

POSITION STATEMENTS
FOR THE
MINNESOTA GOVERNOR'S COUNCIL
ON DEVELOPMENTAL DISABILITIES

Approved by the
Minnesota Governor's Council
on Developmental Disabilities
on
June 7, 1995

A handwritten signature in black ink, appearing to read "Paul Odland". The signature is stylized with a large, looping "P" and "O".

Paul Odland, DDS
Council Chair

MISSION

The mission of the Minnesota Governor's Council on Developmental Disabilities is to work toward assuring that persons with developmental disabilities receive the necessary support to achieve increased independence, productivity, and integration into the community. According to the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 103-230) each state "shall establish and maintain a State Developmental Disabilities Council . . . to promote, through systemic change, capacity building, and advocacy activities (consistent with section 101(c)(2)), the development of a consumer and family-centered comprehensive system and a coordinated array of culturally competent services, supports and other assistance designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities."

Guiding concepts and principles for enabling people with developmental disabilities to achieve increased independence, productivity, and integration into the community include:

- **Neighborhoods and communities must be encouraged to include people rather than to exclude their members.** This vision of community empowers ordinary citizens to offer each other personal support and assistance which makes everyone's involvement in community life possible. Thus, people with disabilities are not only present but are also actively participating in regular community life.
- **Each person is a unique individual, having worth, no matter what the degree of disability.** Personal autonomy is to be promoted; and every effort should be made to encourage self-determination. This includes maximizing opportunities for each individual to develop and exercise competence and to make choices in the pursuit of a personal future.
- **All communities depend on the capacity of people--on their fullness, on their possibility.** The creation of the sense of community is built upon the capacity of individuals served and not on needs. Formal and informal supports will be provided so that people with developmental disabilities can participate in the same settings used by other people. For children, this means supporting families whether natural, adoptive, or foster; all children belong in families. For adults, this means developing the services and supports they need to live in real homes, work in real jobs in typical work settings, and to participate in regular community activities along with

family members, neighbors, and friends. The development of good interpersonal relationships is basic to healthy living.

The purpose of this document is to present a set of position statements on federal and state issues. These position statements are based on the work of the American Association on Mental Retardation (AAMR), the Association for Retarded Citizens--United States (ARC--US), the National Association of Developmental Disabilities Councils (NADDCC), and the Association for Persons with Severe Handicaps (TASH).

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POSITION STATEMENTS

ACCESSIBILITY

The Minnesota Governor's Council on Developmental Disabilities (hereafter, Council) supports barrier-free environments and strong enforcement of applicable access-related state and federal building codes.

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)/HIV

Approved: Public Policy Committee Meeting, February 2, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, April 6, 1994

Acquired Immune Deficiency Syndrome (AIDS) is a major health problem. Individuals with developmental disabilities may be affected and, in addition, those individuals who contract the disease are considered disabled.

Specific areas of concern to the Minnesota Governor's Council on Developmental Disabilities are:

Education: Public education programs must be provided regarding safe sexual practices and the dangers of intravenous drug use at a level appropriate to persons with developmental disabilities. In addition, public education programs must attempt to reduce the number of infants born to mothers with HIV since most of these children will be developmentally disabled and will succumb to the disease.

Testing: The indications for HIV testing and the use of the results must be the same for all other individuals and in accordance with the current federal and state regulations. Confidentiality must be maintained.

Protection: Health care workers who are in contact with individuals with developmental disabilities who are AIDS/HIV positive must be screened and tested for HIV in accordance with the current federal and state regulations. These vulnerable individuals are to be protected from all known risk factors. Universal precautions as prescribed by the Center for Disease Control must be observed. All health care providers will adhere to all federal and state regulations if they are HIV positive or have any reason to suspect that they might.

Discrimination: Individuals who are HIV positive or who have AIDS

are to be considered disabled under the Americans with Disabilities Act. They should be treated with the same dignity and compassion as any other individual with an illness or disability. They should not be discriminated against in terms of employment.

The rules and regulations regarding AIDS are in a constant state of flux. For current recommendations regarding rules for individuals, health care providers, and work place regulations, contact:

1. Center for Disease Control: (404) 639-3311.
2. Commissioner of Health, Department of Health: (612) 623-5414.
3. For health care workers in Minnesota, contact the blood borne pathogens section of the Minnesota office of OSHA: (612) 296-2116.
4. Infection Control Rules Program for the state of Minnesota: (612) 643-0402.

