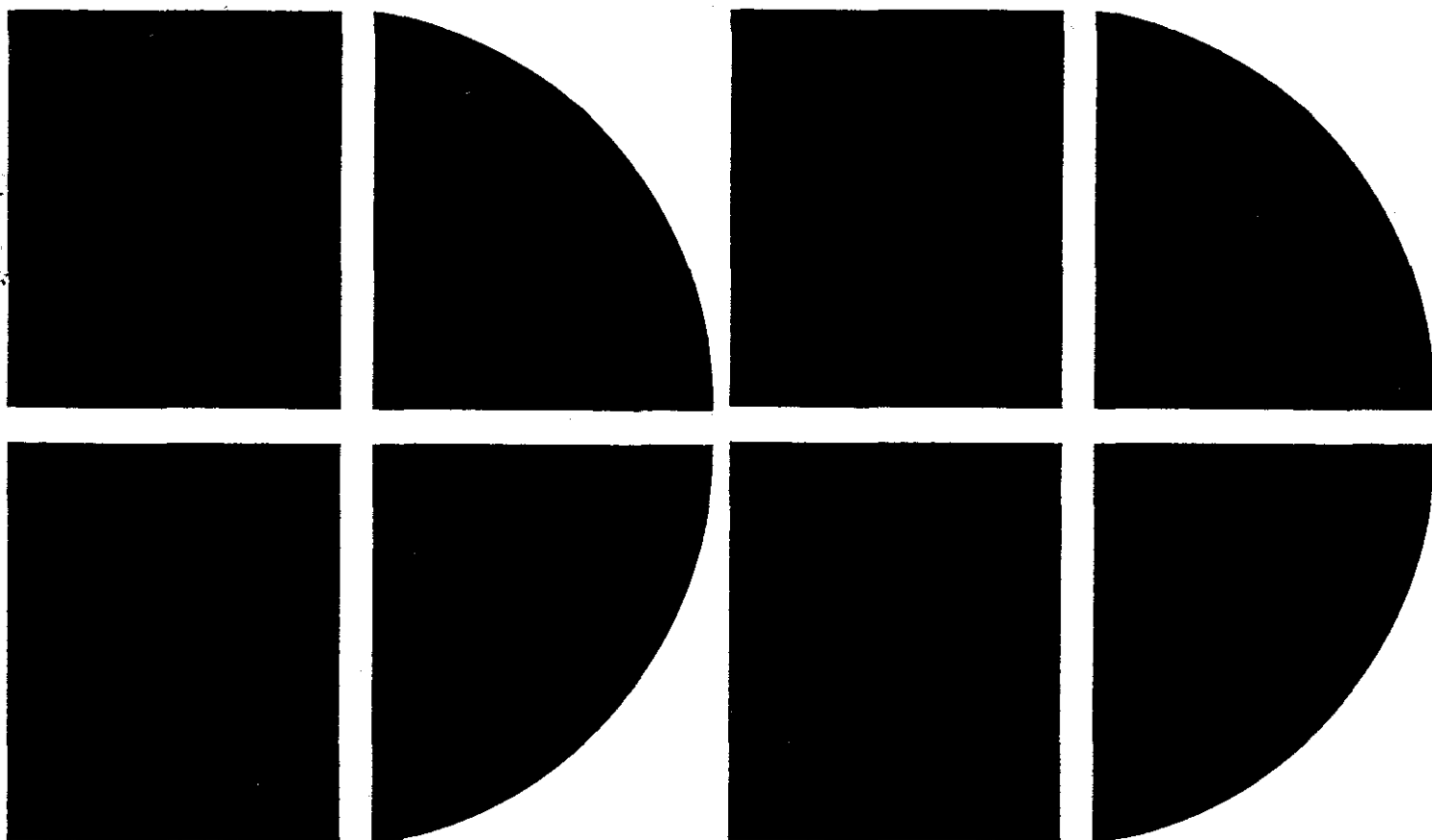


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**Federal Programs
Information and Assistance
Project**

This booklet is one of a series which describes federal resources to assist developmentally disabled people. Other topics in the series include: Orientation to the Governmental Process, Social Services, Income Maintenance, Housing Development Programs, Intermediate Care Facilities, and Planning for Action

Developmental Disabilities



THE DEVELOPMENTAL DISABILITIES PROGRAM

By: Tom Stripling, Technical Coordinator

A training module to provide an understanding of the Developmental Disabilities Program. Discussions include Federal and State programs, University Affiliated Facilities, and Protection and Advocacy Systems.

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Statement of Objectives

This module presents the legislative history, mandates, structures and potentials of the Developmental Disabilities program. Each section will contain information on a particular aspect of the program and will be followed by short questions highlighting the material presented. The intent of this module is to provide an instructional framework for understanding the Developmental Disabilities concept. The reader can use this framework to help recognize the various implementation strategies exercised at the State level. Flexibility is built into the program to enable each State to design its Developmental Disabilities program to best respond to the needs of its citizens within the specific environment of the State. This flexibility results in variations in the program from State to State. The reader should recognize the areas of flexibility and analyze the decisions made as to whether they are the best options in the interests of individuals with a developmental disability.

I. Historical Background

There is a long and significant list of legislative accomplishments and frustrations that preceeded the passage of the orginal Act entitled, Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-517). Individuals and groups began advocating for legislation to benefit individuals with handicapping conditions as early as 1920, however, major achievements were not accomplished until the 1950's. These early initiations were piecemeal and exploratory focusing primarily on health, education and rehabilitation services, and research.

In the 1950's the awareness level of the general public, including some parents and professionals involved with the mentally and physically handicapped, was limited concerning the nature of handicapping conditions; their care and treatment. Executive, legislative and private initiatives responded to the need for a greater awareness level by attempting to develop research, training, and service resources.

By the 1960's many patterns were established which maximized the personal commitment and advocacy of President John F. Kennedy. President Kennedy's intentions for improving the plight of the mentally retarded and other disabled individuals is best stated in his opening remarks to the first meeting of his new President's Panel on Mental Retardation, in October, 1961.

"The manner in which our nation cares for its citizens and conserves its manpower resources is more than an index of its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. Yet, although we have made considerable progress in the treatment of physical handicaps, although we have attacked on a broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive

search for solutions to the problems of the mentally retarded
That failure should be corrected." (Boggs, 1971)

The first piece of legislation in response to the President's concerns was a recommendation by the Panel entitled, the Maternal and Child Health and Mental Retardation Planning Amendments (Public Law 88-156, 1963). The major provisions of this Act authorized special maternal and child health grants to the State's to improve prenatal care for economically and socially disadvantaged women, as well as provide infant care services for children "at risk" of mental retardation because of poor economic and social environments. More germane to this discussion, the Act authorized funds for grants to States to generate comprehensive mental retardation planning of their own on a coordinated intra-agency basis. Each State was required to document its human services problems and its intentions or inabilities to deal with these problems.

Immediately following the passage of Public Law 88-156, Congress enacted a second piece of legislation responding to the Panel's recommendations: the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (Public Law 88-164). This Act essentially dealt with establishing community mental health centers, however, three sections were specifically devoted to mental retardation.

Part A of Title I of Public Law 88-16 was entitled Grants for Construction of Centers for Research on Mental Retardation and Related Aspects of Human Development. It authorized \$6 million in project grants to assist in meeting the costs to construct facilities designed for biological, medical, social, and behavioral research of human development and to assist in determining the causes, means of prevention, and methods of ameliorating the

effects of mental retardation.

