



*A Summary of Reports Prepared by State
Developmental Disabilities Planning Councils*

- Independence
- Productivity
- Integration

for People with Developmental Disabilities



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of
Human Development Services

Administration on
Developmental Disabilities
Washington DC 20201

NOV 15 1990

Presentation of "Independence, Productivity, Integration for People with Developmental Disabilities" marks the beginning of a new era for people with developmental disabilities. It began in 1987 when Congress invited individuals with developmental disabilities, their families, friends, community providers and advocacy groups to present their own stories. Their needs, perspectives and expectations were conveyed through consumer satisfaction surveys and public forums and were expressed in individual reports prepared by the State Developmental Disabilities Planning Councils. The response to the Congressional mandate was overwhelming. Every state and territory submitted a report reflecting extensive policy and program analyses.

But, perhaps even more significant were the personal and often moving accounts of the quality of life enjoyed by people with developmental disabilities and their families and opportunities for independence, productivity and community integration not yet available to everyone.

This document presents a summary of those findings and contains many of those personal stories. This report bears witness to the changes taking place in our society. It reflects accomplishments occurring in the field of developmental disabilities; identifies barriers still to be overcome; and presents challenges for all of us to surmount. Expectations for change are now high. We must build on the momentum established by combining our efforts to respond to the expectations of people with developmental disabilities and their families.

I wish to express my sincere appreciation to the many individuals and organizations that dedicated themselves to making this effort a success. Let us begin this new era by removing the barriers that have prevented some Americans from realizing their full potential. In doing so, this country will indeed hold the same promise for every individual.

Deborah L. McFadden
Commissioner

Table of Contents

Executive Summary

I. Introduction	I-1
People with Developmental Disabilities	I-3
Rights of Those with Developmental Disabilities	I-5
Legislative Authority	I-5
Federal Policy Goals	I-6
Requirements for and Preparation of the Summary Report	I-8
The Consumer Survey	I-11
Organization of the Report	I-14
II. The 1990 Report Process	II-1
Overview of Developmental Disabilities Planning Council 1990 Report	
Activities	II-2
ADD Support to the Developmental Disabilities Planning Councils in the 1990 Report Process	II-17
Results of These Efforts	II-20
III. Supports to Individuals and Families	
State Council Reports: Overview	III-2
Access to a system of supports	III-6
Availability of supports to families	III-13
Supports to communities	III-19
Information and coordination supports	III-24
Sufficient resources	III-29
Accessible, affordable transportation	III-36
Social and recreational opportunities	III-44
IV. Education	
State Council Reports: Overview	IV-2
Educating all individuals with developmental disabilities	IV-4
Education in the least restrictive, most integrating environment	IV-6
Education to become productive adult citizens	IV-11
The special services and supports required for education	IV-14
V. Employment and Income	
State Council Reports: Overview	V-2
Opportunity to work in the community	V-6
Just wages and benefits	V-13
Supports to successful employment	V-16
Informed choices in employment	V-21
Alternatives for those who do not work competitively	V-26
Sufficient income to meet basic needs	V-27
Responsive government employment and income programs	V-32

VI. Housing	
State Council Reports: Overview	VI-2
Fewer and smaller segregated facilities	VI-6
All children in families	VI-14
Adults in homes of their choice	VI-17
Decent, affordable housing	VI-20
Housing quality standards maintained	VI-22
Supported living	VI-27
VII. Health	
State Council Reports: Overview	VII-2
Access to health care as needed	VII-5
Access to private health insurance	VII-12
Comprehensive health care	VII-15
High quality health care	VII-17
Prevention and early intervention	VII-19
Mental health services	VII-21
VIII. Civil Rights	
State Council Reports: Overview	VIII-2
The same rights and protections as all American citizens	VIII-4
Promotion of accessibility and full participation	VIII-7
The empowerment of individuals	VIII-10
Access to legal recourse	VIII-14
Appropriate use of guardianship	VIII-16
Freedom from harm	VIII-18
Appendices	
A. Excerpts from the Developmental Disabilities Assistance and Bill of Rights Act	
B. Members of the National 1990 Report Advisory Committee	
C. ADD Supported Technical Assistance Activities	
D. Information Resources Used by the State Developmental Disabilities Planning Councils	
E. Glossary	

List of Tables and Figures

I. Introduction	
Prevalence of Developmental Disabilities by Severity of Functional Limitations	I-4
Primary Diagnosis (Summary of State Consumer Surveys)	I-12
Comparison of Independence Scale Distributions for Adults with Three and Seven Functional Limitations (Summary of State Consumer Surveys)	I-13
III. Supports to Individuals and Families	
Percent of Population Needing Most Needed Individual Supports (Summary of State Consumer Surveys)	III-8
Percent of Population Needing Most Needed Family Supports (Summary of State Consumer Surveys)	III-15
Percent of Population Needing Most Needed Transportation Supports (Summary of State Consumer Surveys)	III-39
IV. Education	
Percent Distribution of Educational Placements for Children Aged 6-21 (Summary of State Consumer Surveys)	IV-8
V. Employment and Income	
Comparison of Employment Status for Selected Categories (Summary of State Consumer Reports and Harris Poll)	V-8
Employment Status of Respondents Ages 16 and Over (Summary of State Consumer Surveys)	V-8
Hourly Wage Study of those People Aged 16 and Over Working Full or Part-time (Summary of State Consumer Surveys)	V-14
Comparison of Median Hourly Wages Between Sheltered and Competitive (including Supported) Employment (Summary of State Consumer Surveys)	V-14
How Working Age (18 through 64) Adults' Primary Activities Are Determined (Summary of State Consumer Surveys)	V-23
Satisfaction with Financial Assistance Programs (Summary of State Consumer Surveys)	V-27
VI. Housing	
Household Size (Summary of State Consumer Surveys)	VI-2
Where People with Developmental Disabilities Live (Summary of State Consumer Surveys)	VI-5
Waiting Lists for Community Living Arrangements (Twelve State Council Reports)	VI-7
VII. Health	
Percent of Survey Population Needing Selected Health Care Services (Summary of State Consumer Surveys)	VII-2

Independence — Productivity — Integration

for People with Developmental Disabilities

Executive Summary

"We hold these Truths to be self-evident, that all Men are created equal, that they are endowed by the Creator with certain inalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness—"

*—The Declaration of Independence
in Congress, July 4, 1776*

People with developmental disabilities are, as have other groups before them, slowly beginning to realize the American ideal of life, liberty, and the pursuit of happiness. As the United States progresses into the twenty-first century we are a maturing nation that is continuing to apply the truths of our forebears to new groups of people in our country. The summary that follows describes the movement of people with developmental disabilities toward the goals of independence, productivity, and integration, as seen through the reports recently prepared by the State Developmental Disabilities Planning Councils and submitted to the Secretary of the Department of Health and Human Services by the governors of the states and territories. The Executive Summary is about programs and changing priorities, but more than that, it is a tribute to the people behind these new priorities and programs—federal and state and local policymakers, service providers, families, friends and employers, and, most importantly, people with developmental disabilities themselves.

The 1990 Summary Report to Congress and this Executive Summary represent the collective efforts of the Administration on Developmental Disabilities, 55 Developmental Disabilities Planning Councils, several University Affiliated Programs, national organizations, and many other individuals to respond to the legislative requirements of the Developmental Disabilities Assistance and Bill of Rights Act, as amended by P.L. 100 -146.

The term *developmental disabilities* applies to people with a mental or physical impairment that was manifested before their twenty-second birthday, that is likely to continue for an indefinite length of time, and results in "substantial" functional limitations in at least three areas of major life activity. Although precise determinations of the size of the population of people with developmental disabilities are lacking, estimates range from two million to about three million people, nationwide. Developmental disabilities pose significant challenges for families and friends and especially for the individual with a developmental disability. It is to respond to these challenges that the Administration on Developmental Disabilities and its programs exist.

Requirements of P.L. 100-146

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146) required each State Developmental Disabilities Planning Council to conduct a comprehensive review and analysis of services for people with developmental disabilities as they affect their ability to achieve the goals of independence, productivity, and integration into the community. It further required them to survey people with developmental disabilities as to their satisfaction with these services. The Councils were then to convene public forums to provide the results of their analytic work and to obtain the comments and recommendations of the public.

The Administration on Developmental Disabilities supported extensive assistance to Councils in their responses to the requirements of P.L. 100-146, including broad-based technical assistance coordinated by the National Association of Developmental Disabilities Councils. A key component was the design and training in a common approach to the state consumer surveys, used by all but five of the Councils nationwide, and guidance on approaches to the policy analysis. At the state level, Council efforts to involve consumers included the direct input of over 15,000 individuals with developmental disabilities whose responses to the state consumer surveys, participation in public forums, and work on Council committees were essential to the development of the State Council reports. Consumer perspectives were synthesized in the reports with the results of each Council's analysis of the state agency administered programs that are supported by federal and state funds and which affect the lives of people with developmental disabilities.

Section 122(f)(4) of the Developmental Disabilities Act Amendments (P.L. 100-146) required the Councils to submit a report on the results of these activities to their governors and legislatures by January 1, 1990. Fifty-five reports have been submitted to the Secretary of Health and Human Services by the governors of the states and territories. This document is a summary of the fifty-three reports that were received in time for inclusion in the national summary.

The approach to preparation of the Summary Report was a careful review of the reports submitted by the governors of the states and territories. Findings from the State Planning Council reports were summarized in relation to major "life areas": learning (education), working (employment and income), housing, health, civil rights, and related supports to individuals, families and communities. Within each area, the 1990 Summary Report looks at the goals for people with developmental disabilities defined in the individual Council reports, as well as the descriptions of recent accomplishments at the state and local level. The reported perspectives of people with developmental disabilities and family members also have been used extensively in the preparation of the summary report. Altogether, over 3,100 statements of issues and barriers and approximately 3,200 recommendations were reviewed in summarizing the views of the Planning Councils of the states and territories. Supported by funds from the Administration on Developmental Disabilities, a compilation of findings from the reports prepared by the National Association of Developmental Disabilities Councils also was a major resource. A similar compilation of state consumer surveys, prepared by the Temple University Developmental Disabilities Center/University Affiliated Program for the National Association of Developmental Disabilities Councils, was the source of information on the surveys of consumers.

The following graphic conventions to assist the reader are found throughout the executive summary:



Goal/vision statements



Accomplishments



Quotes from consumers and family members



Recommendations directed primarily at the federal level

The recommendations and analyses contained in this report reflect the experience and opinions of the State Developmental Disabilities Planning councils and are not the official position of the Administration on Developmental Disabilities or the Secretary of Health and Human Services.

Goals for People with Developmental Disabilities

Federal Policy Goals

The Developmental Disabilities Assistance and Bill of Rights Act contains a clear vision statement for people with developmental disabilities:



The program goals for people with developmental disabilities contained in the Developmental Disabilities Assistance and Bill of Rights Act are—

...to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community, and

...to protect the legal and human rights of persons with developmental disabilities.

Independence



"The term 'independence' means the extent to which persons with developmental disabilities exert control and choice over their lives."

Productivity



"The term 'productivity' means—

"(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or community."

Integration into the Community



"The term 'integration' means—

"(A) the—

"(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and

"(ii) participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and

"(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities."

—Part A, Developmental Disabilities Assistance and Bill of Rights Act

Goals and Visions in the State Council Reports

Virtually all the State Planning Councils highlighted the federal policy goals of independence, productivity, and community integration in their reports. In addition, most of the Councils identified goals and visions for people with developmental disabilities in relation to the various life areas. The following examples of goals and visions defined by the State Councils also summarize the themes identified in their reports in each of the life areas.

Civil Rights



•• All people with developmental disabilities shall have the same rights as individuals without disabilities (*California report*). •• People with disabilities should be entitled to participate fully in every aspect of American life (*Massachusetts report*). •• People with developmental disabilities...have control over their services, thereby directing their own lives (*Guam report*). •• Advocacy must be available and affordable for all citizens who seek to secure and protect their rights (*Florida report*). •• People with disabilities manage their own affairs.... Very few have guardians or representative payees (*Michigan report*). •• People are protected from neglect and abuse...(*Indiana report*).

Education



- A free and appropriate education should be available to all children in the state. ...and must be based on the presumption that each child is able to learn and develop (*New Mexico report*),
- Education should be provided in the least restrictive, most integrated environment... (*California report*),
- The primary goal of education for all people must be to prepare individuals for participatory, productive, and contributing roles in society (*Ohio report*).
- Special supports will be available to students with disabilities which are designed to meet their educational needs, including individualized instruction, adaptive equipment, accessible buildings, technological aids, and accessible transportation services (*Texas report*).

Employment and Income



- Paid jobs in the community will be available to all persons with developmental disabilities who want them (*West Virginia report*).
- Both direct employment-related services (e.g., training, education, pre-vocational, communications skills, etc.) and support services (e.g., transportation, housing, personal care attendants, adaptive devices, etc.) must be readily available (*Massachusetts report*).
- Every person will be afforded the right to have a choice in his or her employment and have adequate information, training, and experience to make an informed choice (*Ohio report*).
- All people, regardless of the severity of their disability, will choose how to be productive, whether through employment, contributing to their household, or contributing to their community (*Hawaii report*).
- All people are entitled to an income that fosters their highest level of personal independence, enables them to maintain a satisfactory standard of living, and provides for emergencies and old age security (*Indiana report*).
- People with developmental disabilities should have access to income supports which are flexible enough to meet individual needs and are complementary to supports for employment and productivity (*Georgia report*).

Health



- Everyone has a right to comprehensive, affordable health services provided in a reasonable proximity to one's home.... Persons with disabilities will have the same range of health care choices as other citizens in their community have (*Wisconsin report*).
- 'Due to prohibitively high health care costs, health insurance is absolutely necessary for all people for protection from financial burden (*California report*).
- An adequate health care system must provide comprehensive services .. (*Georgia report*).
- All persons (with and without disabilities) have access to quality health care.... The quality of patient care is not dependent upon the insurer (*South Carolina report*).
- The generic health care system should provide appropriate acute care services as well as preventive care, diagnostic services, and early intervention to prevent health problems before they become more difficult to treat (*Louisiana report*).
- In the future world where people with disabilities of any kind are no longer discriminated against, providers of mental health services will be willing and able to treat people with various, long-term disabilities (*New Jersey report*).

Housing



• • • There will be fewer and smaller segregated facilities for people with developmental disabilities (*West Virginia report*). • • • Necessary support services will be provided to families to allow them to maintain their children at home.... There will be alternative, home-like residential settings provided for children who, for one reason or another, cannot live in the natural home (*California report*). • • • Adults with developmental disabilities should be in a home of their choosing, have control over the selection of housemates, and the home, whether leased or owned, should be in their own name (*Louisiana report*). • • • There should be a sufficient supply of decent, affordable, and barrier-free housing so that people of all income levels and disabilities have access to a home of their choice (Georgia report). • • • The [residential service] system guarantees that all staff are both competent and caring (*Rhode Island report*). • • • A vision of housing for people with developmental disabilities includes living in the same homes as those without disabilities, with supports to the individual and adaptations to the living environment as needed (*Vermont report*).

Supports to Individuals and Families



• • • The vision, then, for people with disabilities who require individual and family supports, is to provide whatever it takes to make their independence, integration, and productivity inside the parameters of society, and outside the institution, possible (*Utah report*). • • • There will be an independent case management system which enables people with disabilities to live successfully in the community by assisting them in accessing different services across the life span (*Texas report*). • • • Vision: all persons, including those with mobility impairments, are entitled to the unlimited use of public transportation services which are accessible, affordable, and appropriate (*Massachusetts report*). • • • 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 (*Tennessee report*).

Summary of State Consumer Surveys

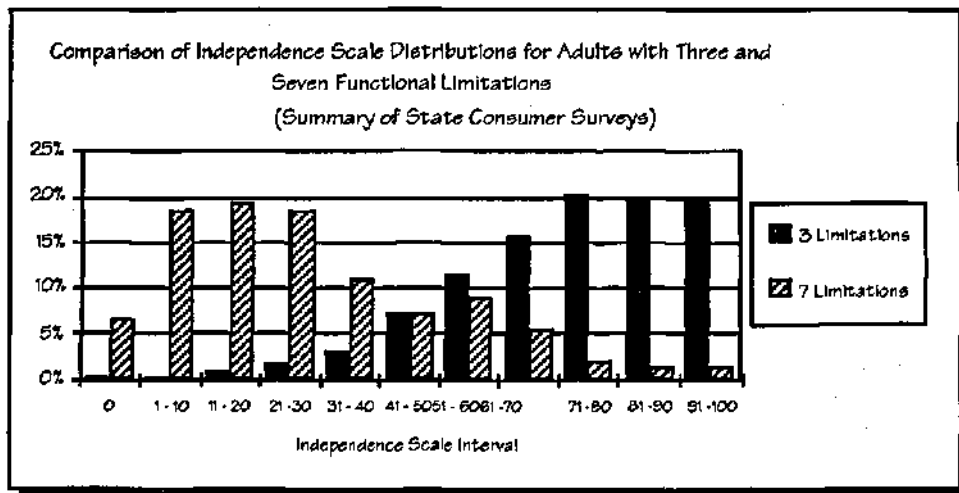
Each Developmental Disabilities Planning Council conducted a survey of consumer satisfaction with services they were currently receiving. In addition, Councils agreed to survey the status of consumers (i.e., people with developmental disabilities) in terms of the goals of independence, productivity, and integration into the community and in terms of current life area status. The Administration on Developmental Disabilities provided support for a national initiative to develop a common survey instrument. Developed by the Temple University Developmental Disabilities Center / University Affiliated Program (UAP) in consultation with State Councils and a scientific advisory panel, the resulting instrument was used in all but five states.

Over 15,000 consumers participated in the surveys. Over 70 percent of the people in the state surveys reported substantial functional limitations in **more than three** life areas. All surveys (except those with very young children) involved the consumer directly; 25 percent of the adults surveyed had no assistance at all in completing the face-to-face interviews, which often lasted two hours or more. In the aggregate, the primary disability of people surveyed was: mental retardation (42 percent), physical disability (41 percent), sensory disability (10 percent), and emotional disability (6 percent).

These proportions and the summary of state consumer survey data presented in the Executive Summary are based on the 13,075 interviews that were sufficiently complete in time to be included in the summary analysis prepared by the Temple University Developmental disabilities Center / UAP for the National Association of Developmental Disabilities Councils.

Summary of State Consumer Survey Findings on Independence, Productivity, and Integration

The common survey instrument included several measures of people's current level of independence, productivity, and community integration. One of the findings highlighted in many State Council reports was that some of the people surveyed with limitations in five, six, and even seven functional areas were reaching significant levels of independence. When people's independence was measured on a scale of 0 to 100, approximately one-fourth of the adults surveyed with seven functional limitations were at the mid-point or higher in independence, as illustrated in the following figure. At the same time, the summary of state consumer survey data also showed that there were substantial numbers of people with only three substantial limitations who were functioning at very low levels of independence.



Data from the summary of state consumer surveys also indicated that some people with as many as seven functional limitations were engaged in productive activities on a regular basis and were well integrated into their communities. Conversely, the summary data indicated that many people with only three functional limitations were at very low levels of productivity and community integration.

Other results from the summary of the state consumer surveys included the following:

- Independence and integration were reported to be important to 75 percent of those surveyed; however, only 26 percent and 38 percent, respectively, saw themselves as independent and integrated.
- People who lived in nursing homes and other institutions were less independent, productive, and integrated than people who lived in community residences.
- People with developmental disabilities had less participation in community living activities and were more apt to feel lonely than people without disabilities,

Summary of the State Consumer Survey Findings in the Life Areas

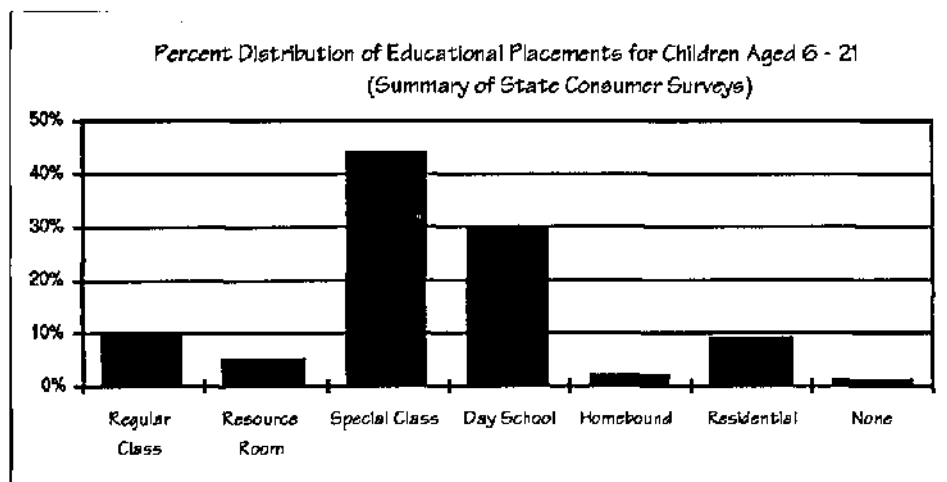
Civil Rights

The Council reports frequently presented consumer survey findings to illustrate concerns regarding the full exercise of civil rights among people with developmental disabilities, as illustrated by the following data from the summary of state consumer surveys:

- 28% of those over 18 years of age voted in the last general election compared with 49% of the general population.
- 39% of those surveyed indicated that they needed legal or protective assistance, but only 27% indicated that they were receiving assistance; therefore, 12% of the population had an unmet need for legal assistance.
- Less than one-fourth of the adults surveyed chose where they were currently living.

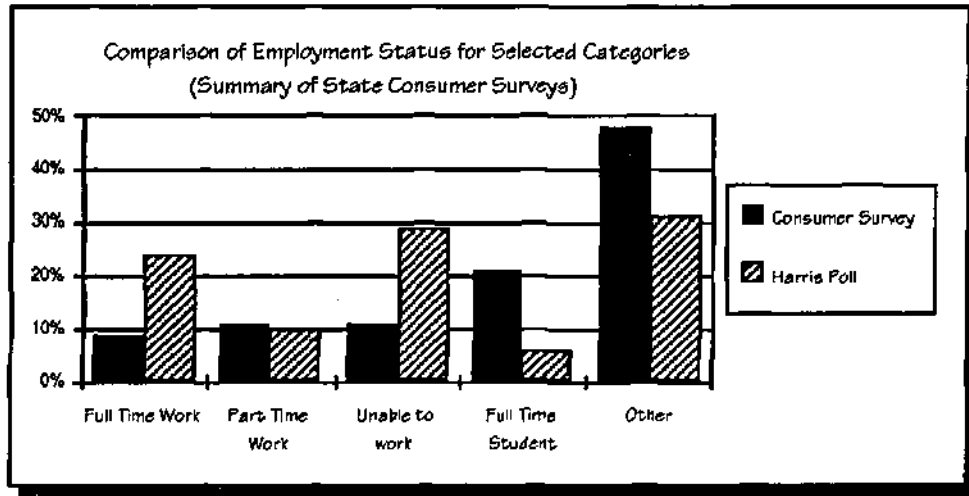
Education

Data from the summary of state consumer surveys indicated that although nearly all children surveyed received education, only 15 percent were receiving their education in integrated classes at least part of the day (i.e., in regular classes or in a combination of integrated classes and resource rooms). Over 40 percent of the children surveyed received their education totally segregated from children without disabilities, and the remainder were being educated in segregated classes in public schools. 73 percent of children birth through age two and 83 percent of children three through age five received either early intervention or preschool programs.



Employment and Income

Some Councils compared the employment experiences of consumers surveyed with the earlier results of a Harris poll of adults with disabilities. These data show that fewer adults with developmental disabilities worked full time; but a larger percentage viewed themselves as able to work. They were much more likely to be enrolled in a full time educational program, probably representing individuals who were in "day habilitation" or pre-vocational programs as well as some young adults still enrolled in public education. These comparisons are illustrated in the following figure from the summary of state consumer surveys.



The hourly wage analysis of the summary of state consumer surveys data showed that those surveyed who had wage earnings were considerably worse off than the general population. A further analysis suggested that the major contributory factor was the sub-minimum wages paid in sheltered employment.

Hourly Wage Study of those People in the Consumer Surveys Aged 16 and Over Working Full or Part Time (Summary of State Consumer Surveys)

- 25% made 49¢ per hour or less
- 50% made \$1.28 per hour or less
- 75% made minimum wage (\$3.30) or less
- 96% made less than the 1987 US average hourly wage of \$9.

Hourly Pay

Mean	\$2.52
Median	\$1.25
Minimum	\$.01
Maximum	\$99.83

Of those surveyed three-fifths were receiving Supplemental Security Income. There was general satisfaction with the programs operated by the Social Security Administration, based on data from the summary of state consumer surveys.

**Satisfaction with Financial Assistance Programs
(Summary of State Consumer Surveys)**

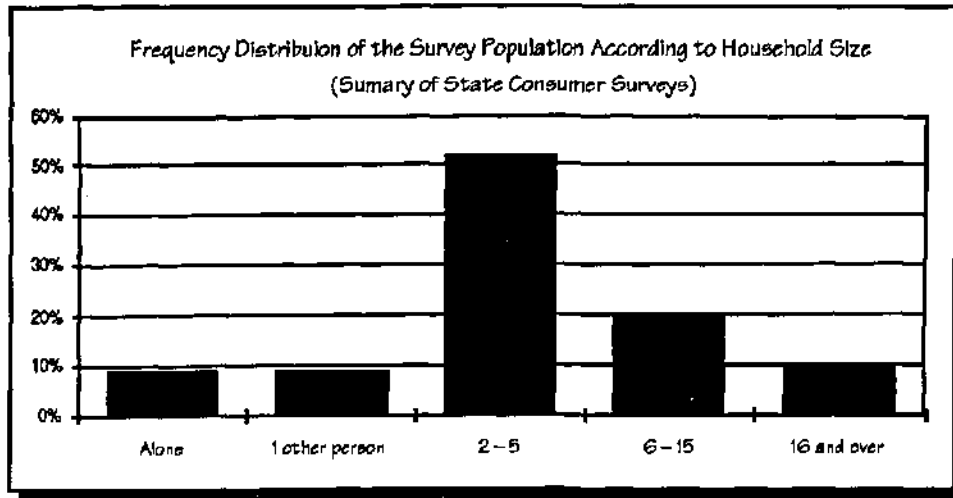
Program	% Receiving	% Using and Dissatisfied
AFDC	10%	31%
SSI	59%	16%
SSDI	22%	14%

Housing

Throughout the reports, the term "housing" was used to refer to where people with developmental disabilities live, including nursing homes and institutions as well as homes in regular neighborhoods. The data from the summary of state consumer surveys indicated that most individuals with developmental disabilities surveyed lived in family-size homes in the community, either independently, with family members, or in family-style arrangements. As illustrated in the following table, nearly one-fourth of the adults surveyed lived in specialized facilities, nursing homes, and institutions, compared to only five percent of children. About one in ten lived with 16 or more people in institutions or institution-like settings.

**Where People With Developmental Disabilities Live
(Summary of State Consumer Surveys)**

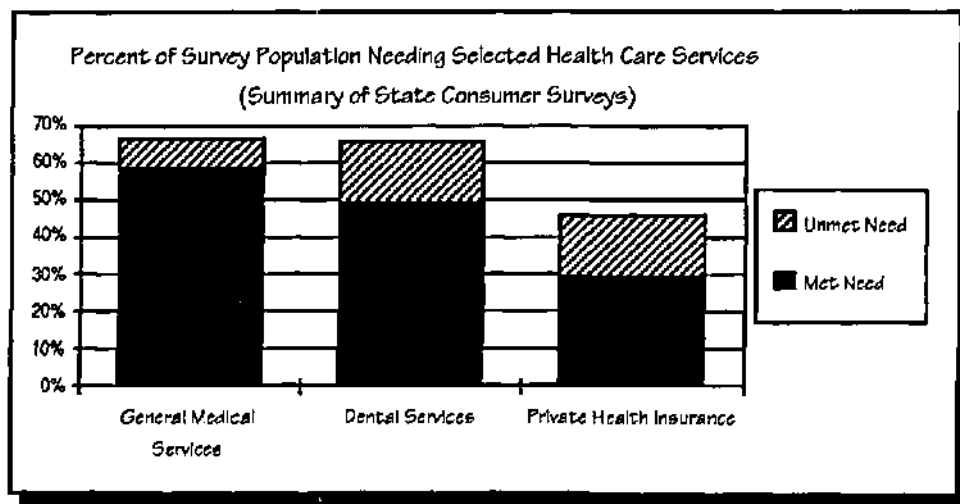
Type	Children	Adults
Home in community	95%	74%
Rooming house	0%	2%
Specialized facility	2%	12%
Nursing home	0%	3%
Institution	3%	9%
Total	100%	100%



A related item on the need for community living assistance showed that 26 percent of all those surveyed needed community living assistance, but only 9 percent were receiving it (for adults only, the figures were approximately 40 percent and 14 percent, respectively); therefore less than one-third of the need for community living support was being met.

Health

Many Councils included consumer survey findings in relation to health care needs. Health care services were needed by a higher percentage of consumers than other services and supports. Although health care needs were being met to some degree, there were serious deficits in the areas of dental services and private insurance coverage, as illustrated in data from the summary of state consumer surveys.

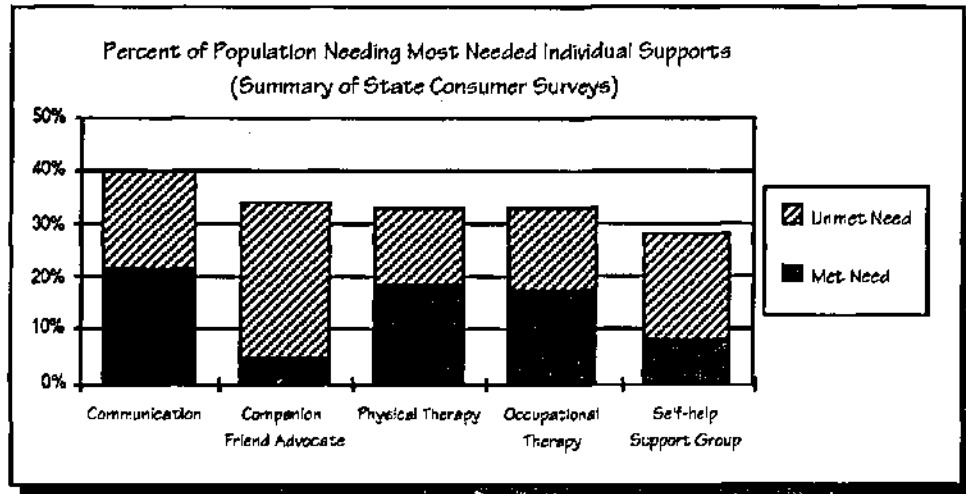


Supports to Individuals and Families

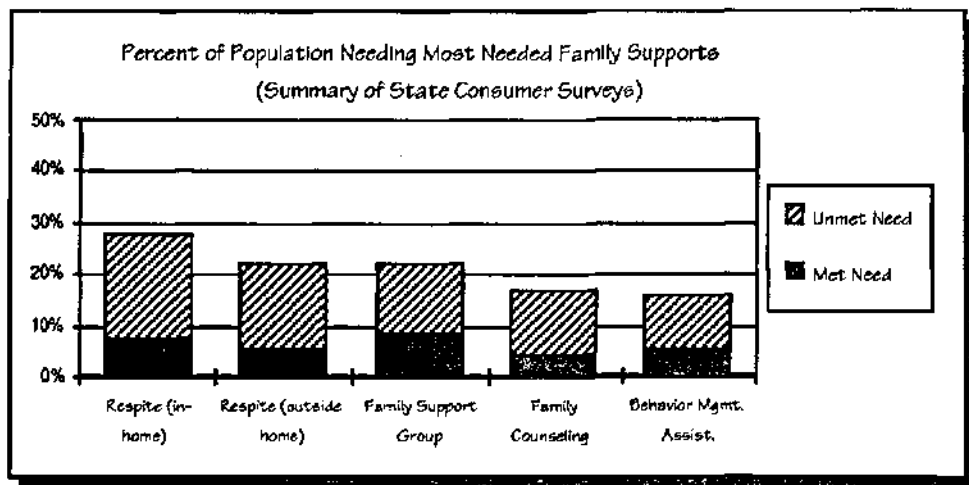
Most Councils included state consumer survey findings in relation to supports. As used in the State Council reports, supports referred to activities and services that assist people with developmental disabilities, or in some cases their family members, in making full use of their opportunities for

independence, productivity, and community integration. Supports focus on people's abilities and accomplishments, rather than on their disabilities and dependence. Some of the supports noted in the reports were communication devices, personal assistance, help with money management and community living responsibilities, adaptations of homes and vehicles, and information and referral services.

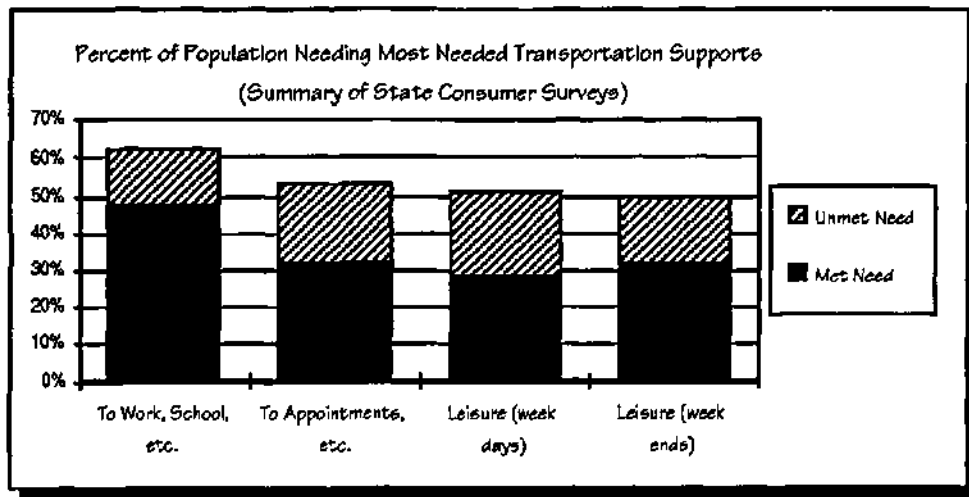
The five most needed individual supports in the summary of state consumer surveys are shown below. Several Councils noted in their reports that next to communication and language support consumers saw the need for a companion or friend-advocate. Although one-half of the need for communication support and physical and occupational therapy was being met, only a small fraction of the need for a friend-advocate and self-help support was being met.



The greatest need for family or caregiver support identified in the consumer surveys was the need for respite care—both in the home and outside the home. As shown in the following figure, this need was being met for only a fraction of those in need. Families needed the support of others who have experienced similar situations, as indicated by the third most needed family support: family support groups. The large size of the unmet need across these five services suggested to many Councils a systemic need to better meet the needs of caregivers. There was also a comparatively high need among those surveyed for family counseling and training that was largely unmet.



Transportation services ranked with the need for medical care as the most needed services of all those contained in the consumer survey. Although two-thirds of the transportation needed to go to work and to attend school and day activities was being met, there were much greater levels of unmet need for transportation to and from appointments, errands, leisure activities, and other personal activities.



The results of these state surveys, collectively the largest survey of people with developmental disabilities ever conducted, will continue to be examined for several years to come. There is a great deal more to be learned from the data about specific age groups, about specific disability groups, and about quality of life issues.

Statements of Consumers and Family Members

The State Planning Council reports contained hundreds of quotes from people with developmental disabilities and their family members. Some reports featured "success stories"; a few examples of these are found in the section on accomplishments. Most, however, were used in the reports to illustrate barriers being encountered, reflecting the emphasis on the identification of barriers in the requirements of P.L. 100-146. Examples from the reports follow.

General

Terry will have to move out of the state because there is a minimum wait of two years for head trauma centers. Terry falls in between cracks of existing services." (Ohio parent)

There are no programs in the state of Oklahoma which address the needs of families who have a child with autism. If we want our children to enter a school and be properly served, we must send them out of state." (Oklahoma parent)

After I graduate, I want to be the first mentally retarded astronaut. If I can't do that, I think I'll be a professional skateboarder!" (Washington consumer)

...people with disabilities are not asking for things that other people don't have, but for the same opportunities as all people have...." (Wisconsin consumer)

Life Areas

Civil Rights/Empowerment

- “ I am afraid to advocate for myself. When I am assertive I am told I am pushy." (Maine consumer)
- “ Consumers assigned state guardianship haven't had any contact with their assigned representatives. Those being serviced are not even aware of the name of the person assigned to their case." (New Jersey advocate)
- “ Section 504 of the Rehabilitation Act has never been enforced. I have not found any real effort to follow through to make public buildings accessible." (Texas consumer)

Education

- “ Parents no longer have to fight to get in the school door, but they have to fight to get a quality education." (Ohio parent)
- “ The school system's position is that they'll not provide physical therapy or occupational therapy because they are medically-related and not educationally-related.... I implore lawmakers to modify the language [of the law] to prevent the districts from denying these services to students." (Michigan parent)
- “ One wish: to go to a regular school and participate in normal activities." (Wisconsin consumer)

Employment and Income

- “ I work in a workshop and get paid very little money. I get \$20 for two weeks of work. I don't think that's right, do you?" (California consumer)
- “ I want to work for the same reason other people want to work, which is to support myself and to feel like part of the world. Why is that so hard for people to understand?" (Maine consumer)
- “ Try living on \$7,200 a year or \$600 a month. Deduct housing, food, clothing, transportation costs, utility bills, heat, medical expenses not covered by Medicaid—like personal care attendants. Could you live on that?" (Michigan spouse)
- “ Do you really think I like going to that summer camp for the disabled? I'm 40 years old! Hell, if I had the money, I'd go to Hawaii like everyone else." (Washington consumer)

Housing

- “ I want to be out of the nursing home and into my own apartment. I have been on a waiting list for six years." (Wisconsin consumer)
- “ People with disabilities can get all the independent living training in the world, but it's a total loss if there's no housing for them to move into." (Washington consumer)
- “ Well, it seems if they have the money for group homes, why can't they have that for the child at home where he's happy and not take him out of his home surroundings." (Utah parent)
- “ Leslie has lived every day of her life in the community. She deserves to continue to live in the community. I want here to have a choice about where she lives. She shouldn't have to go to an institution." (Georgia parent)

Health

- “ Casey is eight and is reaching the lifetime cap on his insurance." (Georgia parent)
- “ My daughter's...medical bills are around \$16,000 a year. There is no way we can pay for her, and the insurance company says that they won't cover her because it's a pre-existing condition. She cannot get off Medicaid and so she can't go to work even if she wants to." (Utah parent)
- “ Mental health services have not been adequate and have not met her needs." (Ohio parent)

Individual and Family Supports

- “ I shouldn't have to choose between having a wheelchair or a communication system." (Georgia consumer)
- “ ...I wish I could just meet friends and go to McDonalds and a movie and not have to ask my family to take me." (Michigan consumer)
- “ I have not been out with my husband in ten years. I need respite care on a weekly basis or the family will fall apart." (Maine parent)
- “ How can a case manager develop good plans and follow through with a caseload of 130?" (Minnesota parent)
- “ I ran up a \$300 phone bill one month just to find out my child isn't entitled to anything." (New Hampshire parent)

State Council Reports: Accomplishments and Opportunities

Many State Developmental Disabilities Planning Councils highlighted recent accomplishments that have improved the opportunities of people with developmental disabilities to reach greater independence, productivity, and community integration. Because some reports did not feature such initiatives, many more examples of accomplishments may be identified in the future. The descriptions of accomplishments were used by the State Councils to demonstrate that the vision of independence, productivity, and integration is today a reality for some people with developmental disabilities.

Federal Initiatives

Important federal initiatives were mentioned by the Planning Councils in a variety of areas:

Civil Rights

- ★ Various federal statutes prohibit discrimination based on disabling conditions. The Rehabilitation Act of 1973 (P.L. 93-112 as amended) includes Section 504, the first civil rights legislation to guarantee an equal opportunity for people with disabilities. The Civil Rights of Institutionalized Persons Act (CRIPA) passed in 1980 (P.L. 96-247) empowers the Department of Justice to initiate action to protect the constitutional and federal rights of people in institutions. The Fair Housing Act Amendments (FHAA) of 1988 (P.L. 100-430) address discrimination against people with disabilities in private as well as public housing and rental accommodations.
- ★ The Voting Rights Act of 1965 provides the right to choose a voter assistant. The Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435) encourages participation and promotes integration by enabling people with disabilities to access polling places.
- ★ The Protection and Advocacy (P&A) program was established by the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103) to pursue legal, administrative and other appropriate remedies to protect the rights of individuals with developmental disabilities under federal and state statutes.

Education

- “ The language of the Act makes it clear that a 'zero reject' policy is at the core of the Act [P.L. 94-142] and that no child.. is to ever again be subjected to the deplorable state of affairs which existed at the time of the Act's passage, in which millions of handicapped children received inadequate education or none at all." (875 F. 2nd, 954, 1st Circuit, 1989). (U.S. First Circuit Court of Appeals)

Employment and Income

- ★ Several Councils commended the federal Rehabilitation Service Administration for its systems change grants, which were seen as important in the progress toward the goal of productivity in their state.

Housing

- ★ Teresa shares her home with two friends and receives training, case management and other support services from staff of the regional [state facility]. She reported that her present home is one of the best places she's ever lived. "It's big, for one thing. We've got our own washer and dryer. We don't have to go out to the laundromat. HUD pays for part of the rent and we pay for the rest of it. If it weren't for HUD, we wouldn't be able to live here." (West Virginia report)

Supports

- ★ Although the majority of Councils were concerned about the need for Medicaid reforms, some identified the Home and Community Based Services waivers as a significant step in the right direction in providing access to individual and family supports.

State and Local Initiatives

Many State Council reports highlighted recent Council and state government actions that have promoted increased independence, productivity, and community integration of people with developmental disabilities. State programs and initiatives in education were frequently cited in the reports, such as the use of "mainstreaming specialists" and Minnesota's mentor/friendship program in the schools. Other Councils pointed out innovative transition programs. Several reports featured the involvement of the private sector in the employment of people with developmental disabilities, including major employers such as McDonalds, Boeing, IBM, and the Marriott Corporation, as well as smaller employers at the local level.

A few State Councils highlighted initiatives in the health area, such as rural outreach programs and services through the children with Special Health Care Needs Program. Some reports cited beginning efforts to address barriers to private health insurance coverage. In housing, many of the reports described state initiatives to reduce the use of their large public institutions, especially for children with developmental disabilities. State and local supported living initiatives also were featured.

Many Councils described initiatives in supporting individuals and families, such as the provision of personal care attendant services, assistive technological aids and devices, parent-to-parent networks, and family cash assistance programs. Councils mentioned the importance of information and coordination and a few examples of model information and referral and case management programs were featured.

Many accomplishments were featured in the State Council reports that have minimal government involvement. These efforts of the private sector, private citizens, and local communities to support people with developmental disabilities in communities were seen by State Planning Councils as some of the best opportunities for them to achieve the goals of maximum independence, productivity, and integration into the community.

Civil Rights

- ★ Several states have enacted legislation patterned after the Rehabilitation Act. These laws prohibit discrimination in programs or activities conducted by or funded through state funds.
- ★ Individuals in many states have become active in the self-advocacy movement (e.g., People First), providing a major forum for people with disabilities to problem solve, vent common frustrations and coalesce around major life issues of critical importance such as housing, employment, transportation, societal perceptions and portrayals of people with disabilities.
- ★ Many states discussed their quality assurance activities in regard to protecting people from harm. In Utah, for example, a volunteer monitoring committee has been established, where volunteers are trained to monitor residential facilities, both congregate and community based. Homes are visited three times; once announced, twice unannounced.

Education

- ★ In New Hampshire several school districts have developed a new role for special education teachers called "Mainstreaming Specialist," "Integration Specialist," or "Consulting Teacher." These individuals act as "consultants, team-teachers, service-coordinators, and in other flexible roles to support the inclusion of students with disabilities in regular educational environments." (New Hampshire report)
- ★ California has a seven year old "WorkAbility" project that has served more than 43,000 students. This project represents the cooperative efforts of the state departments of education, rehabilitation, and employment development to provide assessment, employment preparation and training, community work experience, and support services. In recent years the project has been extended to the community college level. (California report)

Employment and Income

- ★ The Job Accommodation Network was cited by several reports as the kind of private sector initiative that made the work place accessible. This network is totally managed and operated by employers who provide technical assistance to other employers. Their advice is based upon approaches to accommodating the work place that have been used successfully by businesses.
- ★ In October of 1987, the Governor of Colorado signed an executive order promoting state agency employment of persons with disabilities. From November 1987 until April of 1989, 78 of the 142 people with disabilities hired by the state were hired under the provisions of the executive order. (Colorado report)
- ★ "The most tangible benefit is that they build quality products just like everybody else does." (Dave Jay, Director of Production, Physio-Control, a firm manufacturing bio-medical equipment that has hired 15 workers with disabilities—quoted in the Washington report)

Housing

- ★ At the beginning of October 1989, the population of [the state institution] was 95 residents. The population has steadily declined for more than a decade as admissions have ceased and efforts to achieve community placements have been a top priority within the Division of Mental Health and Developmental Services. During the past two years the population has declined by about 30 residents per year and the number of community placements has consistently exceeded projections. (New Hampshire report)
- ★ In a recent deinstitutionalization effort, an employee of the Utah State Training School chose to become a private provider for three women who had resided in the training school for 17, 23, and 31 years respectively. As a private provider, she took these women she had worked with in the institution and helped them integrate into a community setting. Early on she observed that Mary had almost never spoken in the ten years she had known her, but since "coming home" (Mary's description) she has become a regular "chatter box." The provider assumed while at the training school that these women must have dressed uncaringly because of the severity of their disabilities. But in the community each of the women had very definite ideas about how she wanted to dress: one loved purple and lace, another chose levis and sweaters, and another sports clothes like "sweats." She said, "I would like to take credit for teaching them all of the new things they're doing, but I can't. I really haven't done anything but give them a chance...they just haven't had a chance before." (Utah Report)
- “ I lived at Dixon Developmental Center for 28 years...now I have moved to my own apartment.... I signed my own lease, pay my own bills, and for the first time I can stay home without staff. This is the best place I have lived so far. I like my roommates, and this is our place." (Illinois consumer)

Health

- ★ Outreach to rural areas was featured in the Utah report, which described the "travel clinics" of the state's Handicapped Children's Services and Maternal and Child Health (MCH) programs. The MCH outreach includes the expertise of its high risk pregnancy program. The report noted that the outreach philosophy reflected in these activities is found throughout the programs administered by the state public health agency. (Utah report)
- ★ Loyola School of Dentistry's Division of Preventive Dentistry and Community Health has made a commitment to working with their dental students so that they have a wide variety of experiences with people with disabilities during their educational training. (Illinois report)
- ★ The Wisconsin Department of Health and Social Services and the Department of Public Instruction have entered into a cooperative agreement with a pilot county in an effort to address several critical issues for children with emotional disturbances. The Robert Wood Johnson Foundation is providing Wisconsin with a one-year grant of \$100,000 to support the development of a coordinated array of community treatment and support programs for youth with serious emotional

disabilities. This effort is indicative of a relatively new kind of cooperative activity between the public and private sectors. (Wisconsin report)

Individual and Family Supports

- ★ The Pennsylvania Attendant Care program utilizes a combination of state funds and the federal Social Services Block Grant, as well as consumer payments on a sliding scale. The program is available across the state and is currently reaching 1,013 adults with physical disabilities with an average of 40 hours per person per week. A key aspect of the program is its emphasis on consumer control. (Pennsylvania report)
- ★ In Arkansas two pilot family cash assistance programs were initiated in 1988. The pilots are funded through [the state developmental disabilities service agency], with a current funding level of \$206,000 for about 40 families; about 77 families are on a waiting list. Cash may be used to purchase nearly any good or service that is deemed relevant to the family's circumstances and that is not obtainable from other funding sources. (Arkansas report)
- ★ The significance of supports to communities in relation to goals for people with developmental disabilities was recognized in many of the state reports. Some highlighted activities designed to involve community members directly in the lives of their fellow citizens with disabilities. For example, the Colorado report described a project funded by the state Developmental Disabilities Council in 1989 to develop "Circles of Friends" in five communities in the state. As described in the report, the purpose of these programs is to organize communities in ways that connect people with developmental disabilities with other community members, foster long-term relationships, and develop assistance to consumers in their self-advocacy and full participation in community life. It is hoped that these interactions also will promote changes in public attitudes toward people with developmental disabilities. (Colorado report)

State Council Reports: Critical Issues and Barriers

There were service and support areas around which there was State Developmental Disabilities Planning Council consensus, such as the need for individual and family supports, for supported employment, and for community living alternatives. Although there were common issues raised by the State Councils based upon a shared understanding and commitment to the goals of independence, productivity, and integration into the community, there were also major differences. In large part the differences seemed to reflect differences among the states in the evolution of their community service systems. For example, a few states were reported to have virtually completed the deinstitutionalization process while others have barely begun. Some states have extensive case management programs and are primarily concerned about quality, while a few states have no case management programs and are concerned about their availability.

Several issues raised by the State Planning Councils can be generalized as fundamental or "cross-cutting" in that they cut across life areas and program areas. They can be summarized as follows:

People with developmental disabilities too often lack the basics of American life: **a** good job, good and caring friends **and** family, and **a** home (as opposed to a residence or "placement").

- **Services and supports too often fail to promote the goals of independence, productivity, and integration into the community for people with developmental disabilities.**
- **Programs and services too often are inflexible, forcing people with developmental disabilities to conform to the programs and services regardless of individual needs and preferences.**
- **Diagnostic labels, age, cultural background, and severity of disability too often are used to "pigeon-hole" people with disabilities.**
- **Funding too often is allocated to programs and services rather than individuals.**
- **People with developmental disabilities too often are discriminated against and their rights as human beings are abridged***
- **People with developmental disabilities, their family, and friends often lack the information to make informed choices.**

The issues surrounding the realization of the visions and goals that the State Councils put forward for people with developmental disabilities fell primarily into only a few categories. The State Council reports provided detailed descriptions of the unmet needs of people with developmental disabilities generally in terms **of the availability** of particular supports, services, or programs. In some cases, services were unavailable because of eligibility barriers.

Occasionally, Councils reported that services were available, but that they were not accessible to people with developmental disabilities because of barriers such as physical inaccessibility, discriminatory practices, high costs, the lack of financial resources by the person with a developmental disability, and lack of information or outreach.

State Councils pointed out many situations wherein services or programs had a focus that did not meet the goals of independence, productivity, and integration for people with developmental disabilities. Major issues also were expressed about the quality of services.

The last major type of issue had to do with consumer control. Many State Councils felt that people with developmental disabilities frequently did not have enough control over their lives and the services that were important to them.

Availability

In each of the life areas Councils reported that there were significant gaps in services. Generally, these were of two types. The first gap had to do with the fact that particular services, supports, or programs **did not exist**, there were **not** enough services or programs, or there was a **lack of service or support options**. One indicator of insufficient services noted by many Councils was the presence of a waiting list. The second kind of gap had to do with **population** exclusion. Throughout the state reports, there were examples of people with developmental disabilities who were excluded from service because their particular disability did not fit into a particular eligibility category. This was true across all the life areas, particularly for those services operated by state agencies designated to serve people with mental retardation; however, it was also found by some Councils that people who were technically qualified to receive services were turned away or put on waiting lists.

Several barriers that limited availability of services and supports were mentioned by the State Councils. Restricted availability of service was generally traced to a lack of resources within state or federal programs. Although a lack of financial resources was most commonly mentioned, there were also serious concerns raised by a majority of Councils regarding the lack of human resources, in the form of adequate

numbers of trained people to provide services. Several State Councils mentioned the barrier of ignorance and public attitudes about the needs and capabilities of people with developmental disabilities on the part of the general public, elected and appointed government officials, service providers, and even people with developmental disabilities, their families and friends. Other barriers mentioned were the lack of strong state and federal leadership, weak information systems, and the barriers of geography (e.g., rural areas). At another level some State Councils saw the weakness of their state economy as a barrier to developing the fiscal resources needed.

The specific gaps in services reported by the State Councils varied from state to state; the most common availability issues were in relation to individual and family supports, "real jobs for real pay," social and recreational opportunities, and homes in the community. The following list illustrates the primary programs, services, and supports identified in the State Council reports as insufficiently available. It should be remembered that these were not issues in every state and that the nature of the availability "problem" was unique to each state.

Civil Rights

- Affordable legal services
- Guardianship
- Protection and advocacy services

Education

- Adult and post-secondary education
- Assistance/supports to personnel and non-disabled students to support full integration
- Infants, toddler, preschool education and early intervention; Head Start—especially for children with severe disabilities
- Related services and supports
- Vocational education

Employment and Income

- Employment supports—especially long-term; job accommodations, technology in the workplace
- Fair wages; fringe benefits; real job opportunities, opportunities for advancement
- Income subsidies—lack of information and outreach on work incentive programs

- Supports and incentives for private employers

Health

- Community mental health services—counseling and long-term support
- Comprehensive health insurance coverage—Medicare, Medicaid, private
- Eligibility for health insurance—private, some Medicaid and Medicare
- Providers who accept Medicaid

Housing

- Affordable housing units
- Community living alternatives and support services
- Home based services for children with high medical needs

Individual and Family Supports

- Family supports to maintain household—especially respite care
- Individual supports: occupational, physical, speech and language therapies; personal assistance services; technology—adaptive equipment, assistive devices
- Information and referral

- **Integrated programs for older individuals with developmental disabilities**
- **Recreation and leisure time supports, integrated activities**
- **Transportation—especially in rural areas**

Accessibility

Many Councils reported that people with developmental disabilities were unable to have their needs met because, even when services and supports were available, they were inaccessible. Although the reason in many cases was a lack of resources to serve all who needed the service (availability, see above), some services were physically inaccessible. Again, some barriers were geographic, but more often they had to do with the lack of supports and assistive devices. Other barriers identified by Councils were ignorance or attitude. Opportunities to participate in services and other communities were also thwarted by isolation and segregation, often associated with people living in institutions and nursing homes. Another barrier to accessing programs, services, and supports mentioned frequently in the reports was that consumers and family members were unaware of services. As with availability, lack of commitment and leadership was also reported to be a barrier in some states. Issues of accessibility included:

Civil Rights

- **Discrimination on the basis of disability**
- **Enforcement of accessibility rights and protections; voting assistance, polling place accessibility**

Housing

- **Affordable housing that is also accessible**
- **Community living and participation**

Education

- **Fully integrated educational services—all ages, including adult and post-secondary education**

Individual and Family Supports

- **Accessible transportation especially for people with physical disabilities; transportation for people in more rural areas**
- **Interpreters and TDD systems**

Employment and Income

- **Job opportunities for people who require extensive supports or accommodations in the workplace**

Focus

The State Councils frequently took issue with the focus or direction of programs and services. As required by F.L. 100-146, the Councils were to analyze programs in terms of how well they were directed to the goals of independence, productivity, and integration into the community for people with developmental disabilities; therefore, the reports raised many issues regarding the effectiveness of programs and services to achieve these outcomes.