AVERSIVE INTERVENTIONS

The Council opposes any treatment or practice which violates the right to freedom from harm. The Council calls for the cessation of the use of any treatment option which exhibits some or all of the following characteristics: (1) obvious signs of physical pain experienced by the individual; (2) potential or actual side effects such as tissue damage, physical illness, severe physical or emotional stress, and/or death that would properly require the involvement of medical personnel; (3) dehumanization of persons with severe disabilities because the procedures are normally unacceptable for persons who do not have disabilities in community environment; (4) extreme ambivalence and discomfort by family, staff, and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions; and (5) obvious repulsion and/or stress felt by peers who do not have disabilities and community members who cannot reconcile extreme procedures with acceptable standard practice. Educational and habilitative procedures must be free from chemical restraint, aversive stimuli, environmental deprivation, or exclusion from service.

The Council promotes activities that lead to implementation and dissemination of non-aversive alternatives.

CASE MANAGEMENT/SERVICE COORDINATION

The Council supports a case management/service coordination system that is fully funded and manageable; allows sufficient ratios to provide quality service; has reasonable training for case managers/service coordinators; provides full and accurate information for the individual, family, guardian, or other advocates; and encourages full

partnership with individuals and family members or others who are responsible for decisions.

Concentrates on providing services by simplifying evaluation, reviews service coordination; is a goal-oriented process for assuring the coordination of services needed and requested by persons with disabilities and their families; measures quality by the effectiveness, responsiveness, continuity, reliability, and acceptability to the user and respects the right of each individual to make decisions and to take risks based on informed choice and personal goals and values.

CHOICES

The Council supports and encourages individuals with developmental disabilities to make informed choices regarding personal life goals including but not limited to:

1. The choice to live in **regular homes**, including living with parents, self-selected roommates, and varied groupings and environments considered desirable, appropriate, and chosen by persons without disabilities at particular ages in their lives.
2. The choice to attend the **same school** he or she would attend if he/she did not have a disability, and to receive at the school the individualized educational services which are appropriate for his/her needs without compromise to the development of interactions with peers (whether or not those peers themselves have a disability) throughout the school years.
3. The choice of access to a variety of **employment opportunities** which allows for daily interactions with coworkers, employers, and (where relevant) consumers who do not have disabilities. Choice should exist regardless of level or type of disability.
4. The choice to participate in the kinds of extracurricular, **recreational**, and other leisure experiences enjoyed by typical peers and citizens.
5. The choice and opportunities for choices related to daily and longitudinal **social interactions** with peers and other citizens (without regard to disability) that are oriented toward developing a variety of relationships, social support networks, friendships, and the ultimate goal full and active participation in community living.

COMMUNICATION

Approved November 28, 1990

Issue

Communication is that essence of human life which allows expression of individual needs, feelings, thoughts, personal achievement, opportunities for self-definition, and interaction with others. The ability to initiate communication and recognize and address the communicative function of behavior promotes independence to control and influence one's life. From birth, all individuals with severe disabilities are entitled to communicate in the most effective manner. However, throughout Minnesota, people with severe disabilities are not allowed to be informed and active participants in decisions because alternative and augmentative communication systems are often not available. Another problem is the lack of effective teaching to: (1) functionally use alternative and augmentative communication systems and (2) expand communication and language skills. Some people have a "communication system," but are not taught how to use it.

Position

The Minnesota Governor's Council on Developmental Disabilities fully supports the Governor's Advisory Council on Technology for People with Disabilities to carry out these tasks:

- Take a leadership role in the development of, access to, and utilization of augmentative and alternative communication systems and services to enhance all aspects of life for individuals with severe disabilities.
- Support development of lifelong training for individuals with severe disabilities, their family members, and service providers in the use of augmentative and alternative communication systems.
- Provide information, advocacy, and/or training or direct services to ensure that augmentative and alternative communication systems, intervention, and lifelong services are provided to all individuals with severe disabilities.
- Encourage development of new techniques and augmentative and alternative communication technology for individuals with severe disabilities.

The Council supports the right of all persons, regardless of the severity of their disabilities, to fully participate in and affect, through communication, the community in which he/she lives, works, and recreates. Because communication and a person's successful use of communication affords meaningful and understandable exchanges

that recognize and promote the inherent dignity of each person, communication rights should be assured for all persons with severe disabilities.

CONSTITUTIONAL AND CIVIL RIGHTS

The Council supports legislation to protect and restore the civil rights of all people with developmental disabilities. The basic rights afforded to all individuals in this country apply to persons with developmental disabilities. The Council will oppose any attempt to limit the rights of people with disabilities and will actively support any expansion of opportunities for persons with developmental disabilities to live as full participating members of society. The Council will seek continued promotion of equal access to all services and will support legislation prohibiting discrimination in areas such as housing, zoning, voting, medical care, economic programs, education, employment, and habilitation.

The Council supports the enforcement of the Americans with Disabilities Act and its implementing regulations. This legislation provides comprehensive civil rights protections to individuals with disabilities in the areas of employment, public accommodations, state and local government services, and telecommunications. These protections are parallel to those provided on the basis of race, sex, national origin, and religion.