Part B, entitled Project Grants for Construction of University Affiliated Facilities for the Mentally Retarded, was to assist in the construction of clinical facilities that would provide, as nearly as possible, a complete range of inpatient and outpatient services. These facilities acted as demonstrations for specialized services in diagnosis, treatment, education, and care of the mentally retarded.

The final section, Part C, authorized appropriations of \$10 million for Grants for Construction of Facilities for the Mentally Retarded. States could receive a minimum allotment of \$100,000 based on an approved State plan on mental retardation. This provision supported the mental retardation planning amendments of Public Law 88-156 and can still be found in Developmental Disabilities programs.

These two Acts did much to direct the nation's focus on the health, welfare, and livelihood of the mentally retarded. However, neither piece of legislation was comprehensive enough, and only set the stage for continued advancements.

In the same decade, there were two additional pieces of legislation that identified with the previously mentioned Mental Retardation Acts: The Social Security Amendments of 1965 (Public Law 89-97) commonly known as the Medicare-Medicaid Act, and the Mental Retardation Amendments of 1967 (Public Law 90-170). The Medicare-Medicaid Act is a mechanism for Federally funded medical services for the poor, aged, and disabled. While the Mental Retardation Amendments of 1967 supported part of the cost of professional and technical personnel required for the clinical facilities being constructed

under the provisions of Public Laws 88-156 and 88-164.

The Developmental Disabilities movement formally gained national prominence in 1970. On October 30 of that year the first Federal developmental disabilities legislation was signed into law (Public Law 91-517) by President Richard M. Nixon. Known as the Developmental Disabilities Services and Facilities Construction Act, this legislation brought under one legislative umbrella three major disability groups (mental retardation, cerebral palsy and epilepsy) and theoretically, others which share common service needs. "Furthermore, the concept intended to bring within the purview of constructive help and more humane management those many who have been relegated in the past to an unchallenged and unchallenging classification requiring 'custodial care,' whether at home or in institutions." (Boggs, 1971)

The Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-517) was an extension of earlier legislative milestones. However, the Act sets its own pattern which establishes it as a significant legislative effort. The original Act (Public Law 91-517) was amended in 1975 with the passage of the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 93-103). This module will present the Developmental Disabilities concept by explaining the program as it was amended in 1975. These amendments did not seriously change the direction of the program, but rather enhanced the original provisions of the program to allow greater flexibility and responsiveness. A good example of how the 1975 amendments affected the original legislation is the expanded definition of developmental disabilities.

Definition of Developmental Disabilities

According to the original Act (Public Law 91-517) the term "developmental disabilities" included any neurological condition closely related to mental retardation, which originated prior to age 18, was likely to be permanent, and is severely disabling. Furthermore, the Secretary of Health, Education, and Welfare could name specific disabilities eligible for services in addition to mental retardation, cerebral palsy, and epilepsy.

The 1975 amendments, Public Law 94-103, maintained the conditions of mental retardation, cerebral palsy, epilepsy and other neurological disorders closely related to mental retardation as developmental disabilities; but also included autism. In addition, it included dyslexia if it is attributable to mental retardation, cerebral palsy, epilepsy, or autism. Also, the current State plan guidelines issued by the Developmental Disabilities Office go further to explain that, a State may include in its definition of developmental disabilities any conditions which result in similar impairment of general intellectual functioning or adaptive behavior which requires treatment and services similar to those required for individuals with mental retardation.

The amended definition potentially expands the target population to enable a State greater responsiveness in addressing the needs of the disabled individuals residing in the State. Without sacrificing the intent of the Developmental Disabilities Services and Facilities Construction Act of 1971, the new amendment gives a role to each State in identifying its developmental disability population as long as the basic criteria of developmental disabilities are consistently employed.

In the next sections the discussion will focus on the various aspects of

the Developmental Disabilities program. This discussion will address the concept as presently enacted with limited references to the original act and how it was affected by the 1975 amendments.

II. Goals and Services

This section will focus on identifying and explaining the goals and services of the Developmental Disabilities program. To accomplish this task it is necessary to splinter the discussion into four distinct aspects. They are:

- A. State Planning Council and State Administrating Agency
- B. National Advisory Council and Developmental Disabilities Office
- C. University Affiliated Facilities (U.A.F.)
- D. Protection and Advocacy System

Each aspect will be discussed separately, however, the common thought will be to demonstrate how each aspect can further the goal of community residential alternatives. At the close of this section there will be some questions highlighting the information presented herein.

A. State Planning Council and State Administrating Agency

Each State participating in the Developmental Disabilities program must establish by gubernatorial appointment a State Planning Council and a State Administrating Agency. These appointments must be renewed periodically as members leave the Council or as a new Governor assumes office. Some States have strengthened the requirement for these appointments by authorizing them through State statutes.

The State Planning Councils are mandated to be advocates on behalf of developmentally disabled individuals, while the State Admininstrating Agency is fiscally accountable for all funds awarded to a State through this program. The Developmentally Disabled Assistance and Bill of Rights Act of 1975 emphasized the Council's responsibility to plan for services. Its duties and functions reflect this emphasis. They are:

- 1) To supervise the development of and approve the State plan;
- 2) To monitor and evaluate the implementation of the State plan;
- 3) To the maximum extent feasible, review and comment on all State plans in the State which represent programs affecting persons with a developmental disability; and
- 4) To submit to the Secretary, through the Governor, periodic reports on its activities as the Secretary may reasonably request.

Recent guidelines published by the Department of Health, Education, and Welfare, Office of Human Development, have pinpointed four distinct responsibilities of the State Administrating Agency. They are:

- 1) Preparation of the State plan and its subsequent implementation on a daily basis;
- 2) Establish procedures and mechanisms as are necessary to strengthen supporting or "gap-filling" services initiated by funds made available to public and/or nonprofit private agencies, institutions, and organizations;
- 3) Provide ongoing monitoring and periodic evaluation of Developmental Disability activities and projects; and
- 4) Develop jointly with the State Planning Council policies, procedures, and strategies to achieve the goals and objectives of the current State plan and to monitor and evaluate the entire program through the Design for Implementation.

The mingle of the Council's and Agency's responsibilities could be as follows:

- 1) The Council sets the direction for the plan;

- 2) The Agency writes the plan;
- 3) The Council reviews and submits the plan;
- 4) The Agency implements the plan; and
- 5) The Council and Agency monitor and evaluate the implementation of the plan.

The partnership between the State Planning Council and the State Administrating Agency can take any number of arrangements. Since the beginning of the program in 1970, numerous discussions and trials have taken place concerning which organizational arrangements prove most effective. Unfortunately no particular arrangements have been identified as most effective. The reason for this is twofold. First, the relationship, in terms of responsibilities, was not clearly articulated in the original Act; and still remains controversial even though some distinctions were established after the 1975 amendments. Second, the political and social environment of each State has its own unique effects on the program as it develops, therefore requiring flexibility. However, regardless of these factors, it is conclusive that the partnership between the Council and Agency must be functional if the program is to succeed.