State Councils found many programs and services lacking in relation to the attainment of these goals. The major reasons or barriers cited in the reports included: program missions or goals out of line with the promotion of independence, productivity, and community integration; legislative restrictions; a lack of or

misdirected leadership by policymakers regarding the capabilities of people with developmental disabilities; low expectations regarding the capabilities of people with developmental disabilities; and other or vested interests incompatible with those of the consumers. Programs that were mentioned by State Councils as "missing the mark" in relation to independence, productivity, and community integration included:

Civil Rights

- **Guardianship—used inappropriately; too restrictive**

Education

- **Segregated education programs**
- **Special education—not career and life goal focused**
- **Transition to employment, adult services—poor coordination**

Employment and Income

- **Income assistance and subsidy programs—contain disincentives to employment; too low to promote independence**
- **Medicaid—disincentives to employment; weak coverage of employment-related supports**
- **Segregated/sheltered rather than integrated/supported employment**

- **Vocational rehabilitation—not focused on employment / job placement; long-term support guarantee requirement**

Housing

- **General funding bias toward congregate housing and economies of scale in the provision of housing support**
- **Inappropriate nursing home placements**
- **Medicaid Intermediate Care Facility/MR facilities—too restrictive, not "home-like," segregated**

Health

- **Restrictions on Medicaid and other insurance programs—payment for supports, therapies**

Individual and Family Supports

- **Restrictions on how supports can be used**
- **Segregated recreation and leisure opportunities**

Quality

Even when services were available and properly focused, there was yet another set of issues raised by the State Councils: services were of unsatisfactory quality; they did not achieve the results that were desired. Councils also identified some programs that failed to meet the over-arching expectation that programs and services should meet the individual needs of people with developmental disabilities. In some cases Councils related poor quality to poorly trained and motivated staff. Councils identified personnel issues across the life areas, including early and school-age education, supported employment, health care, residential services, case management, personal assistance, and transportation. In others the reports identified weaknesses in quality assurance procedures. Some Councils saw a lack of accountability for services and programs provided with public funds, including lack of information or data on how service participants were doing. Other barriers identified by Councils included the lack of fiscal and human resources. In addition to personnel issues, quality concerns were raised in the following areas:

Civil Rights

- **Monitoring of guardianship programs**

Education

- **High dropout rates**
- **Special education individual planning process - insufficient attention to individual needs**

Employment and Income

- **Income supports—demeaning application process**

Housing

- **Institutions, congregate living programs, nursing homes—lack of individualized programs**
- **Quality assurance programs—weaknesses in monitoring; not based on independence, productivity, and integration; compliance in institutions resulting in less resources for community living arrangements**

Individual and Family Supports

- **Case management programs—caseloads too high, conflicts of interest**
- **Transportation programs—poor service**

Consumer Control

Nearly all State Councils raised the issue of consumers' lack of control or independence in making decisions about their programs, services, and supports, and, most importantly, about their futures. For children, Councils raised the issue of family control and empowerment. The lack of consumer control was seen by the State Planning Councils as having a deleterious effect on the overall quality of life for people with developmental disabilities. The reports pointed out several areas where consumer influence and control were lacking, including the planning and monitoring of services, supports, and programs as well as the choice among services. Many barriers to increased consumer control and choices were identified by the Councils. Low expectations for people with developmental disabilities on the part of some policymakers and family members was seen as a key barrier that was shared with many providers. A related barrier was professionals' fears of losing control over services. Several reports also noted that consumers often lacked the information and skills to control services and other key events in their lives. Areas where a lack of consumer control was reported by Councils included:

Civil Rights

- **Options for limited guardianships**
- **Oversight of civil and legal rights**

Education

- **Educational programs and services—participation in individual education plans**

Employment and Income

- **Employment opportunities/career choices**

Housing

- **Housing and living situation—type, location, furnishings, housemates**

- **Planning, monitoring**

Individual and Family Supports

- **Personal assistance services**
- **Planning and monitoring—individual and family supports; transportation**

State Council Reports: People who are Unserved or Underserved

The State Planning Councils were required by P.L. 100-146 to identify people with developmental disabilities who are currently unserved or underserved in the state or territory. Although every Council report identified at least one population subgroup as unserved or underserved, it should be noted that the one group named in all reports was people with developmental disabilities in general. Others identified, in descending order of frequency, were as follows:


- Individuals with severe, multiple or very challenging disabilities
- People with physical disabilities, such as cerebral palsy, head injury, epilepsy
- People with mental health needs, including people with a dual diagnosis of mental illness and another developmental disability
- Individuals with mental retardation or other cognitive limitations
- People with sensory disabilities
- People with low incidence disabilities
- People with autism

Others found by Councils to be unserved or underserved included residents of rural areas, people with low incomes, members of racial or ethnic minority groups, young adults who "age out" of the public school system, and older individuals with developmental disabilities.

Councils identified many areas of services and supports where people with developmental disabilities were unserved or underserved, as noted in the summary of State Council report findings on critical issues and barriers. In addition, several Councils identified some people with developmental disabilities as being inappropriately served in relation to the promotion of independence, productivity and community integration. The groups identified as inappropriately served were primarily those in segregated settings, including institutional living arrangements, sheltered workshops, and segregated learning environments.

State Council Reports: Recommendations

The recommendations found in the State Council reports paralleled closely their findings on critical issues and barriers. The primary recommendation regarding insufficient availability of programs, services and supports was that they be made more available and more accessible. Similarly, Councils recommended a change in focus of programs and services that were limiting people's opportunities for independence, productivity, and community integration; an improvement in quality and in quality assurance mechanisms; and initiatives to **empower consumers** and give them more choice and control over their lives. Although there were many recommendations to increase program scope or to add services in some areas, the one common exception was in relation to large congregate facilities, which were recommended for reduction in utilization by virtually every Council. Overall, recommendations tended to be "action oriented"; although found in some reports, there were relatively few recommendations that were limited to "further study" of the issues.

The following represents a synopsis of the major recommendations from the Developmental Disabilities Planning Councils of the 55 states and territories. Those recommendations that were directed primarily at the federal level are preceded by a miniature map of the country: 

Availability/Accessibility

The State Council reports called for increased availability of services in order to serve additional people with developmental disabilities, expand services to those already receiving them, and expand the service options available. The expansion or redirection of resources was the strategy most frequently recommended by Councils to increase availability and access. Some Councils recommended the removal of eligibility barriers, including some based on income as well as some on type or severity of disability. Legislation, public education, and education of policymakers were seen by some Councils as ways to counteract some aspects of discrimination.

A strong recommendation was made in 19 reports that the Americans With Disabilities Act be passed and signed into law. The states saw this as a major civil rights initiative that was necessary for people with developmental disabilities in their states. There were also recommendations that state civil rights, guardianship, and accessibility statutes be brought into line with federal policy.

The programs and services listed below summarize the various recommendations made by Councils in relation to increased access and availability for people with developmental disabilities. The basic recommendation in the reports for each of these was that they be made more available and/or that access to them be improved for people with developmental disabilities. As with the summary of critical issues and barriers, it should be noted that the specific recommendations made by the State Council reports varied regarding their focus and the strategies that were considered appropriate within the individual context of the state or territory.

Civil Rights



Enact Americans With Disabilities Act.

- **Enact and enforce state protections.**
- **Guardianship**—increase availability of appropriate options

Education





Education of the Handicapped Act (P.L. 94-142)—require full coverage of ages 0 through 21; increase federal support


- **Educational placement options, related services, vocational education, post-secondary, and adult education**


- Integrated early childhood education
- Transitional services—between pre-school and elementary school and between high school and employment; adult services


Employment and Income

-  Employment supports—more resources /less restrictions for long-term supports
- Employment supports—more resources, increased access for people with physical disabilities, severe disabilities; employer training, technical assistance
-  Improve Supplemental Security Income eligibility determination for children with developmental disabilities.
- State supplemental payment programs—create, expand eligibility.

Health


-  Maternal and Child Health block grant—consider requiring minimum portion to be used for the Children with Special Health Care Needs program.
- Medicaid—expand eligibility at the state level; reduce disincentives for provider participation.

-  Medicare—expand eligibility to people during the first two years of Social Security Disability Insurance benefits.


-  Private health insurance—consider increased federal regulation.

- Private health insurance—expand regulation, access through state actions.

Housing

- Community housing options; community living supports
-  Low income housing that also is accessible

Individual and Family Support

- Family supports
-  Federally funded aging programs—increased access for people with developmental disabilities
- Individual supports—technology, personal assistance, transportation
- Information and referral programs
- Informal supports ("circles of friends"); recreation

Focus


The State Councils recommended changing the focus of a wide range of federal and state programs to better serve people with developmental disabilities in achieving the goals of independence, productivity, and integration into the community. These changes were recommended across all the life areas. Two areas that were seen as most critical by Councils were housing and employment.

Civil Rights

- Guardianship—use less restrictive options
- Involve consumers in planning, policymaking, and oversight
- Promote self advocacy

Executive Summary


Education


-  Education of All Handicapped Act—to promote full social and educational integration of all students; consider mandating individual transition plans; increase federal funding


- Educational transition and life planning
- Special education curriculum and placement options


Employment and Income

- Adult vocational service system—focus on private sector employment for people with severe and persistent disabilities; access to fair wages and employee benefits


 Expand Medicaid coverage of supports to employment.

 Federal work incentives—expanded access and scope of programs

 Rehabilitation Services Act—expand supported employment provisions.

 SSI, SSDI, AFDC benefit levels—increase to promote independence.


Health

 Medicaid—remove bias toward services provided in hospitals, institutions.

Housing

- Redirect resources from large congregate facilities to community living, supported housing models.
- Promote opportunities for home ownership, holding lease in own name.


Individual and Family Supports


 Reform Medicaid in ways that expand the use of Medicaid for supports to individuals; refocus on individuals rather than facilities.

Quality

State Council reports contained many recommendations to improve the quality of services and supports. Often these had to do with improved quality assurance efforts on the part of government and providers, such as increased public accountability. In other cases improvement in quality had to do with making greater and better investments in the people who provide services and supports, including ongoing opportunities for in-service training and consultation. Some Council recommendations focused on the need for more individualized services. The following areas summarize the State Council recommendations for improved quality of programs and services:

Civil Rights

 Enforcement of existing civil rights statutes

 Federal, state, and local program monitoring activities.

- State civil rights law enforcement

Education

- Life and transitional planning and curricula in education

- Post-education tracking to ensure that services were effective
- Special education and related services — personnel preparation
- Vocational education—involve business community.

Employment and Income

- Individual vocational plans
- Vocational services organizations— personnel preparation

- Training, technical assistance, and support to employers

Health

- Health care provider education and training in serving people with developmental disabilities

Housing

- Community living programs—personnel training and qualifications, program monitoring



Consider federal board and care standards.

- Meet institution quality standards, nursing home reform requirements without taking resources away from community programs.

Individual and Family Supports

- Case management—*independent of providers, service system; personnel preparation, reduced caseloads*
- Individual supports—*personnel preparation*
- Transportation—*personnel preparation, responsiveness*

Consumer Control

Increased consumer control over services, supports, and individual choices, as well as family empowerment in relation to children with developmental disabilities was recommended by nearly all of the State Councils. By and large, the Council reports recognized this requirement if the goals of independence, productivity, and integration into the community were ever to become a reality. Cutting across the areas listed below were State Council recommendations that people with developmental disabilities be active participants on the boards, commissions, and committees that plan and monitor the programs that affect them.

Civil Rights

- Civil and other legal rights
- Life planning and major program decisions

Education

- Educational decision making

Employment and Income

- Career choices

Health

- Health and medical care choices

Housing

- Community living choices

Individual and Community Support

- Family supports and services
- Individual supports and services

Cross-cutting Principles

The specific recommendations of the State Planning Councils reflected the differences among service systems and state priorities. At the same time, nearly all of the reports contained statements of principles that were the overarching themes for the Councils' recommendations. There was great consistency among the State Councils in the principles and cross-cutting recommendations that were articulated. These may be summarized as follows:

- Services and supports must focus on the goals of independence, productivity, and integration into the community for people with developmental disabilities.
- People with developmental disabilities need to be supported to be as independent, productive, and integrated as possible; they should not simply be "served."
- Programs must be made flexible to meet individual needs; they should not be based on diagnostic labels.
- People should not be excluded from programs and services that meet their needs because of a particular diagnostic label or because of a particular disability.
- Funding should follow the individual with a developmental disability.
- The rights and responsibilities of people with developmental disabilities must be scrupulously fostered and adhered to. They should not be discriminated against on the basis of their disability.
- A strong information system must be maintained on the status of people with developmental disabilities.

State Council Recommendations for State Agency Responsibility

Under the requirements of P.L. 100-146, one aspect of State Councils' reviews of state agency administered programs was an assessment of barriers to services in relation to the assignment of responsibilities among state agencies. The majority of Councils concluded that some of the barriers to people who are unserved or underserved were related to the assignment of responsibilities among state agencies. Findings were mixed between absence of state agency responsibility for particular populations (e.g., no agency with specific responsibility for people with physical disabilities) and use by state agencies of a categorical (e.g., presence of mental retardation) rather than a functional definition of eligibility, such as the federal definition of developmental disabilities.

Virtually all State Council reports included several recommendations regarding the assignment of state agency responsibilities to improve access to services. These recommendations varied from general assignments of responsibility to designations of specific authority for individual services or populations. The population group mentioned most frequently in these recommendations was people with developmental disabilities other than mental retardation. Others noted in the reports were people with dual diagnosis of mental illness and other developmental disabilities, people with multiple disabilities or severe health care needs, people with head injuries, and people in various age groups. There were also many Council recommendations for state agency responsibilities in relation to people with developmental disabilities in general. About one-third of the Councils recommended that decisions on specific assignments of responsibility for the full range of people meeting the federal definition of developmental disabilities be deferred until a more thorough review of the findings of their reports could be made.

From a different perspective, State Councils indicated that many services needed were not necessarily disability specific. For example, a housing agency might serve people of different disabilities, incomes, and ages. Looking at the state in this way Minnesota recommended, "...that each existing agency work to ensure the needs of all people who are unserved and underserved are met. There is no single agency that can accomplish this mission alone."

The Developmental Disability Planning Councils of the states and territories have presented impressive descriptions of the progress some people with developmental disabilities have made toward the goals of independence, productivity and full community integration. At the same time, the Council reports indicated that these goals have not yet been realized for many other individuals with developmental disabilities, and that there are many barriers to their opportunities for independence, productivity and integration.

The State Council reports contain a wealth of recommendations on ways to reduce these barriers, including Council implementation plans and specific strategies to improve the effectiveness of programs and policies; related strategies can be found in the State Developmental Disability Two-Year Plans recently submitted by the Councils to the Administration on Developmental Disabilities. Collectively, the 1990 reports prepared by the State Planning Councils provide the basis for creating new opportunities for people with developmental disabilities. The information from these reports will serve as a major resource at all levels in the review of current programs and policies and in the development of new initiatives to promote full citizenship for people with developmental disabilities.

I. Introduction

“ We hold these Truths to be self-evident, that all Men are created equal, that they are endowed by the Creator with certain inalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness—”

**—The Declaration of Independence
in Congress, July 4, 1776**

Section 122(f) of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146) required each State and Territorial Developmental Disabilities Planning Council to conduct a comprehensive review and analysis of state agency administered services supported by state and federal funds for people with developmental disabilities as they affect their ability to achieve the goals of independence, productivity, and integration into the community. It further required them to survey people with developmental disabilities as to their satisfaction with these services. The Councils were then to convene public forums to provide the results of their analytic work and to obtain the comments and recommendations of the public.

The amendments also required the State Councils to submit a report on the results of these activities to their governors and legislatures by January 1, 1990. These state reports were to include:

- Recommendations as to the most appropriate state agency(ies) to be responsible for services for persons with developmental disabilities "who are traditionally underserved, such as persons with developmental disabilities attributable to dual mental impairments, and persons with developmental disabilities attributable to a combination of physical and mental impairments, and such other subpopulations of persons with developmental disabilities (including minorities) as the State Planning Council may identify"
- Steps to be taken to include the data and recommendations from the reviews and analyses to be reflected in future Council activities.

Each governor was to transmit a copy of the State Council's report to the Secretary of Health and Human Services by January 15, 1990. The Act further required that the Secretary provide a summary of the State Council reports to Congress by April 1, 1990.

Fifty-five State Council reports have been submitted to the Secretary of Health and Human Services by the governors of the states and territories. This document is a summary of the fifty-three reports that were received in time for inclusion in this summary.

The State Council reports, the consumer surveys, and this summary reflect the collective efforts of thousands of individuals, including federal, state, and local officials, private service providers, and the families and friends of people with developmental disabilities who participated in numerous meetings and forums held across the country. The State Council reports also include the direct input of individuals with developmental disabilities whose responses to a consumer survey conducted in each state were essential to the development of the state reports. More than 15,000 consumers were surveyed by the states and territories, and their input was included in the state reports where appropriate.

This chapter presents the background to this effort beginning with a discussion of the people who are the focus of this report.

People with Developmental Disabilities

"The term 'developmental disability' means a severe, chronic disability of a person which —

"(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

"(B) is manifested before the person attains age twenty-two;

"(C) is likely to continue indefinitely;

"(D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and

"(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

—The Developmental Disabilities Assistance and Bill of Rights Act (as amended by P. L. 95-602)

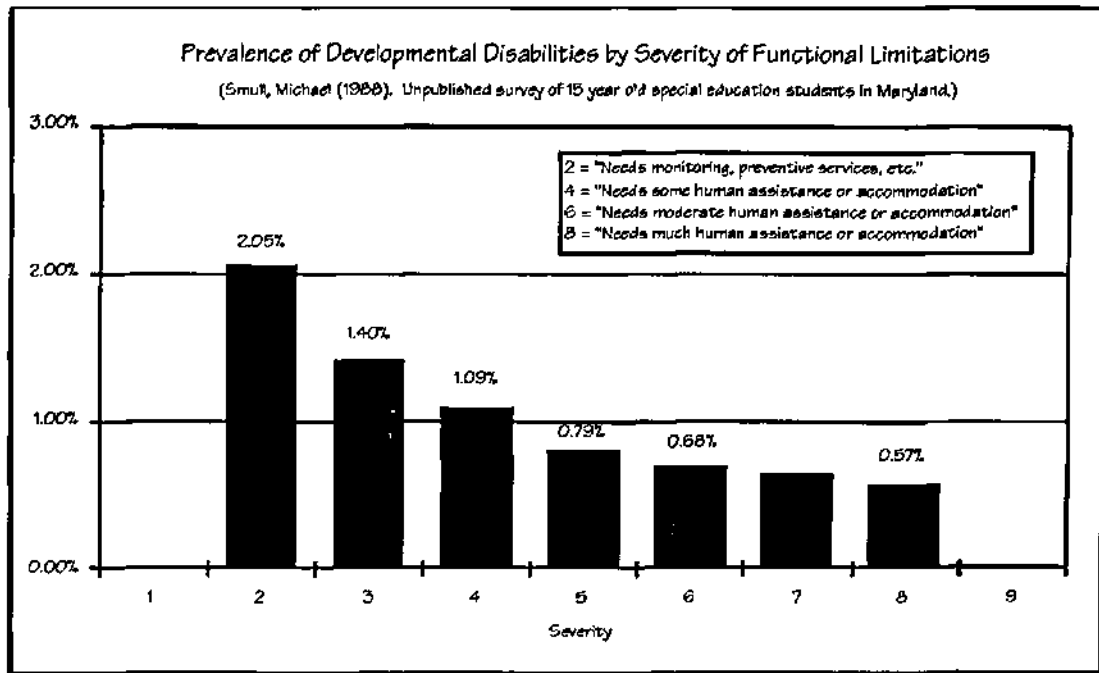
The term developmental disability applies to people with a mental or physical impairment that was apparent before their twenty-second birthday, that is likely to continue for an uncertain time, and results in "substantial" functional limitations in at least three areas of major life activity. These disabilities pose significant challenges for families and friends and especially for the individual with a developmental disability. It is to respond to these challenges that the Administration on Developmental Disabilities and its programs exist.

Although precise determinations of the size of the population of people with developmental disabilities are lacking, estimates range from 2,000,000 to about 3,000,000 people with developmental disabilities nationwide.

Various estimates also have been developed at the state level. For example, depending upon the definition of "substantial limitation," researchers at the University of Maryland estimated the percentage of the population who have developmental disabilities to range from 0.57 to 2.05 percent (Smull, 1988).

Although there has been a great deal of debate over prevalence rates, the debate has focused on the threshold for considering an individual as having or not having a "substantial limitation." Clearly the intent of Congress in establishing the federal functional definition of developmental disabilities in 1978 was to include those with the *greatest* functional limitations; there is no category of person whose

disabilities are too great to be considered as having a developmental disability.



The current federal "functional" definition of developmental disability adopted in 1978 (amendments to the Developmental Disabilities and Bill of Rights Act in P.L. 95-602) replaced a "categorical" definition that included all individuals whose disability was attributable to mental retardation, cerebral palsy, epilepsy, autism, or severe learning disability. The more recent functional definition (1978) can exclude individuals who may have a particular diagnosis (e.g., epilepsy) but who are able with some assistance (e.g., medication) to function adequately in the seven life areas. While excluding some individuals whose disabilities are not so severe, the functional definition potentially includes new groups of individuals (e.g., children born to mothers addicted to "crack" cocaine, individuals with traumatic head injuries, children with AIDS/HIV infection, individuals with severe mental illness with onset in childhood).

The functional definition was an important consideration in meeting the special reporting requirements in P.L. 100-146 that required the State Developmental Disabilities Councils to review and analyze service program eligibility, extent, scope, and effectiveness in relation to all persons with developmental disabilities, regardless of their primary

disability or the presence of multiple handicapping conditions.

Rights of Those with Developmental Disabilities

The Developmental Disabilities Assistance and Bill of Rights Act contains in Section 110 a statement of rights of persons with developmental disabilities. Included in this section are the findings that persons with developmental disabilities have a right to appropriate treatment, services, and habilitation that are designed to maximize the developmental potential of the person and are provided in settings that are least restrictive to the person's personal liberty. The statement of rights establishes minimum protections for persons with developmental disabilities served in institutional or other residential programs. Again in this section of the Act, there is a premium placed on the basic principle of protecting individual liberty through the provision of appropriate services and supports to people with developmental disabilities.

Several states have already addressed or are addressing the inclusion of the statement of rights into state statute or have adopted similar provisions. Several states have considered adopting this or a similar statement, as described by Councils in their reports to governors and legislatures.

Legislative Authority

The Administration on Developmental Disabilities is responsible for administering the programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act. These programs support the development and coordination of programs and services promoting the independence, productivity, integration, self-sufficiency and the protection of the rights of people with developmental disabilities of all ages. Part A of the authorizing legislation defines these goals.

"The purpose of this part is to provide payments to States to assist in the development of a comprehensive system and a coordinated array of services and other assistance for persons with developmental disabilities through the conduct of, and appropriate planning and coordination of, administrative activities, Federal priority activities, and a State priority activity, in order to support persons with developmental disabilities to achieve their maximum potential through increased independence, productivity, and integration into the community."

—Part B, Developmental Disabilities Assistance and Bill of Rights Act

An important means for carrying out this part of the Act is the Developmental Disability Planning Councils that have been established in each of the states and territories and are funded by the Basic State Grant program administered by the Administration on Developmental Disabilities. The fifty-five Councils are responsible to "serve as an advocate for all persons with developmental disabilities." Their membership includes persons with developmental disabilities, family members, representatives of relevant state agencies, service providers, and other individuals appointed by the governor of the state or territory. The Administration on Developmental Disabilities (ADD) also is responsible for fifty-six Protection and Advocacy Programs that provide legal, advocacy, and information and referral assistance to people with developmental disabilities in the states and territories. In addition to discretionary grants ADD manages, it also authorizes and supports a network of University Affiliated Programs in many of the states. These programs engage in a range of academic pursuits from basic research to personnel preparation.

Federal Policy Goals

The program goals for people with developmental disabilities contained in the Developmental Disabilities Assistance and Bill of Rights Act are—

...to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community, and

...to protect the legal and human rights of persons with developmental disabilities.

The Developmental Disabilities Assistance and Bill of Rights Act, as amended, contains goals for people with developmental disabilities that have become a model for all people with disabilities as well as for other disadvantaged populations in our society. These goals are based upon one of the fundamental beliefs that have made this country great: we achieve our greatest potential when we are challenged to be as independent and productive as possible as involved members of the community. Responsibility for achieving these goals is shared by federal, state, and local government, the private and voluntary sectors, and people with developmental disabilities and their families and fellow community members.

Independence

"The term 'independence' means the extent to which persons with developmental disabilities exert control and choice over their lives."

—Part A, Developmental Disabilities Assistance and Bill of Rights Act

A major goal for people with developmental disabilities is that they should have opportunities to exert control over their lives and make important life choices. A lot of factors in our lives influence the choices we make: where we live, how much money we have, how we were educated, who our friends and family are, our racial, ethnic, and cultural heritage. Our particular abilities and disabilities affect our decisions, but most of us have fundamental choices and control over our lives. This is in sharp

contrast to many people with developmental disabilities who do not share that control and choice with their fellow citizens. This is one of the critical issues that the state reports address.

Productivity

"The term 'productivity' means—

"(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or community."

—Part A, Developmental Disabilities
Assistance and Bill of Rights Act

The goal of productivity for people with developmental disabilities is essentially the same as it is for anyone else in society. All people expect to and should be expected to have opportunities to contribute to society in some way. Society tends to view non-contributing members with hostility, charity, or perhaps pity. The challenge for the states and their service systems is to help each person become productive because productive activity opens doors to social acceptance, self-esteem, companionship, and important informal community networks.

As stated in the Developmental Disabilities Act, federal policy identifies two ways for people to be productive. First, people can be productive by making a contribution to the economy, and second, they can make a contribution to their household, friends, or community. The Act goes on to define employment activities to include a range of supported and competitive employment options that will increase a person's independence, productivity, or integration in work settings. Supported employment is a recently defined approach to productivity based on the idea that people with developmental disabilities and other severe disabilities can succeed in mainstream employment situations with non-disabled co-workers if they receive the necessary support and job accommodation.

Since 1984, the Administration on Developmental Disabilities, Department of Health and Human Services, has had an employment initiative. The initiative has led to the diversification of employment opportunities for persons with developmental disabilities, and the operationalization of efforts at the state and local level to address barriers to employment such as health care, housing and transportation problems. Joint public/private sector partnership activities have developed industry-based programs for the training and placement of persons with developmental disabilities in permanent integrated jobs in the community.

Integration into the Community

"The term 'integration' means—

"(A) the—

"(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and

"(ii) participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and

"(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities."

*—Part A, Developmental Disabilities
Assistance and Bill of Rights Act*

Of the three goals, integration into the community is both the clearest and the most complex. On one level integration is simply living in the community outside the institution. But a careful reading of the definition leads to the conclusion that in order to achieve meaningful integration people with developmental disabilities must actually participate in the normal life of the community along with people who do not have developmental disabilities. Integration, therefore, involves many more people than just people with developmental disabilities, their families, and service providers; it involves the broader community, including community institutions such as religious organizations, civic groups, and businesses as well as other individuals.

Requirements for and Preparation of the Summary Report

The program philosophy of independence, productivity, and community integration for people with developmental disabilities has evolved since 1978 with the passage of ensuing legislation changing and shaping the focus of the developmental disabilities program. In 1987 Congress ensured further change with passage of P.L. 100-146, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. These amendments emphasized the role of State Developmental Disabilities Planning Councils by shifting their focus from provision of direct services to one of facilitating systemic change. The amendments expanded training for professionals in the field of developmental disabilities and even targeted federal funds to specific areas of concern. These and other requirements sent a clear message that Congress was paying attention. Most significant was the requirement for states and territories to participate in an unprecedented study to determine the scope and effectiveness of state agency administered programs and services using federal and state funds for all people with developmental disabilities. Specifically, Congress required each State Developmental Disabilities Planning Council to conduct a comprehensive review and analysis of state-administered services for people with developmental disabilities and governors in each state and territory to submit their Planning

Council reports to the U.S. Department of Health and Human Services. The Secretary of Health and Human Services was required to submit a summary of the State Council reports to Congress.

The approach to preparation of this summary report was a careful review of the individual reports prepared by State Developmental Disabilities Planning Councils and submitted by the governors of the states and territories. Another major source was the compilation of findings from the state reports prepared by the National Association of Developmental Disabilities Councils. A compilation of the state consumer surveys, prepared by the Temple University Developmental Disabilities Center/University Affiliated Program for the National Association of Developmental Disabilities Councils, was the major source of information on the survey of consumers which is referenced selectively in this report.

Findings from the State Council reports were summarized in relation to major "life areas": learning (education), working (employment and income), housing, health, civil rights, and related supports to individuals, families and communities. Within each area the 1990 summary report looks at the goals for people with developmental disabilities defined in the individual reports, as well as the descriptions of recent accomplishments at the state and local levels. The reported perspectives of people with developmental disabilities and family members also have been used extensively in the preparation of the summary report. Altogether, over 3,100 statements of barriers and approximately 3,200 recommendations contained in State Council reports were reviewed and analyzed in summarizing the views of the states and territories in this report.

Independence, Productivity and Integration for People with Developmental Disabilities: A Summary of Reports Prepared by State Developmental Disabilities Planning Councils, this summary 1990 report to the Congress, is the product of the State Councils' analyses of the scope and effectiveness of programs and services administered by state agencies (using state and federal funds) for people with developmental disabilities. In addition to the findings on barriers and needs of people who are currently unserved and underserved as required by the legislation, it includes three elements that will enrich its usefulness:

- The State Councils' expectations for the lives of people with developmental disabilities: the desired future, vision, or goals

- The Councils' descriptions of current achievements in relation to the vision/goals
- Direct quotations from individuals with developmental disabilities and family members about their current reality in relation to the vision or future

It is in this context that the examination of the reports has been carried out.

The recommendations and analyses contained in this report reflect the experience and opinions of the State Developmental Disabilities Planning Councils and are not the official position of the Administration on Developmental Disabilities or the Secretary of the Department of Health and Human Services.

Limitations of the Summary Report

The preparation of this summary of State and Territorial Council reports revealed various limitations that should be kept in mind in reviewing its contents:

- Although some State and Territorial Council reports provided information on accomplishments and initiatives, others did not. The examples highlighted therefore do not include many other activities throughout the nation that illustrate success stories, nor have they been selected on the basis of any particular criteria as exemplary.
- The requirements of F.L. 100-146 are essentially focused on the negative, i.e., the identification of barriers and of people who are unserved or underserved. This report is therefore similarly oriented toward "problems," even with the inclusion of information on accomplishments.
- The individual Planning Council reports do not follow any specific format. Other than the nearly universal use of a common consumer survey instrument, the reports reflect unique approaches to their meeting of the federal requirements. This has resulted in extremely diverse reports that do not lend themselves to comparisons among the states in relation to specific services and topics of concern.
- References to federal programs found in the reports were often incomplete or unclear. We have not drawn inferences regarding federal programs, noting only those which were explicit in the state reports.

- Many sources were used by the State Councils in preparing their reports, however, these have not been included in the interest of brevity. Readers are encouraged to read the individual state and territorial reports to identify references of interest
- Most proposals for implementation of recommendations by the State Planning Councils are found in the form of recommendations, rather than strategies. It is expected that most Councils have included their plans to implement activities which begin to address issues raised in their state reports in their Two Year Plans recently submitted to the Administration on Developmental Disabilities.
- Although findings are described as State Council findings throughout the summary report, it should be noted that the reports as transmitted by the governors of the states and territories may, in some jurisdictions, reflect one of several views in individual states on the needs of people with developmental disabilities.

Finally, it should be noted that, similar to the compilations prepared by the National Association of Developmental Disabilities Councils, this report has been prepared in the "people first" language preferred by people with disabilities, i.e., "people with developmental disabilities" rather than "the developmentally disabled". Statements have been modified to conform to this model with the exception of titles and direct quotations.

The Consumer Survey

One of the most important activities required of the State Councils for the 1990 reports was the consumer survey. The 1987 Amendments to the Act required:

Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with, the functions performed by, and services provided or paid for from Federal and State funds by, each of the State agencies (including agencies providing public assistance) responsible for performing functions for, and providing services to, all persons with developmental disabilities in the State. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services from each such agency, and if appropriate, shall include their families.

Primary Diagnosis (Summary of State Consumer Surveys)		
Diagnosis	Number	Percent
Mental retardation	5,533	42.3
Cerebral palsy	1,930	14.8
Other(s), such as learning disability, developmental delay, etc.	1,417	10.8
Emotional (including chronic mental illness)	818	6.3
Epilepsy/seizure disorder	457	3.5
Autism	446	3.4
Blindness/severe visual disorder	419	3.2
Head injury	374	2.9
Deafness/severe hearing impairment	309	2.4
Other neurological impairment	276	2.1
Spina bifida	274	2.1
Orthopedic impairment	171	1.3
Muscular dystrophy	161	1.2
Spinal cord injury	144	1.1
Speech/language impairment	106	0.8
Deafness and blindness	106	0.8
Unknown	61	0.5
Multiple sclerosis	55	0.4
Cystic fibrosis	18	0.1
Total	13,075	100

The Administration on Developmental Disabilities (ADD) provided support for a national initiative to develop a common survey instrument. In collaboration with ADD, the National Association of Developmental Disabilities Councils (NADDC) convened an advisory group to formulate a nationally coherent action plan, and identified a scientific group to assure that the consumer surveys performed by the states were comparable.

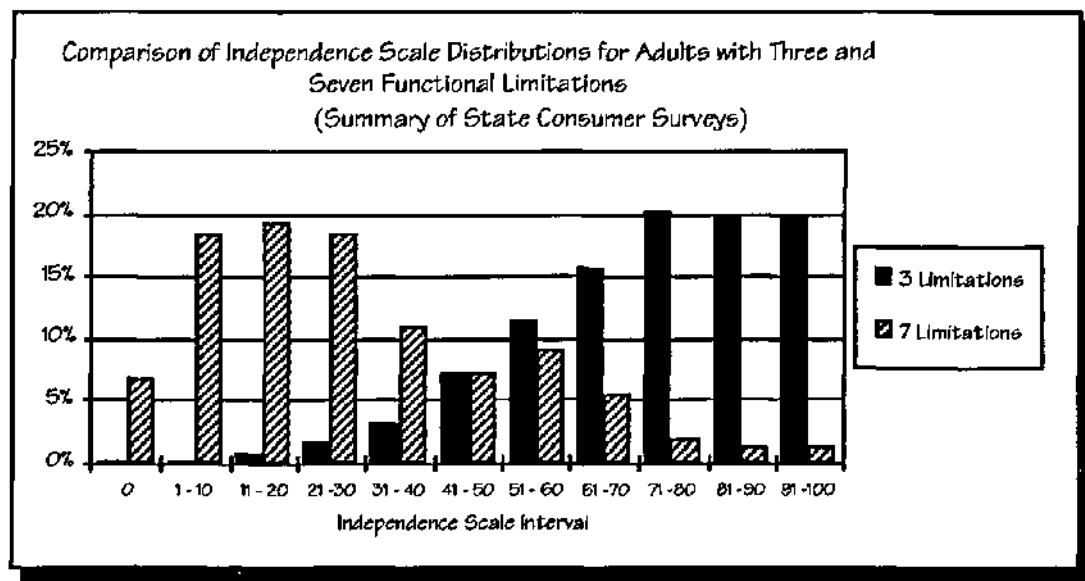
The work is now complete. Although this was not a national survey in the sense that it was based on a nationally representative sample, more than 15,000 people with developmental disabilities have been personally interviewed by representatives of the State Developmental Disabilities Councils. Nearly all of these interviews were conducted face to face. This has been the most extensive survey of people with developmental disabilities ever undertaken.

Copies of the data from 14,282 of these interviews have been forwarded to the Temple University/University Affiliated Program where a central analytical group summarized the results. This summary report presents selected findings from the 13,075 interviews for which the data were complete and usable. The people who were interviewed were of all ages, from one month to 90 years of age. Some were assisted by family members or other caregivers, either because of age or of communication limitations. They also represented a wide variety of diagnoses, as displayed in the accompanying table.

It is important to note that the people included in the state consumer surveys were people with severe, chronic disabilities that began early in their lives. The definition of developmental disabilities requires "substantial functional limitations" in three or more major life areas. Over 70 percent of the people in the state surveys reported substantial functional limitations in more than three life areas.

Results from the consumer surveys are found selectively throughout this report in relation to where people live, their schooling, their work life, and the supports and services they currently receive. One of the consumer survey findings highlighted in many of the State Council reports was that some of the people surveyed with limitations in five, six, and even seven functional areas were reaching significant levels of independence. When people's independence was measured on a scale of 0 to 100, data from the summary of state consumer surveys indicated that over one-fourth of the adults surveyed with seven functional limitations were at the mid-

point or higher in independence, as illustrated in the following figure.



Data from the summary of state consumer surveys also indicated that some people with as many as seven functional limitations were engaged in productive activities on a regular basis and were well integrated into their communities. Conversely, the summary data indicated that many people with only three functional limitations were at very low levels of independence, productivity, and community integration.

Other results from the summary of the state consumer surveys included the following:

- Most people with developmental disabilities think it is important to be independent, productive, and integrated into the community.
- There are significant gaps, however, between the importance of independence, productivity, and integration and people's current experience:
 - Less than one-fourth of the adults chose where they are currently living.
 - Seventy-five percent of consumers who had worked for pay the previous week made less than the minimum wage.
 - People with developmental disabilities have less participation in community

living activities and are more apt to feel lonely than people without disabilities.

- People who live in nursing homes and other institutions are less independent, productive, and integrated than people who live in community residences.

Overall, there were more similarities than differences in consumer survey findings based on type of disability (i.e., physical, cognitive, sensory, or emotional). Differences were noted, however, in a few areas, including the following:

- Children and adults with mental retardation were more apt to live in a specialized facility or institution than people with other kinds of disabilities.
- Adults with disabilities other than mental retardation were more likely to live in a nursing home than adults with mental retardation.
- Nearly 70 percent of the adults with mental retardation reported that they had no choice or control over their living arrangements, compared to 41 percent for people with other disabilities.
- Sheltered workshops were still the most common employment option for adults with mental retardation; for people with other disabilities, this was one of the least likely options.
- People with mental retardation were earning less money across all employment settings than people with other disabilities, even when controlled for the number of hours worked or years of employment in the setting.

The results of these state surveys, collectively the largest survey of people with developmental disabilities ever conducted, will continue to be examined for several years to come. There is a great deal more to be learned from the data about specific age groups, about specific disability groups, and about quality of life issues.

Organization of the Report

This summary report is organized into eight major chapters, beginning with Chapter I - Introduction. Chapter II describes the process that the State Developmental Disability Planning Councils and the Administration on Developmental Disabilities have un-

dertaken to develop the summary findings. The chapter highlights the technical assistance provided through the Administration on Developmental Disabilities by the National Association of Developmental Disabilities Councils, Temple University, and the University of Illinois.

The remaining six chapters (Chapters III-VIII) discuss the findings and recommendations of the State Councils as they apply to six major topical or life areas: individual and family supports, education, employment and income, housing, health, and civil rights. Each of the chapters on life areas begins with an overview of State Council findings and visions or goals for people with developmental disabilities. The chapter is then organized into a series of key topics or "themes" identified by Councils in each life area. Within each theme, the report summarizes major accomplishments and opportunities for positive action, critical issues and barriers, and recommendations.

Reader aids found throughout the summary report include the following designations:



Goal/vision statements



Summary points



Accomplishments



Quotes from consumers and family members



Critical issues and barriers



Recommendations

Appendices include relevant excerpts from the Developmental Disabilities Assistance and Bill of Rights Act, an annotated bibliography of data resources available to the states in developing their reports, a glossary, a summary of ADD-supported technical assistance activities, and a list of the members of the National 1990 Report Advisory Committee.

The survey, policy analysis, public forums and development of recommendations by the State Developmental Disability Planning Councils represent an historic undertaking, one that will affect federal and state policy decisions for years to come.

The summary that follows describes the movement of people with developmental disabilities toward the goals of independence, productivity, and integration, as seen through the State Council reports recently submitted to the Secretary of the Department of Health and Human Services by the governors of the states and territories. It is a report about programs and changing priorities, but more than that, it is a tribute to the people behind these new priorities and programs—federal and state and local policy-makers, service providers, families, friends and employers, and, most importantly, people with developmental disabilities themselves.

Readers will be impressed with the amount of progress that people with developmental disabilities are making as documented in the State Planning Council reports, but will also understand that more needs to be done with and on behalf of people with developmental disabilities. One conclusion that the reader will surely be left with is the complexity of the problems and the issues that the country must face in the decades ahead. We must overlay issues specific to developmental disabilities on those significant domestic issues facing all our citizens. At the same time many people with developmental disabilities are succeeding in their communities. In looking at the many challenges facing people with developmental disabilities, we encourage readers to keep in mind their many accomplishments.

II. The 1990 Report Process

II. The 1990 Report Process

Introduction

Activities to meet the requirements of P.L. 100-146 that each State Developmental Disabilities Planning Council prepare and submit a report to their governor and legislature by January 1, 1990 have come to be known commonly as the "1990 report process." The five activities specifically required of each state and territory by the legislation were the analysis of policies and programs relevant to people with developmental disabilities; a survey of consumers; the presentation of findings from these two activities in public forums; presentation of the report to the governor and the legislature; and the submission of the report to the Secretary of Health and Human Services.

There was general consistency among the State Councils in their approach to the consumer survey and the public forums. At the same time there was much greater variation among the states in the approaches to program and policy analysis. There was even more diversity in the level of detail on the specific 1990 report processes of the individual states and territories. Nevertheless, several common approaches can be discerned, including the major involvement of consumers, family members, and advocacy organizations. These themes are highlighted in the following sections.

Overview of Developmental Disabilities Planning Council 1990 Report Activities

◆ **State Councils formed a "1990 Report" work group.**

The initial activities of many State Councils focused on the establishment of a special "1990 report task force" or committee. Several Councils also established work groups to focus on specific areas, such as education or transportation. Many State Council reports reflected the significant role of the Council membership in the overall design and implementation of 1990 report activities. For example, the Wisconsin report provided the following information:

Throughout the entire development of the 1990 Report, members of the Planning Committee of the Wisconsin Council on Developmental Disabilities played the major role of analyzing consumer survey data, analyzing selected federal and state programs, developing final recommendations, reviewing written materials, providing guidance to Council staff in carrying out Council action,

and providing recommendations to the full Council on the requirements outlined in P.L. 100-146. (Wisconsin report)

The Policy Analysis

The requirements of P.L. 100-146 include a state-specific analysis of the eligibility for services provided to people with developmental disabilities and the extent, scope and effectiveness of state agency services using state and federal funds in relation to their promotion of independence, productivity and community integration. This State Council analysis was to include services with potential impact on people with developmental disabilities, as well as those with current impact. In addition, the analysis was to be conducted in relation to people with various kinds of developmental disabilities, specifically to include people with developmental disabilities attributable to physical impairment, mental impairment, or a combination of physical and mental impairments. The results of this review and analysis were to be used along with the results of the consumer survey to develop recommendations on state agency responsibilities, the removal of barriers to services or people with developmental disabilities, and the Council's future activities.

◆ **States and territories used various approaches in their policy analysis.**

The individual Council reports submitted by the states and territories reflect different approaches taken in the program and policy review process. These included the development of vision statements, goals and principals as the analytical framework for the review; development of quantitative and qualitative data on state administered programs and services; reviews of authorizing legislation, budgets, state plans, and agency annual reports; and key informant interviews with state agency representatives.

◆ **Programs were analyzed according to state agency.**

Virtually all Councils organized their analysis in relation to individual state agencies and the programs they administer. An example of the agency-based approach is found in the Indiana report:

To perform this analysis, a letter was sent by the governor to each relevant state agency director...requesting their cooperation and asking them to designate a staff person to serve as a resource...in the areas of policy, statistics, eligibility and services. The relevant state agencies were asked to provide the following information:

- Enabling legislation (federal and state)

- Promulgated rules and regulations
- Program policies and procedures
- Most recent annual plan
- Most recent annual report
- Most recent annual budgets (federal and state)
- Service delivery structure
- Needs assessments

(Indiana report)

The number of programs reviewed, based on reports which included this information, ranged from around 20 to over 100, depending on the definition of "program."

◆ **Programs were reviewed in relation to life areas:**

- **Supports**
- **Education**
- **Employment and Income**
- **Housing**
- **Health**
- **Civil Rights**

Many of the State Planning Council reports reflect an approach to policy analysis which combined the review of programs organized by state agency with an overall review of policies and programs in relation to particular life or issue areas. For example, the Connecticut Developmental Disabilities Council reviewed over 100 federally and state assisted programs administered by 35 state agencies in relation to the following questions:

- Who is eligible?
- What do you get?
- When can you use the program?
- Where do you apply? (if relevant)
- Why is the agency important to the integration, independence and productivity of people?

In addition the Council conducted detailed policy analyses in five areas: housing; support of communities; transportation; individual and family support ("two analyses in one"); and employment.

Federal programs were generally reviewed by State Councils from two perspectives: (1) their implementation by state (and in some cases local) agencies and (2) their authorization and implementation at the federal level. For example, there were many references to state Medicaid plans, such as eligibility requirements, selection and scope of optional services, reimbursement rates, etc., as well as many references to federal Medicaid policy as it affects people with developmental disabilities and their families. An

example of policy analysis focused on state discretion in relation to the Medicaid program was found in the Maine report, which noted such state factors as:

- Income and resources criteria for the AFDC program
- Optional coverage of additional groups of the categorically needy
- Additional Medicaid eligibility criteria for SSI recipients beyond their receipt of SSI assistance
- Criteria for the medically needy, including income levels and spend-down requirements
- Eligibility for individual program options (e.g., clinic services, rehabilitative services, ICF/MR, etc.)
- Extension of eligibility to individuals with disabilities and other groups at state option who receive state supplementary payments (SSP) even though they are not receiving federal SSI payments

Independence, Productivity, Integration

State Councils' focus on the federal policy goals of independence, productivity and community integration in the program and policy review was reflected throughout the reports, including goals and vision statements of the desired future for people with developmental disabilities, as the basis for the consumer survey, and as a frame of reference for the policy analysis. Councils used these goals in particular as criteria or standards against which to assess the effectiveness of current programs and services.

Some reports included a description of specific standards used in the State Council policy analysis of individual programs. For example, the Iowa Council used questions on independence, productivity and community integration to review the effectiveness of individual program policies, such as:

- Is eligibility based upon individual needs for services? (Independence)
- Does the program policy promote [individual] choices regarding where and who provides the service? (Independence)

- Does the program policy provide for individual levels of service to support people in reaching their maximum productivity? (Productivity)
- Does the program policy allow participation in typical work settings, neighborhoods and community environments? (Integration)
- Does the program policy promote use of typical community resources and not require a separate delivery system for people with developmental disabilities? (Integration)

Under this method, programs received an "effectiveness rating" based upon the extent to which their policies were found to promote independence, productivity and community integration.

Overall, the individual State Council reports reflected a comprehensive analysis of the eligibility, extent, scope and effectiveness of programs and services as they affect people with developmental disabilities. At the same time, one of the severest challenges to the Councils in conducting the policy analysis was the lack of data on federal and state programs serving, or potentially serving, people with developmental disabilities. Several factors impeded the collection and review of data on program availability, scope and effectiveness:

- Lack of common reporting requirements across state administered programs that use state and federal funds regarding participation by people with developmental disabilities, including the use of different definitions (e.g., no comparable application of severity and functional limitation criteria in programs other than those funded by the Administration on Developmental Disabilities)
- Inadequate state-specific data on program participants in general, making it inappropriate in many programs to develop "proxies" that could be used to ascertain participation by people with developmental disabilities
- Minimal and/or optional state reporting requirements for federal programs, in particular those funded through the Social Services Block Grant, the Maternal and Child Health Block Grant, and the Alcohol, Drug Abuse and Mental Health Services Block Grant

- Delays in the availability of state program data, necessitating the use of considerable data from fiscal year 1987 and earlier as the most recent information available

◆ **The majority of findings on eligibility were specific to the individual state or territory.**

The State Council reports reflected relatively few difficulties in the analysis of program eligibility. It should be noted, however, that because of the differences in service systems, the majority of findings on eligibility were specific to the individual state or territory.

Approaches to the Consumer Survey

The Developmental Disabilities Planning Councils of the states and territories approached the consumer survey requirements of P.L. 100-146 in a very consistent manner. Through their national organization, the National Association of Developmental Disabilities Councils (NADDC), Councils selected the Temple University Developmental Disabilities Center/University Affiliated Program (UAP) to design the survey instrument, recommend sampling methods, assist in training interviewers, and give technical assistance in handling the data.

◆ **All but two states and territories used the standardized consumer survey instrument.**

To conduct the consumer surveys, a large majority of State Councils contracted with an organization experienced in survey research; about half of these selected their UAPs. In most states the interviews were conducted by experienced survey personnel. All but two Councils used the standardized survey instrument developed by Temple University/UAP, and three others used it with significant modifications.

There were a few exceptions to the general pattern of using the Temple University instrument and contracting out to survey specialists. One state felt that their timeline did not permit them to wait for the standardized instrument; they therefore wrote their own and conducted the survey before the common instrument was available.

◆ **Most states used consumers to perform interviews.**

The majority of state surveys used some consumers to perform the interviews, and two used consumers nearly exclusively. One state used Council staff members as the surveyors; another chose to use a Council staff person as the sole interviewer. Several others used relatives of people with developmental disabilities.

About 40 of the State Councils attempted to obtain representative samples by using the "proportional method." The sample size of 300 recommended by Temple University was divided into four subgroups in an attempt to make the proportions in the sample mirror those suggested in the literature as the actual proportions of primary disability in the population of people who meet the functional definition of developmental disabilities (Gollay 1981):

Primary Disability	Percent
Mental retardation	42%
Physical	34%
Sensory	15%
Emotional	09%

Eleven states used their own locally developed prevalence estimates instead of these national estimates. Two states used a two group rather than a four group approach: people with mental retardation and people who meet the definition of developmental disabilities but who do not have mental retardation. Another five states used an "equal-N" sampling strategy, entailing three groups of 100 members each, divided on the basis of primary disability: cognitive, physical, or emotional/behavioral.

◆ **Councils experienced difficulties in identifying people with developmental disabilities at the extremes of the age continuum.**

The Councils in the states and territories also made efforts to assure a broad age definition in their samples. They experienced difficulties, however, in identifying people with developmental disabilities at the extremes of the age continuum. For infants and young children, the functional definition itself does not work very well. For example, economic self sufficiency does not apply to an infant. At the other end of the age continuum it is difficult to determine for many aging people that the age of onset had been prior to age 22, as required by the definition. In addition some older people with developmental disabilities may be receiving services only in the general health care system and were therefore less apt to be visible to the developmental disability advocacy and service organizations who assisted in the identification of consumers to be surveyed.

◆ **Disability advocacy organizations identified prospective consumer survey participants.**

Advocacy organizations were the primary resource used to gain access to people with developmental disabilities for the survey. To preserve the privacy of organizational mailing lists, the organizations were asked to mail out introductory letters for the State Councils. Those interested in participating in the consumer survey returned a form directly to the

Councils or to the entities conducting the survey. Although this introduced some (unknown) degree of self-selection bias, it is generally accepted that self-selection produces samples with strong feelings, both positive and negative, with those who are indifferent tending to ignore the invitation to participate. The two opposing biases, however, tend to cancel each other out. A few states followed similar procedures using other sources of potential participants, including state agency lists of service recipients and waiting lists.

Following completion of the survey interviews the responses were encoded for statistical analysis. About 40 of the State Councils used the "data reduction" computer program supplied by Temple University/UAP. Most of the remaining states had contractors with other data reduction packages that could produce data files adaptable to the format used by the 40 states.

For analytical purposes, Temple developed a 400-page custom-designed printout which was used by 45 of the states; five others did all of their own analysis. Fifty states and territories had submitted their consumer survey data to Temple University/UAP for individual analysis as of March 30, 1990. Revisions to the survey instrument made by individual states, combined with difficulties in translating to the standardized data format, made it impossible to include data from two states in the final compilation. Each State Council analysis included the results of all questions, broken down by disability and age groups.

One aspect of the analysis of the consumer surveys that received special attention was findings on satisfaction with services. As noted by Temple in its design of the common instrument, consumer surveys in human services have consistently been found to produce high satisfaction ratings, even if respondents were also very critical of the services in question. Many State Planning Councils addressed this issue in their reports, in some cases speculating that, for many consumers, "some service is better than none." Some Councils also noted that their samples may have been biased toward recipients of services, despite their outreach efforts, and therefore did not include sufficient numbers of those who would have said they were dissatisfied on the basis of lack of access. More detailed discussion of the strengths and limitations of the state consumer surveys may be found in *Report on the 1990 National Consumer Survey*, prepared by the Temple University/UAP for the Na-

- ◆ **Councils noted that giving a voice to consumers through the survey has been significant as an activity of consumer empowerment.**

tional Association of Developmental Disabilities Councils.

Summaries of the consumer survey findings were prepared in each state and territory for use in their Council report. In most states, the summary was initially prepared by the survey contractor, followed by revisions in consultation with the Council. As will be noted throughout this summary report, the findings have focused particularly on the status of people with developmental disabilities in relation to their independence, productivity, and integration into the community. Councils also have noted that giving a voice to consumers through the survey has been significant in itself as an activity of consumer empowerment.

Development of Recommendations

- ◆ **Extraordinary efforts to obtain maximum participation of people with developmental disabilities, family members, and advocates**

The State Council reports described the processes which were used by the Councils in the development of recommendations, including the delineation of issues, the development of preliminary recommendations, the review of recommendations through the public forums and related mechanisms, and the final approval by the Developmental Disabilities Planning Council.

Most reports described activities to identify issues of concern to consumers and their families, and the particular concerns of those who are unserved or underserved. Paralleling activities at the national level, many State Councils reached out to a wide range of disability advocacy organizations to ensure that the views of people with various types of developmental disabilities were reflected throughout the 1990 report process.

Many State Councils conducted "focus groups" of consumers, family members and organization representatives to identify critical issues that could then be used to guide the policy analysis and the development of recommendations. For example, the Vermont report describes a series of "critical issue meetings." These four regional meetings, or focus groups, included people with severe disabilities, family members and service providers. Participants defined what they considered to be the most critical issues related to the effectiveness of services for people with developmental disabilities. The consolidation of critical issues from these meetings produced a statewide identification of the five most critical issues featured in the report.