DEINSTITUTIONALIZATION

The Council fully supports the policy of termination of regional treatment center (state institutional) programs for people with developmental disabilities and the re-directing (or transferring) of funds to community programs to ensure the provision of adequate services, supports, and safeguards for persons with developmental disabilities.

EDUCATION

The Council supports free and appropriate education and related services to all students with disabilities, including individualized curricula, assistive equipment so that an individualized and appropriate education is provided in regular, age-appropriate classrooms, and structured planning for transition to adult life. A quality education should provide choices, meet the student's needs, offer the necessary supports, and value and address the concerns of the student and his/her family. The Council supports education that is integrated and provides quality services that meet individual needs.

The Developmental Disabilities Council supports the comprehensive and coordinated provision of Early Intervention Services through an interagency effort to all eligible children under age five and their families. The Council recognizes and supports the rights of children under age five to receive special education and related services as a primary component of Early Intervention.

The Council supports formalized transition planning that begins at least five years prior to graduation and links the young adult with developmental disabilities to appropriate

adult services and supports, to assure a smooth transition to job placement or advanced educational or training opportunities.

EMPLOYMENT

The Council supports full participation of people with developmental disabilities in all state and federal jobs programs such as the Rehabilitation Act, Vocational Education, and the Jobs Training Partnership Act. Individuals with developmental disabilities have the right to appropriate integrated employment opportunities without discrimination and with reasonable accommodations.

When providing employment opportunities, certain principles should be observed and implemented. They are:

- **Natural Environment:** Employment should occur in environments which offer the opportunity for integration with peers without disabilities. To increase integration, employment should be in actual business and industry sites rather than in segregated, sheltered programs. Work groups should include no more than eight people with disabilities. To increase independence, employment supports should have age and social relevance for the person. To encourage productivity, workers should be paid in accordance with the Fair Labor Standards Act and with priority for prevailing or minimum wage. Benefits available to workers without disabilities should be available to workers with disabilities.
- **Support Services:** All supports should be determined and provided on the basis of the individual's needs and preferences. The degree and kind of support should be flexible and should be time limited, extended, or ongoing, according to individual needs. Supports may be provided at the work site, to transport an individual to and from the job, and away from the work site. The goal of all supports is to enable the individual to engage productively in meaningful work.
- **Employment Strategies:** An employment system should offer an array of job options with opportunities for both upward and lateral mobility. The array of available employment opportunities should include competitive employment, small business, and self-employment opportunities. New and redirected funding should make it easy for business and labor to provide community integrated work opportunities.
- **Role of Business and Labor:** The participation of business should be sought in developing ways to meet employer's needs for the work force--in job development and creation and in dealing with work place issues. The participation of organized labor should be sought with regard to issues which affect workers with disabilities

and those without disabilities. Every effort should be made to demonstrate the economic importance and viability of supported employment so that its job creation and development possibilities will be understood by the business and economic development leaders of the state and community.

- **Interagency Collaboration:** At the local and state level, cooperative working agreements, clearly specifying areas of responsibility should be developed among those who provide employment services and supports. Local entrepreneurial agencies should be encouraged to provide a wider range of opportunities and choices for people. At the state level, interagency agreements should also address interagency, intergovernmental, and state-federal relationships with particular attention to Supplemental Security Income/Disability Insurance (SSI/SSDI), transition from school-to-adult life, transportation, Medicaid, and Department of Labor policies which may from time to time present significant barriers to employment.
- **Individual Choices:** Individuals are to be involved in all aspects of decision making that affect their lives. The preferences of persons with developmental disabilities must be honored. Their integrity, dignity, potential for growth, and ability to contribute must be encouraged. Career planning and counseling for persons with developmental disabilities should start in elementary school, as they should for people without disabilities. Such career planning assistance should be made available as needed over the person's lifetime, and should include consideration of retirement planning.
- **Educational and Career Development:** The Council supports the coordination of education and rehabilitation services within the school experience; promotes lifelong education, career development, and retirement planning; opportunities for self-determination and choice in career-related decisions; and the necessary supports and services so that persons with developmental disabilities have access to an array of employment options.

FAMILY SUPPORT

The Council supports state and federal legislation that enhances the capacity of families to meet the multiple needs of a family member with a disability through the creation of policies that provide equal access to an array of quality family support services and resources, and funding mechanisms that allow a federal match for state family support/cash subsidy programs.

All children, regardless of disability, belong with families and need enduring relationships with adults. When states or agencies become

involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationships with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.

Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "whatever it takes." In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

Family supports should build on existing social networks and natural sources of support. As a guiding principle, natural sources of support, including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professionals or agency-operated support services should be available.

Family supports should maximize the family's choice over the services and supports they receive. Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

Family supports should support the entire family. Family support services should be defined broadly in terms of the needs of the entire family including children with disabilities, parents, and siblings.

Family support services should encourage the integration of children with disabilities into the community. Family support services should be designed to maximize integration and participation in community life for children with disabilities.