Council Membership

The State Planning Council consists of three categories of members: individuals with a disability, governmental agencies' representatives, and non-governmental agencies' representatives. The Governor may appoint any total number of members. However, "at least one-third of the total membership must be persons with a developmental disability, or their parents or guardians, who are not officers of any entity, or employee of any State agency, which receives funds or provides services under this Act." The intent behind the one-third

requirement is to encourage increased involvement of individuals with a disability in this program which has a goal to improve conditions for them. The intention encourages dialogue between those responsible for programs (governmental representatives) those delivering programs (nongovernmental representatives) and individuals with a disability. This does not imply any lessening of the role of parents or guardians.

The category of governmental agencies' representatives should consist of individuals who are capable of speaking and deciding for their respective agencies. These individuals should represent the major programs in the State which concern or impact the developmentally disabled. Such programs include, but are not limited to: vocational rehabilitation, education, mental health, maternal and child health, crippled children's services, public assistance, medical assistance, transportation, and mental retardation services. Unfortunately, often a director or commissioner of a program is appointed to the Council, but scheduling conflicts do not permit his/her regular attendance at meetings. The alternative to non-attendance or involvement of such agency representatives has been the naming of a delegate by the member. This practice maintains a communication link with the program/agency. However, the Council does lose the direct involvement of the person who has authority to make commitments on behalf of the agency.

The final category on nongovernmental agencies' representatives can be from any nonprofit, private or public agency or organization involved in service delivery, higher education, advocacy or other activities which serve the individuals with a disability. These members should represent major service providers from a cross section of the providers in the State.

This triangle of Council membership typifies the major participants in any

human service delivery system: those who provide services in the public and private sectors, those who need or require services, and those who administer a State's responsibility for services. Membership appointments are usually staggered terms which require reappointments or new appointments by the Governor. Councils will offer nominations to the Governor for his consideration in filling vacant positions. Individuals who are interested in becoming a Council member should inquire of the State Council as to the process for being nominated and appointed. Sometimes it is equally affective to coorespond directly to the Governor's office indicating your desire to be a Council member devoting particular attention to those qualities and experiences which you could invest in the Council.

Regardless of whether you are a Council member or not, the State Planning Council's meetings are open public forums. Only if the Council is in an executive session would the general public not be invited to attend and participate. Generally State Councils meet at least four times a year, however, a good number of Council meet monthly or bi-monthly. Citizen participation should be encouraged through public notices of meetings, however, if it is not encouraged, inquiries should be made as to why the general public is not informed.

Council Staff

Public Law 94-103 mandates that the State Planning Council must be adequately staffed, and that staff be identified as solely responsible to the Council. This is a critical issue which had not been clear in the original Act. When the Councils were established initially, staff worked for the State Agency doing Council assignments. This arrangement could only work at cross

purposes neither of which improved the program's effectiveness or organization. Staff often recognized the fact that they were taking directions from both the Council and Agency. This created a situation of "two bosses."

According to Public Law 94-103 staff must be employed through a Civil Service merit system, i.e., classification and pay should correspond to that of a similar position in the State personnel system. With staff reporting solely to the Council, they are able to respond to a single direction and can concentrate on the day-to-day affairs of the Council. Staffing patterns differ from Council to Council but generally include a Planning Coordinator and/or an Executive Director, a Planning Associate or Assistant Director, a Secretary, and a Researcher. Other types of staff to consider are accountants, grants managers, lawyers, evaluators and/or a media or public relations specialists.

Staff to the Council are intended to facilitate activities which cannot be completed in the time available to a volunteer Council. The day-to-day activities of planning, State plan review, monitoring and evaluating must be supported by staff or else these activities could become too disorganized to be considered effective. However, staff are not the Council. They are not in a decision-making role. All inquiries to the Council may be directed through staff, however, staff should be conduits of information only and not decision-makers.

Services

After a State has submitted an annual State plan on Developmental Disabilities to the Regional Office of the Department of Health, Education, and Welfare, and it receives approval, the State will be awarded a formula grant for that fiscal year addressed by the State plan. Section VI of this module

will discuss, in detail, the circumstances surrounding the distribution of these funds.

These funds available upon approval of the State plan may be used to support any one or combination of the following sixteen services:

evaluation	counseling
diagnosis	sheltered employment
personal care	training
education	special living arrangements
treatment	day care
information and referral	transportation
follow-along	socio-legal, protective
recreation	domiciliary care

These services are only general categories and are not intended to be the complete range of services for persons with a developmental disability. However, regardless of the service need, Developmental Disabilities is not a direct services program. This means that unlike vocational rehabilitation or Medicaid, the Developmental Disabilities program will not pay for direct services to a particular client or group of clients. The services delivery system concept associated with this program is oriented toward the provision of grant funds to a grantee who in turn provides direct care services to a population specified in the approved grant application.

Therefore, to use Developmental Disabilities program funds for services, it is essential to receive a project grant from the State Council. Project grants are awarded on the basis of priorities established in the annual State plan (See Section V). Some States do not commit their total service funds to specific priority areas, but set aside a small discretionary fund for unforeseen needs identified during the year. However, the largest commitment of funds is to priority areas listed in the current State plan. Councils will solicit grant proposals that address a priority need and award grants based on applications received.

In this discussion concerning services, it might be beneficial to explore some optional uses of Developmental Disabilities funds in the area of community residential alternatives. First, advocates should consider the potential application of the sixteen (16) services mandated in the Developmental Disabilities legislation. For example, transportation to day programs is essential if house staff are to be successful in having individuals leave a community residence during the day. Since none of us work or go to school all day, recreational activities must be developed for leisure time. Communication and socialization are important aspects in the personal growth and development of individuals with a developmental disability. As well, medical and dental services are needed to assure physical health. And if there arises a difficulty concerning legal rights then socio-legal, protection and advocacy services must be available to assist the individual(s). These underlined services are all part of the universe of services needed to support a community residential alternative, they are all eligible services for Developmental Disabilities funding.

Advocates should review the State plan priorities and the Design for Implementation (See Section V) to discover just how the Council and Agency are defining their activities in the area of community residential alternative. The Developmentally Disabled Assistance and Bill of Rights Act of 1975 includes a provision requiring that the State plan present a plan for the elimination of inappropriate institutionalization, and the improvement of the surrounding for those individuals appropriately institutionalized. These "deinstitutionalization" and "institutional reform" requirements must be accomplished by maximizing the utilization of existing and future community resources. The State Council must commit at least 10% of its funds for Fiscal

Years 76 and 77 toward these efforts.

Advocates should recommend and encourage the State Council and State Agency to direct the implementation of its "deinstitutionalization" efforts toward establishing new community residential alternative or improve (rehabilitate) existing alternatives. Certainly the efforts of the Council in this area need not be solely the workings of the Developmental Disabilities program. Councils may influence other State agencies to commingle their resources with the Council's. For example, a State Council may decide not to establish residences with its funds but rather assist a State Agency's efforts by providing staffing funds during the initial years of residence.

Another example of how Developmental Disabilities can assist through cooperation with other agencies to provide community alternatives is in the area of day programming. Let's say that a local association operates a group home in a rural setting for 10 individuals with severe mobility problems. The association is concerned that educational and vocational rehabilitation services are not readily available because of costly transportation to the nearest programs. The home does own a vehicle, however, it is not large enough to transport all the individuals at one time.

The Council in coordination with the State Agency initiates discussions with the local school department concerning plans to extend existing special services from urban to rural areas. The school department formulates a proposal to increase services through the establishment of rural program sites.

The State Council believes the proposal has merit and will greatly increase the availability of educational services. The timetable for these rural programs is within the next few months, so the only remaining problem concerns the transportation of individuals to the programs on a regular

schedule. The Council has decided to offer project grants in cooperation with the Department of Transportation for a coordinated transportation system in line with the education programs. The resulting projects are funded within a month of the start of the initial classes.

