragmented or duplicated services. <CT>

Cost and budget models must facilitate delivery of multiple services rather than provision of singular program or residential placements. <FL>

The Developmental Disabilities Division and the Mental Health Division should have a written agreement on the provision of services. <HI>

Examine the issue of service coordination between service agencies and programs, including the issue of confidentiality and the nature of its effects upon these programs. <IA>

To assist in coordinating advocacy services for people with developmental disabilities, the three entities created under Public Law 100-146 should participate as members of each other's boards: a representative from the University-Affiliated Program (UAP) and Protection & Advocacy, Inc. should continue to serve as members of the Council; a representative from Protection and Advocacy, Inc. and the Council should serve as members of the UAP's board; a representative from the UAP and the Council should serve as members of the board of Protection Advocacy, Inc. Indiana shall reorganize its service delivery system to eliminate duplication and gaps in service by structuring a flexible, coordinated system focused on the individual. <IN>

Indiana shall establish simplified, standardized, non-restrictive criteria for determining eligibility for all programs, which can be used across agencies. <IN>

Indiana shall establish and promote partnerships with the private sector in the development of programs and services to people with disabilities. <IN>

The governor of Louisiana should form an interagency council on disabilities whose responsibility would involve information dissemination and service coordination across state and federal agencies and organizations with input from the State Developmental Disabilities Council, the Advocacy Center for the Elderly and Disabled, the Human Development Center, the Association of Persons with Severe Handicaps, the Louisiana Association of Retarded Citizens, the Louisiana Coalition of Citizens with Disabilities, and other key statewide advocacy agencies and organizations. <LA>

The president and congress should direct federal agencies to develop new interagency communication and service coordination policies and procedures that will enable agencies on the state level to access training resources, share information, and increase consumer and professional participation in agency planning and evaluation processes. <LA>

The Mississippi Legislature should mandate that all state and federally-assisted programs adopt and uniformly operationalize consistent definitions of services and eligibility criteria for disability programs. <MS>

State agency representatives with major involvement in the, following areas should be invited to become members of the Mississippi Planning Council on Developmental Disabilities: Housing, Insurance, and Transportation - (for each state agency add one more representative). <MS>

"Generic" information and referral systems at the local, state and national levels should strengthen their resource listings of services for persons with developmental disabilities. <NC>

The Council recommends initiation of an "Individual Life Plan" (ILP) at the first contact with the service system which incorporates goals of the individual (and the family, as appropriate), which goes with individuals as they access various agencies, and becomes the single focal point for interagency services. The ILP will focus on opportunities for people with disabilities to develop personal relationships, have positive roles in community life, increase the control of their own lives, and enable them to make meaningful contributions in the home, workplace and community. The ILP should be a flexible planning document which is reviewed at least annually and revised as appropriate. <NC>

DHS should place more emphasis on planning and should prepare on a regular basis a comprehensive written plan for DD services administered by the Department. In developing and administering a comprehensive plan, DHS should maintain mechanisms to obtain consumer and service provider input on a continuity basis. <ND>

Services must be coordinated so that an optimal level of service provision be attained for the person with developmental disabilities. The current discussion in the state concerning community, regional, and state teams to solve problems and assure service integration could be an appropriate solution. <NE>

Coordination among divisions of the Department of Health and Human Services should be strengthened through the clarification of functions, inter-divisional policies, joint training programs, and shared or loaned staff agreements. For example, the role of the Division of Elderly and Adult Services in the provision of services to "incapacitated" adults should be clarified. The Division of Mental Health and Developmental Services should play the role of lead agency. <NH>

Funding for services should be coordinated at all levels so that consumers experience a minimum of discontinuity. Specifically, every effort should be made to insure that consumers enter or leave services based on their individual needs and circumstances, not merely because of a change in funding source. Points of potential discontinuity occur during the transition from Early Intervention to School District funding, School District

to Vocational Rehabilitation funding, and Vocational Rehabilitation to Community Developmental Services funding. <NH>

The Council should coordinate its systems change efforts with the University Affiliated Program, Protection and Advocacy Program and consumer groups. Communication of agendas, identification of areas of agreement and coordination of activities should occur. <NH>

The Council should continue to serve as an interagency forum for the consideration of service issues and participate to the maximum degree possible in interagency initiatives. <NH>

Efforts to improve the efficiency of income support programs in ways that minimize the difficulties for program participants and administrators should be continued. <NM>

Follow-up community and family support services should be better coordinated across agencies for effective transitioning of people with severe disabilities including people with chronic mental illness, from institutional care through community re-entry. <NV>

Federal programs that provide services to individuals with developmental disabilities such as Medicaid, SSI, vocational rehabilitation, and various block and discretionary grant programs must be reexamined to eliminate those elements that work at cross purposes to each other. Program managers and consumers must be involved in these efforts. <NY>

Current successful models of information dissemination should be replicated. <NY>

Information about what services and supports exist and how to get them must be made much more widely available both through the strengthening of existing information services such as the Office of Advocate's "hot line" and the Regional Early Childhood Direction Centers and the development of additional cross agency information systems at the local level. <NY>

State and federal programs that serve individuals with developmental disabilities, including education, health, transportation, vocational and specialized services, must develop consistent eligibility requirements. <NY>

Federal programs that serve people with disabilities such as education, health, and social services should develop consistent definitions. <NY>

The state and federal definition of developmental disabilities should be reviewed to bring about more consistency. <NY>

State and local relations should be depoliticized and long term strategic planning should emphasize shared responsibilities. <OR>

It is proposed that the General Attorney for Persons with Handicaps shall be responsible for establishing a system for facilitating interagency coordination for the provision of services. <PR>

Although interagency agreements for the provision of services to populations with developmental disabilities exists, many times they are not implemented. There must be mandatory interagency meetings at the regional level. <PR>

It is proposed that the Puerto Rico Department of Health and the Puerto Rico Department of Public Instruction shall increase their coordination efforts regarding the services they provide to the special education program population in order to effectively use their limited human resources by avoiding duplication of evaluations and services. <PR>

ODDMH and DECA/SSE should assess the growing role of the educational cooperatives and initiate any policy changes that may be needed to assure that duplicative services are not occurring. <SD>

The Texas Planning Council recommends the Texas Legislature establish mechanisms to assure that the private sector can contract with public agencies to provide services and also establish procedures to monitor and evaluate contracts to ensure the accountability of contracted services. <TX>

The General Assembly should require that all state and federally-assisted programs in Virginia adopt and uniformly operationalize consistent definitions of services and eligibility criteria for disability programs. <VA>

Agencies should agree on the same regional boundaries or there should be some agreement about allowing people flexibility in choosing which sites they wish to access for services so coordination can be possible within and among regions. <VT>

Cooperative agreements should be developed with input from those receiving the service, those directly providing the service, and program administrators. Once formulated, all parties in the agreement should be thoroughly informed and involved in periodic reviews of the effectiveness of the agreement. <VT>

When possible, coordinate and offer services in a single location. <WA>

Combine billing procedures to eliminate duplication of services. <WA>

Develop state regulations to better enable private and public programs to form productive partnerships with each other. <WA>

Poverty level definitions and criteria used by all levels of government should be standardized. <WA>

Wisconsin should incorporate into state law policy changes requiring information and referral, individual service coordination, effective data reporting on met and unmet service needs, and effective statewide long-term planning for funding and providing services. <WT>