FAMILY SUPPORTS AND TRAINING

Families should be provided with opportunities for and access to formal and informal training in order to receive information about: (a) state-of-the-art service principles and practices as a basis for planning and decision making to meet their children's individual needs; (b) the service system and public policy in Minnesota; and (c) strategies for obtaining appropriate services and making system changes.

Families of adults with developmental disabilities should receive support to maintain close contact with each other and to reinforce good sibling relationships that enhance the person's (with developmental disabilities) role as a valued member of the family unit.

GENERIC SUPPORTS

Individuals with developmental disabilities should have access to the full range of regular, typical supports such as housing, legal, medical, dental, fraternal, social, leisure, recreational, educational, employment, and transportation services.

HEALTH CARE REFORM

Approved: Public Policy Committee, February 2, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, April 6, 1994

There are currently several proposals for health care reform in the Congress of the United States. These proposals will have a major impact on the lives of individuals in the state of Minnesota with developmental disabilities. The Minnesota Governor's Council on Developmental Disabilities does not take a position on what health care reform proposal is best but does support the principles of the Health Task Force of the Consortium For Citizens with Disabilities. These were first published in December of 1991 and updated in February 1993. Those principles are as follows:

Non-Discrimination: People with disabilities of all ages and their families must be able to fully participate in the nation's health care system.

This would require that the health care financing system:

- prohibit pre-existing condition exclusions;
- prohibit rating practices that discriminate against higher users of health care;
- ensure that all persons, regardless of income or health status, have access to all the needed health related services;
- provide access without regard to age, race, place of residence, or the characteristics of persons with whom one maintains family relationships;
- ensure continuity and portability of coverage.

Comprehensiveness: People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery.

People with disabilities would most benefit from a health care system that includes

access to:

- preventive services, including services to prevent the worsening of a disability;
- health promotion/education services;
- diagnostic services;
- inpatient and outpatient physician services;
- hospital inpatient and outpatient care;
- long- and short-term home and community-based services;
- long-term care in medical facilities;
- prescription drugs, biologicals, and medically beneficial foods;
- mental health, counseling, and substance abuse services;
- rehabilitation services including audiology, occupational therapy, physical therapy, psycho-social services, respiratory therapy, speech-language pathology services, cognitive, vision and behavioral therapy, and therapeutic recreation;
- personal assistance services and independent living services;
- durable medical equipment and other assistive devices, equipment and related services.

Appropriateness: People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice.

An appropriate health care system is one which:

- includes consumer participation;
- ensures consumer choice in relation to services and provider;
- ensures a range of service settings through an integrated delivery system;
- ensures appropriate amount, scope, and duration of services;
- ensures the availability of trained personnel.

Equity: People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs.

An equitable health care system would be one which:

- limits out-of-pocket expenses and cost-sharing requirements for participants;

- provides access to services based on health care need and not on income level or employment status;
- ensures adequate reimbursement for service providers.

Efficiency: People with disabilities and their families must have access to a health care system that provides a maximum of appropriate effective quality services with a minimum of administrative waste.

An efficient health care system is one that:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources in a more balanced way between preventive services, acute care, rehabilitation, and chronic care management;
- ensures the delivery of effective services;
- maintains effective cost controls so that all people can get the health care services which they need.

In conclusion, we feel that the definition of health care should be expanded to include prevention services, rehabilitation therapy, assistive technology, and health maintenance services. Further, we would like to see health care expenses distributed equitably throughout the population. Finally, we would like to see the health care delivery system more effectively support consumer-directed chronic care management.

HOUSING

Approved: Public Policy Committee, August 3, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, October 5, 1994

The Council promotes and encourages persons with developmental disabilities to have access to an array of housing options. The Council supports persons with developmental disabilities to freely choose where and with whom they live, and to schedule and direct the receipt of supports and services at their convenience and in a manner that makes sense to them.

The Council supports the following activities:

- The creation and maintenance of a variety of affordable and accessible housing and ownership options for persons with developmental disabilities. These options include federal, state, or local subsidized housing programs. Such programs must assure that persons with developmental disabilities have equitable access to subsidized housing and an equitable share of program funds.
- Efforts that enable persons with developmental disabilities to control their own housing, whether it is owned or rented by the person.

- Efforts to maintain affordable rents in current public housing units and to assure that the conversion of subsidized housing to market rate units does not displace persons with developmental disabilities.
- The creation of loan programs that make home ownership a reality for persons with developmental disabilities.
- Separation of the provision of services from the ownership of property.
- There should be no discrimination in access to housing funds.

INCOME MAINTENANCE

The Council supports the protection of current and prospective benefit levels of all types of income programs. Basic economic support is essential to ensure a decent standard of living for persons with developmental disabilities. The Council supports full and fair implementation of Sections 1619(a) and (b) and other relevant provisions of the Social Security Act to assure individuals will not lose their benefits because of earnings.

