



Minnesota State Planning Agency

State of Minnesota
Capitol Square Bldg.
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THE EVOLUTION AND CURRENT STATUS
OF THE MINNESOTA DEVELOPMENTAL
DISABILITIES PROTECTION AND
ADVOCACY NETWORK

Compiled by:

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The Evolution and Current Status of the Minnesota Developmental
Disabilities Protection and Advocacy Network

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I. INTRODUCTION

The purpose of this report is to describe how the Minnesota Developmental Disabilities Protection and Advocacy Network evolved and to help clarify the respective roles, responsibilities and interrelationships of the major components of the "network" as it is in 1981. Minnesota has a rather unique history in protection and advocacy beginning in 1972. In particular, the Minnesota advocacy leaders in the field of developmental disabilities have always played an active (innovative) role rather than a reactive one. In 1975, the U. S. Congress mandated that each state have a Protection and Advocacy System in place by October 1 , 1977. Minnesota had begun planning and implementing advocacy services five years earlier and, therefore, had to "adapt" its "system" to meet federal requirements, rather than create a new system.

The terms "system" and "network" will be used interchangeably throughout this paper. This is done with the intent to differentiate another uniqueness in Minnesota. While the term "system" comes directly from the federal Developmental Disabilities Act and applies primarily to the specific advocacy programs that are funded by Developmental Disabilities Protection and Advocacy dollars, in Minnesota, the term "network" is being used as a substitute and it covers a broader scope in that it includes both Developmental Disabilities Protection and Advocacy funded programs and many additional advocacy related services that derive their funding and authority from other sources. The differences between the two terms should become clearer as the reader gains a better understanding of how the network concept evolved over time.

II. PLANNING AND IMPLEMENTING THE MINNESOTA PROTECTION AND ADVOCACY NETWORK

In response to the 1970 federal legislation that created the Developmental Disabilities program, Governor Wendell R. Anderson appointed the first Developmental Disabilities Planning Council toward the end of 1971. In 1972, the Governor designated the State Planning Agency for the administration of this new federally subsidized program and by June, 1972 the Developmental Disabilities Planning Office began operation.

From the beginning, both the law and the first Minnesota Developmental Disabilities State Plan strongly emphasized the advocacy role of the Governor's Planning Council, especially in systems advocacy. The Advocacy and Protective Services Committee was one of several standing committees created in 1972. The mission of this committee was not only to identify the broad issues, emanating from the unmet needs and rights of persons with developmental disabilities, but also to identify specific advocacy services that were needed by individuals and their families.

A. The Priorities

After a two-day planning session in 1972, the Advocacy and Protective Services Committee presented its long term plan to the Council. The following priorities served as the blueprint for the remainder of the decade:

1. Legal Advocacy Services
 - a. training of lawyers and paralegal personnel
 - b. provision of legal and quasi-legal services to individuals and their families
2. Citizen Advocacy Services
 - a. one-to-one volunteer programs to address the instrumental and/or expressive needs of persons with a developmental disability

3. Residential Advocacy Services

- a. for persons residing in public residential settings
- b. for persons residing in private (community based) residential settings

4. Public information/education

The methods used for achieving the above goal areas were: (a) to provide seed monies in the form of demonstration grants. (b) to provide training and technical assistance to agencies or organizations who wanted to develop advocacy services, and (c) to coordinate plans and efforts with other state agencies in the development and supervision of advocacy programs under their jurisdiction.

B. The Implementation of Advocacy Services via Demonstration Grants

Demonstration grants were awarded under contractual agreements via the State Planning Agency and the Developmental Disabilities Planning Office. Most grants were limited to a one year duration, with the exception of the Legal Advocacy Project, which was renewed and funded annually for seven years.

The success or failure to "spin-off" projects, as intended, was largely dependent upon the grantee's ability to procure ongoing support from other funding sources. The projects that were funded in the 1970s (that were directly or indirectly related to advocacy) are listed as follows:

(Code: **Services terminated upon completion of the grant.
 ***The project became an ongoing, integral part of the agency or of another agency, although certain characteristics of the original project may have changed over time.)

Year Began Agency/Project/Results

1972	***Minnesota Association for Retarded Citizens. Youth ARC Advocacy Program for the Developmentally Disabled. A curriculum was developed and secondary schools were assisted in recruiting and training student volunteers to serve as advocates on behalf of their peers with a developmental disability. Several school districts continue such projects today.
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Year Began Agency/Project/Results

- 1972 **United Cerebral Palsy of Greater Minneapolis, Inc. Advocacy to Provide Programs and Services for Severely Involved Developmentally Disabled Individuals. Results of a survey were used as a basis for establishing a developmental achievement center for adults.***
- 1973 ***St. Paul Independent School District #625. Parent-School-Community Communication Center. Support groups for parent involvement were established in most of the East Metropolitan Schools.
- 1973 ***Augsburg College. Later transferred to CENTS, Inc. (Center for the Education of Non-Traditional Students). This project started out as Career Opportunities in Human Services for the Developmentally Disabled. As a pilot project, the emphasis was to Provide training for persons having a severe disability for eventual employment as paraprofessionals in the human service occupations. This program now functions as a service broker between non-traditional student populations (e.g., physically handicapped, chemically dependent, ex-offenders, mentally ill) and institutions of higher learning. People are helped in overcoming the social (attitudinal), financial, programmatic and physical barriers that often stand in the way of achieving educational and employment aspirations.
- 1973 **University of Minnesota Law School. Legal Advocacy for the Developmentally Disabled in Minnesota (Law Curriculum Development and Seminar). A law curriculum was developed and taught during each quarter of the 1973-74 academic year. Internship opportunities continue for students in cooperation with the Minneapolis Legal Aid Society.***
- 1973 ***Minneapolis Legal Aid Society (Later referred to as the Central Minnesota Legal Services Corporation). Legal Advocacy for Developmentally Disabled Persons in Minnesota. (Also referred to as "The Legal Advocacy Project" and in 1980 as The Minnesota Developmental Disabilities Protection and Advocacy Network.) State-wide legal services have been provided to individuals and their families. Paralegal and law school interns have been trained. Lay (volunteer) advocates have been recruited and trained. Many laws, regulations, and agency policies have been influenced. Informational materials have been developed and widely disseminated. Service providers and consumer groups have received specialized training. Court judgements have established procedures for subsequent litigation cases.
- 1974 ***Association of Residences for the Retarded in Minnesota. (Later transferred to the Mental Retardation Division of the Department of Public Welfare) Information and Referral System for Developmentally Disabled Individuals. This information and referral service was established to promote better use of existing residential resources in Minnesota. Counseling and assistance was provided for people seeking placement in community based facilities.

Year Began Agency/Project/Results (Continued)

- 1974 **Minnesota Association for Retarded Citizens, in cooperation with United Cerebral Palsy of Minnesota, Inc., and the Minnesota Epilepsy League, Inc. Inter-Agency Coalition on Public Information Regarding the Developmentally Disabled of Minnesota. This project identified existing public information programs and developed "Project People", which includes sample news releases and T.V. spots in a community education kit.
- 1974 ***St. Paul Independent School District #625. Advocacy Unit for Multiply Handicapped Youth Residing in the East Metropolitan Area of St. Paul. Provided direct, personal assistance to young people having multiple handicaps and their parents.
- 1975 ***St. Paul Association for Retarded Citizens. Citizen Advocacy Program. Recruitment and training of volunteers to serve as instrumental and expressive advocates. Now combined with a leisure time/social center.
- 1977 ***Reachout Today, Inc. (Later transferred to the ARC of Minneapolis). Project CADRE (Citizen Advocacy Development, Recruitment and Evaluation). Initially designed to advocate for the rights of people with a developmental disability who have become involved as offenders or victims in the Hennepin County criminal justice system this project was later expanded to also provide training and technical assistance to community leaders throughout Minnesota to encourage them to recognize and address similar needs in their localities.
- 1977 ***Association for Retarded Citizens in Duluth, Citizen Advocacy Project. Expressive citizen advocacy concepts were combined with leisure time/recreation opportunities in Cloquet, Duluth, and Two Harbors. This satellite concept is being considered for possible expansion to the Iron Range Area.
- 1980 A.C.T., Inc. (Advocating Change Together), Residential Advocacy Project. Using inter-agency agreements, this non-profit organization will serve people residing in community-based settings in Hennepin County. Emphasis is placed upon helping people to acquire the necessary skills in order to become their own self-advocates (assertiveness training).
- 1980 Region 9 Association for Retarded Citizens (Mankato based). Residential Advocacy Project. A pilot project to demonstrate residential advocacy services in primarily rural (small communities) settings.
- 1980 Minnesota Epilepsy League (in cooperation with United Cerebral Palsy of Minnesota, West-Metro Chapter of the National Society for Autistic Children, and the Association for Retarded Citizens of Minnesota). Minnesota Citizen Advocacy Coalition. To provide state-wide training and technical assistance for the expansion and improvement of citizen advocacy programs.

A careful study of the fifteen projects listed above reveals that the vehicle of providing demonstration grants served as an effective means of accomplishing the prescribed, long term goals. Many projects survived the test of time and have become an integral part of the total picture. The "spin-off" concept effectively encouraged the development of independent, locally autonomous units that maximized citizen participation and involvement.