A final example deals with a very little known aspect of the Developmental Disabilities program and that is that a State Council is permitted to spend up to 10% of its formula grant for the construction of facilities for persons with a developmental disability. In order for this provision to be implemented there are specific State plan requirements which must be completed. These requirements, along with the 10% limit, have not made this construction provision too popular. However, it is a resource which could be employed for the purpose of constructing community residential alternatives.

In concluding this discussion, there are a few points which need to be emphasized. First, the State Council is a gubernatorially appointed volunteer organization which is intended to be a forum for nongovernmental agencies' representatives, individuals with a disability, and State agencies' representatives. Second, the designated State Administating Agency must work cooperatively with the State Council to accomplish the goals of this program. Third, formula grant funds are awarded to a State on the basis of an approved annual State plan and are then awarded to applicants based on identified priority areas established during the State planning process. Fourth, advocates are encouraged to participate in the program either as appointed member of the Council, or as conduits of data and information about conditions confronting disabled individuals, or as applicants for grants to address an identified priority of the Council.

The next discussion will focus on the National Advisory Council on

B. National Advisory Council and Developmental Disabilities Office

The National Advisory Council on Services and Facilities for the Developmentally Disabled (NAC) was established by the original Developmental Disabilities Act (Public Law 97-517) in 1970. The 1975 amendments did alter the NAC to some degree. The duties and functions of NAC as stated in Public Law 94-103 are:

- 1) To advise the Secretary of Health, Education, and Welfare on any proposed regulations or guidelines implementing the Act (Public Law 94-103);
- 2) To study and evaluate programs authorized by Title I (State formula grant program) of the Act to determine their effectiveness;
- 3) To monitor the developments and implementation of Title I of the Act and to report directly to the Secretary any delay in rapid execution of the Act;
- 4) To review grants made under this title and comment to the Secretary;
- 5) To submit an annual report to the Congress which evaluates the efficiency of program administration.

The membership of the National Advisory Council was initially 20 individuals appointed by the Secretary of Health, Education, and Welfare. However, following the 1975 amendments the NAC expanded to 25 members. Members are divided into two categories. Sixteen appointed members including persons with a disability, or their parents or guardian and representatives of State agencies, higher education, and organizations which have demonstrated advocacy on behalf of the developmentally disabled. The other nine members are ex-officio representing major Federal/State programs. They include:

Developmental Disabilities and the Developmental Disabilities Office.

Deputy Commissioner,	Bureau of Education of Handicapped
Commissioner,	Renabilitation Services Administration
Administrator,	Social and Rehabilitative Services
Director,	National Institute of Child Development and Human Development
Director,	National Institute of Neurological Diseases and Strokes
Director,	National Institute of Mental Health

and three other representatives selected by the Secretary from the
Department of Health, Education, and Welfare.

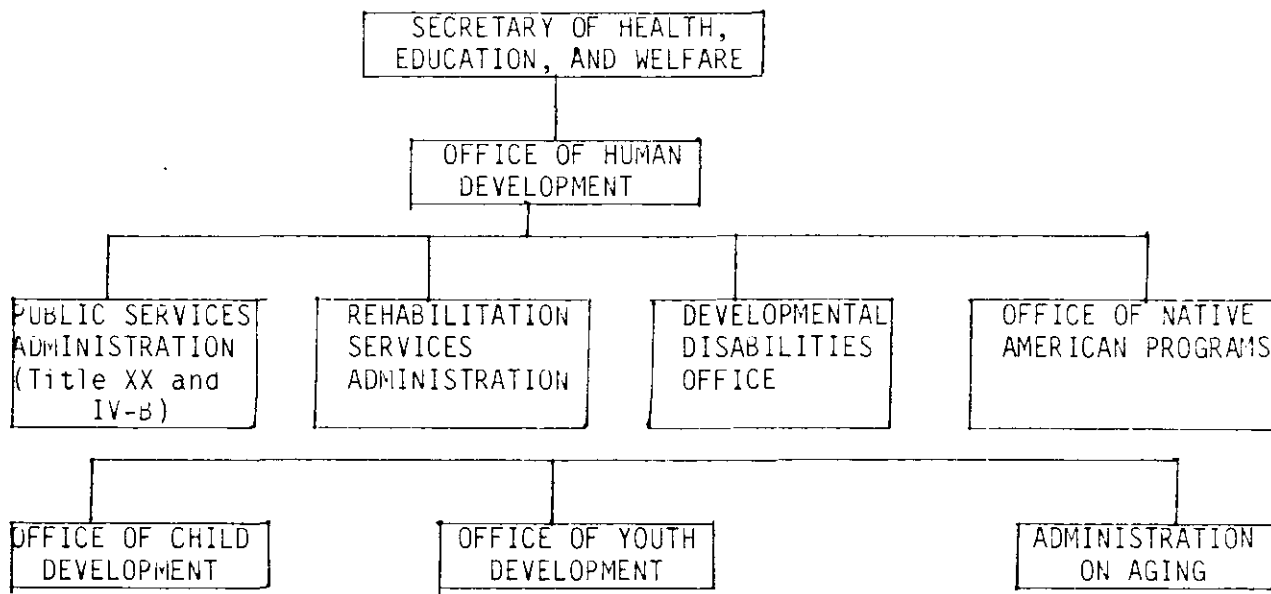
Developmental Disabilities Office

The National Advisory Council is assigned through legislation to the Office of the Secretary of the Department of Health, Education, and Welfare. The Secretary has delegated immediate responsibility for the program to the Assistant Secrerary of the Office of Human Development. Within the Office of Human Development is located the Developmental Disabilities Office (DDO) which is the Federal agency established to administer the Developmental Disabilities program (See chart on next page).

The Developmental Disabilities Office (DDO) is responsible for providing technical assistance to the National Advisory Council as it requires to fulfill its duties and function. This places the DDO in a similar role to that of the designated State Administrating Agency. Although there is no State plan required of the NAC/DDO, partnership similar to that is required of the States. The NAC/DDO partnership must prepare various regulation, guidelines, reports and/or documents necessary for the successful implementation of the program.

The Developmental Disabilities Office is divided into five functioning units.

Organizational Chart: Department of Health, Education, and Welfare
Office of Human Development
Developmental Disabilities Office



The office of the Director is responsible for the central organization of the entire office. The Director is the Executive Secretary of the National Advisory Council and also the liaison between the program and the Office of Human Development. The Planning and Evaluation staff conducts analyses of target populations, needs and resources and prepares short-range and long-range plans. The Program Operations Division is responsible for the State formula grant program and protection and advocacy program. The Research and Development Division is responsible for special projects and the University Affiliated Facilities. Finally, the Executive Services Staff is responsible for budgets, personnel, public information and the day-to-day management of the program.

In addition to the central office, there exists a regional office for each of the 10 regions of the Department of Health, Education, and Welfare. These

regional offices are staffed with a Director and some support staff. It is the responsibility of the Regional Director to maintain a liaison between the Developmental Disabilities Office and each State Developmental Disabilities program in his/her region. This liaison effort consists of technical assistance, information exchanges, review of special projects and projects of national significance, fiscal and program monitoring, and most important, review and approval of State plans.