Additional issues and barriers were identified by many Councils through the consumer survey process itself and the subsequent analysis. Still others surfaced through the public forums during review of the draft recommendations. In addition, the State Council membership frequently provided input on issues through their participation on task forces and committees as well as their general oversight of the 1990 report process. All Developmental Disability Planning Councils include people with developmental disabilities and their family members.

As described in several of the reports, many preliminary recommendations were prepared by Council task forces and committees, which were then reviewed through the public forum process. Some State Councils engaged in additional activities to obtain broadbased review and comment on their recommendations, including surveys of the full Council membership, statewide surveys, and teleconferences. One of the most extensive outreach efforts was described in the Alaska report, as follows:

Two statewide teleconferences were held to gather information from throughout the state, particularly from communities where public forums were not being held....The October 25, 1989 teleconference was sponsored by (state) Representative Mark Boyer from Fairbanks. Fourteen Legislative Information Office sites (Anchorage, Fairbanks, Bethel, Delta Junction, Dillingham, Juneau, Soldotna, Ketchikan, Kodiak, Kotzebue, Mat-Su, Nome, Sitka and Valdez) were a part of the teleconference with an off-network site added in Kake. Of the 85 people attending the teleconference at sites throughout the state, 45 gave testimony. Included in the attendees were three state legislators and aides representing five other legislators. (Alaska report)

The final preparation and approval of recommendations as a formal Council activity was noted in a few State Council reports. For example, the Virginia report stated that the Council held a specially called meeting on November 30, 1989 for final discussion and approval of the state report.

The Public Forums

The 1990 report provisions of P.L. 100-146 include a requirement that State Councils convene public forums to present the findings of their policy reviews and consumer surveys. The forums also were to obtain comments from all interested individuals re-



Public forums on the State Council report recommendations were held in every state and territory.

garding unserved and underserved people with developmental disabilities in relation to the proposed recommendations on the removal of barriers to services and on state agency responsibilities. The State Council reports reflect significant use of the public forum process across the nation. Many reports indicated that public forums were attended by hundreds of consumers, family members, providers and organizational representatives, government officials and community members, following broadbased outreach to involve people in the forum process.

One of the most comprehensive public forum approaches was described in the Michigan report as part of the Council's "Consumer Response Initiative" (CRI). The CRI included public forums held in six communities around the state, attended by 1,300 people. Approximately two-thirds of the forum participants were people with disabilities.

The State Council reports reflect various styles and formats for the forums, from informal discussions to more formal hearings that provided opportunities for testimony. It was clear from the reports that Councils found the public forums to be an important component of their 1990 Report activities, in particular as an additional opportunity for direct consumer input.

Development of Council Plans for Implementation

Many of the State Planning Council reports included recommendations directed to the Council, e.g., "The Council 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." (New York report)

Most of the reports contained only general statements regarding the Councils' plans for implementation. The specific strategies for implementing state report recommendations can be found in the State Developmental Disability Two-Year Plans recently submitted by the Councils to the Administration on Developmental Disabilities.

A few reports included specific plans for implementation. The strategies most frequently noted were coalition building in advocating for the 1990 report recommendations; use of the findings in educating policymakers; supports to consumers in their advocacy and empowerment efforts; and the develop-

ment of models to demonstrate the potential of new approaches to systems building or services. Among those less frequently cited were inter-agency collaboration; improved data collection; public education; and the appointment of Council representatives to other planning units.

One of the most notable examples was the report submitted by Guam, which presented Council "action steps" in relation to the issues and recommendations. For example, the lack of respite care was addressed by the recommendation to investigate and establish an adult day/respite care program for the purpose of determining the feasibility and costs associated with these services. The relevant action steps were that the Council will offer a contract to conduct a feasibility study using funds identified in the Guam Two Year Developmental Disabilities State Plan; complete the study by December 1991; and forward the findings and recommendations of the study to the Guam legislature and governor for appropriate actions.

Identification of People Who Are Unserved and Underserved

The State Planning Councils were required by P.L. 100-146 to identify people with developmental disabilities who are currently unserved or underserved in the state or territory. The Councils' analysis was to include an examination of how those groups identified as unserved or underserved were being affected by eligibility criteria and by the availability, scope and effectiveness of state administered services, as well as the identification of relevant barriers and implications for the division of responsibilities among state agencies. Population subgroups noted in P.L. 100-146 included people with physical or mental disabilities, people with a combination of physical and mental disabilities, people with "dual mental impairments" (e.g., mental retardation and mental illness), and members of racial and ethnic minority groups, as well as other groups identified by the Councils in developing their reports.

The Council reports reflect various approaches to the identification of subgroups of people with developmental disabilities who are currently unserved or underserved within the states and territories. One of the most comprehensive reviews is found in the Colorado report, which included a detailed discussion of the unmet needs and barriers affecting some twenty subgroups of the population of people with developmental dis-



People with developmental disabilities were found to be unserved and underserved.

abilities. The report noted the methods used to obtain this information, including special studies conducted by service agencies; focus groups to reach consumers; follow up interviews with consumers identified as unserved through the consumer survey; interviews with providers and advocacy organization representatives; and review of information on waiting lists.

Although every Council identified at least one population subgroup as unserved or underserved, it should be noted that the one group named in all reports was people with developmental disabilities in general. Others identified, in descending order of frequency were as follows:

- Individuals with severe, multiple or very challenging disabilities, including behavior as well as health-related needs (49 states)
- People with physical disabilities, in particular people with cerebral palsy, head injury/traumatic brain injury, or epilepsy (43 states)
- People with mental health needs, including those with both mental illness and another developmental disability, adults with serious long term mental illness, or children with serious emotional disturbance (42 states)
- Individuals with mental retardation or other cognitive limitations (36 states)
- People with sensory disabilities, especially those with hearing impairments or those with a combination of deafness and blindness (29 states)
- People with low incidence disabilities, such as Prader-Willi syndrome, Tourette syndrome, tuberous sclerosis, and Tay-Sachs (20 states)
- People with autism (16 states)

Other characteristics found by Councils to be associated with being unserved or underserved included being a resident of a rural or other underserved area of the state (40 states); being low income (34 states); and membership in a racial or ethnic minority group (28 states). Some reports also identified barriers associated with age, including young adults who "age out" of the education service system in an area where employment and other adult services are unavailable or older individuals with developmental

disabilities. Seventeen Councils also reported barriers to some people with developmental disabilities because of state administered programs' use of eligibility definitions other than the federal or other functional definition of developmental disability.

Councils identified many areas of services and supports where people with developmental disabilities were unserved or underserved in the state or territory. These observations are summarized throughout this report in relation to the various life areas. In addition, several Councils identified some people with developmental disabilities as being inappropriately served in relation to the promotion of independence, productivity and community integration. The groups identified as inappropriately served were primarily those in segregated settings, including institutional living arrangements, sheltered workshops, and segregated learning environments.

Recommendations for State Agency Responsibility

Under the requirements of P.L. 100-146, State Councils were to examine state agency administered programs and services supported by federal and state funds. One aspect of this review was an assessment of barriers to needed services in relation to the assignment of responsibilities among state agencies.

The majority of Developmental Disabilities Planning Councils in the states and territories concluded that some of the barriers to people who are unserved or underserved were related to the assignment of responsibilities among state agencies. Findings were mixed between absence of state agency responsibility for particular populations (e.g., no agency with specific responsibility for services to people with physical disabilities) and use by state agencies of a definition for eligibility other than the federal or other functional definition of developmental disability, which therefore limited access to services. In addition, Councils in ten states reported that currently unserved or underserved groups, in particular people without mental retardation, were technically eligible for supports and services, but were not receiving them.



State Council reports included recommendations on state agency responsibilities.

Virtually all State Council reports included several recommendations regarding the assignment of state agency responsibilities to reduce barriers to a variety of supports and services for unserved/underserved people with developmental disabilities in general or for specific subgroups. Thirty-two Councils specifi

cally addressed the issue of state agency designations in their recommendations.

State Council recommendations varied from general assignments of responsibility to designations of specific authority for individual services or populations. The most comprehensive set of recommendations was found in the report from the Planning Council in the Commonwealth of Puerto Rico, which included recommendations on responsibility to people with developmental disabilities of various ages and their family members.

The population group mentioned most frequently in these recommendations was people with developmental disabilities other than mental retardation, or, in two reports, those with neither mental retardation nor mental illness. Next in frequency was unserved/underserved people with developmental disabilities in general. Others noted included people with the dual diagnosis of mental illness and another developmental disability, people with multiple disabilities or severe health care needs, people with head injuries, and people in various age ranges.

Among recommendations regarding state agency assignment for specific supports and services, case management was mentioned most frequently. Others noted in the Council reports were supports to individuals and families, housing, employment and vocational supports, aging services, and transportation.

The majority of State Councils made recommendations of specific agency assignments. Councils in three states specified that a recommendation regarding state agency responsibility for people with developmental disabilities was not being made. As proposed by the Minnesota Council, "We recommend that each existing agency work to ensure the needs of all people who are unserved and underserved are met. There is no single agency that can accomplish this mission alone."

Presentation to the Governor and Legislature

◆ **Governors received the 1990 reports from the Councils on January 1, 1990.**

Nearly all State Councils noted that the reports were to be presented to the respective governors and legislatures on January 1, 1990. These presentations were reflected in the transmittal letters from the governors received by the Department of Health and Human Services.

The Secretary of Health and Human Services received reports from State Developmental Disabilities Planning Councils in 55 states and territories. (The Virgin Islands Council was not required to provide a report.) These reports were received by the Secretary from January 9 through April 2, 1990. This summary is based on 53 State Council reports. The remaining two reports were not received in time for inclusion in this summary report.

ADD Support to the Developmental Disabilities Planning Councils in the 1990 Report Process

The Administration on Developmental Disabilities (ADD) has provided extensive leadership in its support to the State and Territorial Developmental Disabilities Planning Councils throughout the 1990 report process. After passage of the legislation, ADD began planning activities to implement the 1990 report provisions. It was determined that if a national summary report to Congress was to articulate the major issues affecting people with developmental disabilities, then states and territories should be encouraged to conduct their 1990 report activities in ways that would produce information that could be analyzed at the national level. An important first step was to encourage consensus among the State Developmental Disabilities Planning Councils on a common approach to meeting their 1990 report requirements.

ADD, in collaboration with the National Association of Developmental Disabilities Councils (NADDC), convened a work group made up of representatives of seventeen State Councils and of ADD. States were selected to participate in such a way as to ensure geographical representation, program size/type (e.g., urban/rural, minimum allotment/maximum allotment), and a mix of Council members and staff, including primary consumers.

The primary vehicle of support has been ADD's technical assistance grant awards to NADDC, the only national organization representing the individual State and Territorial Councils. Grants provided in fiscal years 1988 and 1989 have been used by NADDC to provide technical assistance to the State Councils, as described in the following section. Additional support to the technical assistance effort was provided through ADD supplementary grants to the University of Illinois at Chicago/University Affiliated Program (UAP) and the Temple University Developmental Disabilities Center/UAP.

◆ **The Administration on Developmental Disabilities has participated throughout the 1990 report process.**

ADD staff have participated throughout the 1990 report development process as members of the national advisory committee on the 1990 report appointed by NADDC. In addition ADD has sponsored training sessions and made presentations on the 1990 report at two ADD Commissioner's Forums held in 1988 and 1989. Related assistance to Councils has been available through the following recurring datasets funded by ADD:

- The public expenditures project of the University of Illinois at Chicago/UAP
- The residential services data project of the University of Minnesota/UAP
- The supported employment data project of the Children's Hospital Medical Center/UAP

Several of the State Council reports reflect use of one or more of the recurring datasets, especially information on public expenditures from the University of Illinois at Chicago/UAP. For example, the California report includes a section entitled "Facts - California vs. Nation" which uses findings in the UAP's *Third National Study of Public Spending for Mental Retardation and Developmental Disabilities: Summary* (Braddock et al., 1989) to compare California with other states and with national averages. The comparisons included factors such as the total state and federal commitments to developmental disabilities services 1977 to 1988; state personal income growth over the same period; use of federal funds for institutional and large (more than fifteen person) congregate facility services in the state; public expenditure trends for community-based services; and projected use of state institutions.

More recently, the current ADD grant to NADDC has supported preparation of a thorough compilation of the individual Council reports submitted by the states and territories and of the collective findings of the state consumer surveys. These reports are available to Councils as part of the ongoing ADD/NADDC assistance which is now focused on the implementation phase of the 1990 report process. The State Planning Council reports also have been used extensively in the preparation of this summary report.

The Technical Assistance Activities

Discussions of ways to enhance the 1990 report process began even prior to the enactment of P.L. 100-146. The Administration on Developmental Disabilities has worked closely with an advisory committee of the National Association of Developmental Disability Councils to support technical assistance to the individual Councils through their national organization.

The major components of the NADDC technical assistance program on the 1990 report have been:

- Development of a common consumer survey instrument, used by all but two of the Councils
- Training in consumer survey implementation
- Guidance on policy analysis techniques
- Dissemination of federal program information
- Resource materials on outreach to consumers and advocates for people who are currently unserved or underserved
- Technical assistance on media relations to promote 1990 report visibility

NADDC has worked closely with the Temple University Developmental Disabilities Center/University Affiliated Program (UAP) in relation to the consumer survey activities. In addition to their work in survey design and technical assistance, the Temple UAP also has produced the state consumer survey compilations used by the individual Councils in preparing their reports, as well as the overall compilation of state consumer survey findings. Early technical assistance activities were partially supported by the UAP at the University of Illinois at Chicago, as well as by voluntary contributions of many of the Councils. The primary resource, however, has been the Administration on Developmental Disabilities grant program for Projects of National Significance.

Results of These Efforts

Fifty-five State Developmental Disabilities Planning Council reports have been submitted to the Secretary of Health and Human Services by the governors of the states and territories. The reports range from a twenty-page summary of state findings and recommendations to eight reports with over 300 pages. Many reports included references to additional volumes available from the Council, most frequently separate reports on consumer survey findings and policy analysis.

- ◆ **The 1990 reports include approximately 3,200 recommendations to improve the lives of people with developmental disabilities.**

Altogether, over 3,100 issue statements and approximately 3,200 recommendations regarding the needs of people with developmental disabilities were found in the Councils' reports. They reflect the examination of many hundreds of state programs and of scores of federal programs, as summarized in the following chapters.

- ◆ **Recommendations were sometimes unclear as to whether they were directed at federal or state policy.**

At the same time it should be noted that it was not always clear in some Council reports as to whether the issue, barrier, or recommendation is a matter of federal policy or state policy. Although nearly all reports included findings specific to federal policies, the reports also vary considerably in their relative focus on federal policy issues. Consistent with the focus of the legislative requirements, the preponderance of information in the Council reports was focused on state policies and programs. It should be noted, however, that this information in many cases included state implementation of federal programs.

- ◆ **More than 15,000 people with developmental disabilities were personally interviewed in the consumer surveys.**

The reports contain extensive references to the role of consumers in the identification of issues and barriers and in the shaping of the recommendations. More than 15,000 consumers participated in the state consumer survey process alone, with countless additional consumers and family members providing input through participation in public forums, as Council members, and as members of the many special State Council 1990 report task forces and committees. Collectively these reports represent the largest and most comprehensive examination of the needs and preferences of people with developmental disabilities ever undertaken.

Related materials produced through the 1990 report effort include the state consumer survey database and the baseline data on federal programs prepared as part of the technical assistance activities.



A major resource for the 1990s

The summary information contained in this report will serve as a major resource at all levels in the review of current programs and policies and in the development of new initiatives to promote full citizenship for people with developmental disabilities. The interests and wishes of consumers voiced throughout this summary, along with the comments of their family members, will be an essential referent for policymakers throughout the government. The perspectives of the states and territories will provide further guidance in relation to the potential impact of future changes in federal policy. In addition, the databases on state consumer surveys and on federal programs can be used as baselines in future assessments of progress toward meeting the goals of independence, productivity and community integration of people with developmental disabilities.



A major state planning and policy resource

Similarly, both this summary and the individual State Council reports will be a major resource to the states and territories as they address the issues and recommendations coming out of the 1990 report initiative. The information developed by each Council in preparing its report will serve as a benchmark throughout the 1990s as progress toward implementation of the recommendations is assessed. For example, the North Carolina report included the following recommendations:

- The data from the consumer satisfaction survey be analyzed according to key issues identified by the Council during the two year period beginning July 1, 1990.
- The Council conduct a consumer survey every three years beginning in January 1993.
- The Council conduct a statewide Consumer Call-In every year beginning in January 1991.

In addition many State Councils noted that the 1990 report process will have long-range benefits through the enhancement of collaboration among people and organizations representing many different kinds of developmental disabilities and the outreach to consumers and family members who have previously been unserved and underserved.

Further analysis of the information from the state reports and the consumer surveys also will be extremely valuable to the larger developmental dis

ability research community. This summary report, although providing a wealth of State Council findings as illustrated in the following chapters, represents only the first step in tapping the potential contribution of the 1990 report process.

III. Supports to Individuals and Families

III. Supports to Individuals and Families

State Council Reports: Overview



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.

—Tennessee report

Virtually all State Council reports included discussion of both supports to individuals and supports to families. In a few reports the focus was more on family supports than on those targeted to the individual with a developmental disability, in recognition of the family's critical role in supporting their family member. This focus was evident in most reports in their discussions of the needs of families who are caring for a child with a developmental disability at home.

A variety of state-administered programs that use state and federal funds were reviewed by the Councils in relation to the availability of supports. Programs addressed regarding supports to individuals most commonly included personal care, case management, therapies, and other services that can be financed through the Medicaid program; and programs designed to promote consumer independence, such as Centers for Independent Living. Family support programs identified in the reports were predominantly those that have been developed and funded by the states, although several reports also note the use of the Medicaid Home and Community Based Services (HCB) waiver in relation to both family and individual supports. Other federal program references included the Medicaid Model Waiver component of the HCB program; federal Assistive Technology Development grants; transportation funding through the Urban Mass Transportation Act (UMTA) program; and the Social Services Block Grant.

Most of the Council reports highlighted considerable information from their public forums and consumer survey findings to illustrate the need for more individual and family supports. Some noted, however, that most people want a relatively small number and amount of services: the primary issues were related to basic availability and the need to have services that can be flexibly tailored to accommodate individual needs and preferences.



Vision: people with disabilities can get the supports they need wherever they live. They do not have to accept limited, restrictive 'placements' in order to meet their basic needs. They determine what they need, select the supports they prefer, and evaluate the effectiveness of services provided.

—Michigan report



Vision: children belong with families who are supported and respected. They are the experts in their own lives and the community supports them in meeting their challenges. This commitment is reflected in the policies and actions of the government.

—Hawaii report



Vision: in order for people with developmental disabilities to lead independent and productive lives, they and their families must be afforded the necessary support services.

—California report

Goals and visions regarding supports to individuals with developmental disabilities and their families were found in virtually every State Council report. Examples of supports to individuals included assistance in daily living, or personal assistance services; assistive devices and environmental adaptations ("technology"); assistance with service coordination or "case management"; peer support; training in community living; and other supports as needed and selected by the consumer. The goals and visions in the State Council reports projected systems in which supports were tailored to the individual and that promoted maximum consumer control over their design and delivery.

Goals for supports to families in the State reports similarly advocated that families be able to select those supports that meet their needs. Supports that were typically defined as those that should be available to families included assistance with service access and coordination, training in supports to their family member with a developmental disability, and access to child care. Respite services were defined in the reports as supports that should be available to both individuals and family members.

In many State Council reports a vision of supports was associated with a shift in emphasis away from facilities and services. Policy goals were then redefined in terms of supports that enable the individual to live, work and participate as independently and productively as possible as an integral member of the community.

There were some differences in emphasis between supports to individuals and supports to families, as noted above. In addition, the degree of emphasis and the specific objectives in relation to supports varied among the Councils, depending upon state-specific characteristics and priorities. Nevertheless, it is possible to group the findings in the State Council reports on supports in relation to seven goals:



The vision, then, for people with disabilities who require individual and family supports, is to provide whatever it takes to make their independence, integration, and productivity inside the parameters of society, and outside of an institution, possible.

—Utah report



Vision: to have available services which support families with maintaining their child with a developmental disability at home, and would assist them with finding ways for their child to participate in integrated opportunities in the community.

—Missouri report



It is our policy to reduce dependence on human services by increasing interdependence in community life through a focus on the gifts and capacities of people who have been excluded from community life because of their labels.

—Connecticut report

1. Access to a system of individual supports

One of the most frequently identified goals in the State Council reports was that people with developmental disabilities have access to a system of supports that enable them to have full quality of life and that support them to achieve maximum levels of independence, productivity, and community integration. Related goals were that supports be available in sufficient scope as well as quantity (e.g., in the number of units of personal assistance that is covered) and that supports be affordable. Goals in relation to the quality of individual supports focused primarily on flexibility, responsiveness to the needs of the individual, and in particular on consumer choice and control;

2. Availability of supports to families

Along with supports to individuals, the goal of available supports that enable families in turn to support their family member who has a developmental disability was found across virtually all the State Council reports. The primary family support goal in many of the reports was to support families of children with developmental disabilities, especially in relation to the prevention of out-of-home placements, in relation to goals that all children should grow up in families. Similar to supports to individuals, goals included scope as well as availability (e.g., number of hours of respite care); quality in relation to individual needs as well as quality in general; and approaches that help empower families.

3. Supports to communities

A related goal found in many State Council reports was to support communities in ways that promote greater understanding of the significance of independence, productivity and integration in the lives of people with developmental disabilities and that enhance community efforts to develop interdependent models of support with people with developmental disabilities and their families.



Vision: case management means a life-long, goal-oriented process for coordination of the range of services needed and wanted by persons with developmental disabilities and their families.

—Wyoming report



Vision: service funding and support can then "move" with the person...because the funds are not attached to a residential provider [or] workshop operator....

—Idaho report



Vision: all persons including those with mobility impairments are entitled to the unlimited use of public transportation services which are accessible, affordable, and appropriate.

—Massachusetts report



Friendship and support are important to everyone, regardless of their age or circumstances.

—Georgia report

4. Information and coordination supports

The goals regarding information and coordination services found in the State Council reports were that they be available to all individuals with developmental disabilities and families who need them. The primary goal regarding information and referral in the reports was that there be a free, coordinated information and referral system that all consumers and families could easily access from their homes. Regarding coordination of assistance, e.g., "case management," the typical goal found in the State Council reports was that individuals and families be able to receive coordination assistance that is focused on supporting the person with a developmental disability to reach individualized goals of independence, productivity and integration.

5. Sufficient resources

Cutting across the goals regarding specific supports to individuals and families were goals in the State Council reports regarding resources. The general thrust of these goals were that sufficient resources be available to assure that supports are available when needed. Related goals found in the reports described funding mechanisms that promote choices and control by individuals and families of the supports they obtain, e.g., through non-restricted cash grants or vouchers.

6. Accessible, affordable transportation

Many of the State Council reports identified goals in relation to transportation supports, including public transportation of various modes as well as specialized means. Typical goals included increased accessibility of transportation, affordable transportation that is both safe and accessible, and improved safety and quality of transportation. These goals were frequently tied to goals of enhanced independence, productivity, and active participation in their communities for people with developmental disabilities.

7. Social and recreational opportunities

Goals also were identified across the State Council reports regarding the availability of social and recreational opportunities for people with developmental disabilities. The particular focus of these goals in most of the reports was on opportunities that enable people with developmental disabilities to enjoy a full range of leisure activities and to know the joys of personal friendships with other members of the community.

1. Access to a system of supports

State Council Reports: Accomplishments and Opportunities

★ **Increased availability of personal attendant services**

Many programs were identified by the State Councils in their descriptions of supports to individuals with developmental disabilities, focused primarily on the state or local level. Some included collaboration with advocacy organizations in the private sector. For example, county offices on disability in New Jersey and the Governor's Committee on the Disabled initiated a demonstration program of personal attendant services in 1986 at the urging of the Eastern Paralyzed Veterans Association. Its success led to legislation making the program permanent, with state funding administered by the New Jersey Department of Human Services. The current state appropriation for this program is \$5 million.

The Pennsylvania Attendant Care program utilizes a combination of state funds and the federal Social Services Block Grant, as well as consumer payments on a sliding scale. The program is available across the state and is currently reaching 1,013 adults with physical disabilities with an average of 40 hours per person per week. Attendants may assist with personal care tasks such as bathing and dressing and other daily living activities, e.g., shopping, cleaning, and letter writing. A key aspect of the program is its emphasis on consumer control, with services designed to be at the direction of the people with disabilities who are receiving them. Consumers are expected and encouraged to hire, train, pay, and if necessary to fire their own attendants, with assistance available from the program as appropriate.

★ **Federal grants to support the availability of technological aids**

Most of the nine states which received a federal grant to support expanded availability of assistive technology and adaptive devices authorized by the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) noted its significance in their report. As described in the Arkansas report, the grant proposal was produced through a consumer-focused planning process, including important recommendations on the development and delivery of technology resources.

“ Technology has made it possible for us to express our ideas and feelings and let you discover that we do have things to say. Computer technology is one of the most important keys in making a person with a disability become more productive and independent.”

—Minnesota consumer

Existing centers on technology were featured in the Nevada and Pennsylvania reports, as follows:

- The Nevada Technology Center, established by the Nevada Council on Developmental Disabilities, is designed to be a major resource to the community in offering up-to-date information on the latest advances in technology, the newest applications of assistive devices, and a clearing-house for national information on rehabilitation, special education, and technology related assistance. (Nevada report)
- The Pennsylvania Assistive Device Center has contributed to the dissemination and availability of assistive technology services for children with disabilities who receive special education. This center is funded through P.L. 94-142 (special education) funds administered through the state Department of Education and working through the school system. The Center provides long term loans of technological devices to individual children, to be used at school and/or at home. The Center also loans devices for short periods of time for trial usage. Training activities have focused on regional liaisons that work closely with the individual, teacher, and parent. The Center has been operating for six years and has served over 500 children. (Pennsylvania report)

★ Enhanced technology to benefit people with severe disabilities

The Nevada report also highlighted its Adults Communicating through Technology project, a new program at the Nevada Technology Center that serves non-speaking adults with severe disabilities who would benefit from communication training on computers using alternate input devices. All of the participants in the program were sitting at home because there were no other programs available to them.

★ Improved support to older people with developmental disabilities

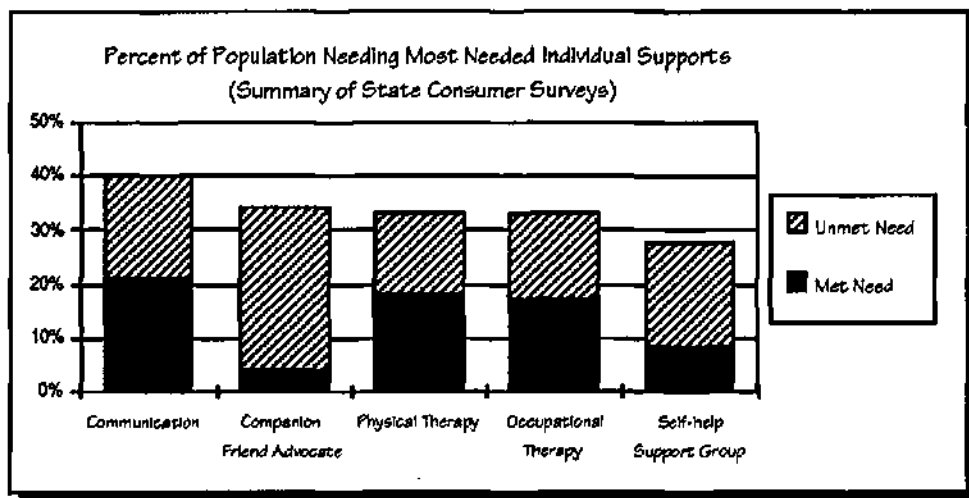
Advances in supports to older individuals with developmental disabilities also were noted in some reports, reflecting the interest in supports that span the entire lifetime. The Wyoming Task Force on Aging and Developmental Disabilities, founded in 1986 by the state Commission on the Aging, is working to improve coordination in both the aging and developmental disability networks. Activities include dissemination and joint training in best practice models. "Master trainers" are being certified who will then train generic service providers in both areas on ways to work with people who are both elderly and have a developmental disability. In Utah, the Governor's Council for People with Disabilities has funded a

project to provide individualized services for people who are elderly or whose parents are elderly.

State Council Reports: Critical Issues and Barriers

The lack of availability of supports to individuals in many communities was a common concern across the Council reports. The need for individual supports was frequently reported in consumer survey data.

Summary data from the state consumer surveys indicated that the five most needed individual supports, other than transportation and case management, were communication support (40 percent), companion/friend advocate (34 percent), physical therapy (33 percent), occupational therapy (32 percent), and consumer self-help or support groups (28 percent). These percentages represent the responses of 13,075 consumers, or, in some cases, their surrogates, when asked which services or supports would provide the most help to them in living, going to school (children) or working (adults), and participating in the community, regardless of whether or not they were currently receiving it. The unmet need for these supports—i.e., the proportion of the 13,075 respondents who said they needed the support but were not receiving it—is illustrated in the following figure.



✓ **Availability of individual supports and therapies is limited.**

Typical observations by State Councils on the availability of individual supports included the following:

- There is a need for physical therapy, including massage and exercise programs, for adults with cerebral palsy. (Colorado report)



Limited resources

- Very limited resources are available to provide attendant care for persons with developmental disabilities. (Georgia report)
- 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 (Medicaid) benefits. Often these same persons do not qualify for Vocational Rehabilitation services. As a result they must rely on the generosity of charitable organizations or do without. (New Jersey report)
- There is a waiting list for the Attendant Care Program for services of 500 persons and some persons have had their number of hours of attendant care cut back as a result of funding shortages. (Pennsylvania report)



Limited coverage

- 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 disorder, 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. (Tennessee report)



There are only two interpreters for people with hearing impairments in the Upper Peninsula..."

—Michigan consumer

- The critical issue with support services is availability, especially in rural areas. (Utah report)
- 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. (Washington report)



I shouldn't have to choose between a wheelchair or a communication system."

—Georgia consumer

The barriers to supports noted most frequently by the State Councils were funding levels (discussed below), eligibility for programs providing supports, and affordability. A mix of eligibility barriers were identified, in particular regarding technology, Centers for Independent Living, and generic programs for people who are elderly. Affordability barriers were found especially in relation to technology, including high costs to consumers in general and lack of coverage by third party payors.

“ *My attendants don't do what I need them to do. Sometimes I have to sleep in a chair because my attendant won't help me to bed. I'm afraid that if I fight back, I will lose my attendant and then lose my independence.”*

—California consumer

About one-third of the State Council reports noted concerns regarding the effectiveness of individual supports. The primary issues involved lack of consumer involvement, supports not being designed in relation to individual needs, and lack of consumer control over their personal assistance services.

Some Council reports also noted concerns regarding the quality of individual supports, in particular personal assistance services. For example, one state (California) reported that "attendant services are often poor in quality, not accessible or not affordable, and people with developmental disabilities often have little control over their attendants."

State Council Reports: Recommendations

→ Supports to individuals should be a major policy goal in the 1990s.

State Developmental Disability Planning Council recommendations to expand the availability and array of supports to individuals found in the reports were stated, for the most part, as general goals. This is exemplified by the following statement in the Louisiana and five other reports:

Supports to individuals with developmental disabilities that promote their independence, productivity and integration into 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. (Louisiana report)

Federal:

→ Expand access to supports through changes in the Medicaid program.

Most individual support recommendations from State Councils targeted to the federal government identified the need for changes in the Medicaid program that would permit expansion of supports coverage at the state level. For example, the Maryland report recommended active support of the Medicaid Home and Community Quality Services Act of 1989 (S. 384) because it would allow states to receive federal financial participation for services such as occupational and speech therapies, dental services, and structural and environmental modifications such as ramps and grab bars, without the requirement to extend similar benefits to the entire Medicaid eligible population. The primary recommendation found in this area was that individual supports financed through the Medicaid program should not be tied to "medical necessity."

→ Increase Medicare coverage of supports to individuals.

State Council recommendations regarding the Medicare program included removal of program restrictions on payment for assistive devices, such as communication technological aids; and the development of long term care benefits as part of the Medicare program.

Without reference to either the Medicaid or Medicare program, the New Jersey report recommended the development of a national program of personal attendant services, with partial federal funding and defined federal quality standards. The Maine report included a recommendation for full funding of the Technology-Related Assistance for Individuals with Disabilities Act.

→ Require access to federally funded aging services.

Expanded availability of aging services was recommended in a few Council reports in relation to programs funded through the Older Americans Act. For example, the Washington report recommended that Area Agencies on Aging be required to provide a written plan of accommodation to serve people with developmental disabilities, coupled with a requirement that they target this population as a condition of receiving federal funds.

Federal/State:

→ Increase the scope of Medicaid services.

About half of the State Council reports included specific recommendations on enhanced state use of federal programs that would increase the availability of supports to individuals. The federal program addressed most frequently was Medicaid. The primary recommendation was for increased scope of covered services under the state's Medicaid program. For example, the Tennessee report recommended that 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 their developmental disability, and that the availability should not be limited to "medically necessary" services. Other recommendations focused on the state's HCB waiver, such as the Maryland recommendation advocating an amendment to the state's current waiver that would broaden the array of services eligible for reimbursement to include speech and audiology, environmental controls, personal attendant services, respite care, and occupational therapy.

Other Planning Council recommendations in this area included enhanced use of the Centers for Independent Living program, improved access to programs funded through the Older Americans Act,

expanded use of the Foster Grandparent Program, and pursuit of Technology-Related Assistance grants.

State:

➔ Expand the availability of technology.

The greatest proportion of the State Council recommendations regarding supports to individuals were targeted to state governments. Several state reports advocated initiatives to expand the availability of assistive devices and technology, as illustrated by the following:

- Alabama should take advantage of state and national expertise and develop a consumer-responsive assistive device/technology program. (Alabama report)
- Improve inter-agency cooperation in the development of consumer-responsive policies and procedures regarding funding and delivery of technology services. (Arkansas report)
- 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. (California report)

Another support that was the focus of many Council recommendations was personal assistance services. The primary recommendation was to increase the availability of these services, presented in most states as a recommendation to expand present services and in a few states to develop them. Other recommendations were addressed to expanded eligibility and increased control of their personal assistance services by consumers.

Other Planning Council support recommendations included:

- The promotion of informal supports
- Increased availability of interpreter services
- Greater availability of therapies such as physical therapy and speech therapy
- Supports to help older individuals enjoy their retirement years
- More flexibility and focus on individuals
- Increased consumer and family input in general

A few Slate Councils recommended that supports be made available to individuals with developmental disabilities within the criminal justice system.

2. Availability of supports to families

Accomplishments and Opportunities

★ Parents helping parents

Virtually all State Council reports noted the significance of family supports that in turn help them provide support to the individual with a developmental disability. A type of support noted in a *few* reports is that of parents helping other parents. For example, the Parent-to-Parent Network in Georgia grew out of parent comments at a series of statewide workshops. Through this program parents who are coping successfully with supports to a child with a developmental disability are screened and trained to provide support to parents of newly identified children with disabilities. Every effort is made to respond to the initial contact within 24 hours. The network has been replicated nationally.

Other examples include:

“ Who takes care of the caretakers?”

—Ohio parent

- Additional child care resources developed in Little Rock, Arkansas, through a state Developmental Disabilities Council grant to the Association for Retarded Citizens (ARC)/Arkansas. The project has promoted integrated preschool services for children with developmental disabilities, including placement into cooperating day care centers who then receive technical assistance on ways to work more effectively with the children. (Arkansas report)

“ We have gotten some respite care from the Family Support program. It has given my husband and me a chance to have time together. We rekindled a friendship with another couple from 23 years ago.”

—Georgia parent

- The Wisconsin Family Support Program began in 1983 with Council-funded demonstration projects. It was designed with the specific intent of providing help to families who have a child with a disability at home and to help families keep their children at home. Its successful beginnings were the basis of state legislation passed in 1985 to establish the program officially. It is the intent of the program that planning and support services be consumer-directed/family-directed.

Because the program provides community supports to children in a system that in the past has primarily served adults, the Family Support

Program has provided the link that makes the "system" now respond to the family, not just the adult individual. Children who are successfully served by the Family Support Program now are connected with a family and a community all of their lives. (Wisconsin report)

- The pilot Family Support Projects that the Council and Oregon Mental Health Division are currently sponsoring in three regions in the state were frequently cited as examples of the more positive orientation of the service system. Many (1990 report) respondents thought that families should become the hub around which would revolve the array of support resources (formal, quasi-formal and informal) offered by the service system. (Oregon report)

State Council Reports: Critical Issues and Barriers

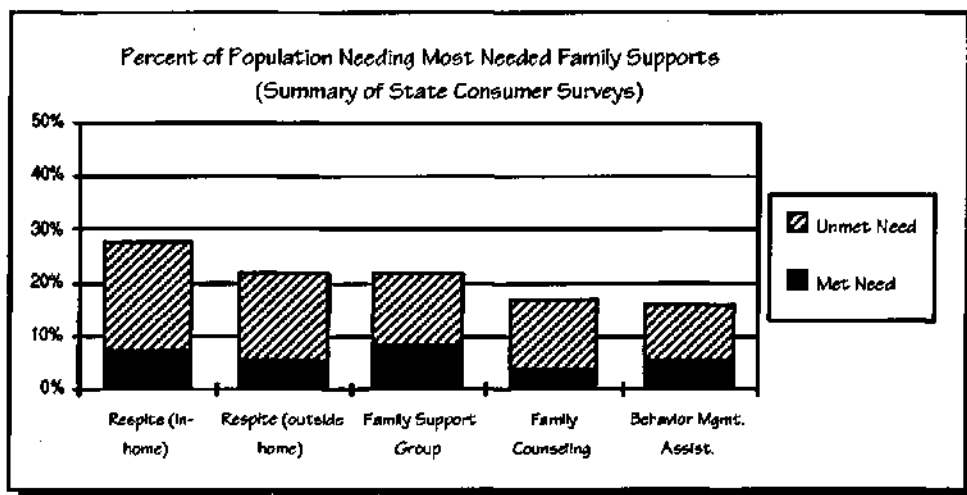
“ I have not been out with my husband in 10 years. I need respite care on a weekly basis or the family will fall apart.”

—Maine parent

As with supports to individuals, the major issues identified in the State Council reports regarding supports to families were that not enough are available, or that they are not available in the form or amount that families need them to be. Forty-two states specifically noted that supports to families are not sufficiently available.

✓ Critical lack of respite services and child care

Two types of support particularly identified as lacking were respite services and child care. This was supported by findings of the state consumer surveys regarding supports to families and other caregivers. The five family supports found to be most needed overall were in-home and out-of-home respite care (28 and 23 percent, respectively, of the 13,075 respondents); family support groups (22 percent); family counseling (17 percent); and behavior management assistance/training (16 percent). The unmet need for these supports is illustrated in the following figure. The summary of state consumer surveys also indicated that although only 12 percent of the respondents expressed the need for child care, over three-fourths of these respondents were currently not receiving child care services at the time they were surveyed.



The primary concern in relation to respite was that it was not available. This was frequently supported by poignant testimony from parents regarding their overwhelming need for such assistance. As illustrated in the following excerpt from the North Dakota report, other significant concerns raised were limits on the amount of respite services available, quality concerns, and affordability:

“All we really want is a good night's sleep...we said earlier this was like a full-time job. But in a job, if you are sick, you can take time off....But the job of caring for Matthew continues.”

—Michigan parent

“One wish: my husband and I could get away for a weekend once in a while. We have not been on a weekend anywhere since the day he was born. Respite care workers could not handle him for that long a period.”

—Wisconsin parent

Access to respite care for persons with developmental disabilities is more restricted than it is for persons who are elderly and those with other kinds of disabilities. Respite care 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.

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 need such services.

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. 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. (North Dakota report)



Parents need child care in order to maintain employment.



One of my priority needs is day care services for my daughter who has severe disabilities. As a working mother, I have to have this service to continue employment. If I lose my job, I will have to become dependent on the state."

—Texas parent

Planning Council concerns about the lack of child care frequently were associated with the difficulties of maintaining employment, as illustrated by the following concerns:

- The gap in day care services often places a single bread winner whose child has an acute problem, such as an upper respiratory condition 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. (Alabama report)
- Very few community day care facilities are willing or able to meet the needs of young children with developmental delays. (Arkansas report)
- A total of 159,000 exceptional needs children in California have employed mothers, and at least 80,000 of these 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 service 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. (California report)
- 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. (Texas report)

Some State Council reports raised the question of affordability of child care supports. For example, a parent who participated in one of the 1990 report focus groups in Utah commented that she had to pay someone \$4.50 an hour to be with her child who has autism, while her own earnings are only \$5.00 an hour. She said it seemed futile to work because she is unable to keep up with the costs associated with her son's disabilities.

In some cases, Council reports noted that family supports are less available for children with more

severe or challenging disabilities. For example, the Massachusetts report noted that "families and caregivers who need specialized kinds of respite care involving medical or behavioral expertise have few places to turn." Other reports identified members of various racial or ethnic groups who are particularly lacking in available and appropriate family supports, including Native Americans living on reservations (South Dakota), people in rural areas (Florida), and Hispanic families (Colorado). Specific eligibility barriers were noted in seven reports.

Several reports also raised the issue of the quality of family supports that are available, primarily in relation to staff qualifications. More broadly, about one-third of the reports cited reduced effectiveness of family supports because of the lack of family involvement.

State Council Reports: Recommendations



Expand access to family supports.

The recommendation made most frequently by State Developmental Disabilities Planning Councils was to expand the availability of supports to families. This recommendation was made by thirty-eight states and territories. The primary recommendation was for supports to families to be more available in general. Other cross-cutting family support recommendations were that they become a priority in the 1990s and that they be established as a mandate or entitlement.

Federal:

Council recommendations on increased federal funding for family supports are discussed in the section on resources.

Related Council recommendations regarding family supports in relation to the prevention of institutionalization are discussed in the chapter on housing. A few other recommendations were targeted to the federal government, such as the Connecticut recommendation that Medicaid reform legislation specifically prohibit deeming parental income available to children with developmental disabilities living at home by requiring that this provision be waived in relation to Medicaid eligibility.

Federal/State:

➔ **Expand use of the Model Waiver.**

Two Council reports included recommendations regarding use of the state's Model Waiver in relation to supports to families. The Connecticut report recommended expansion of their state waiver and the Iowa report recommended clarification on the state's eligibility policies.

State:

➔ **Increase the availability and scope of supports to families.**

Reflecting the dominance of state support in programs that support families, the majority of Council reports included recommendations regarding state actions to increase the availability and scope of these supports. In addition to recommendations for increased funding levels, state reports included a wide range of general recommendations for policies in support of families. The most frequently found recommendations were those addressed to increases in respite care, child care, counseling, and parent training, as illustrated by the following finding from the Alabama report:

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 services, and other resources and services that would allow the family to function. (Alabama report)

➔ **Improve the quality of family supports through provider training and more family involvement.**

Other Planning Council recommendations targeted to the state level focused on improving the quality of family supports, such as training of respite care providers. Many states recommended greater flexibility and family involvement,

Other recommendations from Councils addressed strategies to promote supports to families, including making it a high state priority and related public education activities. As described in the Washington report, "Government should provide leadership in forming public policy as well as individuals and groups coming to a renewed understanding of the meaning of family support."

3. Supports to communities

State Council Reports: Accomplishments and Opportunities

“We must delight in each other, make others' conditions our own, rejoice together, mourn together, labor and suffer together, always having before our eyes our community as members of the same body.” Governor John Winthrop, Massachusetts Bay Colony, 1630

—Connecticut report

★ Initiatives are increasing public awareness and understanding.

The significance of supports to communities in relation to goals for people with developmental disabilities was recognized in many of the State Council reports. Some highlighted activities designed to involve community members directly in the lives of their fellow citizens with disabilities. For example, the Colorado report described a project funded by the state Developmental Disabilities Council in 1989 to develop "Circles of Friends" in five communities in the state. As described in the report, the purpose of these programs is to organize communities in ways that connect people with developmental disabilities with other community members, foster long-term relationships, and develop assistance to consumers in their self-advocacy and full participation in community life. It is hoped that these interactions also will promote changes in public attitudes toward people with developmental disabilities.

Accomplishments in the area of community and public education also were noted in several reports, as illustrated by the following examples:

- There is a growing awareness of this need. An excellent example occurred recently, when the Senate Subcommittee on the Handicapped selected a new name. The Senate Subcommittee on Disability Policy. (Iowa report)
- Increased awareness of the capabilities of persons with disabilities has come about not only through direct contact, but also through the print media and television. The Council provided funds for video tapes which encouraged employers to hire persons with developmental and other types of disabilities. (Colorado report)
- A group of people with physical disabilities in one community had been trying for years to make the mayor and other city officials sensitive to the need for accessibility to public buildings. The mayor had merely applied cement over some stairs to make a ramp that was too steep and too narrow for wheelchairs. The group finally organized a Handicap Awareness Day for city officials and asked each of the officials to pretend to be disabled for a few hours. They put the mayor in a wheelchair and asked him to wheel up the ramp into the city offices. The mayor and his wheelchair fell off the ramp. An accessible ramp was installed the next week. (Utah report)

★ **Employers are expanding job opportunities through public education programs.**

- In 1987 the Developmental Disabilities Planning Council initiated an aggressive statewide "business to business" marketing and sales campaign to increase employment. The purpose of the three-year "We Have A Talent For Work" campaign was to provide a strong image to employers as well as to the general public. Marketing support for smaller training and placement agencies was also provided by the campaign. (Washington report)
- The "Tilting Windmills" attitudinal training by a national consultant trainer was financed by the Council for two years. Over 1,000 Nebraskans received the training and a number of persons in both the public and private sectors have been trained to continue to heighten people's awareness of possible biases against hiring persons with disabilities. The training reached a wide audience of personnel in key state agencies responsible for locating jobs or for hiring practices, as well as private business personnel directors. (Nebraska report)

As illustrated by the Washington State and Nebraska report excerpts, supports and public education targeted to employers and co-workers was a focus of particular interest in the state reports.

State Council Reports: Critical Issues and Barriers

✓ **Lack of knowledge and understanding of developmental disabilities creates barriers.**

The primary barrier identified in this area by State Councils was the general lack of knowledge and understanding of developmental disabilities. Gaps cited included awareness of the significance of opportunities for independence, productivity and community integration; understanding of the characteristics of particular disabilities; and an overall appreciation of the abilities and contributions that people with developmental disabilities can make.

Several Council reports noted attitudinal barriers that affect employment opportunities. For example, the Vermont report notes that "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 worker's ability to 'fit-in' with the rest of the work force, his/her need for costly accessibility modifications, increases in insurance rates, and absenteeism due to illness." Other gaps noted were those affecting educational opportunities; and lack of knowledge of developmental disabilities among

generic service providers, such as health care professionals, representatives of the justice system, and providers in the housing industry. A related issue found in a few reports noted barriers in attitudes among traditional service providers, and, in some cases, among family members. For example, the Louisiana report included the following issue statement:

- ✓ **Some people in developmental disabilities services have not incorporated goals of "real work for real pay."**

Important segments of the disabilities community do not accept the basic premise 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 word. These segments include families of people with developmental disabilities, service providers, agency heads, and political leaders. {Louisiana report}

In relation to supports to communities themselves, the barrier identified most frequently by Councils was the overall lack of such supports. For example, New Hampshire reported the following observations of speakers at the Council's "Community Meetings":

Community connections and relationships for people with developmental disabilities do not and cannot be expected to occur by themselves. Citizens have been separated from people with developmental disabilities and naturally feel a degree of discomfort. As one speaker put it, "We can't just say 'let the community do everything*.'" (New Hampshire report)

- ✓ **Community involvement and informal supports are lacking.**

Several Council reports identified the lack of community involvement and the need to enhance informal supports. As described in the Vermont report, "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."

State Council Reports: Recommendations

- ➔ **Support community involvement and enhance informal supports.**

Ten State Planning Councils specifically identified the need to support community involvement and to enhance informal supports. For example, three reports (Louisiana, Montana and Wyoming) included the following recommendation:

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.

Federal:

➔ **Emphasize neighborhood and community building.**

One State Council (Michigan) recommended an emphasis on neighborhood and community building in federal housing leadership.

Federal/State:

There were no recommendations in the area of support to communities regarding state use of federal programs.

State:

➔ **Educate policymakers and the public on developmental disabilities and community involvement.**

Nearly 60 percent of the State Council reports included recommendations on supporting communities, promotion of informal supports, and public education strategies. About half of the recommendations focused on coordination and other efforts to help communities participate more effectively in supports to individuals and families. The remaining recommendations were primarily focused on media and public education activities; many were addressed to Councils in their role of educating policymakers and systems change advocacy. A few reports included recommendations on the education of policymakers, however, these are more commonly found as implementation strategies planned by the Councils, as summarized in Chapter III. A comprehensive recommendation for Council action was found in the Oklahoma report:

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 Council would be composed of a 5-6 member team, chaired by a person with developmental disabilities, 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 who are being placed in that community, addressing zoning issues related to disability, and distributing disability awareness information. (Oklahoma report)

➔ **Expand informal supports such as "Circles of Friends."**

Several Council reports keyed their community support recommendations to the expansion of community capabilities in developing friendships with people with developmental disabilities and in informal supports to both individuals and families. Eighteen states recommended strategies to enhance the use of informal supports, such as "Circles of Friends" or "Circles of Support." As described in the Connecticut report:

A circle of support is a group of people who meet on a regular basis to help the person with a disability accomplish certain personal visions or goals. The focus person is unable to reach her/his goals working alone, so she/he asks a number of people to work with her/him to overcome obstacles and to open doors to new opportunities. The circle members provide support to the focus person and they take action on her/his behalf.

The members of a circle of support are usually friends, family members, co-workers, neighbors, church members, and sometimes they include service providers. The majority of people in a circle of support are not paid to be there—they are involved because they care about the focus person and they have made a commitment to work together on behalf of the person. Circles in no way exclude paid service providers. Paid providers can be an essential resource to a circle of support, however, the majority of circle members are nonpaid, typical community members. Common to all circles is an emphasis on interdependence among people. Contrary to popular belief, independence is usually not achieved by an 'I'm going to do it all by myself' attitude. The key is to establish and nurture relationships in which everyone is able to do something for someone else. Individual strengths and talents are multiplied *as* circle members join forces. Likewise, weaknesses become less significant because of the combined abilities of the group. People with disabilities and their families acquire more power to influence the direction of their lives through establishing new connections in the community, by changing the systems they depend on for support, and by overcoming personal barriers with the support of the people around them who are committed to the vision. (Connecticut report)

4. Information and coordination supports

State Council Reports: Accomplishments and Opportunities

“ You almost have to know the answer in order to ask the right question.”

—Texas parent

Helping individuals with developmental disabilities and family members make their way through the maze of agencies and services was a recurring theme in the State Council reports. The two strategies identified most frequently were information and referral systems and programs that offer assistance in coordination, commonly referred to as case management.

The New Jersey report provided a description of a successful information and referral program called SCRIP: the Statewide Computerized Referral/Information Program. SCRIP was established in 1972 with a federal grant from the Office of Human Development Services. It is currently operated by the New Jersey Developmental Disabilities Council, having undergone several "technological enhancements" in recent years. The system is accessible by an "800" number, and lists between 1,700 and 1,800 agencies. Nearly 6,000 inquiries are handled by the Council each year.

An independent case management program was featured in the Arkansas report. The system was established during 1989 utilizing a private provider not involved in the provision of direct services. Case managers are expected to work with the individual to develop a personal futures plan as well as an individual services plan, and to "incorporate values associated with quality of life, such as the experience of having a valued place among a network of people and valued roles in community life.

State Council Reports: Critical Issues and Barriers

“ I ran up a \$300 phone bill one month just to find out my child isn't entitled to anything.”

—New Hampshire parent

The primary issue raised in the State Planning Council reports in relation to the need for information and referral systems is that they are not available. Twelve reports specifically identified lack of an information and referral (I & R) system as a barrier to individuals with developmental disabilities and their families. An additional eight noted that lack of information in general is a barrier.

- ✓ **Quality concerns regarding case management was the most commonly identified concern.**

The issue most commonly identified in relation to case management was that of quality, primarily associated with the human resources issues of too high caseloads and, in some reports, high turnover or case managers with insufficient training or qualifications. For example, the California report noted that lack of case management continuity is an issue for people with developmental disabilities, and that people at the California Consumer Forums reported that case manager turnover is a problem. Similar issues were reported by New Jersey:

- “ *How can a case manager develop good plans and follow through with a caseload of 130? How can case managers hold providers accountable if the case manager does not know the person?*”

—Minnesota parent

- ✓ **Case managers need to be advocates, team planners, negotiators and coordinators.**

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. (New Jersey report)

The need for a changing role for case managers was described in some reports in relation to quality and responsiveness to the needs of consumers. In Minnesota, for example, a new state regulation ("Rule 185") was associated with a change from counseling and advising roles to those of team planning, negotiation, coordination and advocacy. The report noted that "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." The report noted further, however, that case managers are attempting to provide expanded and more effective services while struggling with large caseloads.

- ✓ **Concerns that there is no "independent" case management system.**

Five State Council reports raised concerns about the lack of an independent case management system. As described in the Arkansas report:

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. {Arkansas report)

“ You know, I can either deal with the system or I can deal with my kid....I can't handle both.”

—Utah parent

Seventeen Planning Council reports described broader issues of case management availability. For example, the South Dakota report noted that case management services for many people with developmental disabilities—those not currently receiving community based services—are available only when triggered by a crisis in the person's life. Others may have access only to a case manager on the staff of the person's service agency. The report observed that the state's current system 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." Fragmentation was identified as an issue in the Texas report, including possible duplication of effort as the number of agencies providing case management services has grown. At the same time, however, the report also noted concerns that many people were not receiving case management due to differing eligibility criteria between programs.

The need for supports to families in permanency planning, i.e., providing for the family member with a developmental disability as parents age and are deceased, was identified in a few reports as a related issue regarding coordination assistance.

“ Parents and families are having to become their own case managers and we are too exhausted.”

—Texas parent

Barriers to case management associated with eligibility were noted in some reports. For example, the California report indicated that case management services were not available for people who meet the federal definition of developmental disability but who do not meet the more restrictive state definition.

State Council Reports: Recommendations

“ Many families find the term 'case manager' offensive. They aren't 'cases', and they manage their lives. They don't feel that they should have to accept 'case management' in order to get the services they do need, such as respite care, parent education, peer support, or other assistance in caring for a family member at home.”

—Michigan parent

A few State Council reports contained the general recommendation that the case management concept be changed to one of supports to individuals and families.

Federal:

The sole Planning Council recommendation to the federal government in this area was that Medicaid reform legislation must include requirements for independent case management and for low enough caseloads to provide effective supports.

Federal/State:

➔ **Expand Medicaid coverage of case management.**

State use of the Medicaid program in relation to case management was reviewed in several Council reports. Reports from six states included a recommendation that the state seek an amendment to its state Medicaid plan to add targeted case management as an optional service, consider this addition, or improve use of the current system.