C. The Provision of Training, Technical Assistance and Coordination

As previously mentioned, training and technical assistance was provided by the staff of the Developmental Disabilities Planning Office for non-developmental disabilities funded agencies and organizations in order to encourage the development or improvement of other advocacy services. Such services resulted in:

1. Citizen Advocacy Training in Region 10 (1974) and in Region 9 (1977).
2. Assistance in procuring an H.E.W. grant for establishing P.A.C.E.R., Inc., (Parent Advocacy Coalition for Educational Rights), 1977 to the present.
3. Technical assistance was given to the Office of Human Services, which produced the Advocacy/Ombudsman Study, October 1976. This study documented the need to avoid fragmentation and duplication of advocacy functions and called for improving organizational structure and planning efforts at the state level.

It is important to note that many other agencies and organizations became involved in advocacy efforts at this time. Examples of such developments included:

1. The Department of Public Welfare established Review Boards and Humane Practices Committees in each of the State Hospitals (late 1960s) and hired "in-house" advocates starting in 1972. The central office of

the Department of Public Welfare houses an Office of Client Protection.

2. The Department of Corrections Ombudsman Program was established by Executive Order in 1973.
3. 1976 legislation established the Office of Health Facility Complaints in the Department of Health to investigate and enforce the rights of residents in health care facilities, particularly under the Patient Bill of Rights Act (M.S. 144.651).
4. Federal legislation and funds established the Client Assistance Program (CAP) in Vocational Rehabilitation and in Minnesota, the DVR Ombudsman Project (1975) was created.
5. The Older Americans Act helped to create the Long Term Care Ombudsman Office in the Board on Aging (circa 1975).

The above list is not intended to be complete. It omits other important functions carried out by the Department of Human Rights, the State Council for the Handicapped, Consumer Affairs, as well as guardianship/conservatorship and other protective services. A fairly comprehensive inventory completed the Developmental Disabilities Planning Office in 1975 documented at least 50 state level (public and private) agencies and organizations that provided one form of advocacy service or another. In addition, it was estimated that there were at least 200 advocacy related services operating throughout the state at the local or community level. Therefore, when the 1975 Developmental Disabilities Act mandated that each state establish a Protection and Advocacy System, the challenge in Minnesota was not that of creating a new system, but to improve upon the already existing resources. The need for better coordination and communication was paramount.

D. The 1975 Congressional Mandate and the Emergence of the Network Concept in Minnesota

Considered by many as a landmark decision, the U. S. Congress enacted significant amendments to the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) in 1975. Title II of the Act entitled "Protection and Advocacy on Individual Rights" specified that:

"...each state must assure the Secretary of Health, Education and Welfare that it will...have in effect (by October 1, 1977) a system to protect and advocate the rights of persons with developmental disabilities. Such a system will have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the state. Such a system will be independent of any state agency which provides treatment, services or habilitation to persons with Developmental Disabilities." (P.L. 94-103; 42 U.S.C.A. Chapter 6012, 1975) (Emphasis added.)

Although part of the Developmental Disabilities Act, it is important to note that the Protection and Advocacy System was intended to be a separate entity. In other words, the Protection and Advocacy System was to be administered separately from the regular Developmental Disabilities Formula Grant Program which provided for the operation of the Governor's Planning Council on Developmental Disabilities and the Developmental Disabilities Planning Office.

On April 20, 1976, Governor Wendell R. Anderson designated the State Planning Agency as the administering agency of the Minnesota Protection and Advocacy System. This decision was based on the premise that this agency had already established a leadership role in the area of advocacy, and since this agency did not provide direct services to persons with a developmental disability, the agency would be free from potential conflict of interest. Furthermore, direct legal services to clients were being provided under contractual arrangements by the Central Minnesota Legal Services Corporation, thus removing the State Planning Agency from any possible conflict of inter-

est regarding any of the clientele. Therefore, the Developmental Disabilities Planning Office became responsible for operating both the Developmental Disabilities Formula Grant Program and the Protection and Advocacy System.

Although the Protection and Advocacy System within the Developmental Disabilities Planning Office submitted separate state plans and kept separate financial books, there were many common goals and activities between the two programs that were conveniently combined and/or integrated into a single effort. Economic efficiency became the dominant factor for the overall program design, since a "state-wide system" could not exist on \$50,000 annually. Without the continued support and involvement of the Developmental Disabilities Formula Grant monies, regression rather than progression would have occurred.

Some examples of the combined efforts which produced effective results included:

1. The continued financial support of the Legal Advocacy Project and other demonstration grants
2. Co-sponsorship of two annual conferences for advocacy practitioners serving over 400 people
3. Publication and dissemination of
 - a. Advocacy Dimensions (quarterly newsletter),
 - b. Aids to Advocacy for Developmentally Disabled Persons: A Bibliography and Resource Guide (January 1979),
 - c. Potential Funding Sources for Advocacy Programs (February 1979),
 - d. The Minnesota Developmental Disabilities Advocacy Resource Directory (1978 and 1981).

Of most significance, however, is the establishment of the network concept. In February of 1979, over two hundred advocates attended the first statewide advocacy conference entitled, "A conference on Advocating for Persons with Developmental Disabilities: Future Directions for Advocacy Practitioners in Minnesota." A major portion of the first day's session was spent in describing the history and purpose of the Minnesota Developmental Disabilities Protection and Advocacy System. It was at that time that the idea was proposed by the protection and advocacy staff that a "communication network" be established. In order to assure maximum participation in such a network, an interagency agreement was developed and distributed, entitled, "Statement of Mutual Obligation". This document stated not only what possible services could be provided by the central office of the Protection and Advocacy System, but also specified ways that advocates could contribute toward and participate in the overall effort.

Although many of the conference participants expressed the need for a better communication and cooperation among themselves, only a dozen or so "Statements of Mutual Obligation" were signed and returned. Upon further analysis, such a low response was attributed to an underlying "fear" or "reluctance" on the part of many advocates who reacted negatively to the term "system" and all that this word connotes, (e.g., control, bureaucratic manipulation).

Thus, the term "network" was substituted for "system." The word, network, seemed far less threatening and did more aptly describe the intent which was to foster communication and coordination. Therefore, a second attempt was made to solicit participation using the term "network." Coupled with this second effort, a needs assessment was conducted to determine future priorities of services for advocacy practitioners and

to document their problems and concerns. A total of 100 Statements of Mutual Obligation were signed and returned. This number was broken down into two classifications: (a) 75 agencies or organizations as a whole, and (b) 25 individuals.

It is important to note that some individuals could not gain the cooperation or support from their agency/organization, but wanted to participate on an individual basis. Although some individuals were not representatives of a particular agency or organization, they considered themselves as independent advocates.

E. Transfer of Agency Designation by the Governor

On May 1, 1980, Governor Albert H. Quie transferred his designation for the operation of the Minnesota Developmental Disabilities Protection and Advocacy Network to the Central Minnesota Legal Services Corporation, effective October 1, 1980. The removal of this authority from the State Planning Agency was due largely to the amendment in the 1978 Developmental Disabilities Act that stated, "The Protection and Advocacy System may not be administered or controlled by the State Planning Council." Because the State Planning Council and its administrative staff were housed by the State Planning Agency, the new amendment clearly prevented this Agency from continuing as the administering agent of the Protection and Advocacy Network. On the other hand, the law did not prevent the State Planning Council and the Developmental Disabilities Planning Office from remaining as "systems advocates," which is described more fully in the following section.

III. THE ROLES, RESPONSIBILITIES AND INTERRELATIONSHIPS WITHIN THE MINNESOTA PROTECTION AND ADVOCACY NETWORK

This section describes the functions and interrelationships among the major components of the Minnesota Protection and Advocacy Network.

These major components are comprised of:

1. The Governor's Office
2. The Central Minnesota Legal Services Corporation
3. The Minnesota State Planning Agency
 - a. The Developmental Disabilities Planning Office
 - b. The Governor's Planning Council on Developmental Disabilities
4. The Protection and Advocacy Network Member Organizations

Figure A presents a visual depiction of the relationships among these entities.

A. The Governor's Office

The Governor in each state has the overall responsibility for establishing and operating a Developmental Disabilities Protection and Advocacy System. By the authority given by the U. S. Congress under the Developmental Disabilities Assistance and Bill of Rights Act, as amended in 1978 (P.L. 95-602), the Governor:

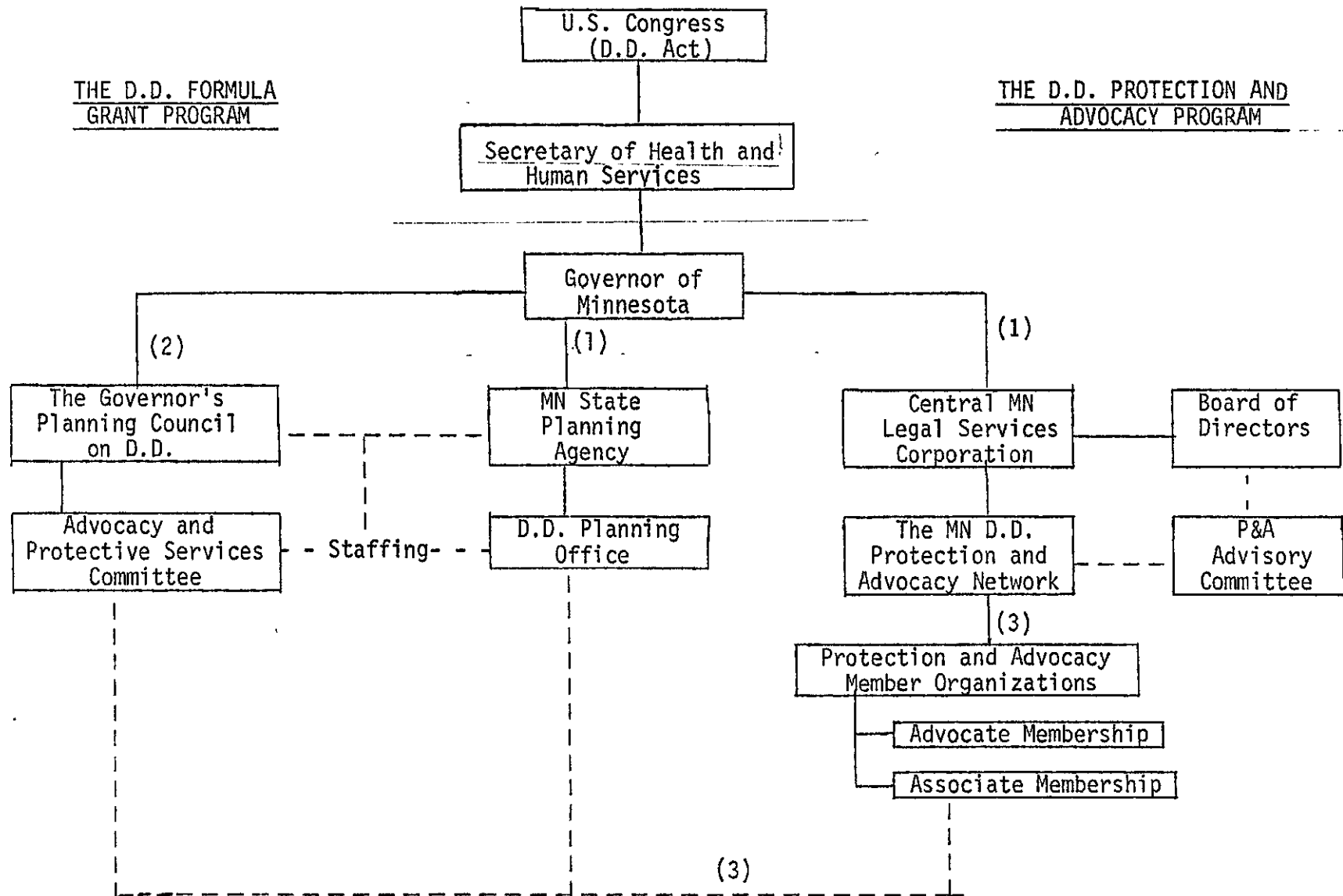
1. Designates the administrative agency of the Protection and Advocacy System. In Minnesota, Governor Albert H. Quie by an Executive Order designated the Central Minnesota Legal Services Corporation as the protection and advocacy agency on May 1, 1980, and was approved by the Secretary of Health and Human Services, when the F.Y. 1981 Minnesota Protection and Advocacy State Plan was approved.
2. Endorses the Protection and Advocacy State Plan that is submitted every three years and up-dated (amended) on an annual basis.

The Governor is also responsible for carrying out the Developmental Disabilities Formula Grant Program under the same act. This includes his appointment of the Governor's Planning Council on Developmental Disabilities and his designation of the State Planning Agency as the administering agent.

- (1) Governor Designates
Administrative Authority
- (2) Governor Appoints
Membership
- (3) Inter-Agency Agreements

Figure A
Organizational Chart

The Minnesota Developmental Disabilities Program and the Protection and Advocacy Network
as Operated Under the D.D. Assistance and Bill of Rights Act, 1978.
(P.L. 95-602)



B. The Central Minnesota Legal Services Corporation

In Minnesota, as of October 1, 1980, this corporation has the authority to administer the Minnesota Developmental Disabilities Protection and Advocacy Network. By law and under Executive Order of the Governor, this agency has "...the authority to pursue legal, administrative and other appropriate remedies to ensure the protection of the rights of all individuals with developmental disabilities who are receiving services or are eligible for services in the State." The Minnesota Developmental Disabilities Protection and Advocacy Network is subject to the regulations as promulgated by the Office of Human Development of the Department of Health and Human Services (45 CFR Parts 1385, 1386, and 1387, May 9, 1980) (See Appendix 2).

The F. Y. 1981 Minnesota Protection and Advocacy State Plan outlines the following services by the Central Minnesota Legal Services Corporation:

1. The provision of legal services to persons with a developmental disability and/or their representatives (e.g., parents or guardians)
2. Training and technical assistance to:
 - a. consumer groups
 - b. service providers
 - c. advocacy practitioners
 - d. the general public
 - e. lawyers and law students
3. Information and referral services
4. Public Information (e.g., brochures, public presentations and training manuals)
5. Legislation and policy reform
6. The administration of the Statewide Protection and Advocacy Network

C. The Minnesota State Planning Agency

This agency participates in the Minnesota Protection and Advocacy Network primarily as an "Associate Member." The Minnesota State Planning Agency contributes to the Network via the Developmental Disabilities Planning Office and the Governor's Planning Council on Developmental Disabilities.

1. The Developmental Disabilities Planning Office provides staff and other resources as a contribution to the Network. Examples of activities and functions as related to advocacy could include:
 - a. Co-sponsorship of conferences and seminars for advocacy practitioners,
 - b. Highlighting advocacy issues and information in publications, such as newsletters.
2. Although the Governor's Planning Council on Developmental Disabilities may not exert direct, administrative control over the Protection and Advocacy Network, this does not preclude the maintenance of a close working relationship between the two entities. In Minnesota, this relationship has been fostered by means of the following rationale and by performance of certain ascribed functions:
 - a. The State Planning Council is a vehicle for collective, or systems advocacy. Council members should be ardent advocates in program development through identification of the resources available and by influencing the service delivery system to better meet the needs of persons with developmental disabilities throughout the state.
 - b. The State Council may evaluate, review and make comments regarding the Protection and Advocacy State Plan. However, the Council does not have the authority to approve or disapprove this state plan.

- c. The State Council may provide leadership to all state agencies in promoting a viable advocacy system in the state, (e.g., via state plans and budgeted expenditures.
- d. The State Council may also collaborate with other official and volunteer efforts related to improving the quality of life for all handicapped persons, e.g., with the Governor's Office of Volunteer Services, the State Council for the Handicapped and the many consumer organizations.

D. The Protection and Advocacy Network Member Organizations

As of the date of this report, there are approximately 100 agencies and individuals that have signed the Statement of Mutual Obligation. This informal interagency agreement has recently been revised in order to include associate membership for service providers. It is estimated that there are at least 300 additional agencies and organizations that are potential members.

The Statement of Mutual Obligation outlines the following responsibilities of the participating members:

1. Contribute ideas, articles, and pertinent information for inclusion in newsletters, position papers, training resources, or other media that will contribute toward the protection and advocacy communication network.
2. Briefly provide basic, statistical data and information about programs at least twice a year on the number of persons served, number of paid and volunteer advocates, services provided and types of problems confronted.

IV. CONCLUSION

At this time, the future of Protection and Advocacy remains uncertain, as does the Developmental Disabilities Formula Grant Program. Such uncertainties stem from current legislative activities and budget considerations in St. Paul and Washington, D. C. The purpose of this paper was not speculative/predictive but a historical review. The reader is advised to maintain contact with Central Minnesota Legal Services Corporation in order to be informed of future directions. The best way to access such information is through their new periodical, Minnesota DD Law Report, which is available by subscription.

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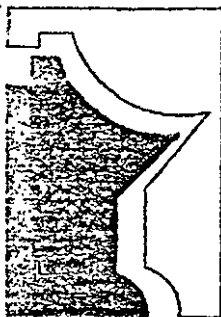
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Appendix #1
Statement of Mutual Obligation
and
Cover Letter
(January, 1980)



Minnesota State Planning Agency

101 Capitol Square Building

550 Cedar Street

St. Paul, Minnesota 55101

Phone 612/296-4018

January 1980

Dear Advocate:

This is an invitation to you and/or your organization to participate in what can be an exciting venture: The creation of the Minnesota Developmental Disabilities Protection and Advocacy Network. As you see from the enclosed "Statement of Mutual Obligation," we are attempting to create supportive services that can help you as you provide advocacy services to your clients. In return, we are asking for your input and participation in this communication network.

If you had the opportunity of attending the first statewide conference for advocates last February, you are already familiar with the "Statement of Mutual Obligation." This interagency agreement has been slightly changed since the conference. The only major alteration is the exchange of the term "network" in the title for the term "system." This was done in order to better describe the overall purpose. To many advocates, who operate quite independently from "the bureaucracy," the term "system" brought with it the connotation of control and manipulation, which is not the intent. Our intent is best described in the enclosed article from Pennsylvania that is so eloquently stated by the Reverend Hobart Campbell, President of the Developmental Disabilities Advocacy Network in that state.

Another major concern raised at the conference was in regard to the amount of reporting that would be requested from us. As stated in the agreement, we want it "brief." The form should be no larger than a postcard and will be requested no more than quarterly.

Also, please find enclosed a form for you to complete and return to us that will let us know what you see as priority activities for our central office staff to perform during the coming year. This will help us to make best use of our very meager budget and to provide those services that will be of most help to you.