Services

The emphasis at the Federal level is not towards the provision of direct care services, but rather an emphasis upon implementation of the overall program. The National Advisory Council and Developmental Disabilities Office partnership develops regulations and guidelines which facilitate the program at the State level where direct care services are provided.

To this point, it is worth mentioning that there are a number of studies specifically required by the Developmentally Disabled Assistance and Bill of Rights Act, which must be conducted by the Secretary of the Department of Health, Education, and Welfare, or his delegate. These studies are intended to improve the Developmental Disabilities program and will be explained from that perspective.

The first study requires the Secretary to conduct or have conducted an indepth study of the definition of the term "developmental disabilities," and to recommend any definitional changes. The final report by the Secretary must be submitted to the Congress by the end of Fiscal Year 77 (September 30, 1977).

A grant award was made to Abt Associates, Inc. of Cambridge, Massachusetts to be staff to a national Task Force in the definition of Developmental

Disabilities. This Task Force is charged with conducting the necessary definitional study and report recommendations to the Secretary. The significance of this study goes beyond a simple change in definition. Some believe that the definition should break tradition by introducing a non-categorical, functional definition. Others strongly oppose this thought on the basis that if more disabilities are included then it would only decrease the available funds for those disabilities presently involved. Regardless of the outcome of the Task Force recommendations, be assured that any change in the definition will alter the Developmental Disabilities program at every level.

A second required study of the Developmentally Disabled Assistance and Bill of Rights Act is designed to review and evaluate all Department of Health, Education, and Welfare administered standards and quality assurance mechanisms. The objective is to recommend to the Secretary, who will report to the Congress, model standards and quality assurance mechanisms based upon performance criteria that will measure and evaluate the developmental progress of individuals. A grant award was made to Government Studies and Systems of Philadelphia, Pennsylvania. Their study is designed to assemble a library of existing standards, to develop an analytical framework for reviewing existing standards, and to recommend model standards. Included in the final step will be to recommend strategies for action by the Federal government, i.e., executive or legislative branches, for changes or supplements to existing standards.

Each of these studies is important to consider when discussing community residential alternatives. For example, if the definitional study alters the populations that can be served by the program, then it may affect how funds can

be used to support community residential alternatives. Similarly the quality assurance mechanisms which result from the second study could be focused upon the assessment of a person's developmental progress while living in the community verses the institutions. For these reasons advocates should consider participating in these two studies by submitting written comments to the individual grantees expressing opinions and/or options that might be considered during deliberations. Comments can also be submitted to the Secretary of the Department of Health, Education, and Welfare, the Developmental Disabilities Office and/or the National Advisory Council.

Special Projects and Projects of National Significance

There are funds authorized through Section 145 of the Developmental Disabilities Act allowing the Secretary after consultation with the National Advisory Council to make specific project grants to public and/or private nonprofit organizations and/or agencies. These funds may be awarded in the following areas:

- 1) Demonstrations of programs for expanding or improving services to developmentally disabled persons. This includes programs for parent counseling and training, early screening and intervention, infants and preschool children, seizure control systems, legal advocacy, as well as community based counseling, care, housing and other services or systems necessary to maintain a person with developmental disabilities;
- 2) Public awareness and education programs to assist in the elimination of social, attitudinal, and environmental barriers;
- 3) Coordinating and using all available community resources;
- 4) Demonstrations of the provision of services to economically disadvantaged

persons;

- 5) Technical Assistance to services and facilities at the Federal, State and local levels;
- 6) Training of specialized personnel needed for service delivery or for research related to training of personnel;
- 7) Developing or demonstrating new or improved techniques for providing services, including model integrated services;
- 8) Gathering and disseminating information related to Developmental Disabilities; and
- 9) Improving the quality of services provided in and the administration of programs for the developmentally disabled.

Grants are awarded on an open competitive basis for a period of 1 to 3 years depending on the scope of the proposal. Requests for Proposals (RFP) are published annually based on the priorities identified jointly by the National Advisory Council and Developmental Disabilities Office. Applicants must conform with regulations and guidelines as prescribed by the Secretary, through the Developmental Disabilities Office. Special projects applications must be reviewed and commented on by the State Planning Council in the State where a project is proposed 30 days prior to submission to the Regional Director of the Developmental Disabilities Office. For any fiscal year the Secretary may appropriate no less than 25 per cent of the total funds available for special projects for grants which he determines, after consultation with NAC, are projects of national significance.

These project funds, special projects and projects of national significance, are very applicable to community residential alternatives.

Unfortunately, there is no convenient opportunity for advocates to impact the priority setting process for these funds. Advocates must express their concerns to the National Advisory Council and the Developmental Disabilities Office attempting to impact their decision-making process. If the priorities do fall in line with an advocate's goals, then careful planning will be needed to complete the required application forms. Completed applications must be submitted to the regional Developmental Disabilities Office, who will complete a technical review. This review and the approval process will be discussed in Section V of this module.

C. University Affiliated Facilities

The concept of the University Affiliated Facilities (UAF) originated when President John F. Kennedy signed into law the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (Public Law 88-164). As previously mentioned (page 3), Part B of that act, entitled Project Grants for Construction of University Affiliated Facilities for the Mentally Retarded, appropriated \$5 million to assist in the construction of university affiliated facilities. These facilities offered, as nearly as possible, a full range of inpatient and outpatient services for the mentally retarded. UAF's, as they came to be known, also provided clinical training for physicians and other specialized personnel needed for research, diagnosis, treatment, education, training and care of the mentally retarded.

The original Developmental Disabilities Act incorporated UAF's by providing funds for administration and operation expenses. A contingent for the funds provided through the act is that UAF's must interact with State Councils. UAF's are presently defined in the statute as:

"....a public or nonprofit facility which is associated with, or is an integral part, of a college or university and which aids in demonstrating the provision of specialized services for the diagnosis and treatment of persons with developmental disabilities and which provides education and training (including inter-disciplinary training) of personnel needed to render services to persons with developmental disabilities."

There are approximately forty UAF's located in thirty different States. These facilities represent a nationwide network of services, training, and research centers organized around various service delivery models. The experiences of more than a decade (1963-1977) have proven UAF's to be a sound concept and an effective mechanism for serving the needs of persons with a developmental disability.

The passage of the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) recognized the fact that a UAF or similar facility is needed in each State. The new law introduced an innovative concept called a "satellite center." As defined in the law and regulation, a "satellite center" is:

"an entity which is associated with one or more university affiliated facilities and which functions as a community or regional extension of such university affiliated facilities in the delivery of training services, and programs to the developmentally disabled and their families, to personnel of State agencies concerned with developmental disabilities, and to others responsible for persons with a developmental disability."

This concept is intended to increase the availability of UAF services to those areas either unserved or underserved by existing UAF's. The satellite center could be attached to one or more UAF's who would receive supplemental funding from the Secretary of Health, Education, and Welfare for establishing and operating such a satellite center.

Services

UAF's offer multiple services in many varying models. Some facilities are specifically geared towards infants and children services, while others are focusing upon adolescent and adult services. Some facilities do provide services to both groups.

