MINNESOTA GOVERNOR'S PLANNING COUNCIL
ON
DEVELOPMENTAL DISABILITIES

Philosophy and Mission
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December, 1979  
Revised  

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This publication represents the joint contribution of many people who voluntarily gave their energies to reviewing literature, making recommendations, and discussing and revising drafts of this statement. Foremost among them were the members of the DD Council's Task Force on Philosophy and Mission; others included members and staff of the State DD Council, members of the regional DD Councils, regional DD planners, State and local agency personnel, members of volunteer organizations, and other interested persons. Their extensive contributions are gratefully acknowledged.
The Minnesota Governor's Planning Council on Developmental Disabilities (DD Council) represents a broadly based approach to planning and promoting better coordination of services for persons with developmental disabilities. The DD Council develops an annual, comprehensive, statewide plan of services for persons with developmental disabilities and advises the Governor of Minnesota on matters pertaining to developmental disabilities.

The DD Council is committed to the goal of improving the quality of life and guaranteeing the rights and dignity of persons with developmental disabilities. The Council believes that both the individual and society benefit when persons with disabilities become active participants in society.

The activities of the Council include planning, evaluation, public information and education, legislative and plan review, research and development. In addition, the Council promotes prevention and early intervention services, appropriate residential services, advocacy and protective services, and training of developmentally disabled persons and personnel to work with developmentally disabled persons.

Developmental disabilities planning efforts are also carried out on a local level throughout the state by seven Regional Developmental Disabilities Advisory Councils.
Historical Background

During the 1960's, American society began to gain increasing awareness of and understanding about the capabilities and needs of persons with disabilities. Much state and federal legislation was enacted which addressed the needs of persons with disabilities (e.g., the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, P.L. 88-156; the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, P.L. 88-164). Numerous organizations became involved in providing the diverse services needed by persons with disabilities throughout their lives. This phenomenal growth of services and programs created a need for better planning and coordination.

Parents and professionals soon became increasingly aware of the inadequacies of programs designed for people with mild and moderate disabilities which were not tailored to the needs of severely disabled people. These programs generally served only persons with a given disability, those with multiple handicaps often did not fit into any particular program and therefore frequently went without service.

A Response: The Developmental Disabilities Concept

In 1970, Congress passed the "Developmental Disabilities Services and Facilities Construction Act" (P.L. 91-517) as a response to this problem. The intent of the Act was to create a comprehensive approach to planning and promoting coordination of services for persons with developmental disabilities. The Act recognized the commonality of service needs among people with long-term substantial, multiply-handicapping conditions that begin early in life.

The 1970 DD Act defined "developmental disabilities" in terms of mental retardation, cerebral palsy, or epilepsy. P.L. 91-517 was amended in 1975 by the "Developmentally Disabled Assistance and Bill of Rights Act" (P.L. 94-103) which added two more disabilities to the definition — autism and dyslexia. In 1978 Congress amended the Act further, P.L. 95-602 ("Developmental Disabilities Assistance and Bill of Rights Act") provides a new, functional definition as opposed to the previous categorical definition:

"Developmental disability" means a severe, chronic disability of a person which—
is attributable to a mental or physical impairment or combination of mental and physical impairments;
• is manifest before the person attains age twenty-two;
• is likely to continue indefinitely;
• results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) receptive and expressive language, c) learning, d) mobility, e) self-direction, f) capacity for independent living, and g) economic self-sufficiency; and
• 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.

To participate in the federal developmental disabilities program and to receive funds, which are disbursed on a formula grant basis, each state must designate a State Planning Council to be responsible for a wide range of planning and evaluation activities. The Minnesota Governor's Planning council on Developmental Disabilities was created in 1971 to plan for the direction, development, implementation, and evaluation of a comprehensive system of services for persons with developmental disabilities in Minnesota and to advise the Governor on matters pertaining to programs, services, and facilities for persons with developmental disabilities. The DD Council annually develops a statewide plan for developmental disabilities services.

The DD Council is characterized by its focus on inter-agency planning, its emphasis on citizen participation and its promotion of human and educational services. The developmental disabilities service concept emphasizes comprehensive, coordinated, lifelong supportive services for developmentally disabled persons and their families. Emphasis is on services for substantially handicapped persons who have similar lifelong needs regardless of traditional labels that categorize specific handicaps. The severity and chronic nature of developmental disabilities sets them apart from most other health-related conditions: service needs are often multiple and continuing.