Opportunities to broaden case management availability through the Part H/Infants and Toddlers provisions of the Education of All Handicapped Children Act (P.L. 99-457) were noted in the Maryland report, which recommended inclusion of children with chronic conditions and their families in the family service planning process being developed in conjunction with the implementation of these provisions.

State:

➔ **Establish information and referral systems.**

The overwhelming majority of State Council recommendations regarding information and referral and assistance in coordination were focused on state government, addressing both availability and quality.

A recommendation to develop or implement an information and referral system was found in thirteen Planning Council reports. A typical recommendation is as follows:

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. (Massachusetts report)

It was apparent from the reports that many states already have a case management system in place. There were, therefore, only two reports (New Mexico and Oklahoma) with a recommendation to establish one.

➔ **Expand the current "case management" system.**

Several Council reports recommended that the present case coordination system be expanded. For example, the Wyoming report stated that "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." Their specific recommendation was that a task force of providers be convened to "assess the creation of such a case management system."

➔ **Improve the quality of case coordination support.**

The primary recommendation on case management, found in twenty-five Planning Council reports overall, was to improve the current case management system. Over one-third recommended development of an independent system, i.e., one that is separate from the service provision system. For example the South Dakota report includes the following recommendation:

It is recommended that South Dakota reassess 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. (South Dakota report)

Other recommendations addressed to quality concerns advocated the exploration of new models of service coordination, more consumer and family input, and reduced caseloads. Others focused on enhancement of skills through training opportunities. For example, the Georgia report included a recommendation that "pre-service and in-service training programs should include components on sensitivity and how to work effectively with persons with developmental disabilities."

➔ **Expand access to coordination supports.**

Case management responsibility for people presently unserved or underserved was recommended in a few State Council reports. For example, the Arkansas report included specific recommendations of state agency responsibility for case management for people with physical disability and "normal intelligence," for people with physical disability and mental illness, for people with head injury, and for people with low incidence disabilities such as Tourette syndrome. More broadly, the California report recommended that case management services be provided for people who meet the federal but not the state criteria for developmental disability.

5. Sufficient resources

State Council Reports: Accomplishments and Opportunities

The accomplishments highlighted in the State Council reports reflected the interest in increased resources for supports and in funding mechanisms that promote more consumer and family control. Four reports featured recent efforts to increase state funding for supports to individuals and families:

★ **Many states are increasing resources for supports.**

- During 1988, the Louisiana Developmental Disabilities Council helped create the Louisiana Citizens for Action Now (LaCAN). This group was formed to advocate for service system reforms in the areas of individual and family support, personal assistance services, and service coordination/case management. As a result of LaCAN efforts, forums were held statewide to educate and receive feedback from parents and the public on individual and family support issues. The major achievement was that legislation was drafted and enacted to develop and implement a Community and Family Support System. (Louisiana report)
- The New Hampshire Family Support Bill was signed into law in 1989. The bill appropriates \$500,000 in each of the next two state fiscal years for the purpose of establishing Family Support Councils and Family Coordinators in each region and providing additional support services to families. The bill will have an impact beyond the specific appropriation allocated. In recognizing that "families must receive the support necessary to care for their children at home," the family support legislation represents a clear commitment by the legislature to supporting the families of children with developmental disabilities. (New Hampshire report)

★ **Families are involved in designing support programs.**

- Families have expressed the concern 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. To address this concern the Council has helped to convene a Family Support Task Force, a parent-directed group of families and professionals whose goal it is to promote and obtain funding for services that support families caring for their children with developmental disabilities at home. Potential funding for these

services is available through reallocation of existing funds spent on out-of-home placements, and through implementation by the state of additional Medicaid options that would benefit families, including the Model Waiver program and the TEFRA eligibility option. (West Virginia report)

- Because of funding increases in the 1990-91 state budget, the Family Support Program will now be expanded and offered in all of the 71 counties of the state. Children served in the program have severe physical, developmental, and/or emotional disabilities. In 1986, 539 of these children were provided services by the program with \$424,698. That number increased in 1988 to 1,143 with a corresponding funding increase to \$1,599,462. (Wisconsin report)

The Wisconsin report also noted that many Wisconsin counties commit additional county dollars beyond the 10 percent match requirement for individual and family services.

As noted above, the Pennsylvania report highlights state support of its Attendant Care program, and the New Jersey report that of its model statewide information and referral system.

One State Council report (Minnesota) highlighted the state's acquisition of a federal Technology-Related Assistance and Development grant, and two (Idaho and Vermont) cited their state's request for a grant under this program. As described in the Idaho report, the grant will support people with disabilities with "technological tools and services that will allow them to integrate more fully into the labor community."

Cash assistance is helping families.

Family support funding strategies were highlighted in the Arkansas report:

In Arkansas two pilot cash assistance programs were initiated in 1988. The pilots are funded through [the state developmental disabilities service agency], with a current funding level of \$206,000 for about 40 families; about 77 families are on a waiting list. The pilots are directed at families who are providing care at home to a family member who is under eighteen years of age and who requires extensive ongoing support in more than one life activity area. The pilots provide an average of \$3,000 in supports per year per family. In addition, families remain eligible to receive other benefits such as medical assistance (Medicaid), rent subsi-

dies, food stamps, etc. To receive cash assistance, project staff and family members discuss the family's needs and concerns. Together they construct an "individual family plan" to guide use of the cash. Cash may be used to purchase nearly any good or service that is deemed relevant to the family's circumstances and that is not obtainable from other funding sources. {Arkansas report)

Several State Councils addressed funding mechanisms as well as current funding levels in their reports.

State Council Reports: Critical Issues and Barriers



There is an overall lack of resources for supports to individuals and families.

Nearly half of the State Council reports identified the need for increased funding for supports. Most of these lamented the lack of resources in general, while others identified funding gaps in relation to particular supports as reflected in the following examples:

- In Louisiana, the budget for the [state agency] 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. (Louisiana report)
- Fiscal incentives to state and county authorities are toward the Medical Assistance program and not toward family support services. (Minnesota report)
- 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 [HCB] 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. (Utah report)
- The primary need cited by Independent Living Center staff was funding for case management. (Colorado report)

“ I have a very difficult time getting around. I was given a loaner power wheelchair, and it helped a lot. MediCal denied it, and the company took my chair away. I had a letter from my doctor stating my need. I'm mad and there isn't anything I can do.”

—California consumer

✓ There is much less funding available for supports than for institutions.

“ Well, it seems if they have the money for group homes, why can't they have that for the child at home where he's happy and not take him out of his home surroundings?”

—Utah parent

✓ Medicaid funding policies limit access to supports.

- If additional funding were available, more dogs could be trained to provide people with hearing impairments of all ages with assistance through the Hearing Dog program which would make them more independent. (Colorado report)
- Difficulties in obtaining MediCal (Medicaid) reimbursement approval for durable equipment purchase, inadequate reimbursement for vendors billing for 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. (California report)

Eight Council reports specifically related the funding issue to the related lack of funding for supports vs. institutions. Examples of the disparities between support for institutional care and home and community based supports are also found in the chapter on housing.

A few State Planning Council reports noted that the issue was more one of targeting of state resources rather than the overall amount of funding. For example, the Minnesota report noted that "Medicaid funds do not start with family support nor move with persons from congregate care settings to support services." The Tennessee report included the observation that the state Medicaid plan does not include personal care services, while 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."

Specific concerns about barriers to supports because of federal funding policies were raised by fourteen Planning Councils. The primary issues raised were in reference to the Medicaid program, including eight which focused on the limited resources inherent in the HCB program. As described in four of the reports:

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.



Federal budget constraints limit funding for supports.

Other federal resource barriers cited by State Planning Councils were the decline in federal funding for the Social Services Block Grant, the issue of federal funding tied to medical needs, and the limited scope of the Medicaid program in relation to supports, similar to the concerns raised in the chapter on health regarding limits on Medicare coverage of durable medical equipment and assistive devices, and on Medicaid coverage regarding individual therapies. Eight reports also noted concerns that 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/MCH Block Grant, the ADM 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), as well as zero funding for the Special Recreation Grant Program.

State Council Reports: Recommendations

Four State Councils included general recommendations to increase resources for individual and family supports:

- Two to expand technology (Colorado, Nevada);
- One regarding stable and expanded funding sources for independence, productivity and integration (New Jersey);
- One for new financing mechanisms to emphasize flexibility in supports to families (New Hampshire)

Federal:



Enact Medicaid reform.

The primary recommendation from State Planning Councils for people with developmental disabilities targeted to the federal government was to increase resources for supports and to enact Medicaid reform. Overall, twenty-six State Councils recommended changes in the Medicaid program that would expand the availability of supports. Other recommendations focused on maintaining federal funding levels for supports to individuals and families and for restoration of Social Services Block Grant funding. As noted above, four reports recommended

elimination of Medicare restrictions on the coverage of technology and assistive devices.

Federal/State:

➔ **Expand use of Medicaid and other federal resources for supports.**

The majority of State Planning Council recommendations were focused on various aspects of the Medicaid program. Specific recommendations included expanded state coverage of personal assistance services and technology and expanded eligibility. Other recommendations included pursuit of Technology-Related Assistance and Development grants, efforts to increase state funding of independent living services, and the separation of personal assistance services from the medical model.

State:

➔ **Increase state funding of supports.**

Recommendations were found in thirty-one State Council reports to expand state revenue funding of individual and family supports, not including increases associated with Medicaid match requirements. Recommendations regarding state funding were a mix of those advocating increases in state resources and those addressed to modifications in the methods of financing services. Examples of recommendations for increased state funding included:

- The Department of Social Services and the Department of Health and Hospitals should coordinate and expand respite services through state and federal funds. (Louisiana report)
- 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. (Texas report)
- 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. (Pennsylvania report)
- Sufficient funding should be allocated to enable the Developmental Center to complete all adaptive equipment for institutional residents as soon as possible so that its adaptive equipment capabilities can then focus on addressing the needs of community clients. (North Dakota)
- 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 individual habilitation plan which includes a long-term view of where and how the individual should live, learn, work and play in one to three years. (Florida report)

➔ **Use vouchers, cash subsidies and other mechanisms to increase consumer and family control over supports purchased.**

Seventeen Planning Council reports included recommendations in relation to funding mechanisms such as vouchers or cash subsidies to individuals and families, to enhance their ability to purchase the supports of their choice. For example, the Virginia report included a recommendation **that** the legislature should require and provide funding to establish a system of family support services **that** would be "uniformly available" throughout the state. The recommended 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."

➔ **Use state tax policy to support individuals and families.**

Two Council reports addressed state tax policy as another aspect of state funding for individual and family supports. For example the Colorado report recommended support of 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." The Massachusetts report included a recommendation for tax breaks as an example of family support services that should be established as an entitlement.

6. Accessible, affordable transportation

State Council Reports: Accomplishments and Opportunities

Transportation emerges from the majority of reports as an area of particular interest: 48 states and territories addressed barriers to transportation in their reports.

Accomplishments identified in the reports touch on the major themes of affordability, accessibility, and quality transportation, as illustrated by the following examples:

- Public transportation services provided in North Dakota are supported primarily by federal funds allocated under the Urban Mass Transit Act

(UMTA) and by a patchwork of local and private funding. Before enactment of HB 1337 by the state legislature in 1989, North Dakota was one of the eight states with no state aid program for public transportation. It is estimated that this new state aid program will generate \$395,000 per year in state funds for public transportation. (North Dakota report)

★ **Coordination strategies are increasing access.**

- When Medicaid funds were made available through the HCB Waiver, a group of city council people sat down with representatives from the state in one southern Utah community to strategize how to maximize federal financial participation to create a transportation system for people who are elderly or who have a handicap. Each town contributed funds to a county wide transportation agency. For HCB clients, funds were contributed back to the state to provide the match and collect Medicaid dollars for transportation services. Vehicles and routes were shared with aging and education services to enable people in the most remote areas of the county to have access to services. Working together through a central agency, funds were maximized as well as vehicles, drivers, and routes. This cooperative plan also allowed small cities to become involved and "own" some of the services for people with disabilities in their community. Because of this approach consumers receive transportation that was not previously available. (Utah report)
- The agencies of Transportation and Human Services have undertaken nine regional studies designed to develop a comprehensive transportation plan for each region of the state. These plans hold promise, for they are based upon local involvement and the resources available in the local region. (Vermont report)
- Efforts are being made in the Puget Sound area (from north of Seattle in Everett, Washington south to Olympia) to increase intersystem travel. The Regional Reduced Fare Permit is recognized by ten local transportation systems and is available to senior citizens as well as people with disabilities. This permit eliminates the need for persons to carry multiple cards in order to receive reduced fare benefits from more than one system. This cooperative program was developed through Puget Sound Council of Governments with support from UMTA and local public transportation agencies. (Washington report)

The examples of "success stories" illustrate another theme found in discussions of transportation: the need for coordination across transportation systems.

State Council Reports: Critical Issues and Barriers

✓ **Transportation is not available.**

The primary transportation issue identified in the State Council reports was its lack of availability—in general, especially in rural areas, and in particular for people with disabilities. The lack of transportation was cited repeatedly as a significant barrier to the effort of people with developmental disabilities to work, to shop, to enjoy leisure activities, and, most important, to participate actively in their communities, as reflected in the following statements:

“ *It seems unconscionable that the number one public transportation priority over the last half of the 1980s was to get gamblers a 24-hour express....Transportation for people with disabilities should have been a high priority in the 1980s and it wasn't.*”

—New Jersey consumer

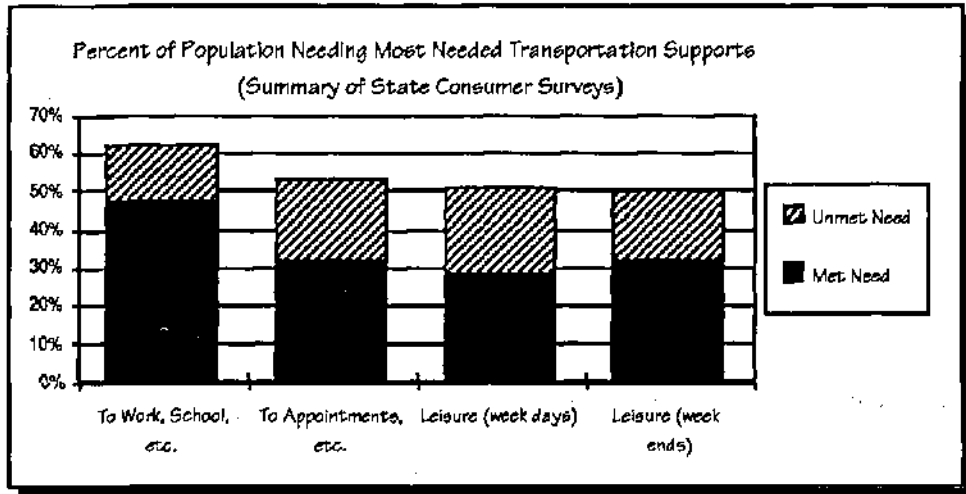
- There is a need to increase and improve Guam's transportation system to address the needs of individuals with developmental disabilities. The system must be affordable, accessible, safe and available to all, including individuals with blindness. (Guam report)
- Access to affordable transportation is critical to individuals with developmental disabilities being able to be employed. (Florida report)
- The Council finds that 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. (Illinois report)
- Lack of 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. (Indiana report)
- Many consumers and parents expressed feelings of social isolation as the result of the attitudes of others and inadequate transportation. Without transportation, meeting others, getting to work and to medical appointments, and having choices concerning living arrangements are impossible for these individuals. (Maryland Report)

“ I wish I could just meet friends and go to McDonalds and a movie and not have to ask my family to take me.”

—Michigan consumer

- The lack of available and accessible transportation continues to be a major obstacle blocking people with disabilities from full participation in society. (Texas report)
- 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. (Michigan report)

Several State Council reports included data from the consumer survey on the transportation availability issue. Data from the summary of state consumer surveys indicated that transportation was considered an important need in relation to living, going to school or working, and participation in the community by the majority of the 13,075 respondents. Transportation to appointments and for personal activities outside school or work was considered nearly as important as transportation to and from a job or classroom; it was also in these areas that more respondents indicated an unmet need for transportation, as illustrated in the following figure.



- ✓ **Lack of accessible transportation is a major barrier.**

One of the major barriers identified by Planning Councils was accessibility, especially for people with physical disabilities. Most discussions of accessibility barriers identified the need for additional public transportation conveyances that are accessible to people with mobility impairments, such as lift-equipped buses. For example, the Washington report notes that of the approximately 2,046 transit vehicles statewide, only 960 are lift-equipped. Other accessibility barriers identified include those related to individual vehicles. For example, the Alabama report noted that one of their local public hearings participants reported that none of the city's post offices has a parking spot wide enough for both a van and its wheelchair lift. A few reports referenced issues of availability and enforcement of parking areas for people with disabilities.

“*I called twenty-six people [with disabilities] to get here today—twenty-four couldn't come, due to transportation...we have a cab, but it is \$1.10 per mile.*”

—Michigan consumer

A second major barrier noted by Councils was affordability, especially for specialized transportation. As described in the South Carolina report, “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.”

Some State Council reports also noted the high costs of adaptations to personal vehicles. For example, the Vermont report pointed out that people may not have the resources to purchase appropriately equipped vehicles for private transportation, with costs ranging from \$500 for more simple control modifications to \$35,000 and up for a new lift-equipped automobile or van.

“*Had I not had a good friend to drive me, I would not have been able to testify. Transportation for social situations and other appointments is definitely needed.*”

—Texas consumer

Another form of transportation barrier identified by several Planning Council reports was the lack of availability for purposes other than being driven to and from a service agency and for trips outside of a narrow schedule. Some reports specifically describe consumer problems with getting to medical appointments. Limitations on transportation to employment, especially if needed at anything but “regular” times, is also noted.

- ✓ **Transportation problems include delays, unsafe equipment, and insensitive drivers.**

A fourth area of concern raised in the Council reports was the quality of available transportation, including lengthy delays, insensitive drivers, and equipment problems. Comments from a member of the Texas Developmental Disabilities Council illustrated one aspect of the problem as follows:

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, the ride was two hours late, delivering him to the wedding long after the ceremony had ended. (Texas report)

Transportation availability in general was an issue raised in several State Council reports, particularly as it affects residents of rural areas. For example, the Arkansas report noted that the state includes only three urban mass transit systems and a limited paratransit system in less than one-third of the counties, with consumers in 68 percent of the 75 counties dependent on "vendor provided transportation made possible by service agencies."

✓ **Lack of funding and poor coordination of existing resources are major barriers.**

According to Council reports, the primary factor associated with these barriers was lack of funding—federal, state and local. Other issues raised included coordination of existing transportation resources, especially those administered by human services agencies; lack of consumer input in designing transportation services; and the limitations of the "three percent UMTA funding rule." As described in the Hawaii report, the UMTA and related transportation anti-discrimination ("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 that the "above full performance criteria is subject to a tradeoff against the three percent limit," i.e., "if satisfying the full-performance criteria would result in expenditures beyond the three percent limit, then the service may be excused from satisfying the full performance criteria." (Hawaii report)

State Council Reports: Recommendations

At a national level, the recommendation most frequently made by State Developmental Disabilities Councils was that all public mass transportation should be accessible. Some states also recommended that all future publicly funded transportation must be accessible.

Federal:

➔ **Increase federal leadership on the right to accessible transportation.**

Reflecting the barriers of availability, accessibility, and affordability identified in most of the State Council reports, the recommendations on trans

“ To get into O'Hare International Airport I am carried up the two flights of stairs on a straight-back, a 'dolly for people'...the whole aspect of having no control and loss of dignity...being carried and the mental image of others around you...that you need to be carried...you are strapped in, and your arms aren't free to protect yourself if they stumbled and dropped you.”

—Michigan consumer

→ Improve coordination of transportation resources.

portation were focused primarily at the state and local level. A few recommendations targeted to the federal government were found, as follows:

- UMTA should have an explicit goal of promoting integration. (Iowa report)
- Study the effects of removing the policy waiver that allows elimination of accessible transportation services if the cost exceeds three percent of the program budget. (Iowa report)
- The federal Urban Mass Transportation Act programs should adopt and enforce user compliance standards as a condition of public transit systems obtaining and maintaining transit equipment purchased with federal funds. (Hawaii report)
- The Federal Aviation Administration (FAA) should do more to ensure that air travel is accessible to persons with disabilities. The FAA should be encouraged to develop regulations for the airlines to promote accessibility and equal treatment on flights. (Massachusetts report)

The Massachusetts report also noted that the Americans With Disabilities Act excludes airline policy for persons with disabilities.

Federal/State:

Recommendations in a few Planning Council reports were focused on the state's use of federal programs. The primary recommendation was that transportation coordination be improved among various agencies and programs whose transportation services are federally and state supported. Regarding Medicaid, the Maryland report included recommendations that the state "administer the Medical Assistance transportation funding program by an agency with expertise in transportation management and operations" and that Medical Assistance transportation funding be coordinated with funding from other sources to expand transportation availability.

Another report (North Dakota) included a recommendation that federal funding through UMTA programs be combined with additional state funding to expand public transportation services into presently unserved areas of the state.

➔ **Increase the availability of accessible transportation.**

State:

Council recommendations for state and local action to reduce transportation barriers were found in all but a few reports. The primary recommendations were for increased availability to people in unserved or underserved areas; for increased accessibility for people with physical and other disabilities; and for increased funding to meet the needs for expansion and increased access. Additional recommendations focused on the following approaches:

- Expansion of scope (services, activities and hours covered)
- Additional help to individuals, including mobility training, outreach, information and referral specifically on transportation, and help with vehicle modification expenses
- Improvements in quality, such as training of transportation personnel in sensitivity as well as ways to provide assistance
- Improvements in affordability, through such strategies as reduced fare plans and voucher systems
- Improvements in overall efficiency, primarily through more effective coordination of existing services

➔ **Provide sensitivity training to transportation personnel.**

➔ **Involve consumers in transportation planning.**

More broadly, several State Council reports also recommended that consumers be actively involved in planning and monitoring transportation systems, both public and private, to enhance its responsiveness to the needs of people with developmental disabilities. Recommendations for increased funding for transportation services, while generally focused on increased state support, include some private sector sources such as employer assistance with job-related travel, private foundations, and human service agencies.

➔ **Recognize the significance of transportation in the lives of people with disabilities.**

Finally, it should be noted that recommendations in several Council reports incorporated references to the significance of transportation in relation to independence, productivity, and community integration:

- 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. (Florida report)

“ *Continuous public transportation must be a top priority, if we honestly want people with disabilities to feel like contributing members of society.*”

—New Jersey consumer

- Create strong incentives by transit operators, such as lower fares and travel training, to enable people with disabilities to convert from being paratransit users to using the mainline system. Offer routinely travel training and encouragement to consumers who may feel intimidated by the mainline system, since mainline transit affords critical opportunities for independence, productivity and community integration. (Maryland report)
- Accessible transportation should become a priority in all communities to insure full participation by all its members. (Nebraska report)

The significance of transportation access to participation in social, recreational and personal activities of interest is particularly relevant to the following section.

7. Social and recreational opportunities

State Council Reports: Accomplishments and Opportunities

As envisioned in the State Council reports, supports to individuals and families would be incomplete without reference to opportunities for socialization, recreation, and leisure activities that promote community participation. Most reports highlighted comments from consumers that these opportunities are limited. An example of current activities in this area was found in the Arkansas report:

A local "Volunteer Match" program in Hot Springs, Arkansas helps people identify a volunteer advocate at a major point in life emphasis. For some this is work, for others church, for others recreational activities. The concept is to create a peer relationship with at least one volunteer who does not have a disability who will then work with the person with a developmental disability to advocate as needed on his or her behalf. (Arkansas report)

★ **Community initiatives include friends and informal supports.**

Complementary to the concept of supports to communities that promote such involvement, several reports described programs that are developing "Circles of Friends:" networks of informal supports that provide the kinds of support and assistance that all people expect from their friends. Activities in two states were described as follows:

“ One wish: to work every day and have good friends.”

—Wisconsin consumer

- In 1989 the Council funded a project to develop Circles of Friends in five Colorado communities. The purpose is to organize communities to connect people with developmental disabilities to others in their communities and to foster long-term relationships. In the process of assisting consumers to be effective self-advocates and fully participating members of their communities, it is hoped that societal attitudes will change. (Colorado report)
- The Logan Square Neighborhood Association sponsors a community building project which is designed to invite community members to include people with disabilities in their everyday life—to go to church together, or a ball game, or simply to have dinner together....The key to community building is making connections and building relationships through family, friends, neighbors, small businesses, churches, associations, libraries, or clubs...by creating "circles of friends," people with disabilities are becoming active members of their communities, complete with the responsibilities which that entails. People with disabilities need friends like everyone else. But they also need someone to offer friendship. The community building project offers that friendship. (Illinois report)

State Council Reports: Critical Issues and Barriers

“ The people I know are sleeping and watching TV. It's not much to live for.”

—Georgia consumer

All but a few State Council reports identify social isolation and lack of opportunities for recreation as a barrier affecting people with developmental disabilities. Data from the consumer surveys were used extensively by the states in highlighting this issue, as illustrated by the following observation:

Perhaps more than any 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 some or strong need, and 110 were not receiving any recreation/leisure service.

The consumer survey included an item asking 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" out rather basic human interactions (e.g., a friend, love, someone to talk with). (Alabama report)



Opportunities for integrated recreation and leisure aren't available.

Data from the state consumer surveys indicated that over 55 percent of the people surveyed expressed a need for recreation and leisure "services" but of these 62 percent were not currently receiving them.

The majority of issue statements found in the Council reports are general descriptions of lack of availability. For example, the California report found that "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." The two barriers identified most frequently were lack of funding and lack of transportation. Other specific areas of concern identified were accessibility barriers in local and state parks and the need for better information and outreach to people with developmental disabilities.

State Council Reports: Recommendations

Federal:

There were no recommendations in this area addressed to the federal government.

Federal/State:



Expand use of the Foster Grandparent program.

As noted *in* the section on supports to individuals, two State Councils recommended expanded participation in the Foster Grandparent program. The Florida recommendation is as follows:

Encourage the expansion of the Foster Grandparent program 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. (Florida report)

The Washington report recommends even broader expansion of the Foster Grandparent program, advocating that it be "available and accessible to all individuals [with developmental disabilities] who request it, not just to those living in institutional settings."

➔ Increase community recreation opportunities.

State:

The majority of State Council recommendations focused on increased access to community recreational activities, with an emphasis on opportunities for integration. Examples of such recommendations include the following:

- 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. (Arkansas report)
- 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. (Louisiana report)
- 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. (Montana report)

A specific recommendation for additional funding was found in the Pennsylvania report, to be used for "the purchase of barrier free recreational equipment and programs sensitive to the requirements of citizens with disabilities." The report also noted that the visibility of recreational needs could be increased with the employment of people with disabilities in recreational planning efforts.

As noted in the section on supports to communities, several Council reports recommended the "Circles of Friends" approach, in particular as a significant informal support to individuals with developmental disabilities.

Finally, an overall recommendation in the California report was found as follows:

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. (California report)

This recommendation relates directly to the recurring themes of both supports and community participation.

IV. Education

IV. Education

State Council Reports: Overview

- ✓ **Education is a lifelong process.**

Education, as dealt with in the State Planning Council reports, was a broad topic that began with early intervention programs and, for some people, continued throughout life. Vocational education was seen as an element of career development for some people with developmental disabilities. Councils highlighted the importance of the development of those skills and knowledge that enabled people with developmental disabilities to be as independent in the control of their lives as possible and to participate fully in an integrated community life. A few reports brought out a new theme that was expected to grow in importance in the years ahead: continuing or adult education.

- ✓ **The Education of the Handicapped Act is essential to meeting the goals of independence, productivity, and integration.**

Perhaps the single critical theme that runs throughout the education references in the State Council reports is Public Law 94-142, The Education of the Handicapped Act (EHA), that guarantees a free and appropriate education to all children, regardless of the nature or severity of their handicap. Except for additional federal funding and technical changes, the issues raised in the Council reports focused primarily on the implementation of the Act.

- ✓ **State Council reports concentrated their analysis on the implementation of P.L. 94-142 in the state.**

In this area, more clearly than in any other, a positive link was established with federal landmark legislation. The different states were at different stages of realizing the promises of P.L. 94-142, but progress was being made. Virtually every Planning Council report concentrated its analysis on the implementation of P.L. 94-142 in its state. Other federal programs that were discussed by the states relative to education were Head Start, the preschool and infant provisions of the Education of the Handicapped Act (Parts B and H), Vocational Rehabilitation Act programs, the Job Training Partnership Act, and the Carl D. Perkins Vocational Education Act. In addition, the State Council reports raised issues involving the interaction between education agencies and the state mental retardation/developmental disabilities agencies.

- “ ***What the best and wisest parent wants for his own child, that must the community want for all its children.***”

—John Dewey

Goals or visions for the education of people with developmental disabilities were found in the majority of State Council reports. As part of their discussion of educational goals, several Councils (Idaho, Louisiana, Montana, Utah and Wyoming) included the statement at the left by the educator John Dewey.



Vision: a free and appropriate education should be available to all children in the state. Education should recognize the special needs of all children and must be based on the presumption that each child is able to learn and develop.

—New Mexico report



Because the ultimate goal of public education is to enable our youth to become productive adult citizens, such education should be provided to individuals in the least restrictive, most integrated environment, with continuing attention to both academics as well as social and vocational skill development.

—California report



The primary goal of education for all people, including those with developmental disabilities, must be to prepare individuals for participatory, productive, and contributing roles in society.

—Ohio report

The four goals found most frequently across the State Council reports were as follows:

1. Educating all individuals with developmental disabilities

Most State Council reports included an emphasis on the goal of education for all people with developmental disabilities, regardless of the type or nature of their disability. Some Councils included goals of the availability of a full range of educational opportunities, from early childhood education to adult education.

2. Education in the least restrictive, most integrating environment

A second major goal relative to education, found throughout the State Council reports, was that people with developmental disabilities be educated in the same schools as other children in their community, in the most integrated educational environment possible. A related goal found in many reports was that the full range of educational opportunities be provided in ways that integrate children with disabilities with non-disabled children, such as preschool and extra-curricular activities.

3. Education to become productive adult citizens

Another goal identified in relation to education by the majority of State Planning Councils in their reports was that education prepare people with developmental disabilities for adult roles and responsibilities, to reach their maximum potential for independence and productivity. Related goals found in some reports included an emphasis on "functional curriculum," access to vocational education, and coordination among systems for an effective transition for students leaving the educational system.



Outcomes: special supports will be available to students with disabilities which are designed to meet their educational needs, including individualized instruction, adaptive equipment, accessible buildings, technological aids and accessible transportation services.

—Texas report

4. The special services and supports required for education

The fourth goal in education noted by most State Councils was that students with developmental disabilities have access to the various services and supports they need for maximum benefit from their educational opportunities.

A cross-cutting goal in education put forth by a majority of State Planning Councils in their reports was that parents, and in a few reports students as well, be full partners in decisions about the student's educational program. Related goals regarding individual education plans were discussed by the Councils in relation to civil rights protections. As the explicit goal, as stated by many State Councils, was to prepare people with developmental disabilities to be productive adult citizens, there is a close relationship between this chapter and the chapters on employment, housing (community living), health care, and supports.

1. "Educating all individuals with developmental disabilities"

State Council Reports: Accomplishments and Opportunities



P.L. 94-142 guarantees a free and appropriate education to all children with developmental disabilities.



The language of the Act makes it clear that a 'zero reject' policy is at the core of the Act [P.L. 94-142] and that no child... is to ever again be subjected to the deplorable state of affairs which existed at the time of the Act's passage, in which millions of handicapped children received inadequate education or none at all." (875 F. 2nd, 954, 1st Circuit, 1989).

—U.S. First Circuit Court of Appeals

The Education of the Handicapped Act (EHA), Public Law 94-142, was referenced by Councils in state after state as both an accomplishment and an opportunity. It was seen as providing a guarantee that all children, regardless of the severity of their disability, receive a free and appropriate education. EHA provides families and advocates for children a means by which to redress the problems children with disabilities encounter. Perhaps more importantly, through the requirement for an individual educational plan, it ensures that each child will have the opportunity to reach his or her maximum potential. The New Hampshire report discussed the May 24, 1989 U.S. Circuit Court of Appeals decision that overturned a previous ruling that a school district could exclude a child on the basis that he or she was "too severely handicapped to benefit from education." In declining to consider a further appeal the United States Supreme Court let stand the Circuit Court's decision.

It is a testament to the importance of the Education of the Handicapped Act that only two State Councils saw exclusion from public education as a problem. The summary of state consumer survey data showed that only 0.5 percent of school age children (ages 6 - 21) surveyed had received no formal education.

This compares favorably with the 4 percent of adults aged 22 through 44 who indicated that they had received no formal education. The data also indicated that 73 percent of the children birth through age two received either early intervention or preschool services. For children from three through five years of age participation grew to 83 percent.

State Council Reports: Critical Issues and Barriers

✓ ***Children are being excluded from needed programs.***

“***The regulations to pay for my son's speech therapy say that it is for improving speech, not maintenance of speech. Since it is not likely that he will be able to improve, he is no longer eligible for services. So although there is a program, he is not able to use it.***

—Maine parent

Several State Councils raised concerns that children were being excluded from educational programs for a variety of reasons ranging from a lack of information about available programs to the lack of programs and available space in those programs. Some programs were seen as excluding people with developmental disabilities on the basis of their disability. In particular, eight states mentioned specific disabilities including serious mental and emotional problems, autism, multiple disabilities, and head injury, that had been used as reason for exclusion from some programs.

Early identification and intervention were critical issues to many State Councils. They pointed out that families with very young children with developmental disabilities are difficult to identify. More generally, one Council stated the issue as follows: "Many individuals and families are unaware of the benefits or of the availability of services for people with developmental disabilities, and do not participate fully in the decision-making processes."

The Head Start program has a federal requirement that 10 percent of the children served in this program be children with disabilities. In at least one State Council report the majority of children making up this percentage were reported to be children with speech disabilities. That Council was concerned that this valuable child development program was failing to serve children with more severe disabilities (e.g., developmental disabilities). Several other State Councils suggested that this program could serve children with developmental disabilities and their families in greater numbers than presently. A few states pointed out that Head Start has insufficient funds even to reach all those children who are income eligible.

Another issue raised by some Councils was the fact that only twenty-one states provide special education and related services to the full age range of children three through twenty-one years of age.

State Council Reports: Recommendations

Federal:

- ➔ **Weight federal funding formulas in favor of serving students with the most severe disabilities.**

It was recommended by several State Developmental Disabilities Planning Councils that federal funding for special education should be weighted to favor students with the most severe disabilities.

- ➔ **Extend the provisions of The Education of the Handicapped Act to cover ages 0 through 21.**

Several State Councils, especially those that do not serve children over the full range of years allowed under the Act, were concerned that children toward the ends of these extremes are not being served by other service systems; nor do they have the necessary skills or resources to live independently in the community. They recommended that the Congress extend the mandated ages from birth to 21 years of age.

- ➔ **Increase the funding and monitoring activities of the Head Start Program.**

The State Councils that saw Head Start as an important resource in the development of children with developmental disabilities felt that funding should be increased, but they also felt that enrollment practices in the program had to be more closely monitored.

Federal/State:

Some State Councils recommended more careful monitoring of compliance with the child find provisions of The Education of the Handicapped Act.

State:

- ➔ **Expand specialized services to underserved groups.**

Several State Planning Councils recommended that specialized services needed to be extended to reach underserved groups (e.g., those with autism, multiple disabilities, and severe emotional disabilities).

2, Education in the (least restrictive, most integrating environment

State Council Reports: Accomplishments and Opportunities

- ★ **Parents support integrated education for children with developmental disabilities.**

The State Councils indicated in their reports that parents were increasingly aware of, and advocating for, education of their children in learning environments integrated with non-disabled children of the same age. They noted that parents at state forums across the country insisted upon these interactions as important to educate both their children with disabilities and the children without disabilities. The fact that three quarters of the states raised the issue

“ Our son has always been in regular classes with his age group. Initially we had our reservations but we've been really pleased. It's just incredible to me to go into the classroom and see these kids interacting with each other. They know how to communicate with him; they show him how to do his science experiments. It's incredible.”

—New Hampshire parent

“ We all are prejudiced toward people with disabilities, whether we want to be or not. It's just the way we were raised and what we saw growing up. I admit to that. I react a little bit differently to someone who's disabled than someone who's not. But I see the kids in Josh's class just interact with him as another kid. And I think, and maybe I'm optimistic, that future generations won't have that prejudice.”

—West Virginia parent

State Council Reports: Critical Issues and Barriers

✓ Most children with developmental disabilities receive their education in segregated settings.

of segregation—the most states on any educational issue—suggests that this is the singular most critical theme raised by the states in the area of education.

In New Hampshire several school districts have developed a new role for special education teachers called "Mainstreaming Specialist," "Integration Specialist," or "Consulting Teacher." These new positions recognize the educational responsibility to achieve full integration of children with developmental disabilities. These individuals act as "consultants, team-teachers, service-coordinators, and in other flexible roles to support the inclusion of students with disabilities in regular educational environments." The report also highlighted the following experience during the community forums:

One of the Council's community meetings last spring was held on the same day decorations for a school dance were being set up. The dance committee included two students with developmental disabilities, assisted by an aide. (New Hampshire report)

Minnesota has developed mentor/friendship programs in the schools which foster greater integration. People with developmental disabilities volunteer alongside others who do not have disabilities.

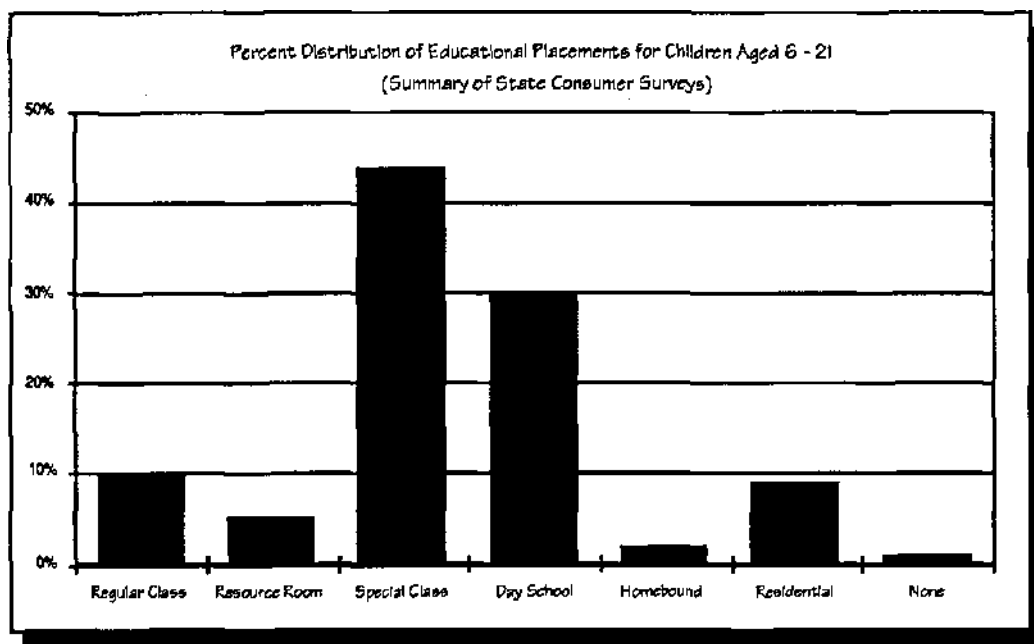
Few examples like these from New Hampshire and Minnesota appeared in the Council reports. Overall it appeared that the accomplishments in educating children with severe disabilities in regular classrooms were the result of the individual efforts of families who insisted on integration for their children and individual educators who have been responsive to these families.

Three-fourths of the State Council reports pointed out that education for children with developmental disabilities (especially mental retardation) was provided in "segregated environments away from age peers and the activities they participate in." One state budget was quoted as saying that there were "...students too severely handicapped to be served effectively by local public schools ..." as a rationale for maintaining segregated state operated schools.

Virtually all State Planning Councils voiced the concern that not enough was being done in their state to

develop educational environments and supports so that children with developmental disabilities could be integrated with their age peers who did not have developmental disabilities. Several states raised the issue that the consumer survey showed that a high percentage of consumers were dissatisfied with education in regular classrooms. Councils identified several barriers in relation to this concern: lack of money, a lack of or improper teacher preparation, a lack of understanding and commitment on the part of decision makers and families, and physical plant limitations.

The following graph of findings from the summary of state consumer surveys shows that 10 percent of the people surveyed between six and twenty-one years of age received an integrated education either in a regular classroom or in a resource room in conjunction with a regular class room. For the remaining 90 percent the degree of integration varied from those served in residential programs (9 percent) to those served in special classes in regular schools (44 percent).



“ One wish: to go to a regular school and participate in normal activities.”

—Wisconsin consumer

The experience of most states mirrored the summary survey data. As stated in the Virginia report, "The majority of students with developmental disabilities are regularly denied access to, and experience with, age-appropriate peers who are not handicapped." The State Council reports reflected that the states are at different stages of responding to this issue. A few states were still concerned with state operated segregated schools while others were critical that too many children are in self-contained classrooms.

✓ Placement decisions are subjective.

State Councils raised the issue that decisions on least restrictive placement are often made subjectively and that procedures vary from school district to school district. As one report put it, "Providing the least restrictive environment is an undermanaged component of the IEP [individual education plan]."

✓ Providing integrated education can be challenging.

A few of the states recognized that the specialized needs (e.g., challenging behaviors, chronic medical conditions) of a few children would pose major challenges to the public school system; however, they also recognized the importance of meeting these challenges with creative new approaches. Two Councils noted that special efforts would have to be undertaken by the school systems to assist children in forming positive relationships.

Several State Planning Councils pointed out that despite a national trend toward regular school and regular classroom placement for children with disabilities, some states have not seen this shift. Several Councils pointed to their residential school placement statistics for children with severe disabilities. A few states were concerned that the developing "profession" of special education with its own jargon is attempting to create a mystique that insulates it from the scrutiny of the public, the educational administration, the rest of education, and the parents of the children receiving services. Massachusetts pointed out that private education providers have become an industry and have become effective political interests in opposition to the integration of children with severe disabilities. According to the Idaho and New Hampshire reports, respectively:

Special education is viewed nationally (and in Idaho) as a separate 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. (Idaho report)

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." (New Hampshire report)

Other barriers and issues to a fully integrated education for children with developmental disabilities raised by the State Councils included:

- Labels that stigmatize children
- Lack of opportunities to participate in extra-curricular activities
- Overly protective attitudes on the part of teachers, administrators, and parents
- The lack of "regular education" teachers prepared to have children with severe disabilities in their classrooms

✓ **Schools fail to promote integration for preschoolers.**

One Planning Council raised the issue of the increasing demand for child care and preschool services from the growing numbers of working mothers in all income groups, and pointed out the importance of early childhood services for children with developmental disabilities. Since the mandate in that state was to begin educational services at age six, other avenues had to be explored (e.g., Head Start, private preschool programs).

✓ **Adults lack integrated education opportunities.**

One of the emerging issues contained in a few State Council reports was an investigation of post-secondary educational systems as resources for adults with developmental disabilities. They pointed out that state service systems tend to be segregated—serving adult learners through "day habilitation" programs—rather than using post-secondary and other community educational resources that could provide integrated education and training for adults with developmental disabilities.

State Council Reports: Recommendations

Federal:

➔ **Integration of students with developmental disabilities should be a federal priority.**

The Nevada Council recommended: "The Department of Education [United States] should establish integration of students with disabilities, including those with severe disabilities, as a priority..." While

a few State Council report recommendations targeted to the federal level addressed improving educational resources to states, most of them focused on using EHA as a means for ensuring state and local action on educational integration for all children with developmental disabilities.

Federal/State:

There were no recommendations in this area.

State:

➔ **Develop curricular approaches to integration.**

Some State Councils saw the need to include in the curricula of the public schools courses on human disability to be taught to students who were nondisabled. Some states went further and requested that their state boards of education develop and implement training programs for parents and professionals on the benefits of integrated options for children with disabilities.

➔ **Provide education and training to "regular" education teachers.**

Several Planning Councils saw the need to improve the preparation of all teachers—especially the "regular" education teachers—to educate children with special needs in an integrated classroom. They recommended that state boards of education establish policies and procedures to ensure that children receive an integrated education.

3. Education to Become productive adult citizens

State Council Reports: Accomplishments and Opportunities

California has a seven year old "WorkAbility" project that has served more than 43,000 students. This project represented the cooperative efforts of the state departments of education, rehabilitation, and employment development to provide assessment, employment preparation and training, community work experience, and support services. In recent years the project has been extended to the community college level.

Oklahoma's rehabilitation services agency makes available to school districts a counselor who contacts every special education student at the age of sixteen to determine what vocational needs they may have.

Critical Issues and Barriers

- ✓ **States report high dropout rates of special education students.**

Many State Planning Council reports cited statistics regarding the educational outcomes for children leaving special education. The dropout rates for children in special education were universally higher than for those who were not labelled as having an educational handicap. Thirteen states explicitly raised the issue of children with developmental disabilities leaving school before they either graduated or aged out of the system. The concern was raised that these young people tended to fall through the cracks with some of them destined to become part of the social malaise of their communities.

- ✓ **Vocational preparation is inadequate.**

These State Councils were specifically concerned about the lack of and poor quality of vocational preparation for young people with developmental disabilities. They pointed out that vocational goals were generally lacking from the individual education plan. Several states pointed out that vocational programs and career counseling, when they did exist, started too late in the child's educational program. States cited the underutilization of programs such as the Carl Perkins Vocational Education Act by students with developmental disabilities.

- ✓ **Adult educational opportunities are virtually non-existent.**

Many State Planning Councils reports were concerned that the educational opportunities for adults with developmental disabilities were severely limited. Many of these individuals could benefit with additional education and including new curricula supportive of employment and community living that may not have been available to many adults whose childhood pre-dated P.L. 94-142. In many states adults were reported to receive education and training in segregated day programs.

- ✓ **Career and life goals for individuals do not determine the educational programs they receive.**

A major issue addressed in reports by the Planning Councils was the lack of clarity in specifying goals for individuals (e.g., "to become productive adult citizens,") throughout the special educational process and, more specifically, through the individualized educational planning process. Reports from several states questioned whether the educational system was preparing children with developmental disabilities for an integrated and productive life in their home communities. For example, the Virginia report stated:

Students with developmental disabilities are exiting schools (e.g., aging-out) without the skills or experience necessary to maximize their current or future independence, pro-

“ After I pass away, where does my child go? I want my son to be independent—to know he can live on his own when I am gone.”

—Maryland parent

ductivity, and integration into community life. (Virginia report)

The issue of transition to adult life is also addressed in the chapter on employment. Much of the services of the Job Training Partnership Act and the Rehabilitative Services Administration have to do with education in a more specific vocational context.

State Council Reports: Recommendations

Federal:

→ A federal mandate for transitional planning

It was recommended in several State Developmental Disabilities Planning Council reports that a requirement be added to EHA that adult living goals and transitional programs be developed for each student.

Others recommended that the Carl Perkins Act funding should be utilized and monitored to ensure that students with developmental disabilities receive meaningful vocational training and preparation.

Federal/State:

There were no recommendations in this area.

State:

→ Realistic life planning should be an integral part of the individual educational planning for children with developmental disabilities.

Most State Councils saw transition planning as a state/local responsibility that needed to be immediately addressed, since students were regularly leaving the public education system inadequately prepared. They felt that transition plans should be mandated and monitored for compliance by their state education agency. It was recommended that the transitional planning and services begin by age 14, cooperatively with other state agencies.

→ States must provide adult education opportunities for people with developmental disabilities.

Many states recognized that education does not end with high school. They recommended the establishment and expansion of adult education opportunities with the same emphasis on integration.

→ Track students leaving education to evaluate educational effectiveness.

Some State Planning Councils recommended that a dedicated system of tracking students for a period after leaving school should be implemented. Several states were keenly concerned about the dropout rates and recommended task forces and other initiatives to focus this problem within their states.

➔ **Involve the business community in vocational education for students with developmental disabilities.**

Councils often recommended that community businesses become actively involved in the provision of vocational training experiences to secondary school children with educational handicaps. Schools were seen as needing to involve the business community in the selection of training sites and the design of training programs.

4. The special services and supports required for education

State Council Reports: Accomplishments and Opportunities

Some states have implemented functional, life skill oriented curricula (e.g., Missouri's Life Centered and Career Education curricula). Other states (e.g., New Hampshire) are conducting system change projects to improve educational services provided to students with severe disabilities. School district personnel receive training and technical assistance to increase their capacity to include children with severe disabilities. Another recent initiative was described in the West Virginia report:

Actions that have been initiated to address the problems [U.S. Dept. of Education, Final Monitoring Report] related to "least restrictive environment" [LRE] include training and technical assistance to local school districts, the development of policies and procedures related to least restrictive environment, and closer monitoring and documentation of the implementation of these policies and procedures by local school districts. In addition, LRE projects have been a high priority for the Department of Education [W. Va.] during the last two years. The Department is also initiating a Statewide Initiative in LRE to develop a model for integrating handicapped students with their nonhandicapped peers that can be replicated by local school districts. (West Virginia report)

State Council Reports: Critical Issues and Barriers

Having raised policy issues regarding access to and the outcomes of the educational systems of the various states, the State Council reports also addressed the critical questions of the means to accomplish these ends. First and foremost, Councils were concerned with the pursuit of a quality education for all students with developmental disabilities. Next they were concerned with the preparation of educational personnel—both "regular" and "special" educators. They raised issues of poor accommodations in existing schools and the lack of transportation. A major concern was the transition from home to school for

parents of very young children with developmental disabilities. About half of the Planning Councils raised the issue of inadequate resources to provide needed services. Finally, they raised a set of issues having to do with the infrastructure of the educational system.

- ✓ **Too few "regular" classroom teachers are qualified to educate students with developmental disabilities.**

The preparation of educational personnel was seen as a paramount concern by a majority of the Councils. Many State Councils raised concerns about the qualifications of "regular" classroom teachers in understanding the unique needs of children with developmental disabilities. Specifically, their qualifications needed to include: educational skill building in teaching in and managing an integrated classroom; teaching using real life experiences; and developing functional skills. Several State reports recommended that "regular" educators and administrators would benefit from additional education and training in providing services and supports to children with severe disabilities. A few states were concerned that these teachers and administrators were unfamiliar with specific disabilities.

- ✓ **There is a shortage of qualified special educational personnel.**

Even more Planning Councils were concerned about severe shortages of certified (qualified) special education teachers. The State Council reports cited problems with high turnover and problems in attracting personnel to rural areas. Most particularly, the states were concerned about the training of special education teachers in educating children in the "real world" skills they would need to live successfully in their local communities.

While State Developmental Disabilities Councils were concerned about a shortage of special education teachers, they were even more concerned about the lack of personnel trained to provide "related services" (e.g., physical therapy, occupational therapy, speech and language therapy, audiological services, individual and group counseling). Again, people with these skills were reported as difficult to attract to more rural areas.

- ✓ **There is a shortage of funding in education to provide essential services to students with developmental disabilities.**

Many State Council reports brought out several issues concerned with funding. Particular services and programs that were considered underfunded included:

- Preschool services for children three through five years of age
- Making schools accessible so that students can be educated in their neighborhood schools

- Vocational assessments
- Vocational services for children with developmental disabilities

Six Planning Councils in particular pointed out that certain funding formulas provided incentives for segregating students. For example, Massachusetts reported:

The "60/40%" law, which reimburses towns for 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. (Massachusetts report)

Twenty-one State Planning Councils reported that there was insufficient overall funding in their states for special education, especially for related services. This shortage inevitably led to overcrowding and confrontations with parents. Several of these states pointed out that federal funding contributions for P.L. 94-142 fall far below the statutory maximums. As noted by Florida and seven other Councils:

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, never exceeded 12% during the late 1970s. It reached a low of 7% in the early 1980s. (Florida report)



Resource shortages have an adverse effect on the education and related services.

State Councils viewed the shortages of financial and personnel resources as having the following impacts on the services and supports that children with developmental disabilities receive:

- The quality and availability of preschool programs varied depending upon where the child lived.
- Assessments did not take into account the racial, cultural, and language differences of children and their families.
- Children either had to wait to receive needed related services or did not receive them at all.
- Related services (e.g., therapies) were unavailable, especially in rural areas, making integration very difficult.

- Transportation services were inadequate, and children with developmental disabilities often were required to travel great distances for long periods of time each day.
- The availability of services determines whether children were included in or excluded from special education programs.
- Relatively sophisticated technologies and devices (e.g., computer-aided) are not available although they can have profoundly positive effects on the education of children with developmental disabilities.
- There is a lack of drivers' education for children with severe disabilities.
- Educational plans do not have high quality multi-disciplinary involvement.
- Children for whom English is a second language are improperly served.
- Social, sexual, and other functional life skills are not included in the curriculum.

✓ **Services to infants, toddlers, and preschool children with developmental disabilities are inadequate.**

The amendments to the Education of the Handicapped Act established a preschool grants program that is to serve all three through five year olds by the year 1991. Several State Council reports pointed out that preschool services were not universally available throughout their states and that they were inadequate to meet the needs of the children. Some indicated that school districts were reluctant to purchase services from other providers of preschool services such as day care centers, nursery schools, or Head Start programs that would provide integrated experiences for children with developmental disabilities.

The latest amendments to the Education of the Handicapped Act established an infants and toddler program for children from birth through age two. This program provides assistance to states to plan and develop a system of services for infants and toddlers with disabilities. Twelve states pointed out that since these services may currently be the responsibility of another state agency, territorial problems arise. In addition they indicated that limited resources result in limited services. They expressed concern that the provisions of the law requiring that all children who meet the eligibility criteria be served (an entitlement to service) will force the states

- ✓ **Post-secondary educational opportunities are virtually non-existent for people with developmental disabilities.**

either to not participate in the federal program, or to seriously restrict the population served or the services provided.

Ten State Planning Council reports expressed concern over the lack of educational opportunity for people with developmental disabilities through post-secondary educational programs. These states pointed out that, like other Americans, people with developmental disabilities needed to continue to develop their skills and knowledge throughout adulthood. These skills could assist them to be more productive, independent, and integrated into their communities. Specifically mentioned was the value of a graduate equivalency diploma (G.E.D.). Data from the summary of state consumer surveys similarly indicated high levels of need for adult educational services.

- ✓ **There is a serious lack of summer programs for children with developmental disabilities.**

Six State Council reports raised the lack of summer programs for children with developmental disabilities as a critical issue. For many children the three-month vacation period was seen as a period of regression when many of the gains of the school year were lost. The summary of state consumer surveys showed that consumers were especially dissatisfied with summer programs and that there was a high relative need for them.