So, please review and complete the enclosed materials. A self-addressed envelope is provided for your convenience. I'm sure you may have questions so please feel free to contact:

Mr. Roger Strand, Planner
Developmental Disabilities
Protection & Advocacy Network
State Planning Agency
200 Capitol Square Building
550 Cedar Street
St. Paul, MN 55101
Telephone: 612/296-4018

Sincerely,



Marylee Fithian, Director
Developmental Disabilities
Planning Office

enclosures: Does Pennsylvania...System?
Statement of Mutual Obligation
Needs Assessment

ROS:kt

STATEMENT OF MUTUAL OBLIGATION

"Creating a Developmental Disabilities Protection and Advocacy Network in The State of Minnesota"

I. Purpose of this mutual obligation:

There are presently over two hundred advocacy organizations in Minnesota that serve persons with developmental disabilities. These agencies are located within and outside of government structures. One long range goal that was stated in the Fiscal Years 1978/79 Developmental Disabilities Protection & Advocacy State Plan addressed the need for better coordination and communication among the many advocates. Therefore, the State Planning Agency, which has been designated by the Governor to implement the State Plan, is asking assistance in defining its role as a central, facilitating office and is requesting (in return for services rendered) for a commitment from each advocacy agency to actively participate in and become an official part of the Minnesota Developmental Disabilities Protection and Advocacy Network.

The overall intent of the central office of the Minnesota Protection and Advocacy Network is to strengthen and expand advocacy services to all persons with a developmental disability who need such services. This goal can best be achieved by acting as facilitator, coordinator, and as a communication link for the many independently operated advocacy agencies that agree to participate in the "network."

II. Services to be provided by the central office of the Developmental Disabilities Protection and Advocacy Network;

A. The services to be performed by the central office of the Developmental Disabilities Protection and Advocacy Network will be dependent upon:

1. The results of an annual needs assessment of those individuals and/or agencies which become part of the Protection and Advocacy Network;
2. The resources available to carry out its duties from the federal and state government, such as appropriations from the U.S. Congress;
3. Any constraints placed upon its function by law or regulations; and
4. The parameters of the scope of work to be performed, as stated in an annual State Protection & Advocacy Plan, and as approved by the Department of Health, Education and Welfare.

B. Specific examples of work that may be performed by the central office of the Developmental Disabilities Protection and Advocacy Network include:

1. Publishing a newsletter
2. Providing technical assistance to local/regional/state level groups
3. Providing and/or facilitating specialized training for advocacy practitioners
4. Sponsoring conferences
5. Sponsoring and/or facilitating special interest mini-conferences in each region
6. Public information/education (Increasing public awareness about the needs and rights of persons with developmental disabilities)
7. Information and referral services
8. Updating and distributing the Advocacy Resource Directory
9. Demonstrating innovative approaches in providing advocacy services
10. Collecting data about the scope/extent and quality of advocacy services provided in Minnesota
11. Evaluating advocacy programs (This could include designing and field testing evaluation instruments.)
12. Serving as an information clearinghouse

III. Reciprocal responsibilities of participating individuals and/or advocacy agencies:

So that I, the undersigned, and/or my agency might be considered as being a part of the Developmental Disabilities Protection and Advocacy Network, I hereby agree to participate in the following activities:

- A. Contribute ideas, articles, and pertinent information for inclusion in newsletters, position papers, training resources, or other media that will contribute toward the protection and advocacy communication network;
- B. Briefly provide basic, statistical data and information about my program (e.g., number of persons served, number of paid and volunteer advocates, services provided and types of problems confronted) at least twice a year on an ongoing basis.

- C. Assist in developing or revising the Annual Developmental Disabilities Protection and Advocacy State Plan by means of reviewing, commenting, and helping to select priorities.

Signature

Date

(AC) /

Print Name

Telephone

Advocacy Agency

Address

(ZIP) _____

Check one:

_____ The above signature represents my participation as an individual only, independent of any agency.

_____ The above signature represents participation of the entire organization, as listed above.

- IV. ON BEHALF OF THE STATE PLANNING AGENCY AND THE MINNESOTA DEVELOPMENTAL DISABILITIES PROTECTION AND ADVOCACY NETWORK, I, the undersigned, do hereby honor this agreement within the constraints listed in Item II, A, above:

Marylee Fithian

Director

Date

MARYLEE FITHIAN
Developmental Disabilities Planning Office
State Planning Agency
Capitol Square Building
550 Cedar Street
St. Paul, Minnesota 55101

Does Pennsylvania Have An Effective
Protection and Advocacy System?*

"Does Pennsylvania have a protection and advocacy system for the developmentally disabled?"

That question has been heard many times and some cynical voices have answered: "There is no effective P & A system at work in Pennsylvania."

On April 29, 1977, a private non-profit corporation was formed under the name Developmental Disabilities Advocacy Network (DDAN) to meet the mandate of the Amended Developmental Disabilities Act, Title II, Section 113. This corporation has been in existence and functioning for a little more than a year--yet the question persists.

Obviously, "a little more than a year" is too soon to expect a statewide system to be fully-established, given the complexities of organizing such a system and its very nature.

At its best, protection and advocacy is a lay movement. But a network of lay activity and lay activists has need for enough organization and professional assistance to assure efficient communications and non-duplication of effort.

It is this need for "professional assistance" which DDAN answers.

DDAN is a supply line to local advocacy units and other groups to help them cooperate in advocating where they are.

As a result, the effectiveness of DDAN depends very much upon the willingness of local organizations to cooperate with each other and with DDAN as the state coordinator and facilitator.

DDAN is a resource center. And, as such, it depends upon "feedback" from these local organizations so that information and remedies can be shared with those in other parts of Pennsylvania with similar problems and needs.

As a matter of philosophic policy, the energies of the DDAN Board of Directors and staff are directed outward across all of Pennsylvania to reach and aid consumers and providers of advocacy services.

DDAN is not a bureaucratic force which can impact the State with its own dynamics. And the Board has promised itself that it will do all in its power to keep Pennsylvania's protection and advocacy system - DDAN - from becoming a bureaucratic monster, feeding itself on self-importance and self-aggrandizement.

DDAN will not try to entrench itself nor justify its existence. If circumstances do not justify DDAN's existence, then DDAN will cease to exist.

But DDAN is an idea. An idea which can ripple outward to inspired minds and make taut the muscles of action- And an idea returns, not to draw things unto itself, but to create a network of cooperation in which all humanity takes ownership of truth and justice.

-The Rev. Hobart Campbell
President
DDAN Board of Directors

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Annual Needs Assessment
Minnesota Developmental Disabilities Protection & Advocacy
Network
June, 1979

The following information will be tabulated and will be incorporated into the future State Plan. The collective response should indicate what the advocates in Minnesota need and want. Every effort will be made to try to meet these stated needs, within the realistic constraints of staff, resources available and money.

Questions: _____

1. What functions/services should the central office of the Developmental Disabilities Protection & Advocacy Network provide? Indicate which you see as the top six priorities by placing a number next to the items, starting with the number "one" as the top priority.

- _____ a. Publishing a newsletter
- _____ b. Providing technical assistance to local/regional/state level groups
- _____ c. Providing and/or facilitating specialized training for advocacy practitioners
- _____ d. Sponsoring conferences
- _____ e. Sponsoring and/or facilitating special interest mini-conferences in each region
- _____ f. Public information/education (increasing public awareness about the needs and rights of persons with developmental disabilities)
- _____ g. Information and referral services
- _____ h. Updating and distributing the Advocacy Resource Directory
- _____ i. Demonstrating innovative approaches in providing advocacy services
- _____ j. Collecting data about the scope/extent and quality of advocacy services provided in Minnesota
- _____ k. Evaluating advocacy programs (This could include designing and field testing evaluation instruments.)
- _____ l. Serving as an information clearinghouse
- _____ m. Other (specify) _____

2. What specific problems or issues would you like to see addressed in newsletter articles, workshops, etc.?

PLEASE RETURN IN THE ENCLOSED SELF-ADDRESSED ENVELOPE

Appendix #2

Federal Regulations Governing
Developmental Disabilities
Protection and Advocacy Systems

Friday
May 9, 1980

Part VII

**Department of
Health, Education,
and Welfare**

Office of Human Development Services

Developmental Disabilities Program

MAY 20 1980

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Office of Human Development Services

45 CFR Parts 1385, 1386, and 1387

Developmental Disabilities Program

AGENCY: Department of Health, Education, and Welfare, Office of Human Development Services (HDS), Rehabilitation Services Administration (RSA).

ACTION: Notice of proposed rulemaking.

SUMMARY: The Rehabilitation Services Administration (RSA) in HDS proposes new and revised regulations. The basis for these regulations is the Developmental Disabilities legislation. In these proposed rules, RSA is also revising and clarifying the current policies and regulations that will have continued applicability. The proposed rules do not include regulations for the university affiliated facilities program, which have been issued separately under 45 CFR Part 1300 (August 6, 1979, Vol. 44, No. 152), except for a new requirement for an assurance regarding the rights of persons with developmental disabilities.

DATE: Comments on the proposed rulemaking must be received on or before August 7, 1980.

ADDRESS: Comments should be addressed to Commissioner, Rehabilitation Services Administration, U.S. Department of Health, Education, and Welfare, Washington, D.C. 20201. Comments are available for public inspection in the Bureau of Developmental Disabilities, RSA, Room 3070, Mary E. Switzer Building, 330 C Street S.W., Washington, D.C. 20201, Monday through Friday, 8:30 a.m. to 5:00 p.m., telephone (202) 245-0335.

FOR FURTHER INFORMATION CONTACT: Ms. Marjorie Kirkland, Bureau of Developmental Disabilities, Washington, D.C. 20201, Telephone: (202) 245-0335.

SUPPLEMENTARY INFORMATION:

General

We are proposing new regulations to implement Title V of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, as well as to meet additional needs of the program which have become apparent. The title of the new Act is the Developmental Disabilities Assistance and Bill of Rights Act. It provides for a three-year extension of the authorizations of

appropriations for: (1) The basic State program; (2) systems for protection and advocacy of individual rights; (3) the university affiliated facilities programs for administration and operation of training and service programs; and (4) special project grants including projects of national significance. The following seven sections present the major changes made to the developmental disabilities programs by the 1978 amendments. The policies and purposes of the changes are discussed in the section-by-section analysis of the proposed regulations.