The services provided are, but certainly not limited to:

diagnosis	training
evaluation	treatment
education	personal care
recreation	counseling
information and referral	follow-along
day care	transportation

The important aspect to remember is that a UAF offers the above services in some twenty (20) different disciplines. Such as:

pediatrics	neurology
education	psychology
speech	audiology
psychiatry	social work
dentistry	vocational rehabilitation
child development	nursing
family planning	

Although UAF's have basically an educational institution base, they are also intended to assist community agencies by providing technical assistance and outreach. With only forty locations, UAF's are not capable of satisfying all the needs of the disabled in all States. Therefore, it has been necessary to define the role of the UAF in relation to each State's needs. It was decided that the UAF could collaborate with a State in those priority areas mutually identified and within fiscal and manpower resources. This arrangement has proven successful and yet, burdensome to accomplish. The UAF's find that

excessive demands easily interrupted their program activities, such as service delivery and training because their limited resources were being stretched to fulfill State requests.

Regardless of the awkwardness of this arrangement, some very creditable accomplishments have and continue to occur at the State level. UAF's have invested time and effort assisting States develop training programs. Additional activities such as staff development, materials development and program consultation have provided needed resources to States. Of course, above all, UAF's have and continue to provide specialized direct care services where these services do not exist locally. Examples of this include inter-disciplinary team diagnosis, evaluation, and treatment of individuals with severe/profound and multiple disabilities.

Question of a Satellite

There have been questions concerning the nature of a satellite center ever since the concept was proposed by the Developmentally Disabled Assistance and Bill of Rights Act of 1975. So it might be constructive to discuss a few issues that have emerged, and why no feasibility studies have been awarded, nor any centers established thus far.

There are two divergent theories dealing with the definition of a satellite. Some believe that the satellite center was only intended to be a physical plant and programmatic extension of a parent facility. As such the center would be in a fixed relationship with the parent facility. Its funding and administration would come from outside itself, i.e., the parent facility. In addition, the satellite is envisioned as a service facility only and not a multi-faceted facility of services, training, and research like the parent UAF.

The other opinion suggests that a satellite center in a community unserved by a UAF should be administered by itself in accord with the community, and not be a UAF, which has no reference or involvement with the particular community. This does not mean that the parent facility is not to be closely integrated with the satellite center, but more in a consultative than authoritative manner. With the satellite center developing as a free standing entity, it should open the potential for the satellite center to evolve into a complete UAF, thereby resolving the need for a parent agency which is needed during the initial years.

Issue

This brings up a most significant issue: can a satellite center evolve into a free standing UAF? This issue brings about the greatest disagreement. As stated above, one group considers the satellite center to be only a service facility extension of the parent UAF. The other opinion is that services might not be the only need a satellite center could address. The satellite center concept intends to increase the availability of UAF resources; which are training, services and research. If the satellite must start with limited resources with the potential for growth that is understandable, and perhaps a wiser development strategy. But ultimately the satellite centers should develop in response to the needs of the community it serves. If the community needs staff training either "in-service" or "pre-service," why couldn't the satellite center develop resources to meet this need? The alternatives would be either no one meets the additional needs, or the parent UAF would have to address these needs. Neither of these alternatives appears to be too positive, primarily because they are contrary to the intent of the satellite center to

meet needs unmet by existing UAF's. Reliance upon a UAF to meet all the needs of all States seems to be the situation which exists presently.

There is one very critical aspect that must be mentioned in relation to this issue which concerns funding. UAF's were originally funded through the Maternal and Child Health (MCH) program. Initially UAF's received between 75% to 90% funding from MCH. Presently, only about 20 UAF's receive funding from the old Maternal and Child Health funds (now the function is administered by the Bureau of Community Health Services). On the average, most UAF's receive less than 15% funding from the Developmental Disabilities program. So, regardless of the size and/or complexity of the satellite center concept, it will require substantial funding from sources other than Developmental Disabilities. All the discussion concerning direction and orientation of a satellite center seems fruitless if other funding sources do not approve of the concept as stated in Public Law 94-103. In addition, Education of the Handicapped funds, vocational rehabilitation funds, private foundations, and various grant mechanisms contribute to the UAF program. (In some cases, there are large investments of State and local funds.) All of these funding sources must act collectively if the satellite center concept is to become operational.

So the fate of the satellite center concept is in serious question. Most believe that the concept will be instituted. Certainly the need for the resources has been documented over and over again. The UAF is a valuable part of the entire Developmental Disabilities movement and, like the State and Federal aspects, will develop and change as the needs are identified and the alternatives explored.

In conclusion, UAF's are a multi-faceted resource for State and local agencies and organizations. UAF's are committed to working with State Planning

Councils to identify areas where UAF resources can be applied. The services component of a UAF may not be particularly germane to the establishment and operation of a community residential alternative. However, UAF's have demonstrated that services can be developed in the community to deal with the most severely disabled, thus opening new avenues in preventing institutionalization. These avenues can be developed in relation with community facilities to avoid institutionalization, as well as to maintain severely disabled individuals who are already in the community.

UAF's have geared their training toward undergraduate, graduate, and doctoral degree candidates. They have involved disciplines across a large range, such as special education, psychology, pediatrics, speech, audiology, social work, child development, physical therapy, occupational therapy, dentistry, etc. Although these are very specialized disciplines and may be involved in institutional settings, i.e., State schools and hospitals, they certainly are valuable professionals in community programs. These professionals can provide treatment and support services for individuals who are in the community already or returning to the community as the result of a deinstitutionalization effort.

UAF's have devoted much effort to the development of materials in human development, behavioral management, personnel training, and other areas. These materials are used in conjunction with meeting identified training needs. All of these materials can increase the capability of community staffs to become trained and oriented to the various techniques that can be employed to increase the potentials of individuals living in the community.

UAF's are committed to working with State Planning Councils. They generally keep a close liaison with Councils and State Agencies, maintaining

communications on available technical assistance. If you are interested in the assistance of a UAF in developing community services, contact the State Planning Council or the UAF directly. The resources can complement the State Council and should be explored for new ways to deal with the problems of individuals with disabilities in the community.

D. Protection and Advocacy of Individual Rights

The Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) introduced an extremely unique provision entitled "Protection and Advocacy of Individuals' Rights" (Section 113). This provision is intended to provide a system of protection and advocacy services that can safeguard the human rights of all individuals with a developmental disability against discrimination, abuse, and neglect.

The provision is founded upon the fact that individuals with a disability have basic rights exactly as individuals without a disability. These basic rights are enumerated in a new Title II of the Developmental Disabilities program, which is called the "Bill of Rights."

The law states four basic human rights that all individuals with a disability are entitled to:

- 1) A right to appropriate treatment, services and habilitation for a disability;
- 2) The treatment, services, and habilitation for a person should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty;
- 3) The Federal Government and the State both have an obligation to assure that

public funds are not provided to any program that does not provide treatment, services, and habilitation which is appropriate to the needs of persons with a disability, or does not meet minimum standards (The specific minimum standards have not been enumerated here. Individuals should consult the text of Public Law 94-103; Section 111 for the complete listing); and

- 4) All programs for persons with a developmental disability should meet standards which are designed to assure the most favorable possible outcome for those served.

The System

The Act indicates that to assure that the rights of individuals are safeguarded, each State participating in the Developmental Disabilities program is required to have a system to protect and advocate the rights of individuals with a disability. The Act specifically states that this system must be in effect before October 1, 1977, as a condition to a State receiving its formula grant allotment for the Fiscal Year beginning October 1, 1977 regardless of an approved State plan.

Each State must provide to the Secretary of the Department of Health, Education, and Welfare satisfactory assurances that the State will have a system in effect to protect and advocate the rights of persons with a disability. That such a system will:

- 1) have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of individuals, and
- 2) to be independent of any State Agency which provides treatment, services, or habilitation to persons with a developmental disability.