- ✓ **Educational programs provide too few life experiences.**

Several Planning Councils were concerned about the lack of opportunities for real life experiences as well as the acquisition of academic and functional skills that have real life applications. These reports made the point that for many children with developmental disabilities actually performing the skills was the only way to learn them, and the schools were not providing those community opportunities.

- ✓ **Educational services for children with developmental disabilities are poorly administered and coordinated with other services agencies.**

The coordination of services issue was especially troublesome in the domain of education for some states. One Council referenced an interagency agreement that held the state's department of education responsible for educational services, including residential schooling, and the state's department of health and human services responsible for "non-educational" services including respite, foster care, etc.

“ The school system's position is that they'll not provide physical therapy or occupational therapy because they are medically-related and not educationally-related....I implore lawmakers to modify the language [of the law] to prevent the districts from denying these services to students.”

—Michigan parent

✓ There are tensions between educators and parents.

“ Schools have learned to use the word 'appropriate' to deny opportunities.”

—New Hampshire parent

The report noted that while the agreement may be sound in principle, educational services are guaranteed by federal law but state services are subject to the availability of funding. Consequently, services to children and their families remain fragmented. For example, a family that needs respite care according to the individual education plan, may not receive that care due to a lack of funding to the non-education agency.

Yet another issue raised by the State Planning Councils had to do with the quality of family participation in the development of the individualized educational plan. As one report said, "Parents object to the practice of bringing a pre-developed final IEP document to a meeting for their signature."

A sense of tension between educators and families about the educational planning and services execution was expressed by fourteen states. Some of the State Planning Councils reported that parents were pressured to accept a particular educational course as the only one appropriate. Parents were not informed about other possible options. Frequently the actual service did not meet the standards established in the plan.

A similar number of State Councils expressed serious concerns that substantial numbers of parents did not understand or participate in the individual plan process. These parents were not knowledgeable about their educational rights. For example, they did not know that they had a right to an independent evaluation. Finally, one state pointed out that the due process procedures were too complex for most parents.

State Council Reports: Recommendations

Federal:

The primary State Council recommendation targeted to the federal level in this area was to increase federal support for the education of children with disabilities, including 14 Councils which specifically recommended that the federal contribution move toward the 40 percent of average per pupil expenditures envisioned at the time P. L. 94-142 was enacted.

Federal/State:

There were no recommendations in this area.

State:

➔ **Improve professional staff preparation.**

Many State Planning Councils recommended that professional staff preparation needed improvement. Recommendations included focusing on the "regular" education teacher who, with additional training, could meet the needs of students with disabilities in his or her own classrooms.

➔ **Provide needed supports**

Approximately one-fourth of the State Councils recommended that supports and related services be provided based on the needs of individual students with developmental disabilities. Several Councils recommended the provision of "whatever is needed" for educational integration and success.

➔ **Expand placement options.**

One State Council report recommended that its state board of education require local education agencies to develop a full range of placement options for children with severe disabilities, and another recommended the adoption by local school districts of a "release time" provision for teachers to visit exemplary programs.

➔ **Make students and parents full partners in educational decisions.**

Several Council reports recommended that a variety of means be explored to improved the sometimes adversarial roles of parents and students. One state also pointed out the importance of involving the student in the educational decisions that will affect his or her opportunity for a reasonable quality of life.

V.

Employment and Income

V. Employment and Income

State Council Sports: Overview

"The term 'productivity' means—

"(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or community.

"The term 'employment activities' means such priority area activities as will increase the independence, productivity, or integration of a person with developmental disabilities in work settings.

"The term 'supported employment' means competitive work in integrated work settings—

"(A) for persons with developmental disabilities for whom competitive employment has not traditionally occurred; or

"(B) for persons for whom competitive employment has been intermittent as a result of a developmental disability, and who because of their disability need on-going support services to perform such work."

—Part A, Developmental Disabilities Assistance and Bill of Rights Act

“ I want to work for the same reason other people want to work, which is to support myself and to feel like part of the world. Why is that so hard for people to understand?”

—Maine consumer

“ One wish: to have a full time job and not be at a sheltered workshop.”

—Wisconsin consumer

Most State Councils reviewed their current employment and vocational programs systematically in the context of the goal of productivity for people with developmental disabilities. The primary focus was on "real jobs for real pay," with particular emphasis on competitive and supported employment.

As used in the Council reports and in this chapter, competitive employment means work for pay in an integrated setting. Competitive employment is what people outside the disability field would generally understand to be employment. Supported employment provides people with developmental disabilities ongoing supports so that they may be competitively employed. Competitive employment excludes working as a client in a sheltered workshop or rehabilitation setting.

In addition to programs focused directly on employment, the State Developmental Disability Planning Councils reviewed day habilitation, pre-vocational and vocational sheltered programs, and school to work transition programs. A few State Council reports addressed other types of productive activities, such as homemaking, volunteer work, and "adult activity" programs. Related discussions of preparation for productivity are summarized in the chapter on education.

Income was addressed by the Councils in relation to both income from employment and payments from income support programs. Federal programs referenced most frequently by State Councils relative to employment included Vocational Rehabilitation, Supported Employment, the Job Training and Partnership Supplemental, and the work incentives of the Social Security Administration's 1619 program, Plans for Achieving Self-Support (PASS), and Impairment Related Work Expenses (IRWE) provisions. Most reports also discussed employment and productivity in relation to state-specific developmental disabilities adult services programs and services provided by state employment security agencies.

Most of the Councils used their consumer survey data on productivity in their reports to analyze their states' current situation regarding the employment of people with developmental disabilities; fewer of the reports cited the vocational services satisfaction data.



Vision: paid jobs in the community will be available to all persons with developmental disabilities who want them.

—West Virginia report

Two emerging areas that were identified by Councils in a few states were retirement and other benefits of integrated community employment which Councils believe people with developmental disabilities require and to which they should be entitled.

Federal programs in relation to income noted in the reports included in particular the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs. Some Councils also referenced other income support programs, including Aid to Families with Dependent Children (AFDC) and the Food Stamp program. The primary state program in income supports found in the Council reports was State Supplementary Payments (SSP). Related information on means-tested programs, in particular the Medicaid program, is summarized in the chapters on supports, housing, and health.

Goals for employment, productivity and income were identified by a majority of State Planning Councils in their reports. They may be summarized as follows:

1. Opportunity to work in the community

The primary goal, found in nearly all the State Council reports, was that people with developmental disabilities should have the opportunity *to* be productive and, whenever possible, to work in the community. The emphasis found in many reports was that people should be in a job where they have co-workers without disabilities and where they share in the responsibility of being a productive member of their communities. Most Councils placed particular emphasis on opportunities for competitive employment. A related goal found throughout the reports was that integrated employment opportunities should be available to all people with developmental disabilities, regardless of the type of disability.

The report from the Washington Council illustrated the goals of community employment with the following vignette:

For 37 years, Jesse lived in an institution for persons with developmental disabilities. To say that getting a job in the community and making real wages for the first time in his life was a major step is to put it mildly. Today, Jesse works alongside other employees at the King County Parks Department. He is steadily increasing his productivity and wages, is entitled to full benefits, and proudly holds union membership. Today, Jesse lives with a roommate, does his own

grocery shopping with a minimum of assistance, and has recently purchased a VCR with the money he earned. For Jesse, this is the first time in his life he can claim his rights as a citizen to the best of his abilities and talents. (Washington report)



Vision: each person who wants to work, regardless of disability, should be employed at a livable wage....As technology and new skills are required in their jobs, the employees' income should increase.

—Florida report



People with developmental disabilities will require special supports if they are to participate in the economic activities of society....These supports are not unlike those required by workers without disabilities.

—New Jersey report



Vision: every person will be afforded the right to have a choice in his or her employment and have adequate information, training, and experience to make an informed choice.

—Ohio report

2. Just wages and benefits

A second goal found in the State Council reports was that people with developmental disabilities receive fair wages and have access to the same employment-related benefits as employees without disabilities. A related goal identified by some Councils was that people with developmental disabilities have increased opportunities for advancement. Some Councils also noted the goal of vacations, retirement, and the other opportunities for respite from work life that society values.

3. Supports to successful employment

Another major goal in relation to productivity reported by Councils was the availability of individual supports that enable people with developmental disabilities to enter and succeed in employment. Several State Councils pointed out the importance of a vision that recognizes the individuality of each person with a developmental disability in relation to their supports and services. Some Councils also noted that the goals of employment supports were an incremental extension of supports already being provided to workers without disabilities, such as tools and flexible scheduling.

4. Informed choices in employment

Many Councils identified goals in relation to enabling people with developmental disabilities to make full use of employment opportunities, including access to information on jobs and supports, effective preparation for employment, and opportunities to make employment choices based on their individual interests and abilities.



Vision: all people, regardless of the severity of their disability, will choose how to be productive, whether through employment, contributing to their household, or contributing to their community.

—Hawaii report



Vision: all people are entitled to an income that fosters their highest level of personal independence, enables them to maintain a satisfactory standard of living, and provides for emergencies and old age security.

—Indiana report



People with developmental disabilities should have access to income supports which are flexible enough to meet individual needs and are complementary to supports for employment and productivity.

—Georgia report

5. Alternatives for those who do not work competitively

Several State Planning Council reports included goals for opportunities to be productive for those who are not competitively employed. The focus of these goals was that adults with developmental disabilities not in competitive employment should have opportunities to engage in some form of productive activity and for rich and stimulating lives. Related goals were found in some reports regarding opportunities for leisure and retirement.

6. Sufficient income to meet basic needs

Most State Council reports identified goals in relation to adequate income levels for people with developmental disabilities, at least at a level sufficient to provide for basic needs. Related goals in some reports addressed the needs of families which include someone with a developmental disability. A few Councils also included goals of income protections for the general population.

7. Responsive government employment and income programs

The seventh goal found in the State Council reports in relation to employment and income was a cross-cutting goal that publicly supported employment and income programs be more responsive to the needs of individuals with developmental disabilities.

1. Opportunity to work in the community

State Council Reports: Accomplishments and Opportunities



People with developmental disabilities want to work.

Most Council reports discussed the desire of people with developmental disabilities to be employed. State Planning Council reports cited the Harris poll findings that two-thirds of the respondents with disabilities who were not working wanted to work. (The Harris Poll surveyed one thousand adults with disabilities in 1986.) They pointed out the proportion of the consumer survey population that see productivity as somewhat important or very important (79 percent nationally).

“ At work we are equals. That's unusual. At work they brought in a couch so that I can rest some. I have flex time. I sense that people care about me.”

—Georgia consumer

★ People with developmental disabilities are employed competitively in the private sector today!

“ The most tangible benefit is that they build quality products just like everybody else does.”

—Dave Jay, Director of Production, Physio-Control, a firm manufacturing biomedical equipment that has hired 15 workers with disabilities

“ We see this as a way to enhance our affirmative action efforts in terms of outreach to the rest of the community, to benefit from the standpoint of community relations, to be an active participant to support people, and to maybe reduce the federal, state and county support of people in this community.”

—Tim Wever, Personnel Manager in Oregon for NEC of America.

The reports noted that those people who were not employed were more dependent on insurance and government benefits. More importantly, they pointed out how important a job can be to the individual's self-esteem, as illustrated by the statements from consumers.

Several Council reports described successful initiatives to employ people with developmental disabilities through marketing efforts focused on private employers. For example, Vermont has a corporate initiative sponsored through the state's vocational rehabilitation agency. Vermont was recognized in 1986 with a national award by the J. M. Foundation for innovative work being done in the areas of adult supported employment and transition employment for students leaving school to enter the community. As of January 1989, these projects had provided 165 people with competitive employment positions through transition projects, and another 97 people were employed in other types of supported employment. Funding of vocational services was provided for people with developmental disabilities through Private Industry Councils (composed largely of private business people) established through the Jobs Training and Partnership Act in at least six communities in Arkansas.

The Job Accommodation Network, a technical assistance program established by a network of private companies, was cited by several reports as the kind of private sector initiative that made the work place accessible. This network is totally managed and operated by employers who provide technical assistance to other employers. Their advice is based upon approaches to accommodating the work place that have been used successfully by businesses.

Private employers were applauded by many State Councils for their progressive approaches to developing job opportunities for people with developmental disabilities. Examples were included in which private employers worked closely with community vocational service providers. Other states mentioned successful efforts by employers to place, train, and provide long-term supports to people with developmental disabilities on their own. Some of the nationally recognized firms mentioned included Boeing, McDonalds, IBM, and Marriott Corporation; others were smaller local or regional employers.

The changing demographics of the United States require that new pools of workers be developed. Several reports highlighted this trend as an opportunity for their states and the federal government to de-

velop new initiatives. They pointed out the need to monitor national, regional, and local economic trends in order to spot emerging employment opportunities for people with developmental disabilities.

- ★ **Opportunities for people with developmental disabilities to work are also found in the public sector.**

In October of 1987, the Governor of Colorado signed an executive order promoting state agency employment of persons with disabilities. As a result, people with disabilities have increased access to state employment. From November 1987 until April of 1989, 142 people with disabilities were hired by the State. Of these 78 were hired under the provisions of the executive order. This important source of jobs was recognized by about one-fifth of the states. In Idaho, the Human Rights Commission Act was amended to add disability as a protected basis for discrimination in employment.

- “ *I wish I had a job that pays and benefits myself and other people. I want to use what I have.*”

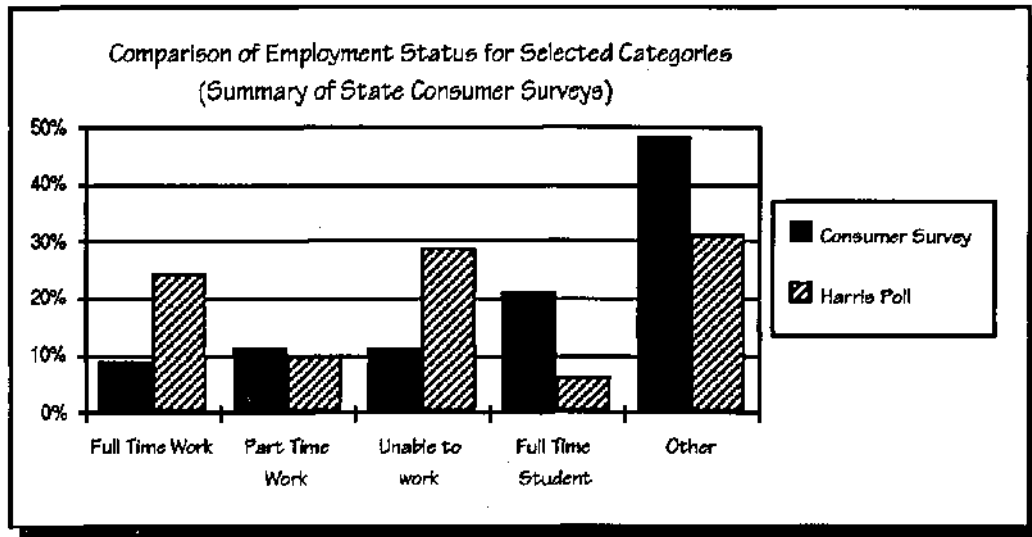
Many State Council reports cited both consumer comments and the Harris study to make the point that people with developmental disabilities want to work, but lack the opportunity to work.

—Maryland consumer

State Council Reports: Critical Issues and Barriers

- ✓ **Too few adults with developmental disabilities are working competitively.**

The major issues addressed by the State Planning Councils focused on the fact that too few adults had real employment. Some of the states compared the employment experience of those surveyed with the Harris Poll national data. The following graph presents that comparison using the summary of state consumer survey data. Based on these data even a smaller proportion of those with developmental disabilities are employed than the population of all people with disabilities sampled by the Harris Poll. These findings were bolstered by consumer comments in the forums and focus groups reported by the State Councils.



- ✓ **Adults with developmental disabilities continue to "work" in segregated day programs rather than "real jobs."**

Several State Planning Councils directly or indirectly made the point that the sheer economic power of the vocational services system was a barrier to employment in the community. States made this point in many different ways. Perhaps the single most telling example was one in the Idaho report that described how the providers' association had effectively promoted state legislation that made it illegal to fund non-association members, thus creating a virtual service monopoly.

Employment Status of Respondents Ages 16 and over (Summary of State Consumer Surveys)	
Element	Percent
Competitive	
Working FT	8%
Working PT	9%
Supported	
FT supported	2%
PT supported	2%
Sheltered	
FT sheltered	11%
PT sheltered	7%
FT student/trainee	21%
Unable to work	11%
Other*	29%
* Other includes individuals who are retired, keeping house, doing full or part-time volunteer work, or doing none of the above.	

Data from the summary of state consumer surveys illustrate the relative use of sheltered employment and training programs compared to community employment. Thirty-nine percent of those surveyed over age sixteen were in full- or part-time sheltered employment (11 percent and 7 percent, respectively) or in full-time education or training programs (21 percent). The 39 percent figure was compared to the 21 percent of those people working competitively (including those receiving supports).

Some State Councils felt that day service providers might have a vested interest in maintaining individuals in programs for which they would be reimbursed, rather than to have individuals in regular employment with reduced or no reimbursement for the service provider. Another report explained the necessity of sheltered workshops to retain the most able workers in order to reach profitable levels of productivity. Councils were concerned about waiting lists for job development and placement services by agencies such as vocational rehabilitation and the mental retardation/developmental disabilities state agency. Questions were raised as to the relative effectiveness of job development and placement services operated by public governmental and non-

profit organizations, rather than for profit agencies with a business orientation.

✓ **There is a shortage of integrated job opportunities.**

In addition to an overall lack of employment or a suffering economy in whole states or in certain sections of states, fourteen Planning Councils specifically indicated a general shortage of integrated job opportunities. Their reports mentioned several possible causes for the shortage. They saw employers as being unaware of the potential of employing people with developmental disabilities and as being fearful of the liabilities and expenses of hiring such a person. They suggested that the agencies within their states had not made the proper overtures to the private sector. Eleven State Councils specifically recognized that government had failed to take a leadership role in the hiring of people with developmental disabilities, yet they were asking the private sector to do so.

✓ **Consumers and families fear a loss of government benefits.**

“ *I have the ability to work part-time. But the amount I could earn does not make up for what I would lose.*”

—Maine consumer

Other barriers mentioned included family resistance brought on by a sense of uncertainty and insecurity. Many people with developmental disabilities and their families were reluctant to risk the loss of health and income subsidies by becoming employed. Specifically, they mentioned the loss of Medicaid, Medicare, Social Security Disability Insurance (SSDI) benefits, Supplemental Security Income (SSI), Food Stamps, and housing subsidies. As will be discussed later in this section, a lack of access to accurate and updated information about these programs is part of the reason for this resistance. Some State Councils pointed out that income needs-based programs do offer disincentives, particularly when there are waiting periods to begin receiving benefits again. Another fear identified was the potential for losing a job and ending up without any source of income or benefits.

✓ **There is a lack of support for employers.**

About one-fifth of the State Planning Councils expressed concern about direct support to employers of people with developmental disabilities. They cited the lack of employer awareness and education programs. As stated above, employers were seen as not being attuned to the employment needs of people with developmental disabilities and the potential benefit to employers of hiring them. More importantly, these states saw a need to actively support interested employers with incentive programs, such as the Targeted jobs Tax Credit. A few states referenced the untapped potential of the Small Business Administration Handicapped Assistance Loans. Yet other state reports suggested that state government needed to play a more active role.

Most of the State Councils referenced specifically or generally the failure to support employers to make necessary job accommodations. They noted that since many of these accommodations are not resource intensive, they can be done by employers at little expense. A few states mentioned the Job Accommodation Network, an employer to employer effort, as an example of useful information for employers. Employers were also seen as needing technical assistance when it came to redesigning jobs so that they could be done by people with developmental disabilities.

✓ **People with disabilities are discriminated against in employment.**

Fourteen Developmental Disabilities Planning Councils explicitly mentioned employer and community prejudice as a barrier to integrated employment. While some reports approached prejudice and discrimination as a product of ignorance that could be remedied through education and awareness, other states tended to see prejudice as the cause of ignorance.

✓ **People with developmental disabilities living in institutions and segregated communities lack access to integrated jobs.**

Four Councils directly referenced institutional living as a barrier to productive activities, especially integrated employment. As stated in the Minnesota report, "Employment opportunities often fall apart because there is no housing." Institutional routines often conflict with the demands of work hours. Some Councils noted that many of the discriminatory stereotypes were reinforced when the employer and co-workers learn that the person with a developmental disability lived in an institutional facility. Other states made the case for transportation and other supports that link individuals' residential and work lives.

State Council Reports: Recommendations

In some cases State Planning Council recommendations were sufficiently general that they could be applied at both a federal and state level. For example, one State Council report recommended that insurance regulations be revised so that they do not pose a disincentive to hiring people with developmental disabilities. Some Councils advocated federal leadership to involve the nation's businesses in solving the unemployment problem for people with disabilities which in turn would reinforce state efforts. The final theme of this chapter addresses these recommendations in more detail.

- ➔ **Pass the Americans With Disabilities Act.**
- ➔ **Expand work incentives in federal assistance programs.**

Federal:

Recommendations made by State Councils in their reports focused on removing discrimination and continuing to reduce disincentives to employment in various federal assistance programs commonly used by people with developmental disabilities. Twenty-one Council reports specifically recommended actions to support passage of the Americans With Disabilities Act that has passed the Senate and was before the House of Representatives at the time the reports were submitted. Several states recommended extension of work incentive provisions of the Supplementary Security Income program to the Social Security Disability Insurance program. Others recommended adjusting the Medicaid and Medicare programs to remove employment disincentives. One Council suggested that Social Security payment levels do not create an incentive for people with developmental disabilities to work.

Federal/State:

There were no recommendations targeted to this area.

State:

- ➔ **States should take a leadership role in employment of people with developmental disabilities.**

A total of ten State Councils recommended that state government should engage in affirmative action programs to hire people with developmental disabilities. The implied rationale for this recommendation was that if the state government was to promote employment of people with developmental disabilities, it had to lead by example. The Idaho and Michigan Council reports contained specific legislative recommendations related to rights protection and affirmative action. One report suggested that five percent of all state government contracts should be set aside for businesses run by people with disabilities.

Four State Council reports recommended that small business development efforts be undertaken with a special emphasis on ownership by, and employment of, people with disabilities. These economic development efforts were seen as critical, especially in depressed areas of the country.

➔ **State executives should promote private sector leadership.**

“*Transfer the ownership of the "problem" of unemployment from the disability service system to employers....*”

—Georgia report

The major Council recommendations for states in creating work opportunities generally had to do with the executive branch taking a strong role in promoting full employment for people with developmental disabilities. Councils called upon their state executive branches to create special initiatives around employment of people with developmental disabilities. Others recommended that their legislatures create incentives such as favorable tax treatment for those businesses that employ people with developmental disabilities. Most of these recommendations focused on the business community playing a major leadership role. Councils in three states went so far as to suggest that the whole supported employment /vocational services system might be contracted to the private sector.

➔ **Conduct public and employer awareness campaigns.**

By far the most popular Council recommendation in this section had to do with public awareness and promotional campaigns conducted by states, and aimed at employers and the general public who make up the labor force. Some state reports recommended forming employer and consumer groups to promote the employment agenda for people with developmental disabilities. One state report called for a "private-public partnership." It was seen as critical that employers hear the success stories of employers and employees with disabilities.

Similar public awareness and education efforts were recommended to be directed toward people with developmental disabilities and their families. These programs would address the issues of the risks and benefits of competitive employment, with or without supports. The section on making informed choices will present other related recommendations.

➔ **Provide training, technical assistance, and support to employers.**

The State Council reports recognized that employers would have to take extra steps in order to ensure that their employees with disabilities are as productive as possible. State government was seen as assisting employers with training and technical assistance as well as other incentives such as tax credits for hiring people with disabilities and making job modifications and special accommodations. One state recommended that employers be assisted in gradually assuming the responsibility of providing the full range of supports required by their employees with developmental disabilities.

One general recommendation made in three State Council reports called for an ongoing analysis of the labor market, particularly with regard to emerging opportunities for people with developmental disabilities.

- ➔ **Convert traditional day activity and sheltered workshop programs to competitive employment support programs.**

“*We would like to someday see the complete phase-out of our sheltered workshop—even people with severe or profound mental retardation can be served in more normalized environments.*”

—Ohio parent

While only three State Councils specifically recommended converting current programs to competitive employment programs with supports, it was evident that many other Councils had already made this assumption as a part of their analysis. One recommendation was a moratorium on the construction of new sheltered work facilities. State Councils recommended that incentives be made available to providers that converted to supported employment; however, the report writers gave no indication as to what these incentives might be or how they would work. One state suggested that disincentives be set up for providers that persist in providing segregated employment and pseudo-employment for people with developmental disabilities.

2. Just wages and benefits

State Council Reports: Accomplishments and Opportunities

- ★ **Some private employers provide just wages and benefits.**

Several State Developmental Disabilities Planning Councils mentioned examples, generally as a result of the Rehabilitation Services Administration system change grants, of individuals with very severe disabilities working side-by-side with nondisabled workers in factories, office buildings, commercial businesses, and other employment settings for significant wages. Several states suggested that projects that have the strong involvement of private employers, who directly hire the person with a developmental disability, are likely to pay wages at or above the minimum level. For example, private employers such as McDonalds, IBM, Marriott Corporation, and the Woodward & Lothrop department stores, have developed their own programs through which people with developmental disabilities become direct employees of the company and receive commensurate pay and benefits with other employees.

State Council Reports: Critical Issues and Barriers

- ✓ **People with developmental disabilities do not receive fair wages.**

State Developmental Disability Council reports relied heavily on their consumer survey data to analyze the earnings of the people with developmental disabilities that they surveyed. Eighteen states explicitly identified low earnings as a major impediment to an employment initiative. Data from the summary of state surveys indicated that few people with developmental disabilities are making a reasonable wage.

**Hourly Wage Study of those People Aged 16
And Over Working Full Or Part-time
(Summary of State Consumer Surveys)**

- 25% made 49¢ per hour or less
- 50% made \$1.28 per hour or less
- 75% made minimum wage (\$3.30) or less
- 96% made less than the 1987 US average wage of \$9.

Hourly Pay

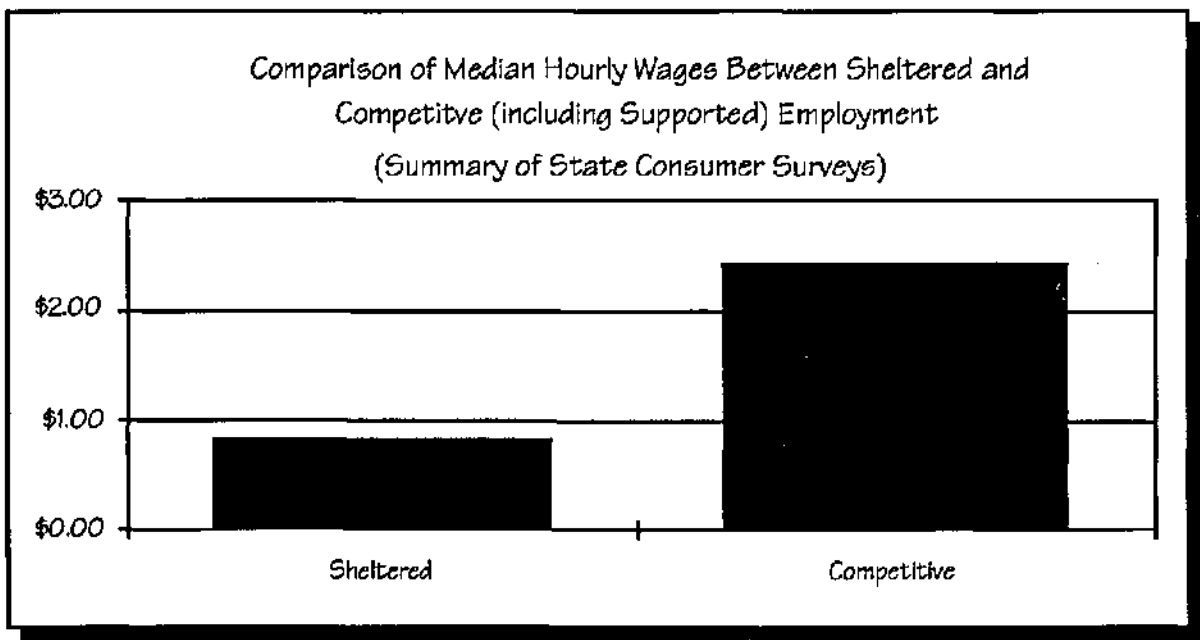
Mean	\$2.52
Median	\$1.25
Minimum	\$.01
Maximum	\$99.83

Consumers complained about extremely low wages being paid by vocational program providers, especially in sheltered workshops. An analysis of the summary of state consumer surveys verified these consumer concerns. Earnings were more than twice as high in competitive (with and without supports) employment programs than in sheltered programs.

In addition to low pay, consumers and State Council reports raised the lack of benefits as an issue, five states explicitly, others by reference. The Councils saw people with developmental disabilities as receiving no or different levels of benefits than those employees without disabilities. They reported that this is more true for people who are technically employed by vocational service providers, while those individuals who are directly employed in the private sector are more likely to share in the benefits received by other employees.

“ Keith's biggest concern is that a lot of time at the rehab center he is not working, but just sitting. He said he could do that at home too. His last check was only \$5.43 for two weeks. Once his check was \$.02.”

—Wisconsin parent



Another critical issue raised in four of the State Council reports was the use of earnings to offset other subsidies. For example, if one person in a group home works and another does not, they may

still end up with the same amount of spendable income. While the state reports commended the SSI Section 1619 provisions, there were concerns that these provisions do not apply to other programs, especially Social Security Disability Insurance and state operated programs. A few State Councils noted that people living in Medicaid supported facilities or participating in the Medicaid Home and Community Based (HCB) waiver program had little incentive to work competitively because earnings above their personal needs allowance would have to be used to reimburse the Medicaid program.

State Council Reports: Recommendations

Federal:

- ➔ **Revise federal wage policies so that people with developmental disabilities receive a just wage.**

A few State Planning Councils suggested that people with disabilities no longer be subject to exemption under the Fair Labor Standards (Sec. 14(c)). Instead, they recommended that employers be subsidized for lost productivity,

- ➔ **Revise federal programs to ensure that people with developmental disabilities are not adversely affected by working.**

To address the issue of replacing a program benefit with earned income, several State Council reports recommended that federal programs should be amended to protect earned income. The Supplemental Security Income program was mentioned as a potential model. Specifically noted programs included: Social Security Disability Insurance, Medicaid, Medicare, HUD housing subsidies, and food stamps.

- ➔ **Equal benefits should be required for all employees without regard to disability status.**

A few State Councils that were concerned with the unequal treatment of people with developmental disabilities recommended that the nation's employers be required to provide equal health and medical benefits to all employees, including those with developmental disabilities.

Federal/State:

There were no recommendations in this area.

State:

- ➔ **Revamp vocational placement philosophy and procedures.**

Several State Council reports faulted the placement practices of those people responsible for making vocational placement decisions. Decisions to place an individual in a sheltered workshop, where earnings might be less than one dollar per hour, as opposed to a supported competitive work situation where the individual could earn the minimum wage, were questioned. Some State Councils recommended that

this process be revamped based upon business rather than human service principles.

- ➔ **Provide interim health insurance coverage until employee eligibility requirements are met.**

Recognizing that there is often a gap between beginning a job and becoming eligible for health insurance benefits, one Council recommended that state government should provide this interim insurance coverage.

3. Supports to successful employment

State Council Reports: Accomplishments and Opportunities

- “ *Supported employment is a must. We spend a lifetime building up our children's self esteem, telling them they can do things, and when they graduate, it's as if the rug is pulled out from under them.*”

—Arkansas parent

State Developmental Disability Council reports almost universally saw competitive employment with supports as the means by which people with developmental disabilities could become productive contributing members of their communities. Without these supports they would continue to be hidden away in segregated day programs with little chance of improving their quality of life. As described above, the benefits of supported competitive employment are slowly beginning to be recognized.

- ★ **The Supplemental Security Income program 1619 work incentives**

Many State Councils pointed to the recent inclusion of work incentives in the SSI program. A few pointed out the January 1990 increases in the amount of the substantial gainful activity allowance from \$300 to \$500 per month. State Councils described the various supported employment initiatives that were going on in their state. They noted that these programs provide an important income support that makes starting out in a real work situation a more viable option for people with developmental disabilities, particularly those who have unusual expenses or whose disability limits their ability to earn large amounts of money.

- ★ **The Office of Special Education and Rehabilitation Services supported employment system change projects**

Several Councils commended the federal Rehabilitation Services Administration for its systems change grants, which were seen as important in the progress toward the goal of productivity in their state. They pointed out that these programs brought a focus to the issues and created a forum for discussion as well as a variety of innovative programs around the development and maintenance of supports.

State Council Reports: Critical Issues and Barriers

- ✓ **Supports are unavailable.**

By far the most important issue (specifically cited in twenty-three State Planning Council reports) was that needed supports are unavailable or poorly coordinated. The most frequently mentioned support was transportation to and from work, an issue for all

employees, regardless of disability. Other specific supports were personal care attendants and adaptive devices and equipment; related issues of availability are discussed in the chapters on supports and education.

In their discussions of supports to employment, most State Planning Councils assumed that a job coach would be present, but several states suggested options to having a job coach present on the job site (e.g., co-workers who act as job coaches). Other individuals might simply need work site modifications. The summary of state consumer survey results for those between the ages of 18 and 64 suggest that 11 percent and 16 percent require work site modifications and on-site aides, respectively, in order to work.

One report defined supports as "whatever it takes" to place and maintain people with developmental disabilities in competitive employment. Several Council reports raised the concern of a lack of flexibility when it came to providing supports. They noted that supported employment must be based upon a comprehensive plan of supports that considers the needs of the individual, the employer, and the requirements of the job. As described by the California Council, "More attention must be focused on employment goals....Flexibility and comprehensive service planning are key factors." (California report)

- ✓ **People are excluded from employment because supports are too expensive or because they are unable to work 20 hours per week.**

Two State Councils pointed out that the supports required by a few individuals are both extensive and expensive, and that some of these individuals are being excluded, on the grounds that their support needs are too great. Several Councils also questioned federal funding requirements that limit supported employment eligibility to those who can work at least 20 hours per week. Such policies were seen by Councils as directly contrary to the supported employment philosophy, that competitive employment be available to those with the most severe disabilities.

- ✓ **Certain disability groups are excluded from supports.**

Fifteen State Council Reports specifically raised the issue of the exclusion of certain groups of people from supported employment based upon the nature of their disability, primarily people who have developmental disabilities other than mental retardation. More particularly, the Council reports highlighted limited access to supported employment for those with physical disabilities, chronic behavior problems, chronic mental illness, multiple disabilities (e.g., dual diagnosis), and autism. Several Councils noted that this problem seemed to be entwined with

the issue of the agency that was designated to pay for or provide the long-term supports; those people who lacked an agency affiliation seemed to be less likely to receive supports or to have access to supported employment initiatives.

- ✓ **The conversion from traditional day programs to supported employment poses serious difficulties.**

Although supported employment was seen by most State Planning Councils as the key to employment of people with developmental disabilities, the nuts and bolts of moving from a segregated, sheltered system of employment to integrated competitive employment with supports was found to pose major challenges to policymakers, providers, employers, consumers, families, and advocates. Several State Council reports recognized the inherent difficulties in moving a day service system that has as a major part of its mission the protection of its client population, to turn around and place them in the competitive labor market. The reports pointed out that there is no economic incentive for service providers to lose their clients to the labor force.

- ✓ **There are serious concerns about the quality of supported employment programs.**

Six State Council reports indicated that there were serious quality issues in the provision of supported employment in their states; twelve states questioned the qualifications and performance of the staff of agencies providing supported employment. A few reports related poor performance to low rates of compensation for direct service staff in supported employment. Other reports saw the problem as being the result of a lack of sound management practices including recruitment, training, supervision, quality assurance, information systems, remuneration packages, etc. State Council reports also indicated that the problem might be caused by a lack of a clear policy direction on the part of government agencies.

- ✓ **Funding for supports is inadequate and inequitable.**

Virtually all of the State Planning Council reports recognized that a shortage of fiscal resources was in part responsible for the lack of employment supports. They pointed out that the responsibility for funding long-term supports fell largely on state mental health and developmental disabilities agencies. Lack of fiscal resources resulted in long waiting lists and the exclusion of particular disability groups.

- ✓ **Funding of vocational rehabilitation programs is inadequate.**

Several State Councils noted that vocational rehabilitation (VR) services are inadequate and not fully funded (i.e., matched) in some states. It was noted by several Councils that supported employment services represent a small proportion of the total VR program. They also pointed out the systemic failure

of vocational rehabilitation to reach people with developmental disabilities, with individuals often denied service because they "would not reasonably benefit from rehabilitation."

- ✓ **Medicaid regulations are too restrictive regarding personal care attendants.**

The funding of personal care attendants through Medicaid was found to be problematic when the individual is engaged in supported employment. Several State Councils pointed out that while the Medicaid program was willing to fund a personal care attendant if the individual did nothing productive, it was not willing to continue that support if the person attempted to work.

- ✓ **People who live in rural areas are less well served than those who live in urban areas.**

Several State Councils, particularly those with large rural populations, raised the issue of the disparity in services and supports between the urban centers and the rural areas of their states. They noted that other supports essential to employment in the private sector are frequently not available or inappropriately targeted.

State Council Reports: Recommendations

Twenty-two State Developmental Disabilities Planning Council reports, the largest number in the employment area, recommended that additional funding be allocated to the provision of supports. Most reports were not specific as to the source of this funding.

Federal:

- ➔ **The programs of the Rehabilitation Services Administration should be reformed to better provide supported employment.**

Several State Councils recommended reforms of the programs administered by the federal Rehabilitation Services Administration (RSA) to better serve people with developmental disabilities, such as establishing a priority for serving people with developmental disabilities and holding state agencies accountable for achieving employment outcomes for these people through the RSA reporting system. Others suggested that the removal of time limitations on VR assistance for supported employment would enable individuals who were currently unserved to be served. Another recommendation was to lift supported employment eligibility restrictions for people unable to work a minimum of 20 hours per week. Five State Councils recommended that the Rehabilitation Services Administration be required to report its success with people with developmental disabilities. One recommended that the vocational rehabilitation system's Client Assistance Program should be required to report on the reasons that clients refuse services or fail to cooperate.

➔ **Medicaid regulations should be revised to support competitive employment.**

Several Council reports called for revision of federal Medicaid regulations to be more supportive of people with developmental disabilities working competitively. They were particularly concerned that provision be made for paying for personal care attendants while people who require them are working.

Federal/State:

The State Councils that made recommendations regarding the change in the Medicaid and vocational rehabilitation programs saw those changes as a first step to actions at the state level to secure similar changes in their state programs.

State:

➔ **Fund supports to the levels required to achieve fairness.**

Several State Planning Councils recommended that funding for long- and short-term employment supports be increased at the state level. A few states, recognizing the fiscal realities of state budgets, made specific recommendations as to how to reallocate funds. The most popular of these recommendations was to transfer funding from segregated day and vocational programs to the provision of supports. One State Council report suggested that the state contract with the private sector rather than the traditional service agencies. Another report suggested that workers with developmental disabilities be given vouchers to purchase their own supports. Another report recommended that employers be assisted to gradually assume the responsibility for providing long-term supports.

Many Councils were specifically concerned about transportation support and personal care attendants. They indicate that these supports tended to be expensive to provide but were absolutely essential for some individuals.

One Council recommendation was to view enclaves and crew models (specific forms of supported employment that tend not to be integrated) as traditional sheltered programs, with resources for those models moved to supported employment.

➔ **Provide supported employment to individuals with developmental disabilities who are currently unserved.**

Several State Councils recommended that supported employment in their state be extended to those people with developmental disabilities other than mental retardation. Specifically, they recommended inclusion of those with severe physical disabilities, chronic mental illness, multiple disabilities, and autism. One state recommended special efforts to include immigrants, refugees, and members of minority groups.

➔ **People in supported employment should have comprehensive individual service plans focused on employment goals.**

In raising the issue of a lack of coordination, a few Councils saw the answer in the development and maintenance of a comprehensive vocational plan that had a goal of competitive employment. One Council suggested that such a plan would consider all possible sources of support and would be designed to maximize the person's independence. The employer would play a key role as would other significant individuals in the person's life such as roommates or residential service providers. The same report recommended that mechanisms would have to be established to allow joint responsibility for administering services to individuals.

➔ **Quality assurance and accountability must be established.**

A reading of the issues raised and recommendations made in most State Council reports indicated that, for most states, the promises of supported employment were accepted, but they were not being met by the service delivery system. A few saw a lack of quality assurance and accountability systems as a cause of the problem. These reports recommended that the relevant state agencies strengthen or establish clear systems of accountability. As a part of these systems they recommended management information systems that would identify people with developmental disabilities and report employment outcomes (e.g., hours worked, dollars earned, interactions with people without disabilities) and supports provided.

➔ **Improve the capacity of all personnel.**

A second type of recommendation to improve the quality of supported employment services was to improve the capacity of the people providing support services. Approximately fifteen State Councils made recommendations in this area. Proposals ranged from improving staff recruitment procedures to supervisory and management skills. Most recommendations were for a much higher level of training and technical assistance based upon clear values and a competitive employment goal. A few State Councils felt that salary and benefit packages should be improved.

4. Informed choices in employment

State Council Reports: Accomplishments and Opportunities

“**After I graduate, I want to be the first mentally retarded astronaut. If I can't do that...I think I'll be a professional skateboarder!”**

—Washington consumer

Several transition programs, continuing education programs, vocational counseling and family support initiatives around career development for people with developmental disabilities were described in the State Council reports.

The New Hampshire Developmental Disabilities Council reported that the New Hampshire Jobs Training Council (state Jobs Training and Partnership Act agency), that led the nation in participation of people with disabilities, has been involved in the development of a number of supported employment projects. It has played an important role in new careers development for people with developmental disabilities.

State Council Reports: Critical Issues and Barriers

✓ **Individuals have little or no control over career choices.**

“*My son is employed as a 'retail clerk'; that means he is a stock boy. Is he to be locked into this job for the rest of his life?'*”

—New York parent

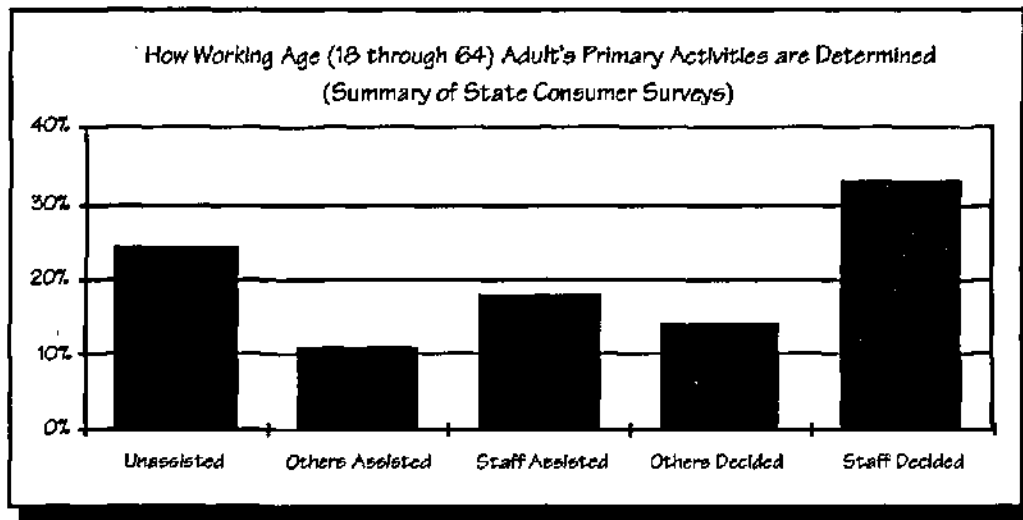
Several State Councils raised as a critical issue the transition from the educational system to the adult service system as a barrier to employment, particularly for those who require supported employment services. Some Councils noted that adult services and supports to employment are not an entitlement, in contrast to educational services under P.L. 94-142. (Only one report—California—indicated that there is an entitlement to adult services in the state.) Several State Councils pointed out that many people with developmental disabilities who reach the upper age limit of their state's public school entitlement find themselves suddenly with no service system.

A continuing theme in the education sections of the State Council reports was the weakness or lack of employment preparation and experiences for young people between the ages of about 12 and 21. The summary of state consumer survey data supports this contention in that fully 26 percent of all respondents to the consumer survey said they needed vocational education and even higher percentages of 27 percent and 33 percent saw the need for employment and vocational training, respectively. This weakness is reflected in the vocational sections of state reports as well.

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. (Virginia report)

As illustrated by the above quotation from the Virginia report, many Councils pointed to the need for "career planning" rather than one-time job placement. These states saw a lack of career planning services for people with developmental disabilities that looked at their job needs and desires over the long haul. Frequently, State Councils used the con-

sumer survey to point out the small percentage of people that had control over choosing their occupation and the narrow range of occupations in which people were employed. They said that too often staff of agencies decided what job people with developmental disabilities had. This concern was confirmed in the state consumer survey summary. Nearly one-half of the working age consumers had no control over their career or day activities. Less than one-fourth made the decisions without assistance as to how they spend their day.



✓ **People with developmental disabilities have very few real job options.**

Several State Planning Council reports raised concerns about the limited job options open to people with developmental disabilities. Specific issues identified in the reports included the following:

- Sheltered workshops are the only options available for many individuals with developmental disabilities. People are locked into the jobs available through the program.
- Crew or enclave models limit opportunities similar to sheltered workshops.
- Sheltered employment provides little or no opportunity for upward mobility.
- Some supported employment situations have limited opportunities for upward or lateral mobility.

Most of the Councils indicated that it is only when people with developmental disabilities have access to the labor markets that they have meaningful job options.

- ✓ **Little information is directly available to people with developmental disabilities and their families.**

A few Planning Councils found that vocational programs are slow to take advantage of new career and job opportunities in the community. They questioned the ability of these service providers to find and develop new jobs with community employers.

Several State Council reports indicated that there is very little accurate and comprehensive information directly available to people with developmental disabilities and their families about the full range of options that might be available. They pointed out that new adaptive devices and technology come onto the market all the time, including new approaches to supported employment (e.g., co-worker support in private sector placements). These Councils noted that this information, while presumably available to professionals, rarely gets directly to the consumer. Some suggested that this lack of information maintains the person with a developmental disability in a subservient role to the service provider.

- ✓ **People with more ability are held back in sheltered programs.**

One Council pointed out a common practice in sheltered programs of not placing out the more talented workers because high output, productive workers are retained to offset those who are slower. This state's report pointed out that, while this practice is logical from a provider view, it is totally illogical from an employee point of view, as the person who has developed vocational skills is denied the opportunity to put them to use in the real world of work.

State Council Reports: Recommendations

- ➔ **People with developmental disabilities should make their own employment choices.**

Several Developmental Disabilities Planning Councils made the fundamental recommendation that no person should be compelled to work at a job not of his or her own choosing; people who have no choice as to their job and who receive very little pay are in peonage. The recommendations that the states proposed under this theme generally focused on ensuring the civil rights of people with developmental disabilities, a fundamental value that ran through the recommendations directed at all levels of government. As recommended by the Washington Council, "No individual should be forced to accept an inappropriate or undesired employment position. Choice should be an inherent part of the employment assessment process." (Washington report)

Federal:

There were no specific federal recommendations.

Federal/State:

There were no specific federal/state recommendations.

State:

- ➔ **Strengthen vocational programs in the schools and prepare young people with developmental disabilities for choosing a career path.**

Several State Councils recommended the establishment of transition planning in the educational system beginning at age 14 or younger for children with developmental disabilities (not all children in special education). They recommended that these transitional vocational programs and services expose the young person to real work settings in the community, and that apprenticeship programs and other community experience programs that expose students to "real" jobs should be promoted. Reports noted that while the educational system may take career planning skills and the actual development of a career plan for granted with some students, young people with developmental disabilities require support and education. Generally, they have fewer options and, by definition, require more assistance than others in society; therefore, the State Council reports recommended that schools strengthen their vocational programs so that they produce jobs for students with developmental disabilities.

- ➔ **Reform existing adult vocational service systems to focus on placements in integrated community jobs.**

Several State Council reports placed a part of the responsibility for poor information and guidance with the current day service system that is dominated by rehabilitation and sheltered employment services. One state recommended the abolishment of sheltered and work activity practices, while another recommended studying their placement policies before making such a decision.

- ➔ **Empower consumers and families to control their own career options.**

In this area by far the strongest recommendation by Councils was to provide education and information to consumers and their families about career opportunities, accommodation strategies for job sites, adaptive equipment and devices, etc. They recommended that families and consumers should learn to assess their own skills, recognize quality employment services, and advocate for themselves.

5. Alternatives for those who do not work competitively

State Council Reports: Accomplishments and Opportunities

None of the reports contained examples of accomplishments in this area.

State Council Reports: Critical Issues and Barriers

✓ **People with developmental disabilities need to be able to take real vacations and retire.**

“*Do you really think I like going to that summer camp for the disabled? I'm 40 years old! Hell, if I had the money...I'd go to Hawaii like everyone else.*”

—Washington consumer

✓ **There is a minority position to maintain traditional day programs for some individuals.**

Several State Planning Councils recognized that people do not work all the time and should not be in a "program" all the time. If people with developmental disabilities are to be independent and integrated, as well as productive, these Councils were concerned that the opportunities for leisure, recreational, spiritual, etc., activities must be provided. A few Councils noted, however, that when they are treated as "services" or "programs" they no longer qualify as "non-work" activities. One report pointed out that adults who work (whether in sheltered or competitive employment) do so only part time (about 25 hours per week according to their consumer survey). Other Councils reported that many people simply spend the rest of their day sitting. The New York report stated, "People living in community residences are aging out and want to retire, but there is no money to retire on because of the low wages they have received working in sheltered workshops."

Eight State Councils raised concerns about the availability of or funding for pre-vocational, sheltered, and other adult activity programs. Two of these reports stated that there would be a group of people who could not benefit from supported or competitive employment. Another raised concerns about the status of those individuals who might lose their job: Where would they go? What would they do? One Council was concerned with the content of these day programs.

State Council Reports: Recommendations

Federal:

There were no federal recommendations.

Federal/State:

There were no federal/state recommendations.

State:

→ **Develop retirement and leisure time options.**

The Indiana report contained the following recommendation: "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 [integrated] environments." Other states simply indicated that options for retirement and leisure time activities need to be developed.

→ **Strengthen traditional day services.**

Eight State Councils recommended that traditional "adult day programs" be strengthened or expanded. These recommendations were in conflict with the much larger number of Councils that recommended elimination of these programs in favor of programs and supports oriented toward competitive employment.

6. Sufficient income to meet basic needs

State Council Reports: Accomplishments and Opportunities

There were no State Council reports that had positive examples of state operated income guarantee or other subsidy programs independent of the Social Security programs of Supplemental Security Income and Social Security Disability Insurance. Many states did, however, mention these federal programs as positive attempts to meet people's basic need. Frequently mentioned were the work incentive provisions discussed above. The Iowa Council made the following observation:

About two of every three consumers surveyed use SSI assistance, making this one of the most highly utilized programs studied in this report. Consumers comment that the program has helped them to be more independent, to learn to handle money and follow a budget, and to locate resources which help with integration into the community. (Iowa report)

Satisfaction with Financial Assistance Programs (Summary of State Consumer Surveys)		
Program	% Receiving	% Dissatisfied
AFDC	10%	31%
SSI	59%	16%
SSDI	22%	14%

The summary of state consumer surveys indicated that a relatively high percentage of people used and were satisfied with the Supplemental Security Income program. The sixteen percent dissatisfaction rating was roughly equivalent to that of the Social Security Disability Insurance program, which was used by 22 percent of those surveyed. For comparison, 10 percent of the respondents received Aid to Families with Dependent Children, but nearly one-third of them were dissatisfied.

State Council Reports: Critical Issues and Barriers

Twenty-nine State Planning Councils raised issues on income. Many of these focused on the work incentive provisions of SSI and SSDI.

✓ **Adults with disabilities are poor.**

Several State Councils pointed out that Americans with disabilities are twice as likely to be poor as their non-disabled counterparts. States pointed out that even with Supplemental Security Income and state supplement payments, people with disabilities still fall below the poverty level. As the Idaho Council noted:

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. (Idaho report)

✓ **SSDI benefits are too low.**

Five State Planning Councils were concerned that 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, according to these states. Most of these also noted that the SSI payment levels were well below the federal poverty level.

✓ **State supplements to SSI are too low.**

Councils reported that the state supplement portions of the Supplemental Security Income program ranged from three states that provided none, to California, in which the supplementary state payment (SSP) of \$364 was higher than the federal SSI payment of \$238 per month at the time of the report. The California report, however, pointed out that because of the higher costs of living in that state, it was very difficult to survive in the community. Louisiana, at the other extreme, had a supplementary state payment of \$12.65. The vast majority of those Councils addressing income needs in their reports felt that these amounts were too low to provide for the basic needs of individuals.

✓ **People with developmental disabilities and their families are not treated with respect when they apply for income support.**

A few State Councils, based upon consumer and family comments and the high percentage of dissatisfaction with the AFDC program reported in state consumer surveys, were concerned about the lack of respect shown AFDC recipients in local welfare offices.

✓ **Provisions of federal and state assistance programs continue to be disincentives to employment.**

Several State Planning Councils pointed out that the low amounts of money that one could earn and still be eligible for SSI and SSDI benefits posed problems for many individuals. Referred to as income from "substantial gainful activity" or "SGA," these levels were at \$300 when the reports were prepared. Subsequently, the SGA level has been raised to \$500. Limits on inheritances or family support (e.g., through a trust fund), or other "unearned" income, were reported to pose difficulties for some people with developmental disabilities and their families.

Many Councils highlighted Section 1619(a) of the Supplemental Security Income program which provides additional benefits on a sliding scale for those people who have limited earned income, and Section 1619 (b), which protects their Medicaid benefits when their income exceeds the levels to entitle them to financial assistance. Several State Councils pointed out that these provisions do not extend to the Social Security Disability Insurance program.

✓ **The work incentive provisions of the SSI program (1619 a and b) are underutilized.**

In reviewing the data from the Social Security Administration on state participation in the section 1619(a) and 1619(b) provisions, several State Councils pointed out the low participation rates in the program in their respective states.

✓ **There is a lack of awareness about the work incentive provisions of the Social Security Act.**

A few Councils mentioned specifically that people with developmental disabilities, their families, and care providers were not receiving information and education on the 1619(a) and (b) provisions in the Supplemental Security Income program. They saw this as part of the reason behind the low participation rates.

✓ **AFDC benefits are inadequate.**

Nine State Councils pointed out that AFDC benefits are inadequate to meet basic living needs, and that further, the benefits have failed to keep pace with inflation. The Louisiana Council pointed out that a family of three would receive between \$174 and \$190 in rural and urban parishes, respectively, compared to the national median of \$360. Massachusetts noted that the entire AFDC grant would equal the cost of a two-bedroom apartment.