Parts of the Rehabilitation Services Administration will soon be transferred to the new Department of Education; the Developmental Disabilities Office will remain in the Department which will become the Department of Health and Human Services. Changes resulting from the reorganization will be made in the final regulations.

★ Definition of Developmental Disability

A major change brought about by the 1978 amendments is in the definition of developmental disability. The new definition is based on a study mandated by Pub. L. 94-103. It states that a developmental disability: (1) is severe and chronic; (2) is attributable to a mental or physical impairment; (3) is manifested before age 22; (4) is expected to continue indefinitely; (5) results in substantial functional limitation in three of seven specified areas of major life activities; and (6) reflects the need for lifelong and individually planned services.

The House Conference Report No. 95-1789, accompanying H.R. 12467, p. 104, 95th Congress, Second Session, noted that "the definition is intended to cover everyone currently covered under the definition and it is also intended to add other individuals with similar characteristics. . . . It is not the intent to exclude anyone who legitimately should have been included under the definition in current law."

★ Rights of the Developmentally Disabled

Section 111 of Pub. L. 94-103 contained a series of "findings" respecting the rights of developmentally disabled persons, including the following:

- (1) Persons with developmental disabilities have a right to appropriate treatment for their disabilities;
- (2) Treatment should be designed to maximize the developmental potential of the person;
- (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 does not meet certain stated standards;

(4) Nonresidential programs must be appropriate to the persons served.

No authority was included in that Act to allow the Department to withhold funds from States on the basis of failure to meet the findings.

The 1978 amendments, however, added a requirement to the basic State grant program that the State assure the Secretary that the rights of developmentally disabled people are to be protected consistent with Sec. 111. The Department has decided to require that all programs authorized under the Act, except for the protection and advocacy systems, comply with Sec. 111 of the Act. The protection and advocacy systems are exempted because they are an extension of the "Rights" provisions and the systems do not provide services, treatment or habilitation. The Department believes that applying this policy to the other programs is within the intent of Congress. Recipients of funds under the Act are to assure the State and the Commissioner that they will provide services which comply with the requirements of Sec. 111 (Rights). Failure to comply with the assurance may result in the loss of Federal funds.

★ Protection and Advocacy Systems

The 1978 amendments made several changes in the protection and advocacy provisions. They are a prohibition against the State planning council's administration of the State's system; a requirement that a report describing the State's activities be submitted to the Secretary at least once every three years; and a requirement that a program performance report be submitted annually. Failure to have an approvable system in place will result in the loss of Federal funds for the basic State grant program as well as for the protection and advocacy system. Minimum allotments of \$50,000 are established for the States.

State Planning Councils

Several changes in the Act affect State planning councils. One-half, instead of one-third, of the members are to be consumers and their representatives. The principal State agencies represented on the council remain the same as in the prior Act, but, in addition, higher education training facilities and local agencies must now be represented. The Governor is to appoint all members and provide for appropriate rotation of the members.

The State council is so constituted that it provides a forum for consumer

involvement in policy and priority determinations.

The council also provides a means for exploring all avenues for the provision of services through State and local, private, and public agencies. Unlike the prior system the council must now develop the State plan jointly with the administering agency.

State Plan

The major part of the Developmental Disabilities Program is the basic State plan. In 1970, the program was seen as a planning and coordinating mechanism, with some funds for augmenting services provided by other agencies. The amendments of 1978 have to a considerable degree, changed the programs to provide services. The priority service areas are: (a) case management; (b) child development; (c) alternative community living arrangements; and (d) non-vocational social development.

The Act provides that until the appropriation exceeds \$60 million a year, a State is required to fund at least one, but not more than two, priority service areas. The State may fund three priority service areas when the Federal appropriation is more than \$60 million. Regardless of the Federal appropriation, however, the State must spend at least 65 percent or \$100,000 (whichever is greater) of its allotment for services.

For those States which would have to reduce the amount of Federal funds spent on planning activities in order to meet these requirements, however, the Act provides a transitional period. Those States need not reduce the amount spent for planning in the fiscal years ending September 30, 1979 and September 30, 1980. By October 1, 1980, however, all States must allocate at least 65 percent for services. These transitional provisions are not included in the regulations because the Department believes they are self-implementing, and because they will soon expire.

The State plan now must be revised at least every three years, instead of annually, as before. It must, however, be reviewed annually by the State council for needed changes in priority service areas. There are now eight major sections of the State plan instead of the 30 previously required.

Allotments

The 1978 amendments increase from \$100,000 to \$250,000 the minimum allotment each State and Puerto Rico may receive for the basic State program. Minimums for the other Territories are increased to \$100,000. The Northern

Mariana Islands may participate in the program if it chooses.

Special Project Grants

New grant authority is available to support the development and demonstration of methods to attract and retain professional personnel to serve developmentally disabled people, and the demonstration of methods to expand or improve protection and advocacy services. The Commissioner is to establish procedures to ensure the involvement of developmentally disabled persons and their parents in the determination of priorities for these grants.

Overview of Regulations

The regulations in these parts are reorganized and rewritten for clarity and simplicity in accordance with HEW's Operation Common Sense.

The following regulations were previously promulgated in 45 CFR parts 1385, 1386, and 1387 and are not changed, but are included in these regulations for the sake of clarity and completeness.

New Location of Regulations Promulgated in 1977, Not Substantively Changed

Present section and title	Proposed section
1385 7—Recovery	1385 6
1385 9—Cooperative or joint effort between States and agencies	1385 5
1385 10—Awards	1385 5
1386 1(b)—Purpose and assurances	1385 46
1386 2(a), (b), (d), (e)—Plan submission and approval	1386 42
1386 3—Designation of State agency(ies) for administration	1386 41
1386 4—Identification of administrative program unit	1386 41(c)
1386 10(a), (b)—Allotments to States	1386 1
1386 11—Reallotment of funds	1386 2
1386 12(d)—Conditions on uses of allotment	1385 9(b)
1386 13—Federal share	1386 5
1386 14—Nonduplication	1386 8
1386 15(a)—Payments for planning, administration, services and construction	1386 9
1386 16(a)—Withholding of payments	1386 11
1386 20—Methods of administration	1386 43
1386 21—Personnel administration	1386 12
1386 22—Fiscal administration	1386 41(e)
1386 23—Special financial and technical assistance to poverty areas	1386 47(f)
1386 24—Reports	1386 41(d)
1386 25(a)—Methods of evaluation	1386 49
1386 25—Use of volunteers	1386 50
1386 47—Habitat plans	1386 52
1386 61—Establishment of State planning council	1386 41
1386 80-112—Subpart D Practice and Procedure for Hearings to States on Conformity of Developmental Disabilities Plans to Federal requirements	1386 80-112
1387 2—Application content	1387 4
1387 3—Eligible applicants	1387 3
1387 20-23—Special project grants	

In proposing the new regulations, we maintain the underlying purpose of the regulations as stated in the Preamble to the Proposed Rules published in the Federal Register on August 30, 1976 (Part II, Vol. 41, No. 169). That purpose is to ensure the continued targeting of funds

and resources to services to developmentally disabled individuals through a national, State, and local partnership. To this end, the goal of the program is to enable States to increase the provision of quality services to persons with developmental disabilities. The goal is to be reached through the design and implementation of a comprehensive and continuing State plan which makes optimal use of Federal, State, local, and private resources, and assures the rights and dignity of all those being served.

The following is a section-by-section analysis of the proposed regulations. (The references in parentheses in the headings are to the applicable sections of the Act.)

Part 1385—General

This part sets out the provisions applicable to two or more of the developmental disabilities programs. We believe that this organization will make it easier for members of the public to locate common policies and procedures, and that it will avoid unnecessary duplication.

Section 1385.1 Purpose of the regulations. (Sec. 109)

This section sets forth the purpose of these regulations which is to implement the Act, and to provide operational and administrative information needed by users to understand the requirements and to act appropriately.

Section 1385.2 Definitions. (Sec. 102)

This section includes definitions used in Parts 1386, 1387, and 1388 of this chapter. Terms relating only to construction have been omitted because the Act no longer provides authority for construction activities.

We have quoted the definition of developmental disabilities from the Act without elaboration. Some people have expressed concern that we need to clarify several terms in the definition. For example, "severe disability" and "substantial functional limitation" are subject to varied interpretations, so that one State might find an individual eligible for services under the Act, but another might not. The Department believes that all of the specifications taken together constitute an adequate definition without further definition of the component terms.

We welcome comments regarding problems encountered in using this definition. We are particularly interested to know whether the term "substantial functional limitations" needs to be defined; also, whether the seven areas of life activity need further definition. We hope to learn whether the

unelaborated definition will bring about greater ease of planning, administration and programming; and, most of all, if it results in providing services to the developmentally disabled population.

Section 1385.3 Rights of persons with developmental disabilities (Rights). (Sec. 111)

The "Rights of the Developmentally Disabled," which was included in but not implemented by Pub. L. 94-103, is being applied by the Rehabilitation Services Administration in relation to all programs authorized under the Act (except the protection and advocacy program for the reasons stated above in "Rights of the Developmentally Disabled"). However, the 1978 amendments require implementation of the provision. The regulations elaborate on the "Rights" in the following ways: (1) we have added to the list of "rights" standards for compliance with Medicare fire protection requirements. The Medicare standards have been proposed in order to avoid confusion for providers of services and States; (2) we have added standards for nonresidential programs; and (3) we have prohibited the award of State and Federal funds to programs or activities which do not meet the standards. Paragraph (b) provides that each grantee, except for the protection and advocacy program, must give an assurance that no Federal or State funds will be used by any project, program, activity, or facility that does not comply with this section. Failure to comply with this assurance may result in the loss of Federal funding.