The DD Council's focus on integrated planning of human services through participation in the planning process by representatives of health, mental health, social work, education, rehabilitation, and other fields helps lessen fragmentation, identify important gaps in services, and facilitate plans for augmenting existing services for persons with developmental disabilities.

The DD Council's diverse representation enhances its ability to influence changes in policies, priorities, and methods of operation of service programs and agencies in order to improve services.
Introduction, Cont.

The developmental disabilities concept encompasses the philosophy that the resources from federal, state, and local government agencies (including co-mingling of funds) together with private service providers and consumers of services, can be melded into a unified force for change on behalf of persons with developmental disabilities. This philosophy provides a context for common effort in which diverse special interest groups and agencies can combine energies for effective planning.

In addition, the involvement of developmentally disabled persons themselves in implementing the developmental disabilities concept is a crucial component of the comprehensive planning process, with the planning under direct influence of those who use and are most directly affected by the services.

The following broad service areas are the focus of planning and development efforts of the DD Council. Many different federal, state, and local agencies are involved in providing these services. These service categories are intended to be comprehensive and inclusive.

Direct Services—programs designed specifically for developmentally disabled clients

• Residential
domiciliary care
special living arrangements

• Day Activity Programs
day care
education
training

• Employment
sheltered
regular

Support Services—programs aimed at getting developmentally disabled clients into service system

• Identification
diagnosis
evaluation
information and referral

• Case Management
counseling
protective socio/legal
follow-along

• Treatment
medical
dental
special

• Family/Program
transportation
personal care
recreation
Fundamental Beliefs of the DD Council

Our nation has proclaimed that all persons have basic rights including those to life, liberty, and the pursuit of happiness. Persons who have a substantial physical or mental disability (especially those whose disability began early in life) may not have an opportunity to exercise these rights. The disabling condition itself and/or established customs and laws may prevent achievement of these birthrights.

The DD Council is committed to the goal of improving the quality of life and guaranteeing the rights and dignity of all persons with disabilities in order to assure their participation in the privileges and freedoms available to all citizens of our state and country. The DD Council believes that both the individual and the society benefit when persons with disabilities become active participants in society by exercising their rights and assuming the accompanying responsibilities.

The fundamental beliefs of the Minnesota DD Council, out of which flow its goals and activities, include the following:

1. All persons, regardless of their disability, deserve the respect of others. The dignity, worth, and potential of every individual, disabled or not, must be respected, preserved, and never compromised in the process of providing services.

2. Our Constitution guarantees equal rights to all citizens. Exercising rights must be accompanied by assumption of responsibility. A belief in basic human rights and responsibilities and Constitutional guarantees shall provide a basis for all decisions of the DD Council on behalf of persons with disabilities. These rights imply, but are not limited to, the assurance of:
   - Adequate food, clothing, and shelter to assure a decent standard of living.
   - Education and training to develop one's potential.
   - Health care, including preventive services, diagnosis, treatment, rehabilitation, and periodic evaluation.
   - Economic opportunities, and productive work or other meaningful occupation.
   - Participation in one's own community, including access to programs and facilities for recreation, transportation, entertainment, and other public services.
   - Protection from discrimination or abuse in any form.
3. No persons with disabilities should be deprived of any basic rights because of cost.

4. In all matters relating to persons with disabilities, potential performance and methods of effective adaptation should be emphasized rather than the disabilities themselves.

5. All persons have the right to function in a setting which provides for development of independence, is as similar as possible to the norms of society, and provides an opportunity for participation in meaningful activity and assumption of personal responsibility in the life of that community.

6. Human life is not static. Each individual should assume maximum possible responsibility for achievement of his or her own human growth and development potentials. As persons move from one level of development to another, changes in settings and circumstances of their lives may be appropriate. These changes may include physical environment, assumption of increased responsibility, and increased freedom of movement.

7. All persons should have the maximum possible choice in making decisions in their own lives. Decisions regarding the lives of persons with disabilities should be made by the persons themselves whenever possible and otherwise by those as close as possible to them. The opportunity to make decisions involves risks and has the potential to contribute to the personal development and human dignity of the persons concerned.

8. When persons need assistance in representing themselves, other individuals or groups have a responsibility to act on their behalf in order to help them obtain and maintain their human and civil rights and exercise their responsibilities. Any assistance to persons with disabilities must be offered with great concern for them, with their consent, and only in instances when they cannot function independently.