- ✓ **Income assistance and subsidy programs contain disincentives for people with developmental disabilities.**

Several Council reports pointed out that programs such as Medicaid, Section 8 Housing, Food Stamps, and AFDC have provisions that make it difficult if not impossible for parents to provide for the long-term welfare of their children through gifts (e.g., property) and trusts, because earned and unearned income and assets affect initial eligibility and the ability to maintain eligibility for means tested programs that put people with developmental disabilities at risk. The reports pointed out that if the limitation on assets does not disqualify the individual, then the income from the trust fund will. Families therefore lack incentives for planning for the future of their members with developmental disabilities.

A few Councils noted that while the SSI program has provisions for earned income, other programs do not. State reports complained that earned income often simply offsets a subsidy, providing no incentive for working.

- ✓ **There is a marriage penalty in the SSI program.**

A few Planning Councils pointed out that if two people with developmental disabilities get married, they will suffer a significant penalty in loss of benefits. The summary of state consumer surveys data show that 89 percent of all adults surveyed were never married.

State Council Reports: Recommendations

Federal:

- ➔ **Increase the federal benefit levels for the SSI, SSDI, and AFDC programs.**
- ➔ **Revise the regulations to the SSI and SSDI programs.**

Virtually all of the State Planning Council reports that addressed the income issue recommended that benefits be raised to at least the poverty level. Councils frequently combined their recommendation for state and federal levels of government.

Five State Councils recommended that the regulations in the SSI program be revised to eliminate the disincentive to marriage. Another Council recommended reduction of SSI program eligibility restrictions on ownership of property. About one-third of the Councils recommended support for the development of work incentives in the SSDI program similar to the 1619 component of the SSI program. Another recommendation in this area, made by thirteen Councils, was to raise SGA levels in both the SSI and SSDI programs to the same level as for SSDI recipients with blindness. A few Councils also suggested the need for a new approach to eligibility determination for income support programs for people with disabilities that would be more complementary to employment. The Connecticut report, for example, contained the following recommendation:

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. (Connecticut report)

A unique recommendation from Guam Council was to petition Congress to extend Supplemental Security Income (SSI) to Guam for individuals with developmental disabilities.

Other Council recommendations included:

- Simplification of SSI application procedures
- Reduction of the waiting period between loss of SSI benefits and reapplication
- Permit children with developmental disabilities to receive SSI benefits regardless of their parents' income while living at home

➔ **Remove disincentives from other federal assistance programs.**

Other federal assistance programs need to be reviewed to eliminate disincentives to employment by people with developmental disabilities, according to several State Councils. For the most part, state reports did not recommend specific technical changes to individual programs.

Federal/State:

There were no recommendations in this area.

State:

➔ **Increase the funding levels of the state supplemental payments.**

The most frequent recommendation put forward by the State Planning Councils was to increase the state supplemental payment to SSI to bring the combined level up to the poverty level. A few states (e.g., California) suggested that these benefit levels needed to be even higher to reflect the high cost of living in their state.

Other State Council recommendations included:

- Simplify application procedures for state assistance

- Provide training to professionals on income assistance programs
- Provide information and training to attorneys and families on long term financial management and planning

7, Responsive government employment and income programs

State Council Reports: Accomplishments and Opportunities

The Connecticut Council described a unified state employment and training initiative, focusing on a "Job Center" concept. This initiative created the Connecticut Employment and Training Commission to develop and recommend to the governor a comprehensive plan for human resource development. This initiative is an example of what one state has done to address the lack of responsiveness of government systems to the employment needs of individuals with developmental disabilities. Other states, particularly among those that participated in the Office of Special Education and Rehabilitation Service's systems change grant program (26 states), shared similar accomplishments in inter-agency coordination and cooperation.



Agencies combine funds to serve people with developmental disabilities.

The Washington State report described such an effort as follows:

Agencies and organizations across the state have learned they must work together if they are to provide adequate long-term employment support. Some collaborative efforts are being used or planned in Washington State. When possible, Job Training Partnership Act (JTPA) program funding is used to provide training and short-term support. This frees up funding under the Supported Employment Program to provide for other support and specialized materials. In some counties, the Supported Employment Program provides training money which then allows local funds to be targeted for long-term employment support. In some areas, the Division of Vocational Rehabilitation and the Division of Developmental Disabilities combine funding to more effectively serve people with severe disabilities. (Washington report)

A collaborative effort involving the Illinois Planning Council on Developmental Disabilities funded by a 5-year system change grant from the Federal Rehabilitation Services Administration provides supported employment to 1,600 people through 87 programs statewide. They list a broad range of partici-

paling employers including banks, department stores, factories, health care facilities, and state agencies. The average wage is \$3.52 per hour.

State Council Reports: Critical Issues and Barriers

- ✓ **Vocational rehabilitation's requirement that long-term supports be guaranteed is unrealistic and creates a barrier to employment of people with developmental disabilities.**

Twelve State Councils described the following barrier and others referred to it indirectly: vocational rehabilitation (VR) supported employment programs provide a time limited service and require that the individual can be rehabilitated. VR agencies have required that another agency (generally state mental health and mental retardation/developmental disability agencies (MR/DD)) certify or guarantee that it will maintain the supports for the individual after the fixed time period set by vocational rehabilitation. Councils noted that state MR/DD agencies often are reluctant to make such guarantees.

- ✓ **Agencies should better serve people.**

In their reports State Planning Councils frequently pointed out the need for inter-agency coordination. Some indicated that at least seven agencies could affect an individual's career decisions (education, MR/DD, vocational rehabilitation, Social Security, JTPA, state financial assistance, state medical assistance), and some states indicated even more. Each agency has different rules and regulations governing eligibility, treatment of resources and income, allowable services, etc. Several Councils felt that the multiple eligibility requirements and requirements to maintain benefits led to consumer confusion and loss of benefits for otherwise eligible individuals. Some pointed out that even professionals and advocates provided incorrect information to consumers because the rules and regulations were too complex and sometimes contradictory.

- ✓ **There is a leadership vacuum at the federal and state level regarding employment of people with developmental disabilities.**

Some State Councils felt that the economic and political influence of the traditional service provision system created a disincentive to cooperative planning and service delivery. States also described a lack of consistent policies that they attributed to a lack of clear and consistent policy goals and leadership to carry them out. The leadership vacuum further exacerbated the complexity of interlocking programs and policies.

Other issues raised by some State Councils in their reports included:

- The lack of consistent federal and statewide employment policies
- State agencies fail to share resources.

- State agencies provide inconsistent individual service plans and goals.
- There is a lack of flexibility in supported employment programs.
- Social Service Block Grant funds are restricted to day services and sheltered employment and cannot be used for supported employment.
- There is no "score keeper." There is no management information system that tells how the system is doing.
- Certain federal and state agencies tend not to serve people with developmental disabilities,

State Council Reports: Recommendations

The Minnesota report contained the following general recommendation that sums up State Council findings on employment well:

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. (Minnesota report)

Federal:

➔ **Clear federal policy leadership should be established for the employment of people with developmental disabilities.**

State Developmental Disability Planning Council report recommendations for the most part were predicated on an overriding recommendation: the development of strong federal leadership, including the authority to carry out policies across several branches of the federal government (e.g., Departments of Health and Human Services, Education, Labor, Commerce, and possibly others).

Several State Council reports saw as a part of the development of federal leadership the development of a "coherent comprehensive" policy on the employment of people with developmental disabilities. A few Councils recommended that a clear, specific competitive employment target or goal be established (e.g., labor force participation equivalent to the general population by the end of the century).

Several Planning Council reports recommended the establishment of an employment tracking system for people with developmental disabilities. It was further recommended in some reports that the Departments of Labor and Commerce be charged with this responsibility as they are now with overall and minority employment reporting. A related recommendation was to engage in inter-agency research and planning around the employment initiative for people with developmental disabilities.

A few Councils recommended that restrictions on the use of federal dollars be loosened to allow for greater flexibility in serving people with developmental disabilities at the state and local levels, such as supported employment eligibility for people unable to work a minimum of 20 hours per week.

Federal/State:

There were no recommendations in this area.

State:

State Councils made parallel recommendations to their state leadership that strong policy leadership in employment be developed.

The reports called for specific strategies to make services more responsive to the needs of the individual. These included:

- Establishing innovative accounting and funding procedures
- Establishing a "lead agency" with the authority to coordinate inter-agency activities related to the employment of people with developmental disabilities
- Conversion of facility-based services to ones whose goal is integrated employment choices for people with developmental disabilities
- Incentive funding to encourage rehabilitation facilities to convert to integrated employment
- Involvement of Employment Security and the Jobs Training and Partnership Act agencies in the initiative

The following recommendation was made by the Ohio Planning Council:

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. (Ohio report)

VI. Housing

VI. Housing

State Council Reports: Overview



What we know about community living: all people with developmental disabilities, including those with severe developmental, behavioral, and health impairments, can live successfully in the community if appropriately supported.

—Connecticut report



The current system of "residential placements" should be replaced by a system of supports to individuals with developmental disabilities and their families in their own homes.

—Tennessee report

Nearly all of the State Planning Council reports identified the need for expansion of the community living options available to people with developmental disabilities. As described by Councils in their reports, the array of desired options should include individual supported living in homes and apartments; family supported living, including substitute family/foster home care for children; family size units for adults choosing shared housing; and homes with specialized staff and supports for people with special needs, such as medical care, challenging behaviors, and intensive training needs. A minority of Council reports included references to group homes larger than family size and other congregate facilities as part of the desired array of housing options.

Most of the State Councils placed primary emphasis in their reports on the need to expand opportunities for community living in general, while some emphasized the need for a conceptual shift from facility-based residential services to a system of supports. Regardless of emphasis, a unifying theme across virtually all reports was the need for increased home and community options for people—both adults and children—whose disabilities are more severe and challenging.

Household Size (Summary of State Consumer Surveys)	
Arrangement	Percent
Alone	9%
1 other person	9%
2 - 5	52%
6 - 15	20%
16 and over	10%
Total	100%

Because of the Councils' focus on home and community-based living, there was considerable overlap between their discussions of housing and those focused on individual and family supports, especially those that enable children with developmental disabilities to remain in their natural family home. Some Councils' discussions of general and mental health issues also identified housing-related matters, such as the bias in health insurance to pay for institutional or hospital care but not for in-home or community-based services. Similarly, many reports noted the relationship between people's income levels and their access to safe and affordable housing. Related information on housing discrimination was found in some Councils' reports, as noted in the chapter on civil rights.

State Planning Council reports tended to define housing broadly in their review of state administered programs using federal and state funds. Because many people with developmental disabilities live in Medicaid-financed settings or are receiving

Medicaid-financed supports in conjunction with their residential services, nearly all Council reports included references to the state's use of the Medicaid program. Specific programs discussed by the Councils included in particular the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program; the Home and Community Based Services (HCB) waiver program, including its "Model Waiver" component; Medicaid financed nursing home care (formerly the Skilled Nursing Facility and Intermediate Care Facility programs, now combined as the Nursing Facility program); and implementation of the nursing home reform provisions of the Omnibus Budget and Reconciliation Act of 1987 (OBRA 1987).

A few reports included references to housing supports related to the child welfare provisions of Title IV of the Social Security Act, including foster care and adoption assistance. It should be noted, however, that several other Council reports referred to foster care and/or supports to adoptive parents without specific reference to the federal programs.

Other federal program references which were included in the State Council reports were:

- Generic and specialized programs of the Department of Housing and Urban Development (HUD), including Section 8/low income rental assistance. Section 202/grants and loans for the construction and rehabilitation of low-income housing, and McKinney Act programs to expand the availability of affordable housing and reduce the incidence of homelessness
- Housing assistance funded by the Farmers Home Administration
- Internal Revenue Service provisions affecting the deduction of home modifications to promote accessibility

Nearly all State Council reports included discussion of state-supported housing, in particular non-Medicaid financed community residences. Related state initiatives included supports to families. Found in most of the Council reports, these are financed primarily with state revenues. The reports also included descriptions of a wide variety of state activities across the full range of issues affecting housing for people with developmental disabilities; some recent housing initiatives described in the reports are included in the section on Accomplishments and Opportunities.



Vision: there will be fewer and smaller segregated facilities for people with developmental disabilities. There will be ample alternatives to institutions and safeguards to prevent unnecessary institutional admissions.

—West Virginia report



Vision: necessary support services will be provided to families to allow them to maintain their children at home....There will be alternative, home-like residential settings provided for children who, for one reason or another, cannot live in the natural home.

—California report



Vision: homes should be located in neighborhoods and communities where individuals and families want to live....Adults with developmental disabilities should be in a home of their choosing, have control over the selection of housemates, and the home, whether leased or owned, should be in their own name.

—Louisiana report

The majority of State Councils defined goals in relation to where people with developmental disabilities live. The six dominant themes of Council goals and recommendations in this area were as follows:

1. Fewer and smaller segregated facilities

Virtually all the State Council reports looked ahead to increased opportunities for people with developmental disabilities to live in homes that were part of the community, with a corresponding reduction in the use of large, segregated congregate facilities such as state institutions and nursing homes. Related goals found throughout the reports included an adequate supply of alternatives to institutions; safeguards to prevent unnecessary institutional placements; homes in areas without concentrations of people with disabilities; and housing that provides opportunities for meaningful interaction with community members without disabilities. A related goal found across the reports was that non-institutional, community based living arrangements be available to people with all types and levels of disability.

2. All children in families

A second goal found in virtually all the State Council reports was that children with developmental disabilities grow up in families, including the availability of "substitute" families as necessary. Many of the reports identified supporting children with disabilities within the family home as the service system's highest priority. A related goal identified by many Councils was that no children grow up in institutions.

3. Adults in homes of their choice

The primary housing goal for adults with developmental disabilities found in the State Council reports was that they live in homes in typical neighborhoods, where they will be active participants in a variety of community activities. Another major goal identified by Councils was that adults be able to choose where and with whom they live, and that their furnishings and possessions will reflect their personal taste. Several Councils also included the goal of expanded opportunity for apartment living and home ownership.



There should be a sufficient supply of decent, affordable and barrier free housing so that people of all income levels and disabilities have access to a home of their choice.

—Georgia report



Vision for the '90s: since services are delivered by staff persons, the system guarantees that all staff are both competent and caring.

—Rhode Island report



A vision of housing for people with developmental disabilities includes living in the same homes as those without disabilities, with supports to the individual and adaptations to the living environment as needed.

—Vermont report

4. Decent, affordable housing

Another goal identified by many State Planning Councils was that there be a sufficient supply of decent, affordable housing so that people of all income levels have access to a home of their choice and that homelessness be eliminated. Many Councils particularly noted the goal of affordable housing that is also accessible to people with disabilities.

5. Housing quality standards maintained

A fifth goal found in the State Council reports was that quality standards be maintained to assure that people with developmental disabilities live in a safe, caring and supportive environment where their rights are fully recognized and protected. Goals in some reports focused on meeting the needs of individuals; another focus was on the need for well qualified and trained housing support staff.

6. Supported living

Many State Councils defined housing goals for people with developmental disabilities in terms of their living in the same kinds of homes as those without disabilities, with supports to the individual and adaptations of the living environment available as needed to enable them to live in non-segregated housing. A related goal found in many of the reports was that resources previously devoted to "residential service programs" be restructured as resources for a flexible system of housing supports to individuals with developmental disabilities and their families that is based on the personal living goals and choices of each individual.

**Where People With Developmental Disabilities Live
(Summary of State Consumer Surveys)**

Type	Children	Adults
Home in community	95%	74%
Rooming house	0%	2%
Specialized facility	2%	12%
Nursing home	0%	3%
Institution	3%	9%
Total	100%	100%

These six goals or themes were found throughout most of the individual State Council reports in their discussion of housing for people with developmental disabilities. It should be noted that the majority of reports with separate discussions of housing treated the subject of housing as "where people with developmental disabilities live." The summary on housing in this chapter does likewise, including the full range of living arrangements, from medically oriented facilities and state institutions to individual and family homes.

1. Fewer and smaller segregated facilities

State Council Reports: Accomplishments and Opportunities

Programs designed to minimize the use of large institutions and other "residential services" that segregate people with developmental disabilities were featured in reports that included examples of recent accomplishments. Examples include:

“ I lived at Dixon Developmental Center for 28 years...now I have moved to my own apartment....I signed my own lease, pay my own bills, and for the first time I can stay home without staff. This is the best place I have lived so far. I like my room-mates, and this is our place.”

—Illinois consumer

★ People do better living in the community.

- The Community Options Program (COP) began in 1982 as part of a newly developed Wisconsin long-term care planning strategy to begin to get a handle on escalating Medicaid nursing home costs and to hold down the growth of nursing home beds. COP uses the state portion of what would otherwise be the state match for a Medicaid-funded nursing home placement to fund a community-based alternative. Services are based on the assessment of individual needs and the development of a plan to address those needs. A full array of services are available under the COP program. In 1988 the total COP caseload was 8,203, of which 1,622 (19.8 percent) were people with developmental disabilities. Without COP funding, these people could very well have no community-based alternatives to a nursing home. (Wisconsin report)

- In a recent deinstitutionalization effort, an employee of the Utah State Training School chose to become a private provider for three women who had resided in the training school for 17, 23, and 31 years respectively. As a private provider, she took these women she had worked with in the institution and helped them integrate into a community setting. Early on she observed that Mary had almost never spoken in the ten years she had known her, but since "coming home" (Mary's description) she has become a regular "chatter box." The provider assumed while at the training school that these women must have dressed uncaringly because of the severity of their disabilities. But in the community each of the women had very definite ideas about how she wanted to dress: one loved purple and lace, another chose levis and sweaters, and another sports clothes like "sweats." She said, "I would like to take credit for teaching them all of the new things they're doing, but I can't. I really haven't done anything but give them a chance...they just haven't had a chance before." (Utah report)

★ **Institution admissions have stopped in some states.**

- At the beginning of October 1989, the population of [the state institution] was 95 residents. The population has steadily declined for more than a decade as admissions have ceased and efforts to achieve community placements have been a top priority within the Division of Mental Health and Developmental Services. During the past two years the population has declined by about 30 residents per year and the number of community placements has consistently exceeded projections. (New Hampshire report)

State Council Reports: Critical Issues and Barriers

✓ **All but three states reported a lack of community living arrangements.**

The primary issue raised in the State Council reports regarding where people with developmental disabilities live was the need for more community-based alternatives to institutionalization. All but three State Councils identified the need for additional community living arrangements. Most reports further noted the lack of alternatives that are available to people regardless of the nature or severity of their disability and community living arrangements that promote full participation in the life of the community.

“*I’ve been on the waiting list for seven years.*”

Twelve reports specifically noted that there are long waiting lists for community living arrangements, as illustrated in the following table:

—Ohio consumer

Waiting Lists For Community Living Arrangement	
(Twelve State Council Reports)	
State	Number
California	8,023
Kansas	550
Michigan	3,000
Minnesota *	500
New Jersey	4,100
New Mexico	172
Ohio	7,000
Tennessee	700
Utah	138
Virginia	"Several hundreds"
Washington	1,100
West Virginia	179
* Semi-independent living only	

“ I want people to remember that when they look at waiting lists that these are not numbers, these are people. It's everyday quality of life that is suffering.”

—Alaska parent

✓ Inappropriate placements in nursing homes

These waiting lists in some reports were described as including significant numbers of current institutional residents who are unable to leave because of the lack of community alternatives. Other reports focused more on adults with developmental disabilities who are currently living with their families but who are at risk of future institutionalization if community options are not available.

Several Planning Council reports noted concerns about people with developmental disabilities in nursing homes and their state's implementation of the nursing home reform provisions of the Omnibus Budget and Reconciliation Act (OBRA) of 1987. Some identified particular concerns regarding people with physical disabilities inappropriately placed in nursing homes, an issue related to findings from the summary of state consumer surveys on where people with various kinds of developmental disabilities live. Specifically, adults with disabilities other than mental retardation were more likely to live in nursing homes (3.4 percent vs. 2.2 percent); however, adults with mental retardation were more likely to live in other institutions (11.8 percent vs. 5.0 percent).

✓ The ICF/MR model is difficult to use appropriately.

A related issue raised by many of the State Councils was the concern that Medicaid Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and other medical care oriented living arrangements are inappropriate for many people with developmental disabilities. As described by eight of the states:

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.

✓ Institutions segregate people from the community.

Views on the role of institutions varied among the reports, with some including a limited but reduced role for large congregate facilities and others advocating the elimination of the use of institutions altogether. Virtually all reports, however, identified the need for a reduction in the reliance on institutional care in the interest of promoting meaningful integration. Several State Councils specifically identified concerns regarding the segregating effect of institutional living; a few further raised the concern that "group homes" sometimes segregate people with developmental disabilities from others in the community. As described in the Connecticut report,

✓ **Funding is biased toward congregate facilities.**

“ *Medicaid will only provide \$343 per month for in-home care, which cannot meet my needs. But if the person with a disability moves into an ICF nursing home, it will provide \$1,074.60 for institutional care at the same level.*”

—Iowa consumer

"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, into a house they don't want or own, and, sometimes, in a neighborhood where they aren't wanted."

The barrier most commonly identified in discussions of the need for more community living arrangements was the bias in funding toward institutional and congregate care, including funding bias in general, federal funding bias (Medicaid in particular), and involvement at the state level in ICF/MR facilities. A related issue noted in a few reports was the state's investment in the ICF/MR program. For example, the Arkansas report observed that the state's investment in the ICF/MR 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." The issue of funding being diverted to institutions from community based programs is discussed below in relation to quality issues.

Nearly half the State Planning Council reports noted barriers to the expansion of community alternatives to institutions associated with the Medicaid Home and Community-Based Services (HCB) waiver program, in particular its cost-neutrality provisions, i.e., the requirement that Medicaid costs for services provided under the state's HCB waiver cannot exceed projected Medicaid costs for serving the waiver clients in an ICF/MR or other Medicaid certified facility. Other HCB barriers included references to implementation issues at the state level, such as lack of start-up funding.

A few states identified the lack of resources for community living arrangements in general. A point made in many Council reports, however, was that public costs for some community options, such as home-based care for some children with complex needs, may be less expensive than the institutional alternatives. As described by West Virginia, for example:

Only four children with developmental disabilities are presently living in state institutions. An additional eighteen children reside in an ICF/MR. The annual cost of these placements is approximately \$1 million.

When out-of-home placements are necessary, the predominant trend is family-based care. Fifty-six children are served in specialized foster homes that have been developed for people with developmental disabilities. The estimated annual cost of these placements is about \$600,000. (West Virginia report)

Only one state, California, indicated that state institution utilization is expected to increase over the next few years.

✓ **Unmet housing needs for people with severe disabilities**

The second major issue raised by the state Planning Councils in relation to community living arrangements was the lack of opportunities for people with various kinds of disabilities. Approximately half of the reports identified unmet community housing needs, particularly for people with severe disabilities or complex medical needs, people whose behaviors are considered challenging, and people with cerebral palsy or other physical disabilities. Other disabilities noted in relation to the lack of non-institutional alternatives included people with autism; people with emotional disabilities, including "dual diagnosis" with another developmental disability; and children affected by their mother's substance abuse, e.g., "crack babies." A variety of such needs were illustrated in the Oklahoma report, as follows:

“ *I want to be out of the nursing home and into my own apartment. I have been on a waiting list for six years.*”

—Wisconsin consumer

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 or higher, or individuals who have epilepsy, for example, remain unserved in this state. 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 and those with multiple handicaps. Nearly 80 percent of those served by the present community programs are people with mild to moderate mental handicaps. (Oklahoma report)

In many of the Council reports identifying the barrier to community living for people with disabilities other than mental retardation, there was recognition of the relationship between this barrier and the primary developmental disability service agency's limited (i.e., narrower than the federal definition of de-

developmental disability) definition of its service population.

Several reports further noted that there remains an attitudinal barrier, or apparent lack of commitment, on the part of policymakers to focus efforts (and therefore target resources) to community living arrangements. In some states the barrier was focused more on the nature or severity of the developmental disability.

State Council Reports: Recommendations

➔ Expand community living alternatives.

The conclusion reached by virtually all the State Developmental Disabilities Planning Councils in their 1990 reports was that more must be done to promote community integration through expansion of the array of community living alternatives. All but six reports included recommendations that addressed the goal of expanded alternatives to institutionalization for people with developmental disabilities. The primary Council recommendation, found in relation to all levels of government, was that resources be redirected from institutions to non-institutional community living arrangements. Typical State Council recommendations included:

➔ Redirect funding to non-institutional alternatives.

- 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.
- Funding utilized for institutional care should be diverted to community-based alternatives.
- 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 recommendations were similar to those addressed more specifically to the federal government and to the individual states.

Federal:

➔ Remove the institutional bias in the Medicaid program.

The State Planning Council recommendations targeted to the federal government in this area were primarily those that addressed the broader area of a shift in Medicaid resources to home and community services. Over one-half of the state Councils indicated support for federal reforms of the Medicaid

program to that end. The recommendation found in most of these reports was to revise the Medicaid program to reduce support for institutional services and to increase federal resources for non-institutional alternatives and supports to community living. As summarized in the Hawaii report, "Congress should require the Health Care Financing Administration to remove the institutional bias within its programs for persons with disabilities." Related Council recommendations addressed the reduction of current limitations in the HCB waiver program, e.g., "Congress should act to remove restrictive language tying eligibility for the Medicaid HCB waiver to eligibility for institutional services."

A different approach, suggested by both New Hampshire and Washington State, was the separation of financing of non-medical services to people with developmental disabilities from the Medicaid program altogether. As defined in the Washington State report:

The ICF/MR program and the HCB waiver program 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, health care needs. 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. (Washington report)

Federal/State:

➔ **Shift Medicaid resources at the state level.**

The Planning Council recommendations regarding state use of federal programs paralleled those targeted to the federal government, i.e., to shift the state's use of Medicaid funding from institutions to community based services. Typical Council recommendations included the following:

- Funding for basic services should be increased—and funding for services should shift from [the state institution] to the community.
- Policies governing financial reimbursement must focus on the resident, not the facility or provider.
- Federal and state funds targeted for expansion of residential services should be utilized to provide for small community-based housing for people with developmental disabilities.

A small minority of reports included recommendations to expand use of the ICF/MR program for community-based residences. Others, however, recommended that the states pull back from increased use of the program. For example, the West Virginia report recommended that "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."

Other State Council recommendations in relation to state use of federal programs included various strategies to increase housing resources. For example, the Pennsylvania Council recommended that "a concerted effort be made by state planners" to expand housing opportunities for citizens with disabilities by using Department of Housing and Urban Development Section 202 funds, Section 8 Existing Housing Certificates and Voucher Programs, Low Income Tax Credits, Farmer's Home Administration Home Ownership Loan Program, Low Income Housing Demonstration Program, and provisions of the Community Reinvestment Act.

State:

➔ Expand community housing capacity.

The major focus of Council recommendations targeted to state government was the expansion of community based services capacity in general. These recommendations were frequently accompanied by recommendations to decrease the use of large state institutions; no report recommended that placements in large public institutions be increased. Specific strategies included increased state resources allocated to community based housing, including reallocation of institutional funding and changes in state tax policy to promote non-institutional housing options; and a wide range of state-specific approaches to reduce the use of institutions and other non-integrating living arrangements. Two Councils recommended consideration of small state-operated community facilities to meet the needs of special populations. Only one indicated plans to develop large congregate units.

➔ Expand community options for people with severe disabilities.

Many State Planning Councils defined specific target populations in their recommendations for expanded community living arrangements. Reflecting the needs identified above, these included people with severe disabilities, people with physical disabilities and, in particular, people with developmental disabilities other than mental retardation. Additional recommendations to promote integration of people

with developmental disabilities into their communities were focused on a wide range of planning and coordination initiatives. For example, the New Jersey report included the following recommendation:

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. The task force should be consumer driven and ongoing, examining all of the critical issues identified in this report....It is recommended that the Developmental Disabilities Council be the agency that convenes this body. (New Jersey report)

➔ **Involve the private sector.**

Several State Councils also recommended increased information and technical assistance to builders, architects, building inspectors, and realtors, as well as consumers and family members, regarding strategies to increase the availability of community living alternatives.

2. Children in families

State Council Reports: Accomplishments and Opportunities

Strategies to help families in raising a child with developmental disabilities were highlighted in many of the reports, as noted in the chapter on individual and family supports. An example of supports to adoptive families is found in the New Hampshire report:

The New Hampshire Division for Children and Youth Services inaugurated a new program in July 1989 to reimburse adoptive families for "special" or "non-recurring" expenses of welcoming into the family a child who is hard to place because of a disability or other reason. Examples of costs covered by the subsidy are medical costs; wheelchairs, braces or other prostheses; and home adaptations or modifications, such as a wheelchair ramp. The new non-recurring subsidy is in addition to existing time-limited and long-term subsidies. (New Hampshire report)

★ **Family supports help keep children out of institutions.**

The Ohio report noted that its Family Resource Program funded by the Ohio Department of Mental Retardation/Developmental Disabilities has assisted some families in keeping their sons and daughters at home. The Alabama report highlighted "A Baby's

Place," a home for up to six children with AIDS/HIV infection.

As noted in the Overview section, many states are moving toward the goal of having no children in institutions. For example, Utah reported that they instituted a foster care family model to put "children first" in their deinstitutionalization initiative. The model emphasizes support and training to the foster family. At the time of the report, 111 children had been brought out of the state facility and only 12 children under the age of 14 remain. The Alaska report noted that of the 57 people residing in the state facility, none are children.

State Council Reports: Critical Issues and Barriers

- ✓ **There is a lack of supports to families in many states.**

Approximately one-half of the State Council reports specifically highlighted children's needs for a home. As with the need for community alternatives in general, the primary barrier identified was the current lack of supports to families and, where necessary, substitute families to preclude the need for institutionalization.

- ✓ **Home-based services are especially needed for children with intense medical care needs.**

Over one-third of the State Councils raising these issues noted particular needs of children who are considered "medically fragile" or who are dependent on medical technology ("technology dependent"). As described in the Colorado report, "Many of these children who have especially challenging health care needs are cared for in foster care and institutional settings such as [state facilities] and hospitals. Although some group homes and other programs provide residential services for these children, there remains a great need for more normalizing environments such as individual family homes." The Utah report noted that "Until five years ago, most of these children would not have survived or would have been sent to the [state facility] to wait out their life span because of their severely disabling conditions. Now, a recent tally from the University Medical Center estimates that there are currently 1,200 of these children living at home across Utah."

- ✓ **Lack of family supports leads to unnecessary out-of-home placements.**

The barrier identified most frequently by Councils was the overall lack of supports to families, which in turn led to unnecessary out-of-home placements for the children. As reported by Missouri, "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 un-

able to receive the level of support needed to maintain the person at home or are unable to find viable community-based alternatives."

The second major barrier found in the reports was the lack of access to health care and health insurance coverage for care provided in family homes rather than in institutions. As discussed in the chapters on health and supports, many states noted that services that are available and reimbursable in institutions are not reimbursed when provided outside the hospital or institution. Other barriers associated with funding constraints included the limitations of Medicaid funding discussed in the previous section and the overall lack of resources for home-based care.

- ✓ **More effective permanency planning is needed for children with developmental disabilities in foster care.**

A few State Councils noted concerns regarding the generic foster care system in relation to children with developmental disabilities, in particular the need for more effective permanency planning. As described in the Ohio report, many children with developmental disabilities do not have their "own home" and remain in foster care for long periods, and are often "shuffled between many different residential facilities and foster families."

State Council Reports: Recommendations

- ➔ **Ensure that children live in families.**

The primary State Council recommendation in this area was a general one to ensure that children live in families. This recommendation is complementary to those summarized in the chapter on supports.

Federal:

The only Planning Council recommendation targeted to the federal government was that children should qualify for Medicaid if at risk of institutionalization, regardless of family income.

Federal/State:

- ➔ **Expand the use of Medicaid for help to children in families.**

A few State Councils included recommendations in relation to the state's use of the Medicaid program, including enhanced use of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) eligibility option for children with disabilities, expansion of the state's Model Waiver, expansion of the state Medicaid program to include therapeutic foster care and a residential treatment option for children, and expansion of the state's small ICF/MR facility program for children who are "medically fragile."

➔ **Increase supports to families in general.**

State:

The major State Council recommendation targeted to state governments was that supports to families be increased, including adoptive and foster families as well as natural families. Related recommendations are found in the chapter on supports. Other recommendations in this area include increased community options for children considered medically fragile or who are dependent on medical technology and reduced funding incentives for out-of-home placements.

3. Adults in homes of their choice

State Council Reports: Accomplishments and Opportunities

The State Council reports which included examples of accomplishments frequently included descriptions of living arrangements for adults which promoted their independence and community participation. Many of the most poignant comments from individual consumers found in the reports provide their descriptions of how much their quality of life has improved since they have moved into their own home, as illustrated throughout this chapter and in the following vignettes:

“ ***My [new] home is one of the best places I've ever lived.***”

—**West Virginia consumer**

Teresa shares her home with two friends and receives training, case management and other support services from staff of the regional [state facility]. She reported that her present home is one of the best places she's ever lived. "It's big, for one thing. We've got our own washer and dryer. We don't have to go out to the laundromat. HUD pays for part of the rent and we pay for the rest of it. If it weren't for HUD, we wouldn't be able to live here." (West Virginia report)

Linda had lived in a nursing home for most of her life. She did not participate in any training programs and thus was not allowed to develop to her full potential. Through a program called Community Support Systems, Inc., Linda moved into a community residential alternative where she began to learn how to live independently. She has a full time job in a local department store, goes to church in her new neighborhood, and has many new friends. Linda is well on her way to reaching her potential. (Illinois report)

Additional examples are found in the section of this chapter on supported living opportunities.

State Council Reports: Critical Issues and Barriers

✓ **Lack of consumer control and choices**

The issue raised most frequently by State Councils in relation to adults (in addition to the overall lack of availability of community housing alternatives) was the lack of consumer control over his or her living arrangements, including choice of where to live, with whom to live, and the personalization of the residence that makes it a real "home." Many reports included consumer survey data to support this finding. As found in the summary of state consumer surveys, only 6% of adults with mental retardation, and 30% of adults with other disabilities, chose the place where they were living without assistance.

✓ **The "continuum" model limits choices and full opportunities for community integration.**

Some of the Council discussions of the lack of housing tailored to meet individual needs were focused on the questions of eligibility or availability in relation to type of disability, as discussed above. Another aspect, identified in four of the reports, was the inherent barrier of the traditional "continuum" approach, i.e., the assumption that people with developmental disabilities must demonstrate their ability to progress through a continuum of decreasingly restrictive living arrangements. As described in the Ohio report:

“*Somehow there seems to be a silent debate about whether I should really be assisted in living independently or whether I should live in a group home. And that should be my decision.*”

—Maine consumer

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 toward independence. The primary role of the large segregated programs is to get the 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. (Ohio report)

Other concerns about the continuum model were identified by Arkansas, which noted that the continuum requires individuals with developmental disabilities to move when they develop new skills and that it "places an emphasis on facilities (buildings) rather than on services to people. Under this model people are placed in the type of facility that meets their needs rather than having supports provided to them where they need them."

✓ **Housing discrimination is a major barrier.**

Barriers to greater independence for adults in meeting their housing needs were found across many areas. The barrier noted most frequently by State

Councils was discrimination and a lack of information on the Fair Housing Act Amendment of 1988. As discussed in previous sections, other barriers included the overall lack of housing options in the community and the lack of independence and integration in the ICF/MR and other medically oriented facilities. Several reports also raised the issue of independence in relation to home ownership opportunities.

State Council Reports: Recommendations

Federal:

The Missouri Council report included a recommendation that the Supplemental Security Income (SSI) eligibility program rules which affect property ownership of low-income people with disabilities be made more lenient.

Federal/State:

Delaware recommended that a Medicaid certified intermediate care facility on its state institution grounds be converted to apartments.

State:

➔ **Increase opportunities for people to own or lease their own homes.**

The overwhelming majority of State Planning Council recommendations in support of adult housing options were targeted to state governments. The primary recommendation was to provide more opportunities for adults with developmental disabilities to own or lease their own homes. A few strategies were recommended, such as guides for consumers on home ownership and state supported loan funds. Another major area of recommendation was the increased availability of choices to adults in selecting their living arrangements. Recommended strategies included better ways to provide consumers with information on opportunities, and supports to adults in exercising their right to choose their living arrangements.

A few additional Council recommendations were found in individual reports, including isolated recommendations for congregate and inpatient living arrangements for young adults in one state and, at the other end of the age continuum, a recommendation for flexible programs for older adults with developmental disabilities that allow them to be "retired."

4. Decent, affordable housing

State Council Reports: Accomplishments and Opportunities

★ Expanded resources for low income housing

The theme of decent and affordable housing was presented by Councils in relation to the housing needs of low income people in general and of people with disabilities in particular. Recent accomplishments in this area emphasized the expansion of resources for low income housing. For example, the Rhode Island report noted that the state spends more per capita on low-income housing than any other New England state. The Washington State report highlighted its initiative in financing low-income housing, including tax exempt bonds and low-income housing tax credits. These activities have financed 10,675 units since 1983, with a market value of \$337 million. The state added the Washington State Housing Trust Fund in 1986 to fill in gaps in federal funding. The Trust Fund uses a variety of sources to help low-income and special needs populations, including people with disabilities, to meet their basic housing needs. Trust fund awards can be used for such purposes as buying new homes, rehabilitating existing structures, rent subsidies, mortgage subsidies, and matching funds for social services directly related to special needs housing. Technical assistance for design as well as finance, administrative costs, and security deposits is covered through the program.

A planning initiative was featured in the Vermont report, including provisions in state law that "call for communities to develop a housing element in their town plan which includes a recommended program for addressing low and moderate income persons' housing needs." As noted in the chapter on health, the Tennessee report highlighted a \$1.7 million grant-funded initiative to provide housing rehabilitation and assistance to people who are homeless and have mental illness.

State Council Reports: Critical Issues and Barriers

✓ People with developmental disabilities are particularly affected by the lack of affordable housing.

Over one-third of the State Planning Council reports dealt with the broader issues of affordable housing. Virtually all of these noted that people with developmental disabilities are particularly affected by lack of availability of low income/affordable housing, because most people with developmental disabilities are themselves low income by virtue of their under- or unemployment or their dependence on income support programs with benefit levels below the

poverty level. These issues were reflected in the Delaware report as follows:

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, specifically people with disabilities, have found themselves without adequate community-based housing options. 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." (Delaware report)

The major issue identified in the State Council reports was the overall lack of affordable and low income housing. Several states noted the increase in homelessness over the past decade; a few noted that the homeless population includes many people with serious mental illness and others who may meet the definition of developmental disability.

“ In order to qualify for low income housing, people have to live in places...where the public transportation is poor and there are no jobs.”

—Utah consumer

Some State Councils included a discussion of housing support programs administered by the Department of Housing and Urban Development (HUD), including in particular the various Section 8 low income rental assistance programs. The primary issue noted was the lack of available rental units that can meet Section 8 guidelines, and the long waiting lists in some areas in order to obtain or use the Section 8 voucher or certificate obtained. As described in the Utah report, "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 [through the program] are located in undesirable neighborhoods." More broadly, several reports also noted the overall decline in HUD funding for affordable low income housing units during the 1980s as a factor in the shortage of such housing in various parts of the state.

State Council Reports: Recommendations

A few State Planning Councils recommended general increases in accessible low-income housing, including one state that recommended more funding for affordable housing in general.

➔ **Expand access to low income rental assistance.**

Federal:

The primary State Council recommendations were addressed to programs administered by the Department of Housing and Urban Development (HUD), in particular the Section 8/low income rental assistance programs and Section 202 loan programs to support the development of low-income housing. The overall thrust of these recommendations was to increase access of people with developmental disabilities to these programs, as well as for low-income people in general. For example, Michigan recommended the expansion of Section 8 housing subsidies or other means of flexible financial support for low income housing, including a set-aside for people with disabilities. The single recommendation found most frequently in this area was advocacy for proposed legislation to increase federal support to expand the supply of low income housing, in particular the proposed National Affordable Housing Act.

Federal/State:

A few Council reports recommended improved coordination and utilization of HUD funding within the state to increase access to affordable housing.

State:

The focus of most of the Council recommendations targeted to the state level was on the expansion of affordable housing that was also accessible to people with disabilities. A mix of strategies was suggested, such as the Virginia recommendation that the state establish and fund a rental assistance program for low income people with disabilities.

5. Housing quality standards maintained

State Council Reports: Accomplishments and Opportunities

“No Ohioan should be forced to accept nursing home placement because of the lack of available lower cost home care.”

—Governor Celeste, Ohio

There were no examples provided in the Planning Council reports of accomplishments in state quality assurance programs. A few reports noted their state's progress in implementation of the nursing home provisions of the Omnibus Budget and Reconciliation Act of 1987 (OBRA 1987), as illustrated in the following excerpt from the Pennsylvania report:

The Office of Social Programs estimates that there are 203 persons in nursing facilities who would require relocation. In response to the OBRA initiative, Pennsylvania elected to serve persons with "other related condi-

tions" [i.e., other than mental retardation] as a distinct target group, in a separate program office from the Office of Mental Retardation. The newly designated Community Services Program for Persons with Physical Disabilities in the Office of Social Programs is charged with relocating the identified persons. To that end, state funding has been approved to assist 20 of these individuals to access alternative living arrangements. Unlike any other state, the services for persons with "other conditions" have been delegated to an agency that is separate from the state mental retardation agency. The move recognizes that this group of people has unique needs. In addition, the funding stream and service mandate should result in strengthened administrative experience with and understanding of the service needs of people with physical disabilities. (Pennsylvania report)

State Council Reports: Critical Issues and Barriers

“ *There is a need for more effective monitoring of programs. Site audits should include parents, relatives, and correspondents.”*

—New York parent

Issues of quality in relation to living arrangements for people with developmental disabilities were raised by many State Developmental Disabilities Councils. One concept of quality, identified either directly or indirectly, related to the concept of housing that is designed to meet the needs of the individual. The more specific quality issues, raised in 22 reports, were focused on concerns in relation to the state's current system of monitoring and quality assurance, personnel and staffing issues affecting residential services, and quality-related questions on resource levels.

✓ Weaknesses in quality assurance programs

Seventeen State Council reports identified issues in relation to monitoring and quality assurance, including the need for more effective residential quality assurance systems and concerns regarding quality levels in both institutions and community settings, as illustrated by the following issues from the reports:

- The [state agency] 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.
- Laws governing licensure and programs for monitoring are areas requiring renewed focus, if improvement in the residential care facilities system is to be realized.

“ I just sit in my room, listen to the radio, have a cigarette, go out to church once a week—that doesn't cost anything. It's like a prison.”

—New Hampshire consumer

✓ Questions about current quality assurance approaches

- There are no developmental disability program standards or monitoring systems in place to assure the quality of community residential programs funded by the [state agency].
- The [licensure agency] staff license 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.

Several State Councils also noted concerns regarding reports of abuse and neglect in board and care homes.

Ten reports raised questions about current approaches to monitoring living arrangements. As noted by eight of the Councils, "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 vs. 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." Other states questioned the use of ICF/MR regulations in relation to quality of life and independence, productivity and community integration. As described in the Connecticut report, "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." The Connecticut report also noted that people who live in ICF/MR facilities have no incentive to work "since regulations require most earned income to be turned over to the facility."

✓ Staff qualifications and turnover concerns in community residences

Several Council reports referred to personnel concerns, especially in relation to community living arrangements. The most commonly noted issues were lack of training and staff turnover. For example, the Arizona report noted that agencies report turnover rates of from 50 to 130 percent in community residential facilities.

All but two of the seventeen State Councils focused these concerns on residential programs in the community. The barrier identified most frequently—in more than half of the reports which cited staffing

concerns—was funding constraints, as illustrated by the following excerpts from the California report:

Residential provider staff in the community are generally underpaid and undertrained which creates high turnover. Staff salaries are inequitable between public facilities [large state institutions] and private facilities (community facilities). There is no career ladder in the community to encourage people to remain in the residential field.

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. A number of very serious problems have arisen as a direct result of the community residential facility shortage. Most alarming is the increase in (state institution) admissions. When a community facility closes, for one reason or another, what options exist for relocating residents?...[During a 28 month period] 188 people were admitted to [state institutions] due to the closure of 11 community facilities. (California report)

A different issue regarding funding levels in relation to quality was raised in ten reports regarding compliance with federal standards for Medicaid supported institutions. Several reports raised concerns in relation to cost increases in their public institutions in meeting ICF/MR certification requirements; two-thirds of these noted that these expenditures resulted in fewer resources for community based services. As described in the New Jersey report, "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 the availability of resources for community services development." Similar concerns were raised by several states in relation to implementation of OBRA 1987.

State Council Reports: Recommendations

A few State Planning Councils made general recommendations regarding the need for enhanced quality through the provision of more individualized housing services and supports.

➔ **Establish federal board and care standards.**

Federal:

The primary Council recommendation in this area was the establishment of federal standards for board and care facilities.

➔ **Meet federal quality standards without taking resources away from community programs.**

Federal/State:

The primary recommendation by State Councils was for compliance with ICF/MR and OBRA 1987 regulations in ways that promote community alternatives and/or that do not increase funding for institutions at the expense of community-based housing development. Arizona recommended specifically that funding not be diverted from community programs to meet ICF/MR certification requirements in state institutions. Related recommendations found in a few reports emphasized the potential of the HCB waiver program in response to ICF/MR and OBRA 1987 quality concerns. Other recommendations included the maintenance of ICF/MR accreditation standards, increased per diem rates in HCB programs, and enhanced training in community based ICF/MR facilities. A recommendation regarding a federal program other than Medicaid was found in the Hawaii report, which advocated use of the Uniform Federal Accessibility Standards in the approval of building permits.

➔ **Improve quality in community residences and methods to oversee their quality.**

State:

The State Planning Council recommendations focused on state government actions were addressed primarily to improvements in the quality assurance process and the promotion of better quality in community living arrangements. Recommendations on process included strategies such as the assignment of an advocate to all individuals in out-of-home placements and the licensure of board and care homes. Two strategies recommended in particular, regarding the improvement of quality in community residences, were to increase staff pay scale and to provide training and technical assistance to the staff. For example, California recommended a rate increase that guarantees a pass-through to community care staff and training modules and incentives for completion of training built into the system. The Council recommended that "In order to build a stronger, more stable community-care workforce, the salary benefits structure must be comparable to that received by care providers in institutional settings."

Other Council recommendations included increased focus on individual needs, and one recommendation

that the state "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."

6. *Supported living*

State Council Reports: Accomplishments and Opportunities

Council reports which included examples of accomplishments in relation to housing were particularly apt to feature illustrations of the shift to homes and supports tailored to the needs of individuals. Examples include the following:

★ **People with severe disabilities who receive supports are living in their own homes.**

- Community Integrated Living Arrangements (CILA) is a major initiative recently launched by the Illinois Department of Mental Health and Developmental Disabilities (DMH/DD) to make significant improvements in the way community services operate for people with developmental disabilities. Under CILA local provider agencies will be funded and licensed by DMH/DD to develop individualized packages of services for consumers who will live and work in the community. A CILA is not a residence or a building, but rather a program which allows consumers to choose a lifestyle, as do people who are without a disability. Consumers may choose to live in their own home or apartment, with roommates, with a foster family, or in any other living arrangements which communities allow. Consumers with severe disabilities are currently being targeted for the CILA program. (Illinois report)
- In 1987 the Council funded a demonstration supported living project through the United Cerebral Palsy Association. This project has been extremely successful and now has six people who are physically involved but not intellectually impaired, living in their own apartments with the appropriate support services provided. The cost per client is \$1,374, which includes case management, habilitation and independent living skills. The individuals' rent, food and personal care service are financed through other sources (SSI, Medicaid, etc.). (Hawaii report)



Supports are designed to meet individual needs.

- James and Susan are romantically involved. James uses a wheelchair, has very limited use of his hands, and cannot communicate verbally. Susan is legally blind, has moderate physical disabilities due to cerebral palsy, and is considered to have mild mental retardation. Before [entry into their supported living program] they had to live apart in two separate nursing homes, though they attended the same day program....Susan and James now live successfully in their own home in the community. To assist them, a live-in roommate stays with them in the evenings and on alternate weekends. A personal care attendant comes from 7:00 - 9:00 a.m. to help them dress, get clean, and eat breakfast. A home support worker comes from 1:00 - 9:00 p.m. to work with them on learning daily living skills. A community support specialist spends three hours each weekday and 8 hours on Saturdays to help them with activities in the community and at home and with transportation. (Illinois report)
- The Department of Mental Retardation (DMR) is initiating a new program to provide residential supports to users of DMR services who live or desire to live in independent living arrangements with staff supports tailored to meet their individual needs. This new supported living program is being launched with the Connecticut University Affiliated Program...the project provides initiative to DMR staff to design supports to suit the individual desires, preferences and needs of each user of service. Staff hired by this program are expected to provide not only typical daily homemaking activities, but more importantly, they are able to help users become truly part of local community life by serving as guides, interpreters and escorts to community associations. (Connecticut report)

State Council Reports: Critical Issues and Barriers



Dollars don't follow the individual.

The primary issue raised in looking at ways to support people with developmental disabilities in having their own home rather than "placing" them in a "residential care facility" was the failure to shift resources from buildings to individuals. As described in the Hawaii report, "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.

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."

“ One wish: to move out of the Center and be in an apartment so I can be closer to my family and friends and be involved in my community.”

—Wisconsin consumer

The primary barriers identified by State Councils were the overall lack of resources for supports and the lack of financing mechanisms that permit dollars to follow the individual rather than being tied to a facility. As noted in the North Carolina report, "Changing the focus of public funds (primarily Title XIX Medicaid 1CF/MR 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'."

State Council Reports: Recommendations

➔ **Focus policy on supports.**

Reflecting the concerns about resources for supported living, nearly one-third of the Planning Council reports included recommendations that policy goals should focus on supports and, in five of these reports, that funding mechanisms be redesigned so that dollars can follow the individual. Examples of these recommendations include:

- 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.

➔ **Focus funding on resources to individuals.**

- 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.
- Funding sources must be realigned to focus on resources to individuals rather than facilities, for example, the Section 8 housing vouchers.
- 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.

➔ **Revise Medicaid to include supported living as an entitlement.**

Federal:

In addition to recommendations addressed to both the federal and state levels, the West Virginia report noted that "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."

Federal/State:

A few reports addressed use of federal programs, including restructuring of the state HCB waiver program, expansion of supported housing programs, and the use of increased federal funding for residential supports.

State:

➔ **Redirect state resources to supported living.**

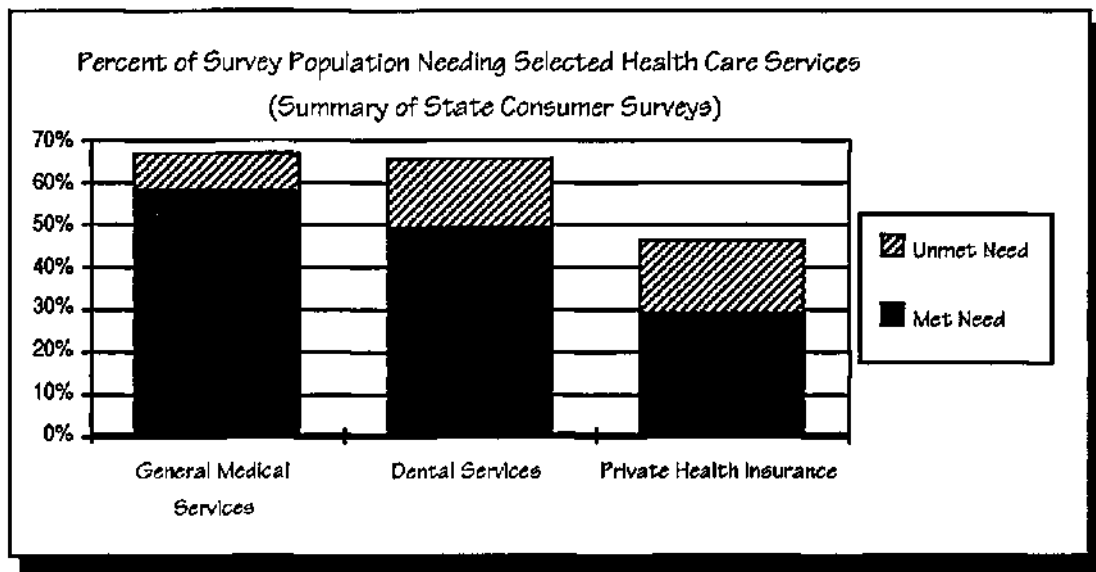
Paralleling the general recommendations, the Council recommendations addressed to the state level focused on policy changes to redirect resources from facilities to supported living models. Typical recommendations included policy to make a conscious shift of funding from facilities to individuals, the expansion of supported living programs, targeting any new/additional resources to supported living models, and to break the funding and program link between housing and services. Other recommended strategies included the development of incentives for current residential service providers to convert to a supported housing approach, discontinuation of the continuum approach, and training/technical assistance on individual supports. Related recommendations are discussed in the chapter on supports, including those targeted to communities as well as those focused on individuals.

VII. Health

VII. Health

State Council Reports: Overview

Nearly all of the State Planning Council reports included a separate discussion of health care as it relates to people with developmental disabilities; many also noted broader health system issues, such as significant numbers of people without health insurance, limited access to health care for people with low incomes, and low availability of health services in rural areas.



✓ **Nearly one in five consumers needed health insurance but did not have it.**

Many Councils included consumer survey findings in relation to health care needs. Health services were identified in the state consumer surveys as those needed by the highest proportion of people surveyed (approximately 60 percent). Data from the summary of state consumer surveys indicated that although many people reported that they were receiving health care, there were unmet needs in the areas of dental services and health insurance. In both cases, 18 percent of the consumers surveyed reported an unmet need.

Health topics covered by the State Planning Councils in their reports generally included early intervention and preventive health programs, benefits available through public and private insurance programs, and eligibility for health benefits, as well as basic health services. A few Council reports covered special issues such as drug abuse and AIDS/ HIV infection. Mental health also was addressed in some of the re-

ports, in relation to people's needs for short-term services and the needs of people with long-term serious mental illness.

Health care services also were noted by the Councils in relation to other areas of life discussed in the summary report, including:

- The use of nursing homes (housing)
- Supports to families caring for children with significant health care needs (housing, supports)
- Access to various therapies needed to support participation in activities (supports, education)
- Availability of job-related insurance (employment)
- Retention of government-funded health insurance (income, employment)

Various federal programs were referenced in the State Councils' discussions of ways to meet people's health needs. The programs most commonly noted were Medicaid, with frequent emphasis on state options in eligibility, service coverage, and reimbursement rates; Medicare; and the Maternal and Child Health Block Grant/Services to Children with Special Health Care Needs. Other federal programs cited included mental health system capability development funded by the Community Support Program (adults) and the Children's and Adolescents Service Support Program, and requirements of the State Comprehensive Mental Health Services Plan Act of 1986.