The guidelines for this section, as promulgated by the Developmental

Disabilities Office, elaborate on the requirements a State must complete prior to approval of a proposed system by the Secretary. The guidelines include a pre-printed "work plan" which a State must complete and submit to the regional Developmental Disabilities Office. This work plan requires information on the target population, the need for this service, responsibilities and authority of the system, staffing patterns, and the method of operation. Copies of the pre-printed work plan should be available through a State Council or State Agency and certainly through the regional Developmental Disabilities Office.

The guidelines continue to explain that any agency may conduct and complete the planning of the system and submission of the work plan. However, only an independent agency removed from direct service delivery may implement the system. The guidelines also explain that the State Council and the State Agency do not have any necessary role in connection with this system. But rather, the Governor may assign responsibility for the planning and implementing the system to whomever is most appropriate, being mindful of the required independence. It is the Governor and not the Council or Agency that is charged with the responsibility of complying with these provisions. The Council and Agency can be involved in the development of a proposal, however, it is contingent upon the wishes of the Governor.

For the purpose of planning for the advocacy system a State receives an allotment separate from the basic formula grant. At a minimum States received \$20,000 each for Fiscal Year 1976, and will probably receive a similar amount for Fiscal Years 1977 and 1978. It is the Governor who must "sign-off" on the use of these funds which is part of the overall responsibility for the system.

Deadline

The implementation of the protection and advocacy system must occur prior

to October 1, 1977. This deadline is extremely significant because the Act clearly states that the system must be implemented by October 1, 1977, if the State is to receive its basic formula grant for the Fiscal Year starting October 1, 1977. Therefore the compliance of a State will determine the future of its Developmental Disabilities program. This is not to say that once the deadline has passed a State which did not comply cannot continue its efforts to implement a system. What it does mean, however, is that regardless of the submission and approval of an annual State plan for the Fiscal Year starting October 1, 1977, the State will not receive any formula grant funds unless the protection and advocacy system is in effect.

The Issues

As can be imagined the implementation of this system has caused considerable controversy at all levels of the Developmental Disabilities program. Governors believe the system is potentially too independent. Therefore, they are a "little" concerned about who is to control and account for this system. This concern is mirrored in the private sector by those who believe that the independence of this system requires it to be totally outside of any governmental structure. Therefore eliminating control by the Governor and/or Government.

Another issue which is related to the question of control is how to fund the system. Universal agreement has emphasized the lack of funds available for this system. If the maximum amount allotted to a State is \$20,000, then obviously additional revenues will be needed to bring the system to an operational level if it is to address the needs of an individual with a disability. If the State is expected to invest in the system, then control of

the system will be required to assure fiscal accountability. Likewise, the private sector's investment into this system would warrant a certain degree of control over how those funds would be expended.

There are a multitude of issues that have developed in response to this proposed system. It is beyond this module to discuss them all. The two issues mentioned above are very straight forward since they deal with two essential considerations; program control and budget. Other issues are important to consider, however, one particular issue stands out as critical to the success of this system.

Simply stated this issue concerns whether the scope of the system is limited to individuals with a developmental disability participating in Developmental Disabilities funded programs. Or does the scope of the system include individuals with a developmental disability participation or not in any program regardless of its source of funding?

Some advocates are encouraging the broadest possible scope for the system, others are interested in a limited system because of their concerns over control and budget. Whichever option is decided it is apparent that this proposed system stands to be critically tested to prove its worth. Opponents of the system believe it will return nothing but class action suits, appeals hearings, and lobbying. Proponents believe this system will provide a most valuable service safeguarding the rights and personal dignity all individuals with a developmental disability.

Advocates and individuals with a developmental disability should contact their Governor's office requesting information about the planning and implementing of a system. It is critical to be involved in the planning phase, especially if the result of the planning is a system which is designed to

assist advocates and individuals with a developmental disability.

Legal and Administrative Advocacy

Some persons have taken the position that the protection and advocacy system is going to be the end of the Developmental Disabilities Program. They base their opinion upon the issues presented above: control, budget, and scope. They are following a particular trend of thought that forecasts the ending of legal advocacy as an instrument for acquiring the services and rights accorded an individual with a disability. They cite the increasing reluctance of Governors, bureaucracies, and legislatures to bend to the forces of a class action suit. They cite the changing trends that courts have taken concerning right-to-treatment suits.

However, what these individuals fail to realize, through no particular fault of their own, is that the protection and advocacy system is not only an instrument of legal advocacy. Legal advocacy is part of the system, but so is administrative advocacy. The system is designed around legal, administrative and other appropriate methods of advocacy. Surely the tendency could be toward legal advocacy, and some early proposals have proven this tendency valid. However, these early proposals are narrow in focus.

To successfully implement this system, being mindful of all the issues, particularly the fears of legal advocacy, the system must develop one simple policy. The system will advocate for the rights and dignity of an individual at the lowest appropriate level. This means that prior to marching a complaint into the director's office of the agency, the advocate must first attempt to solve the problem at the lowest level, i.e., program director, therapist, etc. If this fails then the next level should be explored for a remedy. What this

policy dictates is that prior to marching into court with the world's biggest class action suit, the advocate must explore every other possible solution to the problem. So that the use of legal advocacy is a last resort and not the first action. Through this policy and procedure the fear of launching a rabid chain of law suits upon government and nongovernmental agencies alike should be decreased through the understanding that solutions can and will be developed at lowest appropriate levels in cooperation with all parties.

Advocacy should be envisioned as a helping service for those who require some assistance to assure their rights and dignity are not abused, neglected or denied. Advocacy is not an adversary service, it should not threaten any individuals unless they are particularly liable. The system developed under these provisions is intended to assist individuals who are in need of it. Through this provision the Developmental Disabilities program contains the most unique aspect of any human service program. Rather than the advocacy system becoming the demise of the program, it should be that big step forward insuring the welfare and livelihood of all individuals with a developmental disability.

Conclusion

The remaining sections of this module will discuss the eligibility criteria for service, planning, funding, and the relationship of Developmental Disabilities with other service programs.

The four aspects discussed in this section are the major activities provided by the program. As mentioned in the Statement of Objectives the program has built in flexibility that enables each State to custom design its program within the boundaries presented in this module. This knowledge will allow advocates to participate in the implementation of the program assisting

and improving the welfare and livelihood of individuals with a developmental disability.

Prior to continuing on to the next section, take a few minutes to answer the following questions, since they highlight important concepts mentioned in the text.

Worksheet--Section II

- 1) What two designations must the Governor make in establishing the State's Developmental Disabilities Program?

_____ and _____

- 2) What three features of the human service system does the Council's membership represent?

A. _____
B. _____
C. _____

- 3) A nongovernmental representative must be from what kinds of agencies?

- 4) What is the purpose of a member appointing a delegate to the State Council?

- 5) Name any four programs that should be represented by governmental agencies on the Council.

A. _____
B. _____
C. _____
D. _____

- 6) State Planning Councils are to be _____ on behalf of individuals with a developmental disability.

- 7) What are the two categories of membership in the National Advisory Council?

_____ and _____

- 8) What are two specific studies mandated by Public Law 94-103 that must be conducted by the Secretary?

_____ and _____

9) The Developmental Disabilities Office is attached administratively to the Office of:

- A. Vocational Rehabilitation
- B. Housing and Urban Development
- C. Handicapped Individuals
- D. Human Development

10) What are the three components of a UAF?