The Council supports removal of disincentives in the Social Security Disability Insurance (SSDI) Program. Incentives must be provided that encourage recipients to be productively employed and earn real wages without jeopardizing their eligibility for programs and support services, or without risking the loss of all benefits including medical benefits. The monetary value of support services should not be counted as part of the individual's income when eligibility determinations are made for services and benefits.

LEISURE, RECREATIONAL, AND SOCIAL ACTIVITIES

Participation of persons with developmental disabilities in the same leisure, recreational, and social activities that are offered to all citizens in their communities is an essential aspect of their quality of life. Historically, this need has had lower priority in resource allocation than education, employment, and living arrangements. But now there is growing awareness that this dimension of human need is as essential to them as it is to others without disabilities. There is also increasing evidence that skills and attitudes gained through leisure, recreational, and social activities enhance perceptions of self-worth and abilities needed to live, learn, and work as community members.

Currently, the leisure, recreational, and social opportunities currently available to persons with developmental disabilities are (mostly, usually) segregated activities. They serve only people with disabilities using nondisabled people in hierarchical positions rather than as genuine teammates or in true peer relationships. According to new studies, such segregation can neutralize or actually impede gains that are being made in integrated education, home, or work environments.

Therefore, segregated leisure, recreational, and social activities should be discouraged and increased effort and resource allocation should be directed to integrated activities.

Current realities support moving away from segregated activities to those that are integrated: (1) federal and state legislation mandate provision of educational (including recreation), residential, and employment services in the least restrictive environments; (2) in Minnesota, almost all persons with developmental disabilities will be living, working, and attending school in their communities—it is their right to use community opportunities and services in all aspects of their lives; and (3) tested, successful models of integrated leisure, recreational, and social activities exist showing that obstacles to participation are more a factor of integrated activities attitude than technical impossibilities.

Integrated activities are characterized by:

- Open access to persons with developmental disabilities in all the opportunities for leisure, recreational, and social activities offered to other community members without disabilities; and
- Provision of adequate and appropriate support to persons with developmental disabilities to assure their genuine participation, acceptance, and enjoyment.

Position Statement

The Minnesota Governor's Council on Developmental Disabilities strongly supports:

1. Promoting recognition of the need for integrated leisure, recreational, and social activities as an essential and legitimate component of a good quality of life for persons with developmental disabilities.
2. Promoting the use of current and new resources (approval, human efforts, financial assistance, facilities/equipment, etc.) for activities that are integrated.
3. Inviting organizations currently sponsoring segregated leisure activities to support inclusive community leisure experiences that are physically and programatically accessible.
4. Developing strategies and approaches that assist persons with developmental disabilities and their families to make the transition to a wide range of integrated leisure, recreational, and social pursuits.
5. Creating new and stronger alliances between both specialized and generic agencies to pool their resources in order to institute and expand their capacity to provide integrated activities that are inclusive and supportive of persons with developmental disabilities.

PERSONAL ASSISTANCE SERVICES

Approved June 6, 1990

Issue

Personal assistance services involve having someone help individuals perform tasks that they would do for themselves if they did not have a disability. Central to this definition is the assumption that personal assistance services should be controlled by the user to the maximum degree possible. Such services are aimed at individuals maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society as a whole.

In 1987, a national survey of personal assistance services was completed by the World Institute on Disability. Over 850,000 people were receiving publicly funded personal assistance services. Based on the results of the survey, "for every person who is receiving personal assistance services, there are more than three people who need services but are not getting them."

Personal assistance services are crucial for children and adults with disabilities to live in the community. A national personal assistance program for independent living must be established. Currently, the absence of an appropriate (or relevant) policy has led to states creating medical models of costly, inadequate programs.

The Minnesota Governor's Council on Developmental Disabilities fully supports the Independent Living Model of Personal Assistance Services as proposed by the World Institute on Disability in April 1987. The Independent Living Model should include at least the following ten characteristics:

1. No medical supervision is required.
2. The services provided include personal maintenance and hygiene including catheterization, mobility, and household assistance.
3. The maximum service limit should exceed 20 hours per week.
4. Service is available 24 hours a day, seven days a week.
5. The income limit for eligibility is greater than 150% of the poverty level. Further, persons who are severely disabled whose income exceeds that established for eligibility should be allowed to buy into an insurance policy which would provide attendant care. Marital status and consequent financial circumstances should not govern access to personal care assistance.
6. Individual providers can be utilized by the consumer.
7. The consumer hires and fires the assistant.

8. The consumer pays the assistant.
9. The consumer trains the assistant.
10. The consumer participates in deciding on the number of hours and type of service he or she requires.