9. All persons shall be afforded maximum possible security against unwarranted intervention including protection against violations of privacy and the maximum possible confidentiality consistent with preservation of public interest. All persons should maintain themselves by their own resources to the extent that their capacity and circumstances permit.
Goals

The broad goals of the DD Council include but are not limited to the following:

1. To undertake comprehensive, long-range planning and development efforts to promote effective services for persons with developmental disabilities, including identifying the population, assessing the needs of individuals, determining what services are available, pinpointing service gaps, assisting in the development of new and needed services, and evaluating the quality of services.

2. To foster cooperation and collaborative efforts among the many state agencies, nongovernmental groups, consumers of services, and others concerned with services to persons with developmental disabilities.

3. To insure that developmentally disabled persons themselves and their parents and guardians become active working participants in the planning and delivery of services designed to benefit them.

4. To promote advocacy services for developmentally disabled persons so that they are assured of appropriate protective and legal services.

5. To make an impact on the legislation and political policies of Minnesota and to encourage mutual plan development among agencies related to persons with developmental disabilities.

6. To promote understanding and use of term "developmental disabilities" and understanding of the capabilities and needs of persons with developmental disabilities.
Activities

The DD Council promotes the development of needed human and fiscal resources to support services for persons with developmental disabilities, including support from other public agencies, private organizations, and volunteer groups.

Its activities may include but are not limited to the following:

Planning. The DD Council conducts systematic long-range and short-range planning activities, using a structured, orderly process for establishing goals and objectives and for seeking possible methods to achieve them. Consumers, agency personnel, and service providers participate in the planning process. These efforts seek to promote improved services for persons with developmental disabilities by emphasizing coordination and cooperation between the many human service agencies, consumer groups, and others involved with services for persons with developmental disabilities.

Evaluation. The DD Council promotes implementation of varied evaluation systems to measure the quality, effectiveness, and quantity of services, staff, and facilities for persons with developmental disabilities, while protecting the confidentiality of records and other information describing persons with developmental disabilities.

Public Information and Education. The DD Council disseminates findings from projects and activities it sponsors in order to inform and educate professionals, consumers, parents, agencies, and the general public regarding issues, research findings, and other matters of significance to persons with developmental disabilities. The DD Council supports the establishment of public awareness and public education programs to assist in the elimination of social, attitudinal, and environmental barriers confronted by persons with developmental disabilities. The DD Council submits periodic reports to the Department of Health, Education and Welfare, summarizing its planning and other related activities.

Legislative and Plan Review. In order to facilitate cooperation and eliminate unnecessary duplication, the DD Council provides to the maximum extent feasible an opportunity for its members and staff to give prior review and comment on all state plans which relate to programs affecting persons with developmental disabilities. The DD Council also reviews new and existing laws and regulations which may have some bearing on the planning, delivery, and evaluation of services for persons with developmental disabilities.
In order to promote service quality, accessibility and effective funding and implementation, the DD Council assists in moving its recommendations toward the executive and legislative processes in Minnesota. It further supports the introduction and passage of new laws and appropriate changes in existing laws that would improve the service delivery system for persons with developmental disabilities. The DD Council also seeks effective implementation of existing laws and regulations affecting persons with developmental disabilities.

**Research and Development.** The DD Council supports needed research and development efforts to find new or improved techniques for providing services to persons with developmental disabilities. It also supports efforts to implement and use known research and development findings through programs of translation and dissemination of information.

**Prevention and Early Intervention.** The DD Council promotes programs designed to reduce the incidence of developmental disabilities. Such programs involve the early screening, diagnosis, and evaluation (including maternal care, developmental screening, home care, infant and preschool stimulation programs, and parent counseling and training) of developmentally disabled infants and preschool children, particularly those with multiple handicaps.

**Residential Services.** The DD Council supports efforts to improve the quality of care and the environment of persons for whom institutional care is appropriate and to eliminate inappropriate residential placement of persons with developmental disabilities.

**Community Programs.** The DD Council supports the establishment of community programs and promotes the provision of appropriate and effective services for persons with developmental disabilities. These services should be available to all persons regardless of their place of residence.