Section 1385.4 Grants administration requirements.

This section incorporated 45 CFR Part 74, and other Departmental grants requirements that are applicable to developmental disabilities programs. A new provision has been added providing for a notification and hearing if a specific claim is to be disallowed.

The proposed regulation, in paragraph (c), provides for the first time that States may appeal disallowances to the Departmental Grant Appeals Board. The decision of the Board shall constitute the final agency decision on the disallowances.

Paragraph (d) pertains to the examination of all records of grantees and sub-grantees receiving funds under the Act by authorized representatives of the Secretary or the Comptroller General of the United States. The proposed regulation, although included in 45 CFR Part 74, is added to emphasize the need for access to records, including all records of the protection and advocacy system relating to Federally

funded activities, in order for the Department to carry out its responsibilities and to assure proper use of Federal funds. Some States and agencies have objected to this activity in the past.

Section 1385.5 Awards

Section 1385.6 Recovery of Federal funds used for construction of facilities. (Sec. 107)

No substantive changes are proposed from the present regulations.

Section 1385.7 Assurances regarding evaluation system. (Sec. 110(a))

As a condition to the receipt of Federal funds under the Act beginning October 1, 1980, each State must assure the Commissioner that it will submit a time-phased plan for implementation of a comprehensive system for the evaluation of services to persons with developmental disabilities provided under the Act. By October 1, 1982, the State must also assure the Commissioner that it is using the evaluation system. Failure to do so may result in the loss of Federal funding. Except for a revision of the time schedule for planning and implementation, these provisions are the same as those in present regulations. The Commissioner will issue instructions to the States on planning and implementing the evaluation system.

Part 1386—Formula Grant Programs

The purpose of this part of the proposed regulations is to specify policies and procedures for the conduct of the formula grant programs, including the implementation of the changes in the 1978 amendments. Part 1386 is divided into four subparts. Subpart A contains the general provisions pertaining to one or both of the formula grant programs, except where noted. Subpart B provides details of the requirements of the protection and advocacy system. Subpart C deals with the basic grant program including provisions regarding the State planning councils. Subpart D explains the practices and procedures for hearings when a question of conformity or compliance has been raised.

Subpart A—General

Section 1386.1 Formula for determining allotments. (Sec. 132(a))

No substantive changes are proposed from the present regulations.

Section 1386.2 Allotment for basic grant program. (Sec. 132(a)(2) (A) & (B))

This section informs the States and Territories of the new minimum allotments, increased from \$150,000 to \$250,000 for States, the District of Columbia, and Puerto Rico. The other Territories are to be allotted \$135,000 as a result of this reasoning:

(1) Sec. 132(a)(2)(A) states that the allotment to the Territories may not be less than \$100,000;

(2) Sec. 133(b)(4)(B) states that "not less than \$100,000 or 65 percent * * *, whichever is greater, will be expended (on services * * *) (Emphasis added.)

(3) In order for the Territories to spend \$100,000 (the greater amount) and still have funds for planning and administration, it is evident that their allotment must be more than \$100,000.

(4) We are allotting 35 percent of \$100,000 to the Territories for planning and administration, or a total of \$135,000 to each.

Section 1386.3 Allotment for protection and advocacy system. (Sec. 113(b)(1)(A))

This section incorporates into the regulations provisions contained in the 1978 amendments for allotments for protection and advocacy systems. This section also establishes a minimum allotment of \$30,000 per year (instead of the previous \$20,000 per year) for Guam, the Commonwealth of the Northern Mariana Islands, American Samoa, the Virgin Islands, and the Trust Territories of the Pacific Islands since minimum allotments were not included in the Act. The Department believes these minimums are essential for those Territories to operate a protection and advocacy system in their areas.

The regulations also provide that in the event the appropriation is less than the amount necessary to make allotments to the States and Territories under the previous paragraph, the State's allotment shall be equal to the ratio which the State's allotment bears to the total amount appropriated.

Section 1386.4 Reallocation. (Sec. 132(d))

Section 1386.5 Cooperative or joint effort between States and between agencies. (Sec. 132(c))

Section 1386.6 Federal and non-Federal shares for the basic State grant program. (Sec. 103)

No substantive changes from the present regulations are proposed.

Section 1386.7 Obligation by grantees and subgrantees.

This new section specifies the period of time during which grantees and subgrantees may obligate funds under the Act.

Section 1386.8 Nonduplication. (Sec. 136)**Section 1386.9 Payments. (Sec. 134)**

No substantive changes from the present regulations are proposed.

Section 1386.10 Liquidation of obligations. (Sec. 134)

This new section has been added because the Act (Sec. 134) requires that expenditures be made under the State's current, approved State plan. In the past, funds have sometimes been held for long periods without being used for program purposes. We believe good management practice allows not more than one additional year for liquidating of costs resulting from obligations.

Section 1386.11 Withholding of payments. (Sec. 135)

This section restates the existing regulations. The proposed regulation also extends this provision to the protection and advocacy program. In the previous regulations, this provision inadvertently failed to refer to the protection and advocacy system. We are correcting that omission in this section of the regulations.

Section 1386.12 Standards for a merit system of personnel administration.

This section incorporates the standards for a Merit System of Personnel Administration as promulgated by the Office of Personnel Management (OPM). The standards apply to persons employed by State and local governments under the protection and advocacy system and the basic State program funded under Subparts B and C of Part 1386, including the staff of the State planning council. The Department has adopted these standards which were published in the Federal Register, Vol. 44, No. 34, February 16, 1979. They are available from the OPM, and HEW Regional Offices.

Section 1386.13 Fair hearings.

This section sets out a new requirement which is added because of the 1978 amendments' emphasis on the provision of services. The Department believes that all reasonable means must be used to assure: (1) that persons applying for services are not arbitrarily denied them, and (2) that no one receiving services has them terminated

or reduced without a hearing. To accomplish these purposes we have adopted the language used in the regulations for Title XX of the Social Security Act (Social Services). (See 45 CFR 228.14.)

★ Subpart B—State System for Protection and Advocacy of Individual Rights

As a condition for a State to receive Federal funds for the basic State program, the act requires that the State must have in operation a system to protect and advocate the rights of the developmentally disabled. Failure to meet this requirement may result in the loss of Federal funds under Subparts B and C of this Part and also under Part 1387 (because the State in which a special project is to be carried out must have a State plan approved under Part C).

The Department has had over two years' experience in administering the protection and advocacy program. Based on this experience, it is proposing several new and more detailed regulations.

★ Section 1386.20 Requirements for participation in the developmental disabilities program. (Sec. 113(a))

The legislative requirements for the system are restated from the Act in order to emphasize their importance. In addition, the regulations clarify the population that is to be served. We do not believe Congress intended to exclude the group most urgently in need of advocacy: those persons with developmental disabilities who are not receiving services. We have, therefore, made "all individuals with developmental disabilities in the State" eligible for assistance by the system.

Section 1386.20(c)(2) requires that protection and advocacy systems have the authority to institute legal and administrative proceedings to redress the rights of institutionalized developmentally disabled persons without the necessity of representing a named client. Exercise of this authority is contingent upon the protection and advocacy system certifying to the court or administrative body that certain steps have been taken in an attempt at non-judicial resolution.

The Department is particularly interested in knowing if there are any state constitutional, statutory or judicial barriers to this provision. If there are, is the state willing to eliminate these barriers? What would such changes entail and how long would they take?

Sections 1386.20(3) and (4) require that protection and advocacy system have access to the medical and personal records of institutionalized

developmentally disabled persons. In the case of judicially declared mentally incompetent individuals, their guardians must be given reasonable notice of the protection and advocacy system's intent to examine the records. If the institutionalized person is not mentally impaired, the protection and advocacy system must obtain that person's consent before being allowed access to the records. However, the protection and advocacy system must establish procedures to protect the confidentiality of the records examined.

The Departmental believes that these provisions are essential and will provide the protection and advocacy systems with the necessary mechanisms to adequately protect the rights of institutionalized developmentally disabled persons.

On the basis of our experience, we have required that the protection and advocacy system have physical access to persons with developmental disabilities who are in any institution or program.

★ Section 1386.21 Designated State protection and advocacy office. (Sec. 113(a))

This section specifies what the State must do in designating the State's protection and advocacy office and the limitations on its choices. The present policy of allowing States to select public or private nonprofit agencies to carry out the protection and advocacy program is maintained.

Some States have proposed to place the protection and advocacy office in an agency which provides guardianship. The Department considers guardianship a service. Since Sec. 113(a)(2) requires that the protection and advocacy system be independent of any agency which provides services to persons with developmental disabilities, we believe guardianship and protection and advocacy may not be combined. There is a potential conflict in guardianship cases because guardianship arrangements, especially involving adults, impose limitations on the ward's rights. Our policy will be to assume that a conflict exists any time a reasonable question is raised. This policy is necessary in order to best protect the interests of the individuals because of assuring the independence of the system from service providers.

Section 1386.22 Report on the State system. (Sec. 113(a)(3)(A))

This proposed regulation establishes for the first time the kinds of information which the State must include in the statutorily required report to the Commissioner on the protection and

is essential to assure that States develop a comprehensive plan to bring together all available resources so that the developmentally disabled may be served in the most effective, efficient way. It continues policy now in existing regulations.