State-focused programs were noted in several State Council reports, such as initiatives to provide health services in medically underserved areas; mental health system issues; and state regulation of health insurance. Five reports also noted the exemption from state regulation of self-insured benefit programs under the federal Employee Retirement and Income Security Act (ERISA). Most of the State Council reports identified goals for health care for people with developmental disabilities. These goals may be summarized in the following six areas:



Vision: everybody has access to a full range of health care services, equipment, and supplies, when needed, regardless of income.

—Michigan report



Vision: policy makers must create processes to access the various technologies and services that can increase survivability and compensate for different disabilities through private health insurance that can spread costs in an affordable way.

—Idaho report



An adequate health care system must provide comprehensive services that can respond to the range of health related needs of all people.

—Georgia report



Vision: all persons (with and without disabilities) have access to quality health care...the quality of patient care is not dependent upon the insurer.

—South Carolina report

1. Access to health care as needed

The primary goal identified by the Councils in their reports was that people have access to health care as needed, including people with developmental disabilities who may have more intensive and long-lasting needs than people without disabilities. A related goal found in the reports was that health care be affordable, and that cost not be a barrier to health care, even for people with developmental disabilities who may have costly health service needs.

2. Access to private health insurance

A second goal found in many of the reports was that people with developmental disabilities have access to private health insurance that is affordable and that includes coverage of the kinds of services that often are needed by people with disabilities.

3. Comprehensive health care

Another goal identified by many State Councils in their reports was that available, comprehensive health care, include: preventive care, rehabilitation and developmental services, durable medical equipment, and primary care. Some Councils defined these goals further, such as criteria that services be provided as much as possible in typical health care settings to facilitate independence, productivity, and integration. A related principle noted in some reports was that it should be unacceptable for people with developmental disabilities to be subjected to institutionalization simply to have their health care needs met.

4. High quality health care

Most Councils addressed goals of quality health care in their reports, including health care providers who have been educated about exemplary care practices to meet the medical needs of people with developmental disabilities. A related goal defined by a few Councils in relation to quality was that health care be responsive to the needs of the individual with developmental disabilities.



Vision: the generic health care system should provide appropriate acute care services as well as preventive care, diagnostic services, and early intervention to prevent health problems before they become more difficult to treat.

—Louisiana report



In a future world where people with disabilities of any kind are no longer discriminated against, providers of mental health services will be willing and able to treat people with various, long-term disabilities.

—New Jersey report



Vision: everyone has a right to comprehensive, affordable health services provided in a reasonable proximity to one's home...persons with disabilities will have the same range of health care choices available as other citizens in their community have.

—Wisconsin report

5. Prevention and early intervention

Several Council reports included health goals in the areas of prevention and early intervention, identifying them as components that should be part of the overall health system available to people with developmental disabilities and to all.

6. Mental health services

Another goal in the health area found in some State Planning Council reports was that mental health services be available as needed, including access for people with developmental disabilities and those considered to have a dual diagnosis of mental illness and another developmental disability. Council goals in relation to mental health generally gave priority to community mental health services, including support to families of children with serious emotional disturbance and adults with long term serious mental illness.

Many of the health goals in the State Council reports were linked by a common belief in the basic right to adequate health care, regardless of income or level of disability.

1. Access to health care as needed

State Council Reports: Accomplishments and Opportunities

A few State Councils noted accomplishments in providing health care to their citizens. The Nebraska report included the statement that the majority of state residents "enjoy a healthy lifestyle with relatively high scores on a number of health indicators."

The Idaho report provided a description of the state's Program for Children with Special Health Care Needs (PCSHCN), funded through the Maternal and Child Health (MCH) block grant. The Idaho



Services to Children With Special Health Care Needs

program serves children birth through age 19 with conditions such as neurological impairment, cardiac defects, major orthopedic problems, cystic fibrosis, and other disabilities in collaboration with district health departments. Case finding, diagnosis, habilitative services, and case management services are administered by the state MCH agency. At a current average patient cost of \$367 per child, the program achieves significant habilitation results at a low cost. As noted in the report, the program further provides services to Idaho children with special health care needs "services which are not readily available in the private sector and/or which cost more than many parents can afford."

★ **Bringing health care to rural areas**

Outreach to rural areas was featured in the Utah report, which described the "travel clinics" of the state's Handicapped Children's Services and MCH programs. The MCH outreach includes the expertise of its high risk pregnancy program. The report noted that the outreach philosophy reflected in these activities is found throughout the programs administered by the state public health agency.

Only one State Council report identified an area of accomplishment in relation to health program eligibility. The New Hampshire report noted that coverage for home-based services under the state's Medicaid program has been extended to "children with significant medical needs whose level of care is similar to that provided in a health care facility." The program was established by the state legislature during 1988 and became effective on July 1, 1989, following approval by the Health Care Financing Administration. As described in the report, children whose parents' income and resources exceeded Medicaid eligibility requirements were previously denied coverage for health services provided outside an hospital or institution. Under the state's new Model Waiver, however, only the child's income and resources are counted in determining eligibility. The report noted that this assistance can help avoid catastrophic financial burdens or out of home placement for the children who participate.

Improved access to health care through a state initiative was noted in the New Jersey report, which highlighted the state's system of funding uncompensated care. The Uncompensated Care Trust Fund provides a means of equalizing the cost of uncompensated care across the state's eighty-eight acute care hospitals.

State Council Reports: Critical Issues and Barriers

Twenty-one State Planning Councils reported problems of health care availability. In relation to the population in general, this was noted especially in rural areas. For example, the West Virginia report noted that: "As many as forty-seven of West Virginia's fifty-five counties do not have enough medical care for the population." The indicator identified most frequently was the lack of providers in general or professionals in particular specialties, such as obstetrics and gynecology. In addition to residents of rural areas, others affected include people with low incomes and members of minority groups.

Availability for people with developmental disabilities was primarily associated with access to health care financing in either the public or private sector. Health insurance barriers are discussed separately in the following section of the chapter. People with developmental disabilities were singled out in about one-fourth of the reports which addressed health issues as having access problems in relation to factors such as inadequate transportation and lack of information about available care.



People with developmental disabilities affected by the lack of Medicaid providers

Because of its significance to people with developmental disabilities, the lack of Medicaid vendors was the barrier cited most frequently (13 State Councils). For example, Ohio reported that "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." The primary related factors identified by the states were low reimbursement rates and the complexities and delays of the respective state's Medicaid reimbursement system:

- 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.
- 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.
- 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

“ I was born with a deteriorating physical condition. I have a 'pre-existing condition', so I can never be off public insurance (Medicaid). I would like to be married. But we could never afford my care which can cost as little as \$1,000 a year and as much as \$100,000. My husband-to-be would have to earn less than \$8,800.”

—Maine consumer

“ My son needs a \$500 hearing aid for each ear. He only has one hearing aid and it needs to be repaired. The repair bill is \$250. We do not have enough funds to pay for the repair or for an additional hearing aid.”

—Texas parent

✓ People do not qualify for Medicaid but cannot obtain private insurance either.

medical professionals choose to participate in the program either because of low payments rates or cumbersome reimbursement procedures.

Another significant barrier identified by Councils was the high cost of health care, especially for people with developmental disabilities and their families. One-third of the reports which identified health issues noted this factor. A typical observation is found in the Washington report:

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. (Washington report)

Factors associated with the affordability issue included costs not covered by third party payors; eligibility problems for people and families with moderate incomes but unable to qualify for publicly supported programs; lack of health insurance; and isolated references to high charges by providers and the Medicaid "spend down" provisions for the state's medically needy program.

Eligibility issues were identified in relation to three programs: Medicaid, Medicare, and the Program for Children with Special Health Care Needs (PCSHCN). Twenty-four Council reports included statements of barriers to eligibility altogether.

The primary issue raised by State Councils was the lack of eligibility for individuals and families whose resources exceeded the limits for Medicaid eligibility but who were unable to obtain private health insurance (14 states). Some reports noted that their state does not include "Medically Needy" eligibility in its Medicaid program, with eligibility restricted to those who are considered "Categorically Needy," e.g., through simultaneous eligibility for the Supplemental Security Income (SSI) program. Five reports also noted that some states have even more stringent requirements for Medicaid eligibility, the so-called "209(b) states."

A few Council reports noted that their respective state has not taken advantage of the opportunities under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 to extend Medicaid eligibility to children with disabilities who would otherwise be

✓ **No Medicare eligibility until two full years of SSDI eligibility**

“ *I am forced to recycle syringes and catheters. I know it is dangerous, but I can't afford more.*”

—Georgia parent

eligible if they were institutionalized. The Pennsylvania report included the observation, however, that the drawback from the state's perspective is that the option does not permit the state to target a specific group of children for TEFRA eligibility, and that “the resulting risk of financial exposure has led Pennsylvania, like many other states, to reject this option.”

Thirteen Planning Council reports raised issues regarding limits on Medicare eligibility, in particular the 24-month waiting period following enrollment as a beneficiary under the Social Security Disability Insurance (SSDI) program, a benefit which includes many individuals with developmental disabilities. As noted in eleven reports, as many as one-third of SSDI beneficiaries are uninsured at some point during the two-year waiting period. For both the Medicaid and the Medicare programs, several reports raised concerns about the disincentive to employment when people are fearful of losing their health benefits and cannot be assured of adequate health insurance coverage through employment.

Concerns regarding eligibility for the Program for Children with Special Health Care Needs (PCSHCN) were identified in nine reports. As noted in the example from the Idaho report, this program is being used to support health care for children with developmental disabilities. The primary issue raised in the reports was that the various state programs have discretion in their eligibility criteria, and that limited resources lead them to exclude children in certain diagnostic categories, including children with various developmentally disabling conditions.

The third type of barrier to access raised in the reports was funding levels, primarily in relation to state resources. Seventeen reports noted their state's low Medicaid reimbursement rates and the related effect on the availability of Medicaid financed health service. Also noted were the lack of state funds for Medicaid expansion in general and for Early Periodic Screening, Diagnostic and Testing (EPSDT) and Model Waivers in particular. Eleven reports included concerns about funding for the PCSHCN and other children's health programs. Seven of these specifically noted problems in PCSHCN programs regarding allocation of scarce resources, with some relating it to state discretion in the use of the Maternal and Child Health (MCH) block grant for this program.

More broadly, nine reports noted barriers associated with medical inflation in general, and seven the growing burden of uncompensated care.

State Council Reports: Recommendations

Various cross-cutting recommendations were found in the Planning Council reports from eleven states, focusing on national health policy. For example, three reports included the following recommendation: "Health care financing policies must be changed in order to promote universality, comprehensiveness, equitable financing, and cost controls."

Federal:

➔ **Expand access to the Medicaid and Medicare programs.**

Recommendations from State Councils targeted to the federal government addressed both eligibility and funding issues. Regarding eligibility for the Medicaid program, eight reports recommended that the federal government consider establishing a program that would permit states to make Medicaid benefits available, on a sliding fee scale, to people who do not meet the state's financial eligibility requirements for Medicaid. Regarding the Medicare program, six reports specifically recommended that the two-year waiting period for people receiving SSDI benefits be eliminated. In four of the six, the recommendation was that, if this were not possible, Medicare be designated the secondary payor during the two-year period to protect people from catastrophic expense or deterioration of their condition if they were unable to afford health care.

➔ **Require states to increase resources for the Program for Children With Special Health Care Needs.**

A few reports addressed federal funding to increase access to health care, including three that recommended a federal requirement that states allocate one-third of their MCH block grant funds to PC-SHCN activities. Two recommended changes would permit vocational rehabilitation funding to continue post-employment for follow-along medical services.

Federal/State:

➔ **Increase Medicaid provider participation.**

Recommendations in twelve State Council reports were focused on actions that could be taken at the state level to increase the availability of Medicaid providers, such as increased reimbursement rates and streamlining of the reimbursement claim process. For example, the Florida report recommended that the state continue to seek ways to ease the Medicaid "paper procedures burden" on physicians and other health care providers.

A few additional recommendations for increased resources for federal/state programs were addressed to PCSHCN and to the MCH program. Three reports also recommended that the state Medicaid

program be required to pay for covered services provided to children who are dually eligible for aid under both Medicaid and special education programs.

➔ **Expand use of the HCB Waiver.**

Two reports {Hawaii and Pennsylvania) included recommendations to expand use of the Medicaid Model Waiver, i.e., the Home and Community Based Services (HCB) waiver targeted to individuals with health care needs who would otherwise be treated in a hospital or other Medicaid covered facility. The report from the District of Columbia recommended more outreach of the Early Periodic Screening, Diagnostic and Testing (EPSDT) program.

➔ **Expand access to Medicaid.**

Thirteen reports identified recommendations to enhance Medicaid eligibility, including addition of the TEFRA eligibility option or equivalent (eight of the thirteen), elimination of the state's restrictive "209(b)" requirements {three states), and increased eligibility for low income pregnant women and children (five states). Six reports addressed the use of the "Medically Needy" (MN) program, including expansion of the state's medically needy eligibility criteria {four states), and individual recommendations to study the addition of the MN program (Iowa) and to retain the MN program while reviewing its criteria (Utah). The Utah report also recommended that the federal government approve the state's MN criteria as presently established.

State:

➔ **Increase overall access to health care.**

Recommendations targeted to the state level by Councils included increased transportation and other supports to individuals (eight states) and expansion of home-based services (four states). Many individual reports included recommendations designed to address state-specific needs, such as Idaho's recommendation that access to eye and ear services be improved. Two states, Massachusetts and New Jersey, recommended actions to address the needs of people with AIDS/HIV infection.

The West Virginia report addressed the overall shortage of health care in medically underserved areas. The report recommended that efforts such as the state's Loan Repayment Program for physicians be continued and expanded in order to provide incentives to health care professionals to practice in rural West Virginia.

2. Access to private health insurance

State Council Reports: Accomplishments and Opportunities

The accomplishments cited in the Council reports in relation to private health insurance addressed the availability of insurance for people with disabilities, as follows:

- 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. (Hawaii report)
- Blue Cross/Blue Shield in Michigan is mandated by state law to offer the opportunity to purchase coverage to everyone, regardless of pre-existing medical conditions. (Michigan report)
- To help the medically uninsurable, the 71st Texas Legislature passed Senate Bill 832 which will establish the Texas Health Insurance Risk Pool. (Texas report)

Information on each of these accomplishments noted, however, that other problems remained, as discussed in the section on issues and barriers.

State Council Reports: Critical Issues and Barriers

“My daughter has congenital health problems. Her medical bills are around \$16,000 a year. There is no way that we can pay for her and the insurance company says that they won't cover her because it's a pre-existing condition. She cannot get off Medicaid and so she can't go to work even if she wants to.”

—Utah parent

✓ Health insurers are excluding people with disabilities as a "pre-existing condition.”

Barriers to health insurance were cited in nearly one-third of the State Planning Council reports, including references to the 36 million Americans currently without health insurance (16 reports) and the particular difficulties of people with disabilities (17 reports). Barriers identified, affecting people with developmental disabilities and their families, included exclusion from coverage because the disability is considered a "pre-existing" condition; lack of access to employment-based private health insurance; and affordability issues, including deductibles and co-payments as well as high premiums.

AH of the seventeen Council reports which addressed this issue noted that people with disabilities are increasingly being turned down for health insurance based on the definition of their disability as a pre-existing condition. As described in seven of the reports, "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."

“ It was hard because our insurance company rates kept going up to where we couldn't pay for insurance anymore. Now she's on Medicaid, but we had to go through an Act of Congress to get that. It was really rough on us.”

—Louisiana parent

As described in the chapter on employment, many people with developmental disabilities are unemployed or are working in less than full-time employment. Four of the Council reports specifically noted that this frequently means that they also are not eligible for private health insurance. In addition, seven reports observed that even those who are employed are frequently not covered by health insurance.

A second barrier, the high cost of private insurance, was also noted in seventeen reports. The affordability barrier to people with developmental disabilities was described in terms of high premiums charged to people considered to be higher risk; of health care costs not covered by insurance, i.e., limitations in scope; and of expensive co-payments and deductibles. Examples from state reports include;

- The classification of disability as a pre-existing condition with predictable higher health care costs provides private insurer an incentive to reject people with disabilities, impose pre-existing condition exclusions, or raise premiums, sometimes to an unaffordable level. (Tennessee report)
- The parents were unable to get private insurance because it was too costly. However, they aren't eligible for Medicaid or general relief. (Ohio report)
- 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." (South Carolina report)

Three Planning Council reports noted that existing attempts to address the eligibility problems (e.g., through special risk pools) have resulted in premiums that are still unaffordable to many people with developmental disabilities, who tend as a group to have relatively low incomes.

✓ Only limited services are covered.

Another barrier associated with private health insurance was its limited scope, i.e., the services which are covered by the policy. Sixteen State Councils noted that there are problems related to the general orientation of health insurance to acute care, and the resultant lack of coverage of those services frequently needed by people with developmental disabilities, e.g. rehabilitative technology, long-term restorative

and maintenance services. For example, the Utah report included the following observation:

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...insurance companies consider these assistive devices as luxuries and usually will not pay for them. (Utah report)

“ Casey is 8 and is reaching the lifetime cap on his insurance.”

—Georgia parent

Still another facet of the affordability issue was found in the reports which noted that many insurance policies have a lifetime "cap" on covered expenses; individuals and families who reach this cap and remain ineligible for Medicaid are faced with bankruptcy in order to maintain needed medical services. Problems also were noted in relation to health maintenance organization (HMO) coverage of people with disabilities and the establishment of risk pools at the state level.

✓ High health care costs and weak regulation of insurance

Two factors were identified in the State Council reports regarding the barriers to adequate and affordable health insurance for people with developmental disabilities: the high cost of health care generally, resulting in efforts by the insurance carriers and employers paying premiums to limit risks and costs; and the overall weak regulation of the insurance industry. For example, it was noted in four reports that only two states (Hawaii and Massachusetts) have passed laws requiring employers to provide health insurance, and six observed that there are no federal regulations to prohibit insurers from excluding people with pre-existing conditions. Two of these further noted that there is a lack of federal regulation regarding health insurance coverage even though tax laws permit employers to deduct the cost of health insurance benefits.

State Council Reports: Recommendations

Six reports from the State Developmental Disabilities Planning Councils provided recommendations on private health insurance that cut across all levels of government. The gist of these recommendations was a review of the health insurance situation as it affects people with developmental disabilities and that policies be established that protect people and their families from catastrophic levels of out-of-pocket expense.

➔ **Expand federal regulation of private health insurance.**

Federal:

Ten Planning Council reports included recommendations targeted to the federal government. Five recommended federal legislation to prohibit health insurance exclusions on the basis of pre-existing conditions. Specific recommendations were found in four Council reports for support of S. 768, the Basic Health Benefits for All Americans Act; and in two for support of H.R. 2649, the Federal Health Insurance Equity Act. Other recommendations were for health insurance reform, the addition of federal requirements for scope of coverage, and for federal standards in general. Three reports also recommended that the Employee Retirement and Income Security Act exemption from state insurance regulation for self-insured plans be eliminated.

Federal/State:

No recommendations were found in relation to state use of federal programs.

State:

➔ **Examine risk pools and expanded state regulatory activities.**

The two areas targeted for state action in the reports were the creation of risk pools to provide access to insurance for people unable to obtain private health insurance (thirteen states) and the state regulation of insurance (eleven states). Council recommendations regarding risk pools were divided among improvements to existing programs and the establishment or implementation of new programs. Recommendations on insurance regulation suggested stronger state regulation in general, with particular interest in exclusion on the basis of pre-existing conditions and the scope of coverage. One report (Puerto Rico) also recommended that the commonwealth assure the coverage of government employees with dependents who have a developmental disability.

3. Comprehensive health care

State Council Reports: Accomplishments and Opportunities

In addition to the scope of private health insurance coverage, several State Planning Council reports addressed comprehensiveness of scope in relation to publicly financed health programs. An example of an accomplishment in this area was found in the Wisconsin report, which noted that the state has the most comprehensive array of optional services under its Medicaid program of any state in the nation.

State Council Reports: Critical Issues and Barriers

✓ Gaps in state Medicaid plans

Thirteen Council reports highlighted gaps in their respective state Medicaid plans regarding covered services. Because of the differences in state plans, there was considerable variety in the issues cited, ranging from specific references to the scope of the EPSDT program, dental care, and nursing services for children who are ventilator dependent, to the overall institutional bias of the state's Medicaid program. As with eligibility barriers, a lack of state funding was the primary reason noted regarding limited Medicaid scope.

✓ Gaps in Medicare coverage

Three major gaps in relevant Medicare coverage were identified in the State Council reports:

- A general lack of coverage of health related services that are needed for ongoing health support of people with disabilities (nine reports)
- Lack of Medicare coverage for augmentative communication devices (e.g., computerized communication boards and hearing aids) (nine reports)
- « Lack of coverage for rehabilitation therapies for people who are not expected to make measurable functional progress even though they are likely to degenerate functionally without the rehabilitation therapies (nine reports)

“*They do other dumb things like restrict the number of diapers they will pay for....It seems to me that Medicaid people have never seen anyone with a handicap because if they had, they would change their policies.*”

—Utah parent

Eight Council reports noted a general concern that public health finance programs are limited in scope. A mix of other health care scope issues were raised by individual states, e.g., the limited number of hours some health services are available.

State Council Reports: Recommendations

➔ Expand the scope of Medicare and Medicaid.

Federal:

A few State Planning Council reports recommended changes in the Medicare program to broaden its scope, in particular its orientation toward acute care and resulting relative lack of coverage of services related to chronic conditions. Two reports recommended that a long term care benefit be added. Regarding the Medicaid program, one state (Indiana)

recommended that the federal government put limits on state discretion regarding optional services.

Federal/State:

➔ **Increase the available scope of services through Medicaid.**

Ten Council reports included recommendations that their state expand its use of the Medicaid program to provide a broader array of services. In addition to the general recommendations for expansion, six states recommended a broader scope for their state's EPSDT program. Individual recommendations included Mississippi's that the state increase the Medicaid 30-day limit per year on reimbursable inpatient hospitalization. Five Councils recommended **that** the state examine the possibility of various Medicaid waiver programs as a way of broadening scope.

One report (Alaska) recommended that the state expand its dollar cap on allowable expenses under the state's PCSHCN program.

State:

Only two recommendations were identified. The Florida report urged the state to provide equitable levels of public health services across **the** state, and the Idaho report recommended that dental care be an allowable service in "shelter homes" for people with developmental disabilities.

4. High quality health care

State Council Reports: Accomplishments and Opportunities

The primary issue noted in the State Council reports regarding quality was the lack of knowledge of developmental disabilities on the part of health care providers. An example of an accomplishment in this area was found in the Illinois report, as follows:

Loyola School of Dentistry's Division of Preventive Dentistry and Community Health has made a commitment to working with their dental students so that they have a wide variety of experiences during their educational training. Junior dental students are required to go on three visits, including one involving people with disabilities. Senior dental students are required to complete a 12-hour course on disabilities. The school's general practice residency program includes firsthand experience with people with developmental disabilities. Once each week residents of five different community residences in the Chicago area and people

with disabilities who live in the community come to the Dental School and receive dental care from the residents. (Illinois report)

State Council Reports: Critical Issues and Barriers



Questions about the quality of health care for people with developmental disabilities

Ten Council reports included concerns regarding the quality of health care for people with developmental disabilities associated with lack of provider knowledge of their needs, as described in the following excerpt from the Alabama report:

If one gets by accessibility and attitudinal barriers, the person with 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). (Alabama report)

Four reports noted quality of care concerns in HMOs. Other issues included concerns about state Medicaid requirements that only generic prescription drugs be used, the poor quality of care available to Native Americans, and the overuse of psychotropic medications.

State Council Reports: Recommendations



Enhance education of health professionals regarding developmental disabilities.

The primary recommendation in relation to quality, found in one-third of the Planning Council reports which addressed health issues, was to include more knowledge of developmental disabilities in professional education and training.

Federal:

There were no recommendations in this area addressed specifically to the federal government.

Federal/State:

Two Council reports recommended improvements within the Medicaid program in relation to quality. The Iowa report recommended that a mechanism be added to address consumer complaints and the Montana report recommended more flexibility in the program in order to provide more individualized services.

- ➔ **Include developmental disabilities knowledge in professional licensure requirements.**

State:

Two Planning Council reports included recommendations that education requirements on knowledge of developmental disabilities be added to the state's professional licensure requirements. Other recommendations included the monitoring of HMO utilization by people with disabilities and state-specific recommendations on public health services, improvements in medication review procedures, and provision of "medical case management."

5. (Prevention and early intervention)

State Council Reports: Accomplishments and Opportunities

Reports from a few Councils noted accomplishments in the area of preventive health, prevention of disability, and early intervention:

- ★ **Public health programs are expanding access to health care.**

- Reducing and identifying risk factors is a high priority of the Council. In August 1989 the Council funded a strategic planning effort of state agencies and health and advocacy organizations. Their primary goal was to identify ways to prevent disabilities and, as a result, to reduce the cost of providing publicly financed services needed as a result of disabling conditions. The Disability Prevention Planning Project recommended a unified, statewide program to be implemented at the community level. The project called for the promotion of an "ethic of prevention," that is, a desire to reduce preventable disabilities while remaining supportive and non-judgmental of those families who have or may have a child with special needs. (Washington report)
- The Wisconsin Public Health Plan for the Year 2000, to be completed in January 1990, is a significant planning effort by the Department of Health and Social Services, and with implementation will help Wisconsin to improve and expand public health services. Although expansion is still necessary, the Healthy Start program is a step in the right direction of providing maternity care to some women previously not covered.

Wisconsin's implementation of the Birth and Development Outcome Monitoring Program will provide valuable prevention and planning

information and will assist parents in location early intervention services. (Wisconsin report)

- The Office of Maternal and Child Health has established an automated tracking system to facilitate early and appropriate referral to services for children who may have a developmental disability and to collect data on needs for long range planning purposes. (Arizona report)

Additional examples are noted in the section above on access and availability, and in the chapter on education regarding early intervention that is coordinated through the Infants and Toddlers program (Part H of the Education for the Handicapped Act, P.L. 94-142 as amended.)

State Council Reports: Critical Issues and Barriers

“ You can't go in for preventive medicine because Medicaid won't pay for it. It should be very obvious in this day and age that preventive medicine is the only thing that makes sense.”

—Utah parent

Fifteen State Planning Council reports referenced issues related to preventive health, and fourteen of these reports raised concerns in relation to the prevention of developmental disabilities. About half of these noted the significance of barriers to prenatal care, in particular for low-income women; four specified the particular risks associated with teen pregnancy. Other concerns included the impact of substance abuse and of AIDS/HIV infection on infants in relation to their risk for developmental disability; lead exposure; and the overall lack of emphasis on preventive health. A few reports noted the lack of reimbursement in health insurance, the state's limited Medicaid coverage, or limits in their EPSDT program as factors associated with inadequate preventive health measures.

State Council Reports: Recommendations

Federal:

There were no recommendations in this area specifically targeted to the federal government.

Federal/State:

Two reports from Councils recommended expansion of the Women's, Infant's and Children's Supplementary Feeding (WIC) program.

State:

Six State Councils addressed the need for improved prevention through expansion of prenatal care and

➔ Expand access to prenatal care.

other maternal and child health services. Other recommendations included activities to reduce teen pregnancy, expansion of substance abuse treatment, AIDS/HIV prevention, planning initiatives, and public education efforts. Five reports recommended the expansion of health-related early intervention programs.

6. Mental health services

State Council Reports: Accomplishments and Opportunities

Approximately 40 percent of the Council reports addressed mental health services as part of the overall system of needed health care or in the context of supports needed by some people with developmental disabilities. Recent achievements included the following:

★ **Access to mental health services is expanding for children and adolescents.**

- The Child and Adolescent Service System Program (CASSP) has funded nine community mental health center/local education agency (LEA) projects. All of the centers work with the LEAs to provide mental health services to students with emotional disabilities. CASSP projects were established to accomplish systemic changes in the service system, to become responsive to children's needs, to take advantage of community resources, and to create opportunities. (Indiana report)
- The Wisconsin Department of Health and Social Services and the Department of Public Instruction have entered into a cooperative agreement with a pilot county in an effort to address several critical issues for children with emotional disturbances. The Robert Wood Johnson Foundation is providing Wisconsin with a one-year grant of \$100,000 to support the development of a coordinated array of community treatment and support programs for youth with serious emotional disabilities. This effort is indicative of a relatively new kind of cooperative activity between the public and private sectors. (Wisconsin report)

★ **Issues regarding services for people with "dual diagnosis" are being resolved.**

- In spring 1988 the Council facilitated meetings between the Division of Developmental Disabilities (DDD) and the Division of Mental Health and Hospitals that resulted in a work group dealing with issues of dual diagnosis. Some

work has been done to clarify the definition of dual diagnosis for DDD eligibility criteria. The work group also drafted a proposal for a demonstration project to identify systemic barriers that impede comprehensive treatment planning and coordinated clinical services for this population. (New Jersey report)

- Several of the Council's informants felt that the changing role of the state developmental disability service system, over time, had been a significant and positive development. For example, several persons pointed to the shift by the Mental Health Division to contracting through community mental health programs and the expansion of funding for case management services as positive developments. (Oregon report)
- In Tennessee, three grants totaling approximately \$1.7 million over a two-year period will provide case management, counseling and housing rehabilitation in the large urban centers for homeless persons who have mental illness. (Tennessee report)

State Council Reports: Critical Issues and Barriers

“Mental health services have not been adequate and have not met her needs. There is no constructive day programming to help get her involved in working through her problems.”

—Ohio parent

As reflected in the examples of recent accomplishments, the three major issues identified in the Planning Council reports in relation to mental health were the unmet needs of people with a dual diagnosis of developmental disability and mental illness, concerns about services to children and youth with serious emotional disturbance, and the overall lack of community mental health services in general.

Some Council reports noted consumer survey findings in relation to unmet needs for mental health services. Data from the summary of state consumer surveys indicated significant unmet needs for counseling and mental health services. Approximately 24 percent of the respondents expressed a need for such services, but less than half of these were receiving them.

Eleven Councils identified issues regarding care for people with dual diagnosis. Three of these also noted concerns regarding their inappropriate hospitalization and access to community based alternatives. The primary barriers noted were problems in interagency coordination and related issues in eligibility, funding, and the availability of appropriate services in community settings.

✓ **Lack of mental health services for children**

The primary issue raised in the eight State Council reports which addressed children's mental health concerns was a general lack of services. A few also noted funding issues and problems in interagency coordination.

✓ **Lack of community mental health services in general**

Lack of community mental health services in general was noted in nine reports. Other issues raised in individual reports included needs of people who are both homeless and mentally ill, lack of resources and emphasis on preventive mental health services, and the need for psychiatric review of the use of psychotropic medications for residents of the state developmental disability institution.

State Council Reports: Recommendations

Federal:

There were no recommendations directed to the federal government.

Federal/State:

➔ **Expand Medicaid coverage.**

Three Planning Council reports included recommendations on expanded use of the state Medicaid program to increase the availability of mental health services. Two reports recommended use of the state mental health plan in conjunction with requirements of the State Comprehensive Mental Health Services Plan Act of 1986 (P.L. 99-660) to improve services.

State:

➔ **Improve the public mental health system including better services for people with "dual diagnosis."**

Ten of the thirteen State Planning Council reports that made recommendations in the area of mental health indicated support for improvements in the state's community mental health system; about half of these specifically addressed their recommendation to the community mental health needs of people with developmental disabilities. Four reports targeted recommendations specifically to those with a dual diagnosis, including better coordination, improvement of services, and clarification of eligibility. Recommendations on services to children were found in four reports, focused on the prevention of out-of-home placement and supports to families.

VIII. Civil Rights

VIII. Civil Rights

State Council Sports: Overview



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.

—New Jersey report

Nearly all State Council reports included discussion of the empowerment of people with developmental disabilities and their civil rights; over half of the reports included a separate section in these areas. The thrust of these discussions was that people with developmental disabilities have the right to the full range of protections afforded those without disabilities.

Federal programs and provisions cited by the State Councils included Section 504 of the Rehabilitation Act Amendments of 1973 (P.L. 93-112), the Civil Rights of Institutionalized Persons Act (CRIPA) passed in 1980 (P.L. 96-247), the Protection and Advocacy program authorized by the Developmental Disabilities Assistance and Bill of Rights Act, the Fair Housing Act as amended by P.L. 100-430, and the voting rights provisions of the Voting Rights Act of 1965 and the Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435). The Americans With Disabilities Act, pending federal legislation at the time the State Council reports were submitted to the Secretary of Health and Human Services, also was referenced in several reports.

State programs addressed by the Councils included state anti-discrimination provisions regarding areas such as employment, polling place accessibility initiatives, and state statutes on guardianship. Local initiatives also were referenced in a few reports, in particular those affecting accessible parking spaces. Related discussions of civil rights and empowerment were found in State Council presentations on the various life areas, in particular in education and housing.

The majority of State Council reports identified goals in the area of civil rights and consumer empowerment, either as general statements of full rights and protections or in relation to specific goals. The goals identified by the Councils included the following:



It is the State Council's vision that all people with developmental disabilities shall have the same rights as individuals without disabilities.

—California report



Vision: people with disabilities should be entitled to participate fully in every aspect of American life.

—Massachusetts report



Vision: people with developmental disabilities...have control over their services, thereby directing their own lives.

—Guam report



Advocacy must be available and affordable for all citizens who seek to secure and protect their rights.

—Florida report



Vision: people with disabilities manage their own affairs...Very few have guardians or representative payees.

—Michigan report

1. The same rights and protections as all American citizens

One of the goals found most frequently in the State Council reports was that people with developmental disabilities have the same rights and protections as everyone else. Specific goals included legislative protections at the federal and state levels, and effective enforcement of legal and regulatory protections.

2. Promotion of accessibility and full participation

A second type of goal found in virtually all of the State Council reports was the promotion of accessibility and community participation for people with developmental disabilities. Goals of accessibility and participation were identified by the Councils across the life areas and in relation to such basic civil rights areas as the right to vote.

3. The empowerment of individuals

Another goal frequently found in the reports was the empowerment of people with developmental disabilities, including full access to information, exercise of personal choice and control over their lives, and self-advocacy.

4. Access to legal recourse

Access to supports that assist people with developmental disabilities in exercising their legal rights was also a goal identified by the State Councils in their reports. Goals included the availability of legal services, protective services, and advocates.

5. Appropriate use of guardianship

Goals in relation to the appropriate use of guardianship were identified by several State Councils. The thrust of these statements in the Council reports was that guardianship of people with developmental disabilities should be used only when needed and should be limited to those areas in which the person requires assistance.



Vision: People are protected from neglect and abuse, and are assured their full human, legal and civil rights.

— Indiana report

1. The same rights and protections as all American citizens

State Council Reports: Accomplishments and Opportunities



Federal civil rights legislation

6. Freedom from harm

A sixth type of goal in the civil rights area found in the State Council reports was the protection of people with developmental disabilities from harm, through effective program monitoring and quality assurance activities across the life areas.

Several of the State Council reports cited federal statutes through which the federal government has attempted to prohibit discrimination based on disabling conditions. As noted above, these included Section 504 of P.L. 93-112, as the first civil rights legislation to guarantee an equal opportunity for people with disabilities through provisions applying to recipients of federal funds.

Several Councils reported that their states have enacted legislation patterned after the Rehabilitation Act. These laws prohibit discrimination in programs or activities conducted by or funded through state funds.

Another set of protections cited by several of the Councils was the Fair Housing Act Amendments (FHAA) of P.L. 100-430, which became effective in March of 1989. The reports noted that while Section 504 could protect people with disabilities from discrimination in housing financed with federal dollars, the FHAA reaches private housing and rental accommodations.



State anti-discrimination legislation

Specific accomplishments at the state level identified by the Councils included the following:

- The Idaho Human Rights Commission Act, passed in 1969, prohibits discrimination because of race, color, sex or national origin in connection with employment, public accommodations, education and real property transactions, and discrimination because of age (40 and over), or disability in connection with employment. The addition of disability as a protected basis became effective July 1, 1988. (Idaho report)
- The Montana Legislature passed in 1983 a Veteran's and Handicapped Persons' Employment Preference Act. Under this Act, a person with a

disability who is substantially equally qualified for a position must be hired over a person not eligible for the preference. (Montana report)

- In 1971 the State of Washington passed civil rights legislation. The statute includes areas such as: employment, age, sex, real estate and education. A Human Rights Commission was established to enforce the provisions of the law. (Washington report)

State Council Reports: Critical Issues and Barriers



Enforcement provisions are weak.

A major issue that surfaced in the State Council reports was the weakness of the enforcement provisions of federal, state and local legislation. As described in the Alabama report, "Existing laws to protect Alabama citizens with disabilities are frequently inadequate, ignored, minimally implemented or inconsistently enforced."



Few anti-discrimination statutes at the state or local levels

Five State Council reports specifically referred to the lack of anti-discrimination statutes in the private sector or at the state level.

A few reports also noted concerns that the protections of Section 504 have been weakened by some judicial decisions or by weak enforcement. For example, the Texas report included the following statement:

Section 504 of the Rehabilitation Act has never been enforced. I have not found any real effort to follow through to make public buildings accessible... Besides monitoring and enforcement, we also need technical assistance and education to help people comply." (Texas consumer)

State Council Reports: Recommendations

Most of the recommendations made by the State Councils in this area dealt with the enforcement of current legislation or the passage of new legislation.

Federal:



Enact, implement and enforce the Americans With Disabilities Act.

The primary State Council recommendation in this area targeted to the federal level was the passage and enactment of the Americans With Disabilities

Act (ADA), an omnibus civil rights statute that reaches into the private sector in its prohibitions against discrimination on the basis of disability. State Council reports noted that the ADA specifically prohibits discrimination against individuals with disabilities in private sector employment, all public services, public accommodations, transportation and telecommunications, and places the federal government in the central enforcement role. Nineteen State Councils specifically recommended the passage of the Americans With Disabilities Act with assurances that the ADA, when passed, would include strong enforcement provisions. As recommended by the Michigan Council, "Congress should pass, and the President sign, without weakening amendments, the Americans With Disabilities Act, and assure direct, prompt, full implementation."

As noted above, the ADA had been passed by the Senate and was awaiting action in the House of Representatives at the time the State Council reports were prepared.

➔ **Enforce Section 504 at the federal, state and local levels.**

Strong enforcement of Section 504 of the Rehabilitation Act also was recommended by many of the State Councils. A few Councils recommended increased levels of enforcement at the federal level.

Federal/State:

There were no recommendations in this area other than more effective enforcement of Section 504 and other protections, as noted above.

State:

➔ **Anti-discrimination laws at the state and local level should be enacted.**

The major recommendations in this area dealt with the passage of legislation at the state and local levels to mirror anti-discrimination legislation that currently applies only at the federal level. Some State Council reports warned against passing legislation without strong enforcement provisions. For example, the Nebraska Council recommended that the state "should consider adopting a State Bill of Rights for persons with disabilities to ensure that state laws include strong nondiscrimination and enforcement provisions." (Nebraska report)

2. Promotion of accessibility and full participation

State Council Reports: Accomplishments and Opportunities

★ **Voting rights for people with disabilities**

Several State Council reports noted accomplishments in the promotion of full voting accessibility for people with disabilities. At the federal level these included the Voting Rights Act of 1965 which provides the right to choose a voter assistant who may aid the individual with a disability to whatever extent is deemed necessary. Another federal action cited by the Councils was enactment of the Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435), which encourages participation and promotes integration by enabling people with disabilities to access polling places.

Several Councils also noted that their state has made progress in assuring that polling places are accessible.

★ **Increased accessibility**

Accomplishments in promoting accessibility were cited by the Colorado Council as follows:

Denver has become a model for physical accessibility of public transportation. The Denver Commission on the Disabled has been active for many years in advocating and providing funding for curb cuts, snow removal, and other accommodations which permit persons with handicaps to move about Denver more easily. (Colorado report)

Accomplishments in the promotion of accessibility through public education can be found in the chapter on supports.

State Council Reports: Critical Issues and Barriers

✓ **Lack of accessibility as a barrier to independence, productivity and integration**

Most Council reports identified lack of physical and communications accessibility as a major barrier to the full integration of people with disabilities. State Councils referred specifically to inaccessibility in residential settings, at work sites, and in places of recreation. For example, the Idaho Council included the following statement:

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 taint and distant. Many of these have been ignored or abused because accommodation is costly, inconvenient or infrequently requested. (Idaho report)

✓ **Polling places are inaccessible to people with disabilities.**

An issue raised by a majority of Councils was the inaccessibility of many voting places. Several reports noted that despite the fact that all individuals over the age of 18 have a legal and constitutional right to vote, many individuals with disabilities are denied that right due to physical and attitudinal barriers. Fifteen State Councils mentioned voting as an area where individuals are often prevented from exercising a civil right and responsibility. For example, the voting accessibility issue was described in the Colorado report as follows:

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. (Colorado report)

✓ **Low voter participation**

Several State Council reports also included data from their consumer surveys to highlight their concerns about the participation of people with developmental disabilities in exercising their right to vote. The summary of the state consumer surveys indicated that of the 8,296 adults who responded to the question, "Did you vote in the most recent general election?" 28 percent responded affirmatively, compared to 49 percent in the general population (League of Women Voters, 1988).

A particular concern raised in some of the State Council reports was that individuals living in congregate care settings are often denied the right to vote, based on a presumption that their disability precluded them from voting.

“Society is making people second class citizens.”

—Georgia consumer

Several Councils reported that public attitudes and prejudices act as a barrier to accessibility. For example, the New Mexico Council noted that:

Community education is needed to promote an understanding of the significance of independence, productivity and integration in the lives of people with developmental disabilities. (New Mexico report)

State Council Reports: Recommendations

Federal:

The primary recommendation in the State Council reports addressed to the federal government in this area was the enactment of the Americans With Disabilities Act, as noted in the previous section.

Federal/State:

A few reports included recommendations that states move more aggressively in the enforcement of existing federal accessibility legislation.

State:

→ Enforce state laws.

Many State Council reports referred specifically to state legislation dealing with architectural barriers or barrier-free environments. For those states with accessibility statutes, recommendations were primarily in the area of education and enforcement. Other State Councils advocated for passage of legislation specific to accessibility issues, both physical and communication. For example, the Utah report stated that "The Council's recommendation regarding access includes stronger legislative action to eliminate architectural barriers."

→ Educate policymakers and the public.

To address attitudinal barriers to accessibility, approximately half of the State Council reports included recommendations to educate policymakers and the larger community about the rights of people with developmental disabilities and their potential for independence, productivity and community integration.

3. The empowerment of individuals

State Council Reports: Accomplishments and Opportunities

- ★ **The self-advocacy movement has gained momentum during the past decade.**

Several State Councils reported on recent accomplishments in the promotion of empowerment of individuals with developmental disabilities, in particular their self-advocacy:

- Arkansas, the self-advocacy movement began at the local level- In Conway, a group which called themselves the Community Client Club organized in 1982...The individuals living in homes owned by First Step Center in Hot Springs have nightly meetings without staff members present at which they deal with any topic they wish. (Arkansas report)
- The Speaking for Ourselves organization consists of self-advocates who meet periodically to discuss barriers to their integration into the community, their unmet needs, and other issues. (Colorado report)
- In 1989, the [self help project operated by the Association of Retarded Citizens/New Jersey] held its fifth conference, attended by more than 400 people from throughout the state. (New Jersey report)

“*In the past, it was up to us to decide what to do with our daughter. When people would ask, what will you do, what will she do, I could never answer. In the last year or so, Jylle has been telling us what she wants to do. It has taken me to task, because in the past I didn't really think she had the right or the ability to make a choice. She would like to live in an apartment. She would like to choose with whom she lives. I think she has the right to do that.*”

—Arkansas parent

Exercise of consumer choice and control was noted by several Councils, especially in relation to housing. For example, the Utah Council reported that \$500,000 had been allocated to the state Department of Mental Health for a demonstration project to move 25 individuals from a state hospital to community settings. Individuals are to be asked in which town they wish to live and in what type of setting. The support system will then be built around the individual at his/her direction.

Empowerment of family members also was featured in the Arkansas report, which noted a series of leadership training sessions sponsored by the State Planning Council in 1989 which brought in several national experts to provide training to parents from around the state.

- ★ **Over 15,000 consumers were surveyed.**

The strong consumer participation required in the 1990 report process was noted by several Councils as an accomplishment, in particular the state consumer surveys that involved over 15,000 consumers across the states and territories in providing information about their needs and preferences.

“ I’m really glad they asked the person with a disability [in] this survey instead of the parents and guardians like they usually do.”

—Ohio consumer

★ Consumers provide guidance on policies and programs.

Efforts to give consumers a voice in the service system also were noted by Councils, as illustrated by the following examples:

- The Subcommittee on Consumer Involvement (SCI) of the State Council on Developmental Disabilities is comprised of people with developmental disabilities and has as its mission to increase [their] active participation in the policy making, service planning, service delivery, monitoring and evaluation aspects of the developmental services system in California, including the constitution of a forum for primary consumer input on systemic issues of concern. (California report)
- Membership on Wisconsin's Consumer Advisory Council for the Division of Vocational Rehabilitation includes a broad representation of consumers.... It meets on a regular basis to advise the Administration, which has taken that advice many times. The Division's leadership in establishing such a Council and its reliance on this Council for policy and program guidance is quite unique among state agencies and reflects a commitment to consumer participation and empowerment. (Wisconsin report)

State Council Reports: Critical Issues and Barriers

“ I live in a group home with a roommate. I don't like my roommate, but I have no choice. I want my own place and my own job. I am 57 years old. Another thing, my brother keeps all my money, and I don't like that either. I think that I should have some choice in things.”

—Oklahoma consumer

✓ Limited consumer role in decisions on programs

Many State Council reports indicated that consumers had voiced their frustrations with the service delivery system and the extent to which it precludes independence, productivity, and integration. Nearly all the reports included data from the state consumer surveys in relation to their independence. The summary data in this area revealed that when individuals were asked, "How independent do you think you are?" and "How important is it to you to be independent?", 75 percent of the individuals said it was important to them to be independent; however, only 26 percent said that they were, in fact, independent.

A related concern identified by some Councils was that people with developmental disabilities are seldom included in planning and monitoring the programs that affect them. For example, the Michigan Council report noted that:

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. (Michigan report)

✓ **People with disabilities don't know or understand their rights.**

A major concern expressed by State Councils in their reports was that the provisions of various laws are not, for the most part, known to people with disabilities and their advocates. These Councils noted that for people to be empowered, it is imperative that they know and fully understand their rights and responsibilities. As described by the Washington State Council:

By law, citizens of the state of Washington who are disabled 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. (Washington report)

✓ **The legal/judicial community needs to be educated about disability issues.**

State Councils also raised the related issue of the lack of education of the legal community in advocating on behalf of people with disabilities. This lack of education was noted to extend beyond lawyers (both private and public interest) to judges and others in the judicial system. As stated in the Utah report:

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. (Utah report)

Some Councils indicated that this lack of education prevented attorneys from representing people with disabilities in legal actions, be they civil or criminal. As described in the Massachusetts report, "The Massachusetts Legal Assistance Corporation reports that 85% of the civil legal needs of the poor, including people with disabilities, are unmet."

State Council Reports: Recommendations

- ➔ **Federal, state and local government must take responsibility for educating people with disabilities, their families and advocates.**

More than two-thirds of the State Planning Councils recommended that government at all levels take responsibility for educating people with disabilities and their families and advocates about legislation that exists to protect their civil rights. Another recommendation made by some Councils was that requirements be added for consumer participation in program planning and monitoring.

Federal:

A few State Council reports included recommendations targeted to the federal level regarding consumer empowerment. The Massachusetts Council stated, for example, that "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."

Federal/State:

Some State Council reports noted that the education of people with disabilities and their advocates should be the responsibility of the Protection and Advocacy agency and the Developmental Disabilities Planning Council in the state.

State:

- ➔ **Promote increased consumer control.**

Most of the recommendations in the State Council reports in this area were focused on activities at the state and local level. The primary recommendation in this area was to increase the opportunities of people with disabilities to exercise choice and control over their lives (recommended by over 80 percent of the Councils).

- “*As an adult I have the right to live my life as independently as everyone else. That right and my desire to exert that right should never be questioned.*”

—Maine consumer

- ➔ **Promote self-advocacy and empowerment.**

States were encouraged to develop service approaches that enable the consumer to choose the type of setting in which they live, work or recreate, the type of supports they receive, and the person or agency who provides services.

Nearly half the Councils also recommended the promotion of self-advocacy and empowerment in general. Most State Council reports addressed the issue of education of consumers on their civil rights as well as education of policymakers and the public in their recommendations.

➔ **Consumers should be represented on all boards and commissions.**

Another strategy recommended by several Councils was to include consumers on the various boards and commissions that plan and oversee the programs that affect them, as people with disabilities and as residents of their communities.

➔ **Consider new funding mechanisms that increase consumer and family control.**

Several Councils recommended consideration of new funding mechanisms that promote increased control of consumers and family members over the supports and services they utilize. For example, some Councils suggested exploration of the use of direct cash payments to families based on the needs of the child as identified by the family or vouchers and variations on individual family service plans. As recommended by the Maine Council, "Policy 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." Related State Council recommendations can be found in the supports chapter.

4. Access to legal recourse

State Council Reports: Accomplishments and Opportunities

★ **Protection and Advocacy systems were established to protect the rights of people with developmental disabilities.**

The primary accomplishment noted by Councils in this area was the establishment of the Protection and Advocacy (P&A) program in the Developmental Disabilities Assistance and Bill of Rights Act as amended by P.L. 94-103.

State Council Reports: Critical Issues and Barriers

✓ **Funding levels for P&As are inadequate to meet the need.**

Many Councils reported that the funding level of the Protection and Advocacy program is insufficient to provide services to all who need them. As stated in the Massachusetts report:

The present Protection and Advocacy Program for Developmental Disabilities and Mental Illness does not have sufficient resources to represent all the legal needs of people with developmental disabilities. (Massachusetts report)

Some Councils also noted that there is a dearth of expertise in the legal community to deal with issues that go beyond those involving discrimination under federal and state statutes, and that it is difficult for individuals to find attorneys who are

- ✓ **People with developmental disabilities are in need of legal and protective services.**

willing and able to represent people with developmental disabilities.

Related data from the summary of the state consumer surveys indicated that although 23 percent of the individuals surveyed expressed a need for legal or protective services, only 8 percent were receiving these services.

A few State Councils also noted that under CRIPA it is unclear whether Protection and Advocacy agencies have a right to initiate actions, despite their readiness to do so.

State Council Reports: Recommendations

- ➔ **Increase funding levels of P&A agencies.**

Federal:

Some reports recommended that the funding level of the Protection and Advocacy program be reexamined and increased to ensure services to all individuals who need them.

Federal/State:

As noted above, some Councils recommended that P&As continue to be involved in informing people with developmental disabilities about their rights.

State:

A few Councils recommended that there be a continued emphasis on the need for pro bono work on behalf of people with developmental disabilities at the state and local level, so that people with disabilities have access to counsel regardless of their ability to pay.

5. Appropriate use of guardianship

State Council Reports: Accomplishments and Opportunities

- ★ **Federal legislation establishing standards for guardianship is pending.**

A few State Councils noted that a National Guardianship Act (HR 1702, S 235) has been introduced in the U.S. Congress, covering people with developmental disabilities as well as people who are elderly. Councils cited provisions of the legislation such as federal minimum standards for potential guardians, delineation of the substantive and due process rights of people alleged to be incompetent, provisions for the presence of attorneys as advocates, and incentives for state adoption of

the federal guidelines. Similarly, a few Councils noted that a model statute on guardianship and standards for adjudication of competency was prepared by the American Bar Association's Commission on Mental Disability in 1979.

★ **Volunteer guardian/advocates**

At the state level, the Arkansas Council described a program of volunteer guardian/advocates, a private, non-profit corporation that is funded through federal, state and private sources. The project recruits, trains, monitors and supports individuals who are willing to become volunteer guardians for people with developmental disabilities. As described by the Council in its report, the volunteers frequently serve in the capacity of citizen advocates rather than assuming responsibility of legal guardians; volunteers are encouraged to promote maximum independence and choice for the person with a developmental disability as well as to ensure stringent protection where it is needed.

State Council Reports: Critical Issues and Barriers

✓ **Guardianship is often used inappropriately.**

Approximately one-third of the State Council reports raised concerns about the protection of civil rights in the use of guardianship for people with developmental disabilities. Several of these Councils noted that guardianship can represent the most intrusive form of state government intervention into the life of a person with a disability. Another concern raised by Councils was that guardianship is sometimes used inappropriately when other less intrusive means could be employed. For example, the Ohio Council noted its concern as follows:

While guardianship is needed for many people with developmental disabilities, especially those with 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. (Ohio report)

Other reports noted that state laws are often unclear in defining when guardianship is needed and to whom guardianship should be awarded.

✓ **Guardianship is not available to some in need.**

Six Councils reported that guardianship is not available to all those in need of guardianship. Lack of resources also was noted as a barrier to effective guardianship by a few Councils. For example, the Alaska Council reported that the state has a guardianship law that is considered a model

statute by the American Bar Association; yet, understaffing and large caseloads make the high standards set in the law impossible to maintain. A few Councils also observed **that** becoming a guardian is often an expensive undertaking.

Some Councils expressed concern that guardianship is often provided by the same department in state government that provides services, potentially creating a conflict of interest or preventing the person with a disability from receiving the best advocacy possible.

State Council Reports: Recommendations

Federal:

➔ Develop national guardianship standards.

The primary recommendation of the Councils at the federal level was that uniform national standards on guardianship be developed (four reports) or that the National Guardianship Act be enacted (two reports).

Federal/State:

There were no recommendations in this area.

State:

➔ Increase the availability of quality guardianship.

The majority of State Council recommendations on guardianship were targeted to the state level. The primary recommendation was that guardianship be made available to all those with developmental disabilities in need of guardianship. At the same time several Councils recommended that the quality of guardianship should be improved, for example, by more emphasis on the promotion of people's independence or by providing it through an entity not involved in the provision of services. Another Council recommendation in this area was to provide options for limited guardianship.

6. Freedom from harm

State Council Reports: Accomplishments and Opportunities

A few State Councils noted that the United States Constitution guarantees that all American citizens be protected from harm, and that this protection is implicit in federal legislation that has been enacted to protect individuals with disabilities, such as the Developmental Disabilities Assistance and Bill of Rights Act and the Civil Rights of Institutionalized Persons Act (CRIPA).



States have developed quality assurance systems to protect individuals from abuse and neglect.

Many Councils discussed state quality assurance activities in regard to protecting people from harm. The Utah Council described the following approach:

A volunteer monitoring committee has been established, where volunteers are trained to monitor residential facilities, both congregate and community based. Homes are visited three times: once announced, twice unannounced. (Utah report)

More information on Council observations on the states' quality assurance activities can be found in the chapter on housing .