**Advocacy.** The DD Council promotes and supports systems advocacy which aims toward achieving legislative, social, and policy reform. In addition, the Council seeks to influence and heighten public awareness about the problems encountered by persons with developmental disabilities in order to gain support for improving the nature, extent, and quality of services available to handicapped persons.
Regional Programs

Developmental Disabilities Planning efforts are also carried out on a local level throughout Minnesota by regional DD planning programs. Regional Development Commissions (RDCs) serve as host agencies for each of the seven regional planning programs; each RDC has responsibility for implementing the regional components of the DD State Plan, establishing a Regional DD Advisory Council, and submitting annual work plans. The relationship between the RDC and the Regional DD Advisory Council is formally documented in a memorandum of agreement or is clearly stated with RDC policy statements. The employment and supervision of staff to carry out the regional DD work plan is the responsibility of the RDC.

Upon the recommendation of the State DD Council and the submittal of an acceptable work plan, planning grants are awarded by the State Planning Agency to RDCs to help carry out DD planning at the local level.

This support of regional planning programs reflects a desire to promote, conduct, and coordinate planning at the local level in order to achieve a continuum of programs and services in each region of the state. Support of local planning, which involved key parties from the human services system, acknowledges that the nature of problems and their solutions will vary by region.

While recognizing the role of regional agencies as part of the statewide planning framework for developmentally disabled individuals, each region exercises flexibility in using available resources in documenting and establishing needs and priorities, and in implementing appropriate plans that address priority service needs of persons with developmental disabilities.

Regional DD Councils perform an important advisory function at the local and state level as well. Regional DD Advisory Council membership parallels that of the State DD Council. At least one half of the members must be persons with developmental disabilities, or their parents or guardians. In addition, Regional DD Councils must include service providers, agency personnel, and representatives of other groups concerned with services for persons with developmental disabilities.
The Regional Advisory Councils are expected to include in their local planning efforts, on behalf of persons with developmental disabilities, the following activities:

- Defining and determining the population in need of services;
- Identifying local gaps in and needs for services;
- Establishing appropriate local priorities for planning, developing, and evaluating efforts to make comprehensive services available to all persons with developmental disabilities, and
- Submitting annual comprehensive plans to the State DD Council and staff.

The Regional Advisory Councils advise the State DD Council, state agencies, and agencies in their region on matters pertaining to local administration. Regional Councils also seek to facilitate and encourage the development of inter-agency planning and coordination of programs, services, and facilities at the local level; they are encouraged to review plans of regional and local agencies or groups which impact on the service program for persons with developmental disabilities.

Regional DD Advisory Councils seek to ensure protection of the human rights of persons with developmental disabilities. They also seek to increase public awareness to assist in the elimination of social, attitudinal, and environmental barriers confronted by persons with developmental disabilities and to involve consumers in their activities to the maximum extent feasible. The Regional DD Councils receive partial financial sponsorship from local agencies and have responsibility to the local agency as well as to the State DD Council and Office.
Council Composition
The Council members are appointed by the Governor of Minnesota. Citizen participation is an important feature of the DD Council. At least one-half of the membership of the Minnesota DD Council consists of persons with developmental disabilities or their parents or guardians. The Council also includes in its membership representatives of the principal state and federal agencies that provide services to persons with developmental disabilities, local agencies, and non-governmental agencies and groups concerned with services for persons with developmental disabilities.

The 1970 DD Act as amended by P.L. 94-103 and P.L. 95-602 requires that each state designate a single agency to administer the State DD Plan and the monies which flow to the state under the DD Act.

In Minnesota, the State Planning Agency was named in March, 1972, by the Governor as the designated agency for administering the DD Council and the DD State Plan. A DD Planning Office was established within the State Planning Agency.

Provisions under the statute establishing the State Planning Agency (Minnesota Statute 4.12) emphasize long-range, inter-departmental planning. The statute mandates review of all plans filed with the federal government by Minnesota state departments and agencies, and review of current programming and future planning of all state departments and agencies. The statute further emphasizes that the powers and duties of the State Planning Agency include the preparation of "comprehensive, long-range recommendations for the orderly and coordinated growth of the state." These provisions are similar in mission, intent, and requirement to the 1970 DD Act and its amendments.

While the DD Council itself does not provide direct services, it emphasizes integration of services and policies among the many other agencies and organizations relevant to persons with developmental disabilities, cooperative funding to increase efficiency in the use of public resources, and local planning activities. The DD Council seeks to establish and maintain communication with agencies and groups in the state and region and to continuously develop liaison activities necessary to acquire and disseminate important information for planning and decision-making.

The DD Council participates with other programs within the State Planning Agency and with other state-level groups in efforts to promote the planning, development, and improvement of needed human services for persons with developmental disabilities.