Subsection (c) requires that the State plan describe the extent and scope of priority services which will be provided each year under the plan. We expect that the annual review will lead to a shift from one area to another if the State determines that the change will result in more or better services.

Subsection (d) requires the establishment of a method and criteria for evaluating the effectiveness of the State plan in meeting its objectives. No substantive change from the present regulation is proposed.

Section 1386.45 Priority services. (Sec. 133(b)(4))

Since 1970, the Developmental Disabilities Act and its amendments including the 1978 amendments, have contained a list of 16 specialized services needed by persons with developmental disabilities at various periods throughout their lifetimes. This list was intended to be illustrative rather than restrictive. The purpose has been to suggest the variety of services needed.

Instead of leaving States free to choose one of these 16 services for support by funds under this Subpart, the Act now establishes four priority service areas for the use of Federal funds. The House Report states several advantages to focusing on the four priority service areas instead of leaving the selection entirely to the discretion of the States. (H. Rept. 95-1188, *supra*, p. 10)

The four priority services are: (1) case management services, (2) child development services, (3) alternative community living arrangement services, and (4) nonvocational social-developmental services. They are further described in this section.

States may not provide activities in their State plan that are necessary but subordinate parts of one priority service as a separate priority service area. For example, alternative community living arrangement services obviously are focused on one's residence and the services directly related to residence. Case management services are focused on the need for people in residential and non-residential settings. If a place to live is to be provided under the plan, the alternative community living arrangement services would be the priority area selected. Case management services provided to people in the community living setting may not be

identified as a separate priority service area.

Section 1386.46 Use of funds. (Sec. 133(b)(3))

No substantive changes are proposed from the present regulation.

Section 1386.47 Provision of priority services. (Sec. 133(b)(4))

Subsection (a) requires the State council to select one or more priority service areas for which Federal funds will be expended. The priority service areas selected must be identified in the State plan. Paragraph (2) states the statutory criteria for determining the number of service areas that may be funded in any year. Until the appropriation exceeds \$60 million per year, a State is required to fund one, but not more than two, of the priority service areas. No more than three priority service areas may be funded if the appropriation exceeds \$60 million but is less than \$90 million per year.

Paragraph (3) authorizes a State, once it has selected a Federal priority service area, to select a service area of its own choice as a substitute for one or more additional Federal priority service areas.

Paragraph (4) allows a State to request that the Commissioner grant a waiver of the limitations set forth in the two previous paragraphs. The waiver allows the State to fund additional service areas. This paragraph states the conditions on the granting of the waiver. The purpose of providing for a waiver is to allow States, under limited circumstances, to use Federal funds for a service other than those specified in the Act. The basis for the waiver is Section 133(b)(4)(C) of the Act.

Subsection (b) requires the State council and State agency to review annually the priority service areas and the need for continuing them. Changes may be made if needed.

Subsection (c) allows the State to put into effect its plan for comprehensive services immediately, or not later than October 1, 1980. The basis for this is Section 133(b)(4)(A)(ii). The Department has interpreted this section to mean that a State must meet the priority service requirements not later than the start of the 1981 fiscal year.

Subsection (d) requires that the State plan indicate what portion of its allotment is being expended in the priority service areas. The amount specified must be not less than \$100,000 or 65 percent of the State's allotment, whichever is the greater.

Subsection (e) lists the activities costs of which may be assigned to "service activities." The purpose is to allow

States to support activities necessary to the provision of high quality services.

Subsection (f) continues the previous provision of the Act and regulations for special financial and technical assistance to urban and rural poverty areas. States shall use the areas designated by the State Health Planning and Development Agencies (HPDA) and approved by the Secretary. The list of those areas was published in the Federal Register, Vol. 43, No. 19, January 27, 1978, and is available from the State HPDA and HEW Regional Offices.

Section 1386.48 Standards for services and protection of rights. (Sec. 133(b)(5))

This section of the proposed regulations lists other assurances that must be in the State plan. The plan must assure the Commissioner that: (a) The facilities in which services are furnished comply with the Architectural Barriers Act, (b) individual habilitation plans will be developed for each individual served, (c) the human rights of each person (especially those persons without familial protection) will be protected, and (d) affirmative steps will be taken to ensure an opportunity for participation of the developmentally disabled population in programs with special attention given to minority groups.

The required assurances described in (a), (b), and (c) above are consistent with policies issued previously by the Department. The assurance required by subsection (d) is a statutory requirement.

Section 1386.49 Professional assessment and evaluation programs. (Sec. 133(b)(6))

The State plan must provide for assessing the adequacy of the training of personnel providing service to developmentally disabled people, and of the State programs supporting training of professional and paraprofessional personnel. The State plan must further indicate how these training activities will bring about high quality services. Among other resources, university affiliated facilities must be utilized in States where they are available and appropriate.

Subsection (c) requires planning and implementation of a comprehensive system for the evaluation of services provided to developmentally disabled persons assisted under the Act, as mandated by Section 110 of the Act. As a condition for the receipt of Federal funds, the States must submit a plan for implementing the system by October 1980 and must implement it by October 1982.

"Consumer" means a person who meets the requirements of the definition of developmental disabilities.

"Consumer representatives" means a parent, other immediate relative, or guardian of a consumer.

"Department" means the Department of Health, Education, and Welfare.

"Director" means the Director, Bureau of Developmental Disabilities, Rehabilitation Services Administration.

"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 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.

"Facility for persons with developmental disabilities" means a facility, or a specified portion of a facility, designed primarily for the delivery of one or more services to persons with developmental disabilities.

"Governor" means the chief executive officer of the State or Territory, or his or her designee who has been formally deputized to act for the Governor in carrying out the requirements of the Act and these regulations.

"Institution" means any residential facility in which a person with a developmental disability is housed with non-related persons.

"Poverty area" means an urban or rural area that meets the criteria contained in § 1386.47(f) of these regulations.

"Protection and advocacy office" means the instrumentality designated by the Governor or legislature to administer the State's protection and advocacy system.

"Protection and advocacy system" means all protection and advocacy services and the means used to provide them described in the approved report required by § 1386.22.

"Public agency" means any State, unit of local government, combination of States or units, or any department, agency, or instrumentality of them, including State institutions of higher

education, hospitals and any Indian tribal government.

"Recipient" means a developmentally disabled person or his or her parent, guardian or close relative receiving services assisted under the Act.

"Secretary" means the Secretary of Health, Education, and Welfare, and references to the Secretary include any individual authorized to carry out the Act by delegation or redelegation.

"Services for persons with developmental disabilities" means priority services (as defined in § 1386.45), and any other specialized services or special adaptations of generic services for persons with developmental disabilities. "Special adaptations of generic services" are services that are generally available to the public and require modification to meet the special needs of the developmentally disabled person. Generic services include diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual with a developmental disability and of his family, protective and other social and socio-legal services, information and referral services, follow-along services, and transportation services necessary to assure delivery of services to persons with developmental disabilities.

"State" means the 50 States, the District of Columbia, Puerto Rico, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, Guam, American Samoa, and the Trust Territory of the Pacific Islands, except as otherwise provided in the Act or regulations.

"State agency" means the State agency or agencies designated in the State plan to administer or supervise the administration of all or designated portions of the State plan.

"State plan" means the approvable document or documents submitted by the State to comply with the requirements for participation under Parts 1385 and 1386.

"State planning council" (also referred to as "State council" or "council") means a body which meets the standards of § 1386.30.

"University affiliated facility" means a public or non-profit facility that is associated with, or is an integral part of, a college or university. These facilities must provide for at least the following activities: interdisciplinary training for personnel concerned with developmental disabilities; demonstration of the provision of exemplary services; dissemination of findings of those and other

demonstrations, and furnishing researchers and government agencies sponsoring service-related research with information on the needs for further service-related research.

"Volunteer" means a person who provides a service without compensation, except for reimbursement of actual expenses.

★ § 1385.3 Rights of persons with developmental disabilities (rights).

(a) Section 111 of the Act, "Rights of Persons with Developmental Disabilities", is applicable to the programs authorized under the Act, except for the protection and advocacy system. The basic State plan and all applications for university affiliated facilities or special projects grants must contain an assurance to the Commissioner that the grantee will not provide Federal, State or other public funds to any activity which serves persons with developmental disabilities that is not in compliance with these Rights.

(b) Failure to comply with this assurance may result in the loss of Federal funds under the Act.

(c) The Rights include:

(1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.

(2) The treatment, services, and habilitation for persons with developmental disabilities shall be designed to maximize the developmental potential of the person and shall be provided in the setting that is least restrictive of the person's personal liberty.

(3) Federal and State funds shall not be expended or provided to any institutional or other residential program for persons with developmental disabilities that—

(i) does not provide treatment, services, and habilitation which are appropriate to their needs; or

(ii) does not meet the following minimum standards:

(A) Provides a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program;

(B) Provides appropriate and sufficient medical and dental services;

(C) Prohibits the use of physical restraint unless absolutely necessary and prohibits the use of physical restraint as a punishment or as a substitute for a habilitation program;

(D) Prohibits the excessive use of chemical restraints, and the use of chemical restraints as punishment or as a substitute for a habilitation program;

State plan. In making this determination, he is to disregard the amount of any other Federal funds expended and the amount of any non-Federal funds required for matching. Any exception must be expressly provided for by Federal statute.

§ 1386.9 Payments.

(a) The Commissioner will pay the Federal share of expenditures incurred in the fiscal year under the approved State plan, and under the approved report on the protection and advocacy system. For purposes of this Part the term "expenditures incurred" is interpreted to mean allowable costs pertaining to that year. A cost resulting from an obligation incurred during a year is deemed to pertain to that year.