PLANNING ACROSS THE LIFESPAN

Revised: Public Policy Committee, December 5, 1994

Approved: Public Policy Committee, April 5, 1995

Approved: Minnesota Governor's Council on Developmental Disabilities, June 7, 1995

Like all individuals, people with developmental disabilities will pass through many maturational phases in their life. While the transitions that occur between life phases are predictable (e.g., preschool to grade school, adolescent to adult, middle aged to senior citizen), often individuals with developmental disabilities and their families lack important information about the supports available to prepare for these new life phases. This is largely due to the fact that many current service delivery systems and supports are age-based, so transition to a new life phase often means a transition to a new array of service options.

While this issue is formally addressed through transition planning for individuals preparing to enter the adult world of work and community living, the Council recognizes the need to establish and sustain planning efforts across the entire lifespan. Therefore, the Council supports and encourages formalized planning for individuals with developmental disabilities from infancy throughout the individual's life. Planning must cross system boundaries and allow individuals and their families to gain timely access to information about a full array of services and supports. Specifically, cross-system planning must address the following important lifespan transition points well in advance of their occurrence:

- Entry into early intervention systems.
- Entry into middle childhood (elementary school).
- Entry into early adolescence (middle school).
- Entry into adolescence and young adulthood (high school).
- Entry into the adult world of postsecondary education, work, and community living.
- Entry into older adulthood and retirement.

PREVENTION

The Council supports efforts to prevent developmental disabilities and to limit

causes and consequences. The Council supports several activities:

- Improved planning to ensure interagency service delivery.
- Additional research into causes, screening, diagnosis, and interventions.
- Development of a comprehensive state plan.
- Improved interventions such as genetic screening, counseling, family planning, nutrition, prenatal care, early intervention, and protection must be made available statewide.
- Increased public and private awareness of prevention strategies.

PUBLIC AWARENESS AND EDUCATION

The Council supports efforts to educate the public regarding people with developmental disabilities. The media should increase the public's awareness of needs and abilities of people with developmental disabilities.

The Minnesota Governor's Council on Developmental Disabilities supports efforts to increase awareness, sensitivity, and knowledge of policymakers, elected officials, state officers, and staff of generic organizations about issues affecting people with developmental disabilities.

To ensure representation of Minnesota's largest minority, the Council encourages people who have a disability perspective to serve on all types and levels of policymaking and advisory committees.

RECRUITING, TRAINING & RETAINING PERSONNEL¹

Approved: Public Policy Committee, October 5, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, February 1, 1995

Background

As the 21st century approaches, the dynamic nature of education, health care, and human services will require new or at least revised techniques in recruiting, retaining and retraining qualified personnel. Personnel preparation initiatives must address curricular relevancy, long-term value and utility, current research, best practices, and consumer empowerment.

¹Source: Based in part on the American Association on Mental Retardation (undated): *Policy Positions On Legislative and Social Issues*. Washington, DC: Author.

Education, health care, and human service providers will experience a labor supply shortage throughout this decade and into the 21st century. The personnel demands of these labor-intensive services now exceed the supply of available professional and para-professional staff and the future holds even more extreme shortages. Such shortages jeopardize the long-range capabilities of the service delivery system to meet increased demands for an extensive array of programs. Service providers must focus on new solutions to meet anticipated needs. Developing service alternatives that are less labor intensive in concert with initiatives to recruit and retain qualified personnel may offer some relief to the expected work force shortages. As consumers and families assume more active roles in working with service providers, their expectations and outcomes will influence trends in education and training.

Principles

Initiatives to enhance the recruiting, training, and retraining of personnel should address seven specific principles:

1. **Competency-Based Training:** Preservice and continuing education must be competency based to assure quality services and supports are provided.
2. **Family Participation:** Family members who provide support to their relatives with developmental disabilities benefit from educational opportunities in a manner identical to other service providers.
3. **Access:** Educational opportunities must be delivered geographically and physically to all individuals who provide direct care services in accessible locations throughout the state.
4. **Long-Term Value and Utility:** Contemporary education and training programs must be developed within parameters that encourage professionals to invest in health care and human services as a career.

To recruit and retain staff, compensation levels must correspondingly reflect the demands and competencies needed.

5. **Consistency with Current Research Findings and Best Practices:** The dynamic nature of the service system requires ongoing refinement of programs reflect current research and best practices. Special attention should be given to offering training programs to personnel who are in transition from institutional to community-based settings, to training programs on family support, gerontological services, preventive programs, and community inclusion.
6. **Consumer Empowerment:** Services in the 21st century will include an increased level of consumer decision making as citizens self-advocate for needed programs and reforms. Education and training

programs should recognize self-determination and develop professional competencies to support consumer empowerment. Consumers and families should be involved in designing, implementing, and evaluating educational and training efforts.

7. Technical Assistance: The effectiveness of preservice and continuing education is increased with the availability of technical assistance, follow-up, incentives for individuals and agencies, and consequences.