State Council Reports: Critical issues and Barriers

Many of the issues raised by the states in regard to protection from harm have been discussed in the sections on civil rights protections and guardianship, and in the chapter on housing. A few Councils addressed additional issues. For example, the Mississippi Council report stated that:

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. (Mississippi report)



Consumers and families are excluded from monitoring activities.

Ten Councils cited the exclusion of individuals with developmental disabilities and their families from the process of monitoring and assuring service and support quality as a major barrier to independence, productivity, integration and satisfaction.

Two Councils raised concerns about the use of aversive measures in treatment and "behavior control". As discussed in the Massachusetts Council report:

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 (Massachusetts report)

State Council Reports: Recommendations

- ➔ **Include consumers and families in monitoring activities at the federal, state, and local levels.**

Council recommendations in relation to freedom from harm generally did not specify particular programs or levels of government. The primary strategy recommended by Councils in this area was increased emphasis in quality assurance on individual outcomes. Another recommendation was that individuals receiving services, and their families where appropriate, be included in the planning, delivery, and monitoring of the provision of services. For example, the Minnesota Council recommended that "consumers and families use simple but powerful checklists to monitor and evaluate services."

- ➔ **Examine the issue of aversive interventions.**

Review or decreased use of aversives was specifically recommended by three Councils.

APPENDIX A

THE DEVELOPMENTAL DISABILITIES AND BILL OF RIGHTS ACT

SELECTED EXCERPTS

THE DEVELOPMENTAL DISABILITIES AND BILL OF RIGHTS ACT

SELECTED EXCERPTS

Definition of Developmental Disability

"SECTION 102

"(5) The term "developmental disability" means a severe, chronic disability of a person which—

"(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

"(B) is manifested before the person attains age twenty-two;

"(C) is likely to continue indefinitely;

"(D) results in substantial functional limitations in three or more of the following areas of major life activity:

"(i) self-care,

"(ii) receptive and expressive language,

"(iii) learning,

"(iv) mobility,

"(v) self-direction,

"(vi) capacity for independent living, and

"(vii) economic self-sufficiency, and

"(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated...."

Definitions of Independence, Productivity and Integration

"SECTION 102

"(6) The term "independence" means the extent to which persons with developmental disabilities exert control and choice over their own lives.

"(7) The term "productivity" means—

"(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or community.

"(8) The term "integration" means—

- "(A) the—
 - " (i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and
 - "(ii) participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and
- "(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities...."

Rights of Persons with Developmental Disabilities

"SECTION 110. Congress makes the following findings respect[ing] the rights of persons with developmental disabilities:

- "(1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.
- "(2) The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty.
- "(3) The Federal Government and the States both have an obligation to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that -
 - "(A) does not provide treatment, services, and habilitation which is appropriate to the needs of such persons; or
 - "(B) does not meet the following minimum standards:
 - "(i) Provision of a nourishing, well balanced daily diet to the persons with developmental disabilities being served by the program.
 - "(ii) Provision to such persons of appropriate and sufficient medical and dental services.
 - "(iii) Prohibition of the use of physical restraint on such persons unless absolutely necessary and prohibition of the use of such restraint as a punishment or as a substitute for a habilitation program.
 - "(i v) Prohibition of the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such persons.
 - " (v) Permission for close relative of such persons to visit them at reasonable hours without prior notice.

"(vi) Compliance with adequate fire and safety standards as may be promulgated by the Secretary.

"(4) All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable outcome for those served, and -

"(A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services, which are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 1, 1974 (39 Fed.Reg. pt. II), as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

"(B) in the case of other residential programs for persons with developmental disabilities, which assure that care is appropriate to the needs of the persons being served by such programs, assure that the persons admitted to facilities of such programs are persons whose needs can be met through services provided by such facilities, and assure that the facilities under such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

"(C) in the case of nonresidential programs, which assure the care provided by such programs is appropriate to the persons served by the programs.

"The rights of persons with developmental disabilities described in this section are in addition to any constitutional or other rights otherwise afforded to all persons."

Requirements for the 1990 Report

"SECTION 122(f)

"(1) Each State Planning Council shall conduct a comprehensive review and analysis of the eligibility for services provided, and the extent, scope, and effectiveness of, services provided and functions performed by, all State agencies (including agencies which provide public assistance) which affect or which potentially affect the ability of persons with developmental disabilities to achieve the goals of independence, productivity, and integration into the community, including persons with developmental disabilities attributable to physical impairment, mental impairment, or a combination of physical and mental impairments.

"(2) Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with, the functions performed by, and services provided or paid for from Federal and State funds by each of the State agencies (including agencies providing public assistance) responsible for performing functions for, and providing services to, all persons with developmental disabilities in the State. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services from each such agency, and if appropriate, shall include their families.

"(3) Each State Planning Council shall convene public forums, after the provision of notice within the State, in order to —

"(A) present the findings of the review and analyses prepared under paragraphs (1) and (2);

- "(B) obtain comments from all interested persons in the State regarding the unserved and underserved populations of persons with developmental disabilities which result from physical impairment, mental impairment, or a combination of physical and mental impairments; and
 - "(C) obtain comments on any proposed recommendations concerning the removal of barriers to service for persons with developmental disabilities and to connect such services to existing State agencies by recommending the designation of one or more State agencies, as appropriate, to be responsible for the provision and coordination of such services.
- "(4) By January 1, 1990, each State Planning Council shall prepare and transmit to the Governor of the State and the legislature of the State a final written report concerning the review and analyses conducted under paragraphs (1) and (2). The report shall contain recommendations by the State Planning Council concerning—
- "(A) the most appropriate agency or agencies of the State to be designated as responsible for the provision and coordination of services for persons with developmental disabilities who are traditionally underserved, such as persons with developmental disabilities attributable to physical impairments, persons with developmental disabilities attributable to dual mental impairments, and persons with developmental disabilities attributable to a combination of physical and mental impairments, and such other subpopulations of persons with developmental disabilities (including minorities) as the State Planning Council may identify; and
 - "(B) the steps to be taken to include the data and recommendations obtained, through the conduct of the review and analyses under paragraphs (1) and (2) in the State Planning Council's ongoing advocacy, public policy, and model service demonstration activities.
- "(5) By January 15, 1990, the Governor of each State shall submit to the Secretary a copy of the report required by paragraph (4). By April 1, 1990, the Secretary shall transmit a summary of such report to the appropriate committees of the Congress...."

State Planning Councils' Mandate

"SECTION 124

- "(a) Each State which receives assistance under this part shall establish a State Planning Council which will serve as an advocate for all persons with developmental disabilities.
- "(b)
 - (1) The members of the State Planning Council of a State shall be appointed by the Governor of the State from among the residents of that State.
 - "(2) The Governor of each State shall make appropriate provisions for the rotation of membership on the State Planning Council.
 - "(3) Each State Planning Council shall at all times include in its membership representatives of the principal State agencies (including the State agency that administers funds provided under the Rehabilitation Act of 1973, the State agency that administers funds provided under the Education of the Handicapped Act, the State agency that administers funds provided under the Older Americans Act of 1965, and the State agency that administers funds provided under title XIX of the Social Security Act for persons with developmental disabilities), higher education training facilities, each university affiliated program or satellite center in the State, the State protection

and advocacy system established under section 142, local agencies, and nongovernmental agencies and private nonprofit groups concerned with services for persons with developmental disabilities in that State.

"(4) At least one-half of the membership of each State Planning Council shall consist of persons who -

"(A) are persons with developmental disabilities;

"(B) are parents or guardians of such persons; or

"(C) are immediate relatives or guardians of persons with mentally impairing developmental disabilities, and who are not employees of a State agency which receives funds or provides services under this part, who are not managing employees (as defined in section 1126(b) of the Social Security Act) of any other entity which receives funds or provides services under this part, and who are not persons with an ownership or control interest (within the meaning of section 1124(a)(3) of the Social Security Act) with respect to such an entity.

"(5) Of the members of the State Planning Council described in paragraph (4)—

"(A) at least one-third shall be individuals with developmental disabilities, and

"(B) (i) at least one-third shall be individuals described in subparagraph (C) of paragraph (4), and

(ii) at least one of such individuals shall be an immediate relative or guardian of an institutionalized or previously institutionalized person with a developmental disability

"(c) (1) Each State Planning Council may prepare and approve a budget using amounts paid to the State under this part to hire such staff and obtain the services of such professional, technical, and clerical personnel consistent with State law as the State Planning Council determines to be necessary to carry out its functions under this part.

"(2) The staff and other personnel of a State Planning Council, while working for the State Planning Council, shall be responsible solely for assisting the State Planning Council in carrying out its duties under this part and shall not be assigned duties by the designated State agency or any other agency or office of the State.

"(d) Each State Planning Council shall—

"(1) develop jointly with the State agency designated under section 122 (b)(1)(B) the State plan required by this part including the specifications of Federal and State priority area activities under section 122(b)(5)(D)(1);

"(2) monitor, review, and evaluate, not less often than annually, the implementation of such State plan;

"(3) to the maximum extent feasible, review and comment on all State plans in the State which relate to programs affecting persons with developmental disabilities; and

"(4) submit to the Secretary, through the Governor, such periodic reports on its activities as the Secretary may reasonably request, and keep such records and afford such access thereto as the Secretary finds necessary to verify such reports.

APPENDIX B

MEMBERS OF THE 1990 REPORT ADVISORY GROUP

MEMBERS OF THE 1990 REPORT ADVISORY GROUP

Co-Chairs:

Robbie Davis, Planner, Texas Developmental Disabilities Council
Robert Steig, Chair, Virginia Developmental Disabilities Council

Members:

Tim Andriano, Planner, Illinois Council
Allan Bergman, United Cerebral Palsy Association
Brantley Cagle, Member (Consumer), Louisiana Council
Kay Conklin, Director, Missouri Council
Elizabeth Ferguson, Director, Michigan Council
William Gannon, Member (Consumer), Pennsylvania Council
William Gorman, Director, Colorado Council
William Jones, Executive Director, American Association of University Affiliated Programs
James Keene, Director, North Carolina Council
Sharron Kelsey, Director, Wyoming Council
Stephen Knapp, Planner/Acting Director, New Hampshire Council
Lynne Lau, Administration on Developmental Disabilities
Paul Marchand, Director of Governmental Affairs, Association for Retarded Citizens/US
Frances Morse, Director, Utah Council
Richard Nugent, Director of Governmental Affairs, Epilepsy Foundation of America
Dagne Olson, Member, North Dakota Council
John Pride, Administration on Developmental Disabilities
Michael Reif, Chair, New York Council
Kristen Rogge, Administration on Developmental Disabilities
Bobby Silverstein, Senate Subcommittee on Disability Policy
Steven Stanek, Planner, Wisconsin Council
Bruce Treichler, Planner, Washington Council
Colleen Wieck, Director, Minnesota Council

Ex-Officio Members

Lucy Biggs, Former Commissioner, Administration on Developmental Disabilities
Dan Boomer, Immediate Past President, NADDC
Carolyn Gray, Former Commissioner, Administration on Developmental Disabilities
Deborah McFadden, Commissioner, Administration on Developmental Disabilities
Katherine Raggio, President, NADDC
Robert Stovenour, Former Commissioner, Administration on Developmental Disabilities

NADDC Staff and Consultants

Susan Ames-Zierman, Executive Director
Vickie Barr, Intern/Consultant
James Conroy, Consultant (Temple University UAP)
Celia Feinstein, Consultant (Temple University UAP)
Tecla Jaskulski, Consultant
Christina Metzler, Associate Executive Director

APPENDIX C

ADD-SUPPORTED TECHNICAL ASSISTANCE

ADD-SUPPORTED TECHNICAL ASSISTANCE

The Administration on Developmental Disabilities leadership on the 1990 Report process included a series of grants to the National Association of Developmental Disabilities Councils and related support provided through the University Affiliated Programs. These resources were used for a wide range of technical assistance activities that assisted the Developmental Disabilities Planning Councils in their fulfillment of the requirements of the Developmental Disabilities Assistance and Bill of Rights as amended by P.L. 100-146.

The Technical Assistance Activities

Individual Developmental Disabilities Planning Councils approached the National Association of Developmental Disabilities Councils (NADDC) even prior to the enactment of P.L. 100-146 to outline the need for technical assistance. An NADDC advisory committee on the 1990 report process was appointed in October 1987, including State Planning Council members, executive directors and planners; representatives of other national developmental disability organizations; and staff of the Administration on Developmental Disabilities. The advisory committee recommended that NADDC pursue funding from ADD to support technical assistance activities, to focus initially on the development of common approaches to the consumer survey and the policy analysis activities. A list of advisory committee members is included in Appendix B.

The advisory committee's recommendations were adopted by the full NADDC membership in January 1988, including a statement regarding the major purposes of the 1990 Report:

- (1) To present a measurement of the current levels of independence, productivity and integration into the community of people with developmental disabilities
- (2) To compare the status of persons with developmental disabilities thus measured with persons in the general population using social indicators, census or other available national information
- (3) To analyze the service system's progress through a "report card" indicating past, present and future public policy goals and accomplishments
- (4) To study the status of persons with developmental disabilities across their lifespan and across disabilities
- (5) To present federal and state policy recommendations
- (6) To present, through best practice descriptions and personal vignettes, a vision of full independence, productivity and integration for people with developmental disabilities, comparable to the general population

Prior to receiving funding from the Administration on Developmental Disabilities (ADD), NADDC received contributions from individual State Councils in fifteen states to initiate its technical assistance activities. The focus of these efforts was on the preliminary development of common methodological and analytical approaches that could be used by the Councils, reflecting their consensus that the use of such frameworks would promote the development of analyses at the national level. ADD supplemental grants to the University of Illinois at Chicago/UAP and the Temple University UAP also provided support during the early phase of the technical assistance program.

Technical Assistance on the Consumer Survey

Temple University/UAP provided extensive technical assistance to the State and Territorial Councils, beginning in the fall of 1987 with the passage of P.L. 100-146. Much of this assistance was funded through ADD's grant to NADDC, which in turn contracted with Temple for the work on the consumer survey. These activities included development of the consumer survey instrument, design of the survey methodology, sample designs, development of consent and field procedures, interviewer training, development of a common data reduction package, custom-designed analysis of individual state data files, and telephone consultation on survey implementation and analysis.

To address the challenges of the consumer survey requirement, NADDC and Temple convened a meeting of senior researchers in the developmental disability field to provide recommendations on methodology. The input of this design group, coupled with the recommendations of the advisory committee and the research staff at Temple University, produced guidelines that included the requirement for face-to-face interviews with consumers; the use of questions from the U.S. Census for comparisons of people with developmental disabilities and the general public; the similar use of questions from a "quality of life" study and the Harris poll of people with disabilities; the use of questions related to consumer independence, productivity and community integration as well as satisfaction with services; and the strong suggestion to the Councils that a minimum of 200 consumers be interviewed per state.

The common survey instrument underwent over 30 revisions before its final distribution in September 1988. The most important revisions occurred following Councils' review of the preliminary instrument. Thirty-four states provided written critiques, including general consensus on the need for more emphasis on consumer satisfaction with services and descriptions of consumer life styles, with less emphasis on U.S. Census questions that were designed for comparability to the general population.

The Councils received guidance from Temple and the design group regarding the survey methodology. In addition to the recommendation for face-to-face interviews, Councils also were advised that using client lists of the state mental retardation/ developmental disabilities service agencies was not recommended for identifying candidates for the consumer survey interviews. It was felt that agency lists in many states would be restricted to people with mental retardation; and that many agencies would be unable to identify which service recipients meet the functional definition of developmental disabilities.

The design group's primary recommendation for the sampling methodology was for the equal-N approach: three groups of 100 each, divided by cognitive disability, physical disability, and emotional/behavioral disability. Most Councils, however, preferred a proportional sampling methodology, using proportions based on the estimated primary disability proportions within the developmental disability population overall. Guidance on this approach was provided to the Councils in Temple's **Final draft**: Rationale for design of national consumer survey process.

The debate on sampling strategies reflected the inherent challenge of the application of the developmental disability definition. Because the functional definition is not a clear one, it is unknown how many people in the United States have a "developmental disability" and very little is known about their characteristics, including such basic questions as the actual proportion of people with mental retardation. It is therefore theoretically impossible ever to determine whether any sample is "representative" of the developmental disability population at large. Many sampling strategies are acceptable in such a situation, and none can be shown to be "best". The ultimate consideration has been to assure breadth of coverage, making sure that no subgroup is left out completely.

Councils also received guidance in consent procedures, protection of privacy, and field procedures for identification and screening of participants, and for conducting of the interview itself. Temple

conducted four regional training sessions (Dallas, TX; Seattle, WA; Honolulu, HI; Philadelphia, PA) in cooperation with NADDC in 1988, as well as a pilot training session in one of the pilot states and a specially scheduled session for one state that had been unable to attend any of the regional sessions. Written information on procedures was provided to all Councils and their contractors.

Council analysis of the consumer survey data was facilitated by the use of a common data entry tool developed by Temple and ultimately used by more than 40 states and territories. The forty-four which submitted data disks to Temple received assistance in review of their data for completeness and format, as well as a tabulation and analysis of results. Each was provided with a printout of its analysis tailored to the sampling stratification used by the individual state or territory, including disability group definitions, age groupings, and assignment of respondents with particular developmental disability diagnoses. For example, analyses varied as to the designation of consumers with autism between cognitive disability, physical disability, or emotional disability.

Throughout the consumer survey process, the Temple University/UAP national consumer survey team provided telephone and written consultation to Councils and their contractors. Over 600 requests for technical assistance were responded to. Although a few involved intensive consultation, many others involved merely a simple response to a straightforward question, reflecting an impressive ability on the part of the states and territories to learn and perform a complex task that they had never previously undertaken.

Program **and** Policy Review

Suggested approaches to the review of federal and state programs also were developed and provided to the councils. Extensive information on federal programs was collected at the national level to minimize the data collection duplication of effort, as well as to highlight potential questions on state implementation of federal programs. A series of "Technical Bulletins" was distributed to Councils, including basic descriptions of relevant federal programs focused on their purpose, target population(s) and eligibility requirements; tables on state-specific expenditures in key federal programs; information on the numbers served in various federal programs and guidelines on possible ways to estimate the proportion of service recipients who were people with developmental disabilities; and, for several programs, some indicators of effectiveness in relation to operational measures of independence, productivity, and integration. Information from the ADD-sponsored recurring datasets also was highlighted. The annotated bibliography provided in Appendix D includes the materials provided to the Councils.

The technical assistance activities also included the dissemination of various monographs to assist Councils in their approach to the requirements of P.L. 100-146. One monograph described a basic approach to the kind of policy analysis appropriate to the purposes of the 1990 Report. Another monograph, developed at NADDC's request by one of the major national organizations advocating on behalf of people whose developmental disabilities are primarily physical in nature, focused on the techniques Councils could use in examining the questions of services and barriers to people with developmental disabilities who are currently unserved or underserved. A third presented information on the use of focus groups to elicit input on critical issues affecting people with developmental disabilities. The fourth, known as The Source Book, provided Councils with a comprehensive "road map" on the preparation of the 1990 reports themselves.

The involvement of the broader developmental disability community was central to the technical assistance program. As noted above, representatives of various national organizations participated in the NADDC advisory committee on the 1990 Report. These included the United Cerebral Palsy Association, the Epilepsy Foundation, the Association for Retarded Citizens - U.S., the American Association of University Affiliated Programs, and the National Association of Protection and

Advocacy Systems. In addition Councils received summaries of focus groups on critical issues held at the national level with representatives of these and other national advocacy organizations.

The technical assistance provided by NADDC to the Councils included a variety of workshops, training sessions, and personal consultation. In addition NADDC prepared and disseminated a comprehensive compilation of the individual 1990 reports, as well as a compilation of the aggregate findings of the consumer survey. These materials will be useful to the Councils as they address the implementation of their respective 1990 report recommendations in the years to come.

APPENDIX D

INFORMATION RESOURCES USED BY THE STATE COUNCILS

INFORMATION RESOURCES USED BY THE STATE COUNCILS

The following references include the major sources cited by the Developmental Disabilities Planning Councils of the states and territories in their individual 1990 reports. Also included are sources used to prepare the summary 1990 report to Congress, Independence, Productivity and Integration, and the summary of state consumer surveys prepared by Temple University/UAP (Report on the 1990 National Consumer Survey: Fourth Draft).

Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., and Mitchell, D. (1990). *The State of the States in Developmental Disabilities*. Baltimore: Paul H. Brookes Publishing Company.

This report was prepared by the University Affiliated Program in Developmental Disabilities, Institute for the Study of Developmental Disabilities, School of Public Health, University of Illinois at Chicago. It was previously available under the title *Public Expenditures for Mental Retardation in the United States* (3rd edition). This third national study and in-depth compilation provides data on programs affecting people with mental retardation and other developmental disabilities. The data, covering over ten years of program funding, focus on public monies spent on community and institutional services. This third and latest edition of the study contains new and additional information on non-residential community services, nursing home care, and other community services. The expanded data collection was spurred on by several new policy initiatives in the field adopted by the 99th and 100th Congresses: early intervention services (P.L. 99-457), supported employment (P.L. 99-506), inappropriate placement of people with mental retardation and related conditions in nursing homes (P. L. 100-203), and the 1987 amendments to the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146) which set new priorities in family support services and services to older persons with developmental disabilities.

Gollay, E. (1981). *Operational Definition of Developmental Disabilities*. Santa Fe: Gollayand Associates.

An analysis of the application of the federal definition of developmental disabilities contained in the Developmental Disabilities Assistance and Bill of Rights Act as amended by P.L. 95-602; used in the development of recommendations for consumer survey sample design prepared and distributed to State Councils by Temple University/UAP.

Jaskulski, T., Metzler, C, and Zierman, S. (1990). *Forging a New Era: The 1990 Reports on People with Developmental Disabilities*. Washington: National Association of Developmental Disabilities Councils.

This compilation of the individual State Planning Council reports summarizes over 7,000 items abstracted from the reports. It is organized by life area/primary focus as well as by type of item (consumer or family quotation, example of program accomplishments, critical issue or barrier, and recommendation). The compilation also includes a summarized statement of the vision for people with developmental disabilities and highlights from the summary of state consumer surveys in each life area, as well as a discussion of the implications of the State Council findings in relation to federal and state policies.

Kiernan, W., McGaughey, M., Schalock, R., and Rowland, S. (1988). *Employment Survey for Adults with Developmental Disabilities: A National Survey*. Boston: Training and Research Institute for Adults with Disabilities, Children's Hospital.

This report of a national study conducted in 1988 of vocational service providers documents changes in the job placement patterns and employment outcomes of adults with developmental disabilities. It expands on a 1986 survey of more than 3,137 agencies, organizations and facilities providing vocational services by collecting additional data on facility and environmental characteristics, staffing patterns, follow-up services, and degree of integration into the community workplace. The report also describes placement of individuals with developmental disabilities into sheltered employment, transitional training/employment, supported employment, and competitive employment.

Lakin, K., Jaskulski, T., Hill, B., Bruininks, R., Menke, M., White, C, and Wright, E. (1989). *Medicaid Services for Persons with Mental Retardation and Related Conditions*. Minneapolis: University of Minnesota, Institute on Community Integration.

This report summarizes an analysis funded by the Health Care Financing Administration to examine policy related trends and projections in the use of various Medicaid-funded services for persons with mental retardation, and to some extent, related conditions, and to identify factors influencing these trends nationally and in the various states. Three sets of research activities are summarized: analyses of various longitudinal data bases on residential services for people with mental retardation; a survey of all state mental retardation/developmental disabilities agencies regarding current and projected residential services policy and program utilization; and in-depth case studies of ten individual states covering a broad ranges of issues related to residential and related services for people with mental retardation and related conditions.

National Association of Developmental Disabilities Councils (1988, 1989).

The National Association of Developmental Disabilities Councils (NADDC), Washington, DC, published a series of four monographs and 21 "Technical Bulletins" during 1988 and 1989 to assist the Developmental Disabilities Planning Councils in meeting the requirements of P.L. 100-146:

NADDC (1989). Monograph Number 1: *How to Plan and Conduct Focus Groups*, January 25, 1989.

A practical step by step guide to forming and managing focus groups, a suggested technique for obtaining input on issues of concern to a wide range of people with developmental disabilities.

Knapp, S. (1989). Monograph Number 2: *Using Data in Public Policy Analysis*, March 21, 1989.

A guide to using both quantitative and qualitative data in reviewing and analyzing publicly supported programs. The monograph includes definitions and principles of various forms of data, references to data sources, and guidance on how to interpret and use such information in program and policy analysis.

Vocational rehabilitation: Used in Council reports to refer to a variety of programs designed to assist people with developmental and other disabilities to prepare for and obtain employment, through short-term publicly supported training, amelioration of disabling conditions, and assistance in job placement.

Work incentive programs: Programs such as the Section 1619 component of the SSI program which eases the transition to economic self-sufficiency by maintaining cash benefits and Medicaid eligibility for people with disabilities who become employed while receiving federal SSI payments.

Supported employment: Competitive employment of people with severe disabilities who receive assistance in learning and maintaining job performance in worksites with non-disabled co-workers. Supports may include technological aids as well as personal assistance and "coaching". Individuals may work at less than full time levels, so long as wages are on the same basis as for non-disabled workers and there is interaction with non-disabled co-workers and supervisors. In some Council reports refers in particular to supported employment that is at least partially supported through grant programs administered by the Department of Education, Office of Special Education and Rehabilitation Services. (Also see Chapter V for the definition of supported employment in the Developmental Disabilities Assistance and Bill of Rights Act.)

Supported housing/supported living: Assistance to individuals with developmental disabilities to live in their own home, without 24-hour "supervision." Supports may include personal assistance services and help with independent and community living skills, or in some cases a live-in friend /advocate. Similar to programs referred to in a few reports as "semi-independent" living.

Supports: Assistance to individuals with developmental disabilities or to family members and other caregivers with the purpose of enabling the person with a disability to reach maximum independence, productivity and community integration. Distinguished in some State Council reports from services because of its emphasis on people's abilities and strengths rather than on their disability, as well as because supports can often be provided effectively outside the formal "service system," i.e., by friends, neighbors, co-workers, etc.

Supports to individuals cover a wide array of assistance across the life areas, including service coordination assistance, personal assistance services, individual therapies, assistive devices and other technology aids, transportation, advocacy and legal assistance, and social/leisure activities. Supports are referenced in the reports across all the life areas, as reflected in the terms "supported employment" and "supported living."

Supports to families or family supports tend to focus primarily on families with a child who has a developmental disability or in some cases on those who have continued as caregivers even though their family member has reached adulthood. Family supports referenced in the Council reports typically include respite services, service coordination assistance, child care, parent training, peer support, and, in some states, cash assistance or vouchers.

Supports to communities refer to the promotion of "circles of friends" and other efforts, such as public education, designed to enhance community members' abilities to support and interact with people with developmental disabilities.

Technology: See "adaptive equipment/assistive devices."

Transition: The movement from one program phase to another, especially age-related changes such as from pre-school to elementary education, from secondary education to employment and adult services, and from productive activity to retirement. The most frequent references in the State Council reports were to the transition from school to adulthood, in particular the preparation for employment.

Transition plan: Referenced by several Councils regarding the need for specific objectives and strategies to improve students' transition from school to employment or other adult activity.

University Affiliated Programs (UAP): Federally funded university-based centers found in nearly all states that provide research and personnel preparation in the developmental disabilities field.

Residential services: Used in the State Council reports to refer to many different types of housing and housing supports that are considered part of the service system for people with developmental disabilities, such as "group homes". Most commonly refers to residences in the community rather than to large state institutions. May include supports to individuals in their own homes. (Also see "supported housing.")

Respite care/respite services: Short-term relief for family members and other caregivers from responsibility for the individual with developmental disability. Frequently available for only a few hours or days, commonly as a central component of state "family support" programs. May be provided outside the home in some states. Also refers in some Council reports to relief for the person with a disability from his or her caregivers.

Section 8: Various types of low income rental subsidy provided through programs administered federally by the Department of Housing and Urban Development, and designed to improve low income people's access to rental housing by providing additional resources for rental payments.

Segregation: As used in the State Council reports, refers to the lack of interaction between persons with developmental disabilities and those without disabilities, as well as to their physical separation. Found in the Council reports in relation to the various life areas, especially regarding education, such as the use of separate schools and classrooms; in housing, in particular the use of nursing homes and other institutions; and in employment, regarding employment in sheltered workshops rather than community or competitive employment.

Self advocacy: Efforts of individuals with developmental disabilities to exercise their civil rights, their control over their lives, and to make choices. (Also see "empowerment.")

Sheltered workshop/sheltered employment: Primarily refers to facility-based programs which employ persons with disabilities in non-competitive conditions, typically with special certification to pay sub-minimum wages. May include preparation for non-sheltered or competitive employment for some individuals.

1619 program: See "work incentives."

Specialized services: Programs targeted specifically to people with developmental and other disabilities, such as special education and the ICF/MR program, as distinguished from "generic" services.

Summary of state consumer surveys: The survey of over 15,000 individuals with developmental disabilities undertaken by the Developmental Disabilities Planning Councils to meet the requirements of P.L. 100-146 for the 1990 report; specifically, the aggregate national data from the states which used a common survey instrument and whose findings were available in time to be included in the initial national compilation as used in the summary Report to Congress, representing data from 13,075 consumers. Referred to in the developmental disabilities network as the National Consumer Survey.

Supervised home/apartment: See "group homes."

Mental retardation/developmental disabilities (MR/DD): Used in some reports in reference to the state agency with administrative responsibility for services to people with mental retardation and other developmental disabilities, or, in a few cases, to programs and services targeted to this population.

National Association of Developmental Disabilities Councils (NADDC): The national organization representing the individual Developmental Disabilities Planning Councils of the states and territories.

National Consumer Survey: See "summary of state consumer surveys."

People First: an organization of people with disabilities, primarily mental retardation, formed to advocate on their own behalf in relation to independence, productivity, integration, and quality of life. (See also "self-advocacy".) Also used in connection with "people first" language to describe preferred/non-stigmatizing terminology such as "people with developmental disabilities" rather than "the developmentally disabled".

Permanency planning: The delineation of objectives and strategies to ensure that children in foster care are supported in becoming part of a permanent family home, either through return to their families or by joining a substitute family on a long term basis. Occasionally used to refer to long range planning for adults with disabilities.

Personal assistance services: Services and supports which assist individuals to manage their activities of daily living, such as bathing, dressing, and eating. May include assistance with community living such as shopping and banking. Also referred to in some reports as "personal care," or "attendant care" and occasionally extended to include assistance in the workplace.

Prevention: Activities designed to reduce or prevent the incidence of developmental disabilities, such as reduction or treatment of drug abuse among women of child bearing age and improved access to prenatal care. Also used in some Council reports in relation to preventive health measures in general.

Productivity: Defined broadly as engagement in activity that in some way contributes to the welfare or betterment of self, relatives, friends, or the community at large, as well as more specifically to income-producing employment. (See Chapter I and Appendix A for the definition of productivity in the Developmental Disabilities Assistance and Bill of Rights Act.)

Protection and Advocacy (P & A): Advocacy and legal assistance provided by designated state and territorial P & A units, primarily the pursuit of legal, administrative and other appropriate remedies to protect the rights afforded under federal and state statutes. Advocacy services in many Council reports also refer to consumer and parent training in advocacy and exercise of individual rights as well as other non-legal advocacy activities outside the formal P & A system.

Quality assurance: The system of setting and maintaining standards for the provision of services. Quality assurance activities referenced in the State Council reports include establishment of standards and regulations, licensure and certification, and program monitoring.

Related services: Any developmental, corrective or other supportive services which assist a person with a developmental or other disability to benefit more fully from services to which they are entitled or eligible. Used most frequently in relation to special education because of provisions of P.L. 94-142 that require inclusion of essential related services in students' IEPs and authorize the use of special education funding for related services so designated, for example, physical therapy for students with mobility impairment.

Information and referral: A systematic collection of information about programs and services that is made easily accessible to those in need of services, including information and in some cases assistance in referral to the program(s) in question.

Institutionalization: As used in the State Council reports, generally refers to placement or residence in large facilities such as state institutions, but also commonly used to refer to residence in any 24-hour facility with 16 or more residents. Used by some to refer to residence in ICF/MR facilities of any size.

Integration: Most frequently used to describe meaningful interaction between people with disabilities and those without disabilities, as opposed to just physical proximity. Report references include all aspects of living, including schools, community living, working and social/leisure activities. (Also see Chapter I and Appendix A for the definition in the Developmental Disabilities Assistance and Bill of Rights Act.)

Intermediate Care Facility for the Mentally Retarded and Related Conditions (ICF/MR): An optional component of the Medicaid program that permits Medicaid funding to be used for 24-hour care facilities that serve a minimum of four people with mental retardation and "related conditions," such as cerebral palsy but excluding mental illness, and that meet conditions specified in federal regulation, such as the requirements for active treatment discussed above. Residents of ICF/MR facilities must meet state determined Medicaid eligibility requirements as well as federal eligibility criteria, such as the need for 24-hour care and for active treatment. Most commonly referred to in the state reports in relation to state institutions and, in some states, ICF/MR certified facilities in the community.

"Katie Beckett" Waiver: See "Home and Community Based Services Waiver."

Least restrictive environment: The setting in life areas such as education, employment and housing that promotes interaction to the maximum extent possible between people with disabilities and those who are without disabilities and that is least restrictive of the person's personal liberty and independence. Used in particular in relation to provisions of P.L. 94-142 regarding the use of non-segregated educational settings such as regular classrooms or combined use of regular classrooms and "resource rooms" in the neighborhood school that are attended by children in the area who do not have a disability.

Low incidence disability: Various syndromes and conditions that produce developmental disabilities that occur much less frequently than more common disabilities such as mental retardation; also refers in a few reports to rare causes of mental retardation and other developmental disabilities.

Mainstreaming: Integration of people with developmental and other disabilities into full community participation, with particular emphasis on access to the same schools, employment opportunities, housing, health care, recreational activities, and other community services used by people without disabilities.

Medicaid reform: Various proposed changes to the Medicaid program, primarily to expand opportunities to finance community-based supports to individuals with developmental disabilities and their families, and to shift the current emphasis in Medicaid expenditures away from institutions and facilities. As discussed in the State Council reports, also may include expanded eligibility, particularly in relation to family income and resources; and/or various federal mandates regarding services to be covered by the states. May refer to specific Medicaid reform proposals before the Congress or to reforms in general.

Model Waiver: See "Home and Community Based Services Waiver."

Handicap: Characteristic that limits a person's ability for full independence, productivity and integration unless mitigated by supports. Generally considered less preferable as a term than "disability."

Handicappen Term used in the Michigan State Planning Council report for people with a disability.

Home and Community Based Services (HCB) Waiver: Optional Medicaid waiver program that permits states to use Medicaid funds to provide approved services to people in the community who would otherwise be institutionalized at Medicaid expense, so long as total costs to the Medicaid program are not increased. Specific definitions of covered services and eligible populations vary among the participating states. One form of the HCB waiver, the Model waiver, includes the same kinds of provisions but is specifically targeted to people who would otherwise be eligible only if they were hospitalized or in a Medicaid funded institution. Because this waiver is frequently used to permit Medicaid coverage of home care for children with serious medical care needs who would otherwise be hospitalized, and because it replaced the case-by-case waivers known as "Katie Beckett" waivers, some reports continue to refer to Model waivers as Katie Beckett waivers. A related Section 1915(c)(7)(b) waiver was authorized as part of the Omnibus Budget Reconciliation Act of 1987 in relation to nursing home reform, to permit Medicaid coverage of home and community-based services to people with developmental disabilities who were formerly in nursing homes.

Income assistance/income supports: Primarily used to refer to government funded payments such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Aid to Families of Dependent Children (AFDC), State Supplementary Payments, Food Stamps, and other income assistance provided by state and local governments. In a few Council reports it may include payments to individuals or, more commonly, to family members as a form of family support.

Independence: As used most commonly in the State Council reports, refers primarily to the exercise by the individuals with developmental disabilities of choice and control over their lives in such areas as living arrangements, employment, finances, and social life. (See Chapter I of the report and Appendix A for the definition in the Developmental Disabilities Assistance and Bill of Rights Act.)

Independent case management: Case management that is administered and provided by an agency, public or private, that is not directly involved in the provision of other relevant services and supports.

Independent living: Maximum control and independence for the person with a developmental or other disability. Sometimes associated with Centers for Independent Living, programs that receive federal and state funds to promote independent living in particular for people with severe disabilities.

Individual Education Program (IEP): The written report that details the special education and any needed related services, e.g., speech and language therapy, to be provided to students with disabilities under provisions of The Education of the Handicapped Act (P.L. 94-142, as amended). Also found in the reports as "Individual Education Plan."

Individual Family Services Plan (IFSP): The written plan of services and family supports for children with or at risk of developmental and other kinds of disabilities ages 0 to three and their families that will be required with full implementation of Part H of The Education of the Handicapped Act, as amended by P.L. 99-457.

Infant stimulation: Activities such as physical exercise and sensory stimulation with young infants who are suspected of having developmental disability or developmental delay that are designed to mitigate the effects of these disabilities.

Dual diagnosis: As used in the State Council reports and generally in the developmental disabilities field, refers to the presence of mental illness and (another) developmental disability, such as mental retardation or severe hearing impairment; regarding a diagnosis of both mental illness and mental retardation, "dual diagnosis" is analogous to the term "dual mental impairment" in P.L. 100-146 regarding the 1990 report requirements.

Early intervention: Interaction with infants and very young children to minimize the effects of a developmental disability; may include training of parents and other caregivers as well as direct intervention with the child. (See also "infant stimulation.") Also used in some State Council reports in relation to health care in general, such as screening and primary care supported through the Medicaid Early Prevention, Screening, Diagnostic and Treatment program, Maternal and Child Health programs, and Children with Special Health Care Needs programs.

Earned income: Income from employment or the proceeds from self-employment, as distinct from "unearned income" from income support programs such as Supplemental Security Income (SSI) or income from investments.

Empowerment: Promotion of independence and exercise of individual choice; control over one's life. May also refer to the process of supporting people with developmental disabilities (or in some cases family members) in increasing their independence and control, for example, by providing vouchers so people can choose which services and supports they will use.

Family supports: See "supports."

Foster home/foster care: Generally used in reference to substitute families for children whose "natural" families are unable to care for them on either a short term or long term basis, usually administered through the public child welfare system. Occasionally used in reference to adults (see "board and care" above).

Follow along services: A less intensive form of case management that provides intermittent follow up with people who no longer need assistance on a frequent basis.

Functional curriculum: Curriculum, primarily in reference to special education students, that focuses on preparation for adult roles and responsibilities and that bases education on "real life" experiences and expectations.

Generic services: Services and supports that are not specifically targeted to people with disabilities, such as public transportation, most low income housing supports, and programs for people who are elderly.

Group homes: Residences of various sizes for people with developmental and other disabilities, generally located in the community (as opposed to being on institution grounds) and typically providing extensive support and supervision. Group homes may be apartments as well as houses; staff may live in the home or be present on a "shift" basis, and are generally responsible for helping the residents to increase or maintain community living skills. Group home staff also may be responsible for health related services for residents who require medical assistance on a regular basis. Group homes are known by many different terms in the various states, including "supervised homes," "community living arrangements," and "shelter care." Some states also have group homes that are certified as ICF/MR facilities.

Habilitation: Supports and services designed to promote greater independence and productivity, such as self care, social and community living skills.

Case management/case coordination: Support services to individuals with developmental disabilities, families or other caregivers that assist them in obtaining and coordinating needed services and supports. Typical activities include assessment of individual needs, facilitation of referrals and enrollment in programs, and ongoing monitoring to assure that needs are being met. In some states, emphasis is on case management that focuses more on facilitation and advocacy than on gatekeeping and control of access to resources. Terms such as "coordination assistance" are used in a few State Council reports as an alternative to "case management" which may be seen by some consumers and others in the developmental disabilities field as patronizing. (Also see "follow along services" and "independent case management.")

Circle of friends/Circles of support: A network of friends, neighbors and paid helpers who provide friendship and support to individuals with developmental disabilities, primarily on an informal basis, to promote their maximum success in reaching full levels of independence, productivity and community participation.

Community employment: See "competitive employment."

Community living training: Training in skills needed to live and participate in the community, such as use of transportation, shopping, and maintaining a household. Sometimes referred to as independent living skills, as well as being related to supported housing (see below).

Competitive employment: Jobs in regular places of employment as opposed to "sheltered" employment specifically for people with disabilities, including wages, salaries and benefits at the same level as people without disabilities and in the same work area. May include the provision of support(s) that enable the person with a developmental disability to succeed in the position (see "supported employment").

Consumer; The individual with a developmental disability.

Consumer survey: See "summary of state consumer surveys."

Continuum: An approach to the organization of services based on the consumer's progression through a sequence of environments, from the most restrictive to the least restrictive, presumably based on the individual's "readiness" to move on to the next level; most commonly associated with residential programs. This approach is challenged in some Planning Council reports as not providing sufficient opportunity and choice to individuals with developmental disabilities.

Council: See Developmental Disabilities Planning Council.

Crisis intervention: Services provided as a response to specific situations or problems encountered by individuals with developmental disabilities that threaten their well-being or place them in jeopardy of institutionalization.

Developmental Disabilities Planning Council: The Council appointed by the governor of each state and territory (with the exception of the Pacific Trust Territory) to advocate on behalf of people with developmental disabilities and to develop plans to meet their needs. (See Chapter I of the report and Appendix A for additional information on the function and composition of the State Planning Councils.)

Developmental disability: Condition expected to be of lifelong duration which results in substantial functional limitations in three or more areas and which originates in childhood (i.e., before age 22). (See Chapter I of the report and Appendix A for the federal statutory definition.)

GLOSSARY

Accessibility: The policy of making available to persons with disabilities the full range of life experiences and services available to persons without disabilities. As used in the State Council reports, accessibility frequently includes physical modifications of the environment, such as a wheelchair ramp or lift, and/or adaptive equipment and assistive devices used by the individual to increase access, such as a computerized communication device. In some cases accessibility includes the availability of transportation and other supports which increase access, such as interpreters for people with hearing impairment. Accessibility is relevant across the full range of life areas, with particular emphasis on full community participation and integration, e.g., accessible polling places, schools, and worksites.

Active treatment: A component of federal requirements for participation in the Medicaid Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program, including individual "plans of care" that set forth measurable goals and desired outcomes and the interventions designed to meet these individual goals; evidence that the plan is being followed, including access to appropriate professional staff; and a minimum of annual reevaluations of progress and the continuing appropriateness of the plan of care.

Adult day services: Used variously by states to describe facility-based programs for adults who are no longer eligible for public school programs, most commonly referring to training in social, self-care, communication, and daily living skills, and, in some cases, preparation for vocational training. Also known by such terms as adult activity, adult day care, adult day treatment, and adult day habilitation training. In a few states adult day care may include regular in-home care as well as facility-based programs.

Adaptive equipment/assistive devices: Equipment and devices designed to support individuals with developmental disabilities in their activities, such as communication devices, computers that "read" printed materials out loud, wheelchairs and other mobility aids, vehicle adaptations, etc. Frequently referred to as "technology," reflecting the increased application of technology in this area.

Adult foster care: See "board and care homes."

Augmentive communication devices: Devices specifically designed to enhance people's ability to communicate; may also be referred to as "augmentative" devices.

Aversive therapy: Very controversial form of "behavior management" (see below) that tries to reduce or eliminate undesirable or dangerous behavior patterns through negative reinforcement, such as electric shock or pinches. Also known as "aversives."

Behavior management: Assistance in the reduction or elimination of behaviors that are considered either socially inappropriate or unsafe, primarily by teaching and reinforcing alternate behaviors.

Behavior management training: Generally refers to training provided to parents and other caregivers to help them in their behavior management activities.

Board and care homes: A residence providing basic care and supervision to adults with disabilities and people who are elderly, usually on a for-profit basis. May also be referred to as adult foster care.

Caregiver: The family member or other person who has primary responsibility for seeing to it that the needs of the person with a developmental disability are met.

Temple University/UAF (1988c). Taxonomy of Services.

Definitions of the 95 services included in the standardized survey instrument.

Temple University/UAF (1988d). Use of the National Consumer Survey for Children.

A description of special survey procedures and interpretations for consumers who were children.

Temple University/UAF (1988e). Surveyor's Guide.

A general introduction to the consumer survey methodology for new surveyors.

Temple University/UAF (1988f). National Consumer Survey Notes, September 16, 1988: On the Meaning of the Seven Major Life Areas.

A detailed analysis of how the concepts of "substantial" in the seven major functional areas specified in the definition of developmental disabilities in the Developmental Disabilities Assistance and Bill of Rights Act have been interpreted by various authorities.

Temple University/UAF (1988g). Final Survey Instrument: A National Survey of Consumers of Services for Individuals with Developmental Disabilities.

The standardized survey instrument used by all but five State Developmental Disabilities Councils.

Temple University/UAF (1990). Report on the 1990 National Consumer Survey (Fourth Draft).

Draft report on the summary of state consumer surveys prepared for the National Association of Developmental Disabilities Councils, summarizing design of the survey instrument used by all but five of the State Developmental Disabilities Councils, data analysis performed at the national level, and summary findings, based on the 13,075 surveys conducted nationwide available for analysis at this time (May 4, 1990).

White, C, Lakin, K., Hill, B., Wright, E. and Bruininks, R. (1988). Persons with Mental Retardation in State-Operated Residential Facilities. Year Ending June 30, 1987, with Longitudinal Trends from 1950 to 1987 (Report Number 26). Minneapolis: University of Minnesota, Department of Educational Psychology.

This report presents extensive data on people with mental retardation in state-operated facilities in the United States. It includes data from recurring surveys conducted by the Center for Residential and Community Services (now the Center on Community Integration) since 1978 and a comparison of profiles from a variety of studies from 1950 to 1987.

Smith, G., Katz, R., and Gettings, R. Medicaid Home and Community-Based Services for Persons with Developmental Disabilities: The Home and Community-Based Waiver Experience (1989). Alexandria: National Association of State Mental Retardation Program Directors, Inc.

This report reviews in detail the turbulent eight year history of the home and community-based waiver (HCB) program as it is used to provide services to individuals with developmental disabilities. It examines the program in terms of its statutory base, the manner in which it is administered by the Health Care Financing Administration, the scope of the HCB programs in operation in the states, and the effects the program has had on the deployment of federal Medicaid dollars on behalf of Americans with developmental disabilities. A thorough analysis of federal and state policy issues that affect the program also is included, as well as a discussion of the implications for "Medicaid reform."

Smull, M. (1988). Survey of 15 Year Old Special Education Students in Maryland. Baltimore: University of Maryland (unpublished manuscript).

A report on the examination of the characteristics of special education students of the state of Maryland in relation to estimates of the prevalence of developmental disabilities and definitions of substantial limitation relevant to the federal definition of developmental disabilities.

Taylor, H., Kagay, M., and Leichenko, S. (1986). Bringing Disabled Americans into the Mainstream: A Nationwide Survey of 1,000 Disabled Persons. New York: Louis Harris and Associates, Inc.

A report of a Harris poll of people with disabilities on their self-perception of level of disability and their participation in life activities, as well as their opinions on disability related issues.

Temple University/UAP (1988, 1990).

In addition to the Technical Bulletin (NADDC/Temple University, 1989) listed above, the Research and Quality Assurance Group at the Temple University Developmental Disabilities Center/UAP, Philadelphia, Pennsylvania, published several resources to assist the State Developmental Disabilities Councils in consumer survey sample design, use of the standardized consumer survey instrument developed by Temple, and protection of confidentiality and other rights of consumers. These materials were disseminated to all Developmental Disabilities Planning Councils of the states and territories.

Temple University/UAP (1988a). Second Draft* Rationale for Design of National Consumer Survey Process.

Recommendations provided to State Developmental Disabilities Councils on consumer survey methodology and sample design through national conferences and dissemination of written materials.

Temple University/UAP (1988b). Final Draft: Rationale for Design of National Consumer Survey Process.

Revised recommendations provided to State Developmental Disabilities Councils to incorporate changes to the standardized consumer survey instrument made following extensive reviews by the State Councils on their goals for the consumer survey and related implications for the survey methodology.

Knapp, S. (1989). Technical Bulletin Number 11: Vocational Rehabilitation Programs and Other Employment-related Programs Data Sets, April 17, 1989.

Data and explanatory information on three federally assisted programs related to employment for people with disabilities: vocational rehabilitation, Section 1619 of the Social Security Act, and the Job Training Partnership Act.

NADDC (1989). Technical Bulletins Numbers 12 and 12A: Descriptions: Eligibility, Program Purpose, and State Discretion in Priority Federally Assisted Programs (Group 2), (Group 2A), n.d.

Descriptions of over 25 federally assisted programs of interest to people with developmental disabilities, including Section 1619 work incentives program, foster care, Medicare, transportation, and low income rental assistance.

Jaskulski, T. (1989). Technical Bulletin Number 13: Social Services Block Grant Data Charts and Accompanying Notes.

Jaskulski, T. (1989). Technical Bulletin Number 14: Maternal and Child Health Block Grant Data Sets and Accompanying Notes.

Jaskulski, T. (1989). Technical Bulletin Number 15: Head Start Program Data Sets.

Jaskulski, T. (1989). Technical Bulletin Number 16: Independent Living Program Part A Data Set.

Jaskulski, T. (1989). Technical Bulletin Number 17: Selected Programs Data Sets.

Jaskulski, T. (1989). Technical Bulletin Number 18: Alcohol, Drug and Mental Health Administration Data Sets.

Jaskulski, T. (1989). Technical Bulletin Number 19: Supplemental Security Income and State Supplement Data Sets.

National (state-specific) data on expenditures and utilization of various programs, with suggestions on follow-up analysis that could be done at the state level.

Jaskulski, T. (1989). Technical Bulletin Number 20: Additional Information Received since the Sourcebook, November 21, 1989.

Provides 1988 data on state income levels, highlights from the 1989 Census Bureau Populations Profiles of the United States, and state population trends and projections. Also included is updated information on the Medicaid Home and Community Based Services waiver.

Temple University Developmental Disabilities Center/UAP Research and Quality Assurance Group (1989). Technical Bulletin Number 21: Making the Best Use of Consumer Survey Data, October 24, 1989.

Guidance to Councils in the interpretation and presentation of data from their consumer surveys, including the types of questions that can be used to move beyond the statistics and relate the findings to the other components of the 1990 report analysis.

NADDC (1989). Technical Bulletin Number 4: Report on the National Organization Focus Groups on Education, Individual and Family Supports, Employment Income, and Housing/Residential, January 23, 1989.

Results of focus groups convened to identify critical issues in field. Participants from major disability organizations provided input on what they considered to be critical issues and then explored what the associated problems, preferred practices and future resolutions might be.

Jaskulski, T. (1989). Technical Bulletin Number 5: Medicaid—Expanded Program Descriptions, January 25, 1989.

Detailed descriptions of the basic Medical Assistance (Medicaid) program as well as individual components: Medical Optional Services, the Early Periodic Screening, Diagnosis and Treatment program, the program for Intermediate Care Facilities for the Mentally Retarded and Persons with Related Conditions, the Home and Community-Based Care Services Waiver, and the Model Waiver, highlighting options at state discretion as well as federal requirements.

Jaskulski, T. (1989). Technical Bulletin Number 6: Medicaid Data and Accompanying Notes, January 25, 1989.

Detailed charts of selected Medicaid expenditures by program, per capita expenditures, eligibility, utilization, optional services available per state, and related information on state economic indicators and disability rates, accompanied by explanatory notes on how such information can be used by individual Councils.

Jaskulski, T. and Metzler, C. (1989). Technical Bulletin Number 7: Key Elements of the 1990 Reports at the State Level and Selected State Processes and Formats, January 25, 1989.

Suggestions regarding approaches to the reports in relation to the key issues of scope, availability, and effectiveness, in relation to the life areas.

Ames-Zierman, S. and Jaskulski, T. (1989). Technical Bulletin Number 8: Working Outline of State 1990 Reports Table of Contents and Explanatory Information, March 17, 1989.

Discussion of possible organization of state 1990 reports, areas to be covered.

Barr, V. and Jaskulski, T. (1989). Technical Bulletin Number 9: Education Data Charts and Accompanying Notes (Group 1), March 27, 1989.

Barr, V. (1989). Technical Bulletin Number 10: Education Data Charts and Accompanying Notes (Group 2), April 17, 1989.

National (state-specific) data on special education, including numbers of children served, use of various educational settings, expenditures, and state mandates for upper and lower age limits, with accompanying notes on how these data might be used by the states.

NADDC (1989). Monograph Number 3: The Sourcebook for Developmental Disabilities Councils' 1990 Reports.

The Sourcebook provides comprehensive suggestions and models of data presentation for the 1990 reports in relation to the life areas (i.e., education, employment, housing, etc.) as well as additional facts and references. Each chapter examines the major barriers to independence, productivity and community integration suggested by preliminary analysis and discussions with national organizations on disability, as well as suggestions for complementary examinations and analysis at the state level.

NADDC (1989). Monograph Number 4: Report on the UCPA Forum, September 25, 1989.

This monograph summarizes proceedings at a forum convened by the United Cerebral Palsy Association at NADDC's request and held in Washington, D.C., on April 11 and 12, 1989. The forum was convened for intense examination of a shared vision for people with developmental disabilities; the fundamental purposes of services for people with developmental disabilities; principles of access, eligibility and funding for specialized services; and recommendations for selecting a state agency (or agencies) responsible for the delivery of such services. The monograph summarizes the discussion of these issues, of recent experiences of two states which recently adopted a full functional eligibility definition for developmental disabilities, and of strategies regarding increased access for people across the full range of developmental disabilities. Also featured are a summary list of conclusions and recommendations.

Ames-Zierman, S., Jaskulski, T., and Metzler, C. (1988). Technical Bulletin Number 1: Getting Started on the Review of Federal and State Programs, September 26, 1988.

Suggests a common approach for Developmental Disabilities Planning Councils in the states and territories to use in analyzing federally-assisted and state funded services and provides a suggested approach to collecting information on programs and services. Includes a list of federal programs organized by type of service and sample tables for data collection.

NADDC (1988). Technical Bulletin Number 2: What to Expect from NADDC regarding Federally Assisted Programs - and What Not to Expect.

Lists resources for data collection and analysis on federal programs such as ICF/MR, Medicaid Home and Community-Based Services waiver. Vocational Rehabilitation State Grants, SSI, and Special Education.

Barr, V. and Jaskulski, T. (1988). Technical Bulletin Number 3: Descriptions: Eligibility, Program Purpose and State Discretion in Priority Federally-assisted Programs (Group 1), November 15, 1988.

Descriptions of federally assisted programs in vocational rehabilitation, special education, income maintenance, and the Social Services Block Grant.

**U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES**
Washington, D.C. 20201

OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE, \$300