(b) An authorized State official may request the Commissioner to pay from the State's allotment under Subpart C of this Part not more than 50 percent of the costs of administering the State plan. The payment is not to exceed 5 percent of the allotment or \$50,000, whichever is less. In order to receive this payment, the State must expend from its own sources, for the current fiscal year, an amount equal to or greater than that expended in the previous fiscal year for administration of the State plan. Costs of administering the State plan do not include costs for planning activities or provision of services.

§ 1386.10 Liquidation of obligations.

All obligations made by the State agency or subgrantees under the State plan and the report on the description of the State's protection and advocacy system must be liquidated within one year of the close of the Federal fiscal year in which obligations were incurred. This requirement may be waived only where the validity of the obligation or the amount of the obligation is being actively disputed by the State agency or subgrantee.

§ 1386.11 Withholding of payments.

After notice to the State and an opportunity for a hearing, the Secretary may withhold payments to the State with respect to costs resulting from obligations incurred after opportunity for the hearing or after a final decision following a hearing if he finds that there is a failure to comply substantially with the State plan, or with the report on the description of the protection and advocacy system, or the Act, or applicable regulations. Hearing procedures will be conducted in accordance with Subpart D of this part.

§ 1386.12 Standards for a merit system of personnel administration.

The State plan and the report on the protection and advocacy system must provide that methods of personnel administration and affirmative action plans for equal employment opportunity in the State and local agencies administering the programs will conform to the Standards for a Merit System of Personnel Administration, Subpart F, Part 900, and other standards prescribed by the Office of Personnel Management. The standards for a Merit System were published in the Federal Register, Vol. 44, No. 34, page 10238, February 16, 1979. The affirmative action plan must be available to the Secretary for review, upon request.

§ 1386.13 Fair hearings.

The State plan shall provide for a system of hearings under which applicants or recipients or their representatives may appeal the denial, reduction, or termination of a service, or failure to act upon a request for service with reasonable promptness. The procedures and provisions of 45 CFR 205.10 govern these hearings.

Subpart B—State System for Protection and Advocacy of Individual Rights

§ 1386.20 Requirements for participation in the developmental disabilities program.

(a) In order for a State to receive an allotment under Subpart C, it must have in effect a system to protect and advocate the rights of persons with developmental disabilities.

(b) Failure to submit a report of or to carry out an approved system to protect and advocate the rights of persons with developmental disabilities will result in the loss of Federal funds for programs authorized under this subpart and Subpart C (State Plan for Provision of Services).

(c) The Protection and Advocacy (P&A) System must meet the following requirements—

(1) The P&A System must have the authority to pursue legal, administrative, and other appropriate remedies to ensure the protection of the rights of all individuals with developmental disabilities who are receiving services or are eligible for services in the State.

(2) The P&A System must have the authority to institute administrative and legal proceedings to redress the rights of institutionalized persons with developmental disabilities without the necessity of representing a named client. At the time of commencement of any proceeding under this section, the P&A

System shall certify to the administrative body or court that:

(i) The P&A System has endeavored to eliminate the alleged conditions and practices by informal methods, including discussion with appropriate officials of the possible costs and fiscal impacts of alternative remedial measures;

(ii) The P&A System is satisfied that the appropriate officials have had a reasonable time to take appropriate action to correct such conditions or practices but have failed to do so;

(iii) The P&A System believes that administrative or legal proceedings are of general public importance and will materially further the protection of the rights, privileges, or immunities of developmentally disabled individuals secured by the Constitution or laws of the United States or of any State or locality.

(3) The P&A System must have appropriate access to the personal, medical, and other records pertaining to the care of institutionalized developmentally disabled persons who have been judicially declared mentally incompetent after giving reasonable notice to the guardians of such persons. In the case of an institutionalized developmentally disabled person who is not mentally impaired, the P&A System must have appropriate access to that person's relevant records after obtaining the consent of that person.

(4) The P&A System must establish procedures to protect the confidentiality of the records examined under 1386.20(c)(3). These procedures must conform to the requirements of 42 CFR Part 442.502. This requirement, however, in no way limits or restricts the Department's access to the records of the P&A System.

(5) The P&A System may not be administered or controlled by the State Planning Council.

(6) The P&A System must be independent of any agency, public or private, which provides treatment, services or habilitation to persons with developmental disabilities.

(7) The P&A System must have the authority on its own initiative to obtain access to institutions and programs serving persons with developmental disabilities. This right to access shall include the right to meet with persons with developmental disabilities in residential and non-residential facilities to explain the purposes of the protection and advocacy system, assistance that is available to them, and other details of the program. Exercise of this authority shall not require advance notice as long as the visits take place at a time and in a manner that does not disrupt the operation of the facility or program, for

example, a visit during normal visiting hours.

★ § 1386.21 Designated State protection and advocacy office.

(a) The Governor shall designate the office for administering the State protection and advocacy system.

(b) The State protection and advocacy office must be a public or private, non-profit entity.

★ § 1386.22 Report on the state system.

(a) At least once every three years the Governor shall submit an approvable report to the Commissioner describing the State system. The report must conform to these regulations and with guidelines issued by the Commissioner.

(b) The report must include—

(1) Assurances that the system will comply with the requirements listed in § 1386.20, including—

(i) An assurance that members and staff of the State planning council together with providers of services do not constitute a majority of a quorum of any board of directors of the system; and

(ii) An assurance that the staff of the State planning council will not serve as staff of the protection and advocacy office.

(2) An explanation of the administrative structure of the system including the executive order or a citation to the law establishing the system and the following information:

(i) If it is a public entity, an explanation of the office's location within the State structure; or

(ii) If it is a private non-profit entity, the name and title of the person in State government to whom it reports, and a copy of the articles of incorporation and bylaws;

(3) The goals and objectives for the system;

(4) The methods being used to ensure that the system is available to persons with developmental disabilities especially those residing in institutions, and those not receiving services;

(5) The procedures by which the office determines which clients will be served, if choices must be made;

(6) A statement of the ways legal, administrative and other appropriate remedies are utilized by the system to achieve its goals;

(7) An explanation of the facilities and resources that are being used to operate the system;

(8) A list of other protective and advocacy services in the State which relate to this program, and explanations of cooperative relationships with them;

(9) Other information the Commissioner may require.

★ § 1386.23 Submittal of the report on the State system.

(a) The report must be submitted by the Governor to the Commissioner for approval. The report must be submitted to the appropriate HEW Regional Office 60 days prior to the period for which it is applicable.

(b) Failure to submit an approvable report prior to the beginning of the period covered by the report shall result in the loss of Federal financial participation in costs resulting from obligations incurred during the period of the fiscal year for which an approvable description or revision has not been submitted. Failure to submit an approvable report at the appropriate time may also result in loss of Federal funds under the State plan submitted under Subpart C.

(c) The Secretary will not disapprove any report describing the protection and advocacy system or revision of the system until he or she has given the State reasonable notice and opportunity for a hearing governed by Subpart D of this part.

★ § 1386.24 Amendments to the report on the system.

The Governor shall approve and submit to the Commissioner a description of any change in the system which will affect the way it is to carry out its required functions. These amendments must be submitted to and approved by the Commissioner prior to their implementation. The amendments must include a procedure for providing continuity of services to persons with developmental disabilities during the transition.

★ § 1386.25 Annual reports.

(a) The following reports must be submitted to the Commissioner annually:

(1) Proposed budget for the next Federal fiscal year;

(2) Program performance report; and

(3) Financial status report.

(b) The program performance report shall describe the activities carried out under the system and any changes made in the system during the previous fiscal year.

(c) The proposed budget and the program performance report must be submitted by the Governor to the appropriate HEW Regional Office. The proposed budget for the next Federal fiscal year must be received in the regional Office 60 days prior to the beginning of the fiscal year to which it is applicable. The Financial Status Report must be submitted by either the Governor or the appropriate State financial official.

★ § 1386.26 Federal financial participation.

(a) Federal financial participation is allowable for costs incurred—

(1) Under the State's approved report on the State system;

(2) For providing information and referral services to persons who contact the system for aid whether or not those persons are developmentally disabled;

(3) To solve or alleviate problems of discrimination or denial of rights related to the eligible person's disabilities.

(b) Costs for which Federal financial participation is not allowable are—

(1) Payments made after the end of the Federal fiscal year following the fiscal year in which the underlying obligation was initially incurred. (Sec. 1386.9, Liquidation of obligations);

(2) Except for information and referral services, costs incurred on behalf of persons who do not meet the definition of developmental disability in § 1385.2;

(3) Costs incurred for activities not included in the approved description of the system;

(4) Costs incurred for activities on behalf of persons with developmental disabilities to solve problems not directly related to their disabilities and which are faced by the general populace, for example, drawing up wills and initiating or defending against divorces; and

(5) Costs not allowed under applicable regulations.

★ § 1386.27 Prohibition of use of protection and advocacy system for lobbying.

No money available under this subpart shall be used to lobby Congress as set forth in 18 U.S.C. 1313. For this purpose, lobbying means any unsolicited communication with members of the Congress for the purpose of influencing their actions relating to any legislation or appropriation before or after introduction of a bill.

Subpart C—State Plan for Provision of Services for Persons with Developmental Disabilities

State Planning Council

§ 1386.30 Establishment of the State planning council.

Each State which receives Federal assistance under this part must establish a State planning council.

§ 1386.31 Makeup of the council.

(a) The Governor shall appoint the members of the council from among the residents of the State, and shall make appropriate provisions for rotation of all members except the representatives of State/Federal programs. The State plan shall contain a statement of the policies