Recommendations

The Council recognizes personnel as a critical and ongoing issue and will work to support improved recruitment, training, and retention of personnel:

- The Council supports educational initiatives for training professionals in disciplines designated as critical need professions.
- The Council supports programs that prepare personnel for work in varied service settings and improve job skills.
- The Council supports wage parity legislation.
- The Council promotes the infusion of information regarding developmental disabilities into generic personnel preparation programs for persons in the education, medical, nursing, legal, and other professions.

The Council urges Congress and the Legislature to appropriate funds for training programs for persons who will serve people with developmental disabilities. Funding should be made available to schools of higher education (e.g., university affiliated programs, medical schools, universities, schools of allied health, colleges, community colleges) and technical colleges.

SERVICE PROVISION BY MULTIPLE AGENCIES

Approved: Public Policy Committee, February 2, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, October 5, 1994,

In the past, many people with developmental disabilities were institutionalized primarily for the purpose of protecting such individuals or protecting society from those individuals. Under these arrangements, individuals were subjected to total control over their lives with few opportunities for self-determination. Because some state institutions and large community residential programs still exist, and case management services often are unable to provide adequate monitoring and supervision of services to persons with developmental disabilities, it is important that any one service provider not have 24-hour responsibility for services.

Quality of life is enriched by having a variety of associations with others. Generally, people have contact with a variety of individuals and service providers as they carry out their daily activities. Only in unusual circumstances, is one's landlord, employer or banker, for example, one and the same. Similarly, individuals with developmental disabilities should have a variety of interested people in their lives to assure that their needs and rights are not ignored, subordinated, or abused. The interplay and checks and balances between service providers as they strive to meet the needs of the individual, increases the likelihood that interests and rights of persons with a developmental disability will be honored. Individuals with developmental disabilities should have choices about how, when, where, and by whom services are provided along with increased opportunities for decision making, productivity and inclusion in the community.

Therefore, the Minnesota Governor's Council on Developmental Disabilities does not support the practice of a single service provider having 24-hour control over the lives of persons with developmental disabilities. Specifically, a provider of residential services should not also be a provider of habilitation or employment services for the same individual.

In circumstances in which following this principle would result in an individual with developmental disabilities not receiving necessary services, the steps to be taken and the timelines to be followed to secure a second service provider should be determined at the outset and specified in the individual's plan developed by the interdisciplinary team.

SERVICES

Approved: Public Policy Committee, August 3, 1994

Approved: Minnesota Governor's Council on Developmental Disabilities, October 5, 1994

The Council supports a new definition of services as whatever personal assistance, adapted environments and modified equipment is required for each individual with developmental disabilities to become increasingly independent, productive, and integrated. Funding streams should follow individuals and be used to meet specific identified needs rather than to fund programs or services such as ICF-MR, DACs, sheltered workshops, or special education levels. All assessments should be based on the individual's **needs and desires**; and real efforts should be made to offer alternatives and choices that mesh with the needs and desires of the individual client.

The Council supports services with the following characteristics:

- The provision of specialized staff, resources, and services to meet individual needs in the regular classroom, neighborhood school, home and family, and community program and setting.
- The substantive training and retraining of personnel, both special and generic service professionals—to prepare them for providing instruction to a variety of heterogeneous groups of individuals.

- The systematic shifting of service delivery design and services away from a categorical, homogeneously grouped, and separate model to one which requires integration and thrives on a variety of grouping arrangements.
- The philosophical and administrative merger of special and regular education and specialized and generic services into one service delivery system, evident by the integration of both professional staff and recipients.
- Inclusion without exception into regular community environments and proximity to family and peers and other citizens who do not have disabilities.

SUPPORTED EMPLOYMENT

Approved November 28, 1990

Issue

The Minnesota Governor's Council on Developmental Disabilities affirms the right of all people with severe disabilities to full participation in community life with support tailored to individual abilities and needs. Integrated employment is a critical element of community living.

Even though individuals with severe disabilities repeatedly demonstrate success in integrated employment, the vast majority of individuals with severe disabilities do not have access to integrated jobs. Most individuals with severe disabilities continue to be isolated and segregated in developmental achievement centers and rehabilitation facilities or are unemployed and unserved on waiting lists.

Position

In the interests of full participation in community life, the Minnesota Governor's Council on Developmental Disabilities endorses the following features of employment for all people with severe disabilities:

- **Integration:** Employment of people with severe disabilities must be in regular employment settings where they work with and among people without disabilities. Opportunities for frequent and ongoing interactions and the development of friendships are crucial outcomes of employment.
- **Income and Benefits:** Care and planning is needed to prevent an overall loss of income and benefits and assure stability of the same. Employment must result in meaningful compensation for work performed and include benefits comparable to coworkers in similar positions.

- **Choice:** Job selection, retention, and number of hours of employment must be based on choice by the individual with a severe disability.
- **Ongoing Career Advancement.** Employment for persons with severe disabilities must be viewed the opportunity to build careers over time where job changes and advancement occur in the interest of higher pay, greater responsibility and variety, better working conditions, and individual interests.
- **Individualized and Natural Supports.** The assistance and support provided to persons with severe disabilities should be individualized according to needs and abilities and should maximize natural supports by coworkers and friends in the work place.
- **Equal Access:** Individuals with the most severe disabilities must be a priority in the implementation of community, integrated employment.

SUPPORTIVE COMMUNITIES

The Council supports creative and varied initiatives to build community connections that create and maintain personal support networks for individuals with developmental disabilities.

TITLE XIX, MEDICAID REFORM

The Council supports the restructuring of the Medicaid program to significantly expand opportunities for individuals with developmental disabilities and their families to acquire family support and community services including case management, respite care, personal care assistance, and individual support services. The Council continues to advocate for a full range of alternatives to ICF-MR programs that promote greater integration, independence, and productivity.

The Council fully supports the strengthening and full implementation of all waiver programs to support people living in the community.

TRANSITION FROM SCHOOL TO WORK

Revised: Public Policy Committee, October 5, 1994

Approved: Public Policy Committee, April 5, 1995

Approved: Minnesota Governor's Council on Developmental Disabilities, June 7, 1995,

Background

The state of Minnesota (M.S. 120.17) requires that beginning with grade 9 or age 14 years students with disabilities have as a part of their Individual Education Program a

plan for transition from school to work. In addition, in May 1994, President Clinton signed The School to Work Opportunities Act of 1993 (P.L. 103-480). The Act is a joint effort of the Departments of Education and Labor and may provide more transition resources and opportunities for youth with disabilities. The Act is intended to provide all students with additional education and training opportunities to earn portable credits, prepare them for first jobs in high skill, high wage careers and increase opportunities for further education including at four year universities. Youth with disabilities are specifically referred to as a target population. The Act specifies that efforts to serve youth with disabilities must be guided by the transition requirements of Part B of the Individuals with Disabilities Education Act (IDEA).²

In spite of the legislation cited above, on completion of high school students with developmental disabilities may find themselves unemployed, underemployed or on waiting lists for training, support services needed to secure and hold employment.

Recommendations

The Minnesota Governor's Council on Developmental Disabilities recommends that:

1. High school students with developmental disabilities must be given opportunities to actively participate in all phases of planning and implementing of their individual transition plan.
2. High school students with developmental disabilities must receive information about various kinds of technology and support services which would enable them to be more independent on the job and increase their employment opportunities. As much as possible, students should be trained to select and supervise the support services they need. The use of generic rather than specialized services should be encouraged.
3. In developing transition plans for high school students with developmental disabilities, an effort should be made to foster as much economic and personal independence as possible using generic rather than specialized services.
4. High school students with developmental disabilities with appropriate support services, should have opportunities for career exploration, mentoring relationships, job shadowing, apprenticeships, and work/study experiences.

²North Central Regional Information Exchange. (Fall 1994). Youth with disabilities and the school-to-work act. *Regional Perspectives*, 1(4), 1.

5. Following completion of high school persons with developmental disabilities should have opportunities for training/education to enhance their employment potential. Such training/education should be provided in inclusive settings with appropriate support services.
6. There is important work to be done within the state of Minnesota's business community toward the development of work opportunity. Presently, there is underway, a great many programs being developed to improve vocational education skills. However, there remains a major void between vocational preparation and work opportunity. The Minnesota business community is just not systematically involved, and there exists a major void. Immediate planning must be initiated to join this state's business community as a working partner in this vital phase of transition.
7. Once a person with developmental disabilities is employed he/she should be kept informed of opportunities for advancement with his/her current employer or with other employers.
8. Employment in segregated day programs (day training and habilitation programs) and rehabilitation programs (sheltered workshops) should be an option only if there are currently no other options available. If such an arrangement is made, a plan should be developed with timelines to meet the goal of obtaining supported or competitive employment for the individual.
9. If an individual with developmental disabilities receives Supplemental Security Income (SSI) the possibility of developing a Plan for Self Support should be encouraged.

TRANSPORTATION

The Council supports public transit and paratransit services funded by all levels of government on a nondiscriminatory basis. The Council supports the strong enforcement of the transportation provisions of the Americans with Disabilities Act (ADA) and its implementing regulations, including the ADA Accessibility Guidelines for Transportation Vehicles.

Paratransit services must be provided in a manner that is as adequate, flexible, responsive, and reliable as transportation provided to the general public.

The Council supports full architectural, physical (mechanical) and programmatic accessibility of all publicly funded transportation services. Any future expansion, renovation, or replacement of transportation services must be completed to remove all existing barriers which prevent full access.