- A. _____
- B. _____
- C. _____

11) What new concept was introduced by Public Law 94-103 concerning UAF's?

III. Eligibility Criteria and Application Process

The Developmental Disabilities program is not a direct care services program. This means that an individual cannot receive directly from the Council services or funds. But rather, the Developmental Disabilities program does award grants to public, private nonprofit agencies and organizations, who then provide direct care services to individuals and/or their families.

Agency or Organization

The criteria for any agency intending to apply for Developmental Disabilities funding is the same regardless of the level to which the application is submitted, i.e., Federal or State. The applicant must be a public or private nonprofit agency or organization. This means an agency or organization in which no part of the net earnings are for the benefit of any private individual or share holder.

Individuals

Fundamentally, any individual who fulfills the developmental disabilities definition is eligible to benefit from services provided by any agency receiving Developmental Disabilities funds. The only exception to this criteria is the admissions criteria established by each individual grantee receiving Developmental Disabilities funds.

For example, let's say that agency B is receiving funds for a day care program from the State Council. As a contingent of funding the agency had to describe the target population of the program. The agency has targeted the program for boys and girls between the ages of 1 and 5 who have a severe or multiple disabilities and are non-ambulatory. These criteria have been imposed

because the project is attempting to provide a resource which prior to the project was not available.

This is not to presume that day care services exist for all other children between the ages of 1 and 5 who are ambulatory. Rather it is simply a limited access program because it hopes to emphasize a particular target population who have an identified need documented in the State plan. These exceptions to the fundamental definition are not truly exceptions, but rather they are stipulations that direct funding to specific populations in need.

University Affiliated Facilities

The criteria for receiving funds as a UAF are extremely complicated. If you remember the discussion concerning funding of UAF's (Section III, page 28-29) there are multiple funding sources that must be approached. It would be beyond this module to discuss all the eligibility criteria involved with each funding source. Suffice it to say that funding for a UAF must be pursued through Maternal and Child Health, Bureau of Education for the Handicapped, Vocational Rehabilitation, State and local governments and private foundations and grants. Generally the criteria will require a public, private nonprofit agency or organization, however, there will be additional stipulations to consider (See definition of UAF, page 24).

UAF Satellite Center

The statute requires an existing UAF sponsor a "satellite center." The feasibility studies required by the Secretary prior to any funding for a satellite center must be conducted by an existing UAF. The results of this study will yield a description of the kind of facility desired to meet the identified needs. This description will influence the kind of applicants

sought to be in the center (See definition of satellite center, page 25).

Application Process

The process which follows will mirror that process employed at the State level. There are many variations, however, the fundamentals will remain the same. The process will also conform, somewhat, with that process employed at the Federal level, although specific mention will be made to critical variation from the Federal process.

Request for Proposals

When priorities are established in the State plan, the Council will solicit grant proposals from any nonprofit private or public agency to accomplish any one or more of the identified priorities. Generally the Council or State Agency will publish newspaper advertisements called a "Request for Proposals" (RFP). These RFP's, as there may be several, announce the priority or priorities for which grant proposals are being requested. They will indicate the type of proposal(s) being requested by stipulating the priority, the dates for submission and tentative award, the forms to be used, the amount of funds to awarded for that priority, as well as for each approved proposal, any necessary geographic information (like counties to be served), and a contact person. Although most State Agencies and State Councils use the RFP process, (i.e., newspaper advertisements) personal contact with either group will insure that if you by chance miss the RFP's publication you will know that proposals are being solicited.

At the Federal level, RFP's are published in the "Commerce Business Daily." This paper is a daily listing of all Federal contracts, sub-contracts, surplus property, land and grant awards, and RFP's. It is published by the

U.S. Department of Commerce on subscription basis and distributed by the Government Printing Office.

There is no limit to the number of RFP's a Council may publish since there is no limit on the number of priorities that may appear in the State plan. Sometimes a priority will be published more than once depending on the response the Council received in terms of the proposals submitted. Proposals do not have to request all the funds allocated for a particular priority, but generally cannot exceed the amount allocated.

Grantsmanship

When a nonprofit private or public agency or organization applies for a grant in response to the request for proposals, or in some cases, for discretionary funds, they must use prescribed application forms designed for that specific purpose, i.e., Developmental Disabilities funding. Grantsmanship is a long and sometimes complex process that requires documentation of the need for services, population(s) to be served, content and methodology of the proposal, personnel involved, budget, project evaluation procedure, and a statement on continuation funding.

Grant writing is a process requiring preplanning in two ways. First, the program content and the methodology must be organized so that it adequately presents a project which conforms with the priorities of the Council. Applicants should arrange each goal, objective(s), and major milestones/tasks on a "time-line." A "time-line" will indicate in a comprehensive manner all of the project activities which occur sequentially and simultaneously.

The second preplanning aspect is related to the first by preparing the budget on a "time-line." Budget projection should coincide with projected

activities. This way the expenditure of funds can be monitored according to activities. There are many examples to demonstrate why the use of a "time-line" makes for an orderly presentation of a proposal in terms of a well thought out program. The best example concerns allowing for "start-up" time necessary for all projects. A general practice is that grant staff and grant participants (those to be served) are not solicited for the project until the grant is awarded. In some cases, the grant might not be awarded until three or five months after submission. Therefore, the applicant would not hire staff or enroll clients until funds were awarded. This delay may take 1 to 2 months, which on a 1 year grant leaves only 11 or 10 months to accomplish the program's objectives. By using a "time-line" concept, the grantee can indicate when operation will start after the grant award allowing for "start-up" preparations, i.e., hiring staff and enrolling clients.

Monitoring and Evaluating

Monitoring grant activities is not simply a Sherlock Holmes adventure. The true value of monitoring is its ability to identify strengths and weaknesses of a grant and direct assistance to the grantee to balance the program. If there is a weakness, the monitoring process should bring attention to the problem by alerting the Council, State Agency and grantee. This way the problem might be rectified before it causes the demise of the grant. Constant or periodic monitoring is a helpful tool to grant progress, and can save a grant with early problems, or can document why a particular project should not continue. Therefore, monitoring is a unique process with a goal to identify with a grant as it progresses and to assist grantees to identify any weaknesses and/or take advantage of any strengths that develop during the grant period.

While monitoring observes program performance during the grant period, evaluation is an assessment of a grant's successes and failures either during or at the end of the project period. Due to trends toward accountability, evaluation of grants has become a very conscious and aggressive activity that deeply concerns the grantor, the grantee, the participating clients, and the general public.

Following the monitoring process, evaluation takes into account the periodic monitoring reports, as the evaluator assesses the results of the grant. Monitoring reports give the evaluator a basis for understanding the kinds of successes and failures experienced by the project and what remedies were suggested and successful.

Aside from monitoring reports, the evaluation of a project usually includes a final report by the grantee giving a self-evaluation of the project and a final site visit, if the project is still operating, should yield a report that offers justification and accountability of the grant award.

"Evaluation, therefore, has two dimensions: a dimension of objectivity, which is characterized by factual results and outcomes and a dimension of quality, which is characterized by judgement and by indicators of worth and value." (Vitalis and Cherington, 1967)

Continuation Funding

The final consideration for potential grant applicants in preparing a grant proposal is a statement regarding continuation funding of the project beyond the period for which funds would be awarded. Most State Councils or State Agencies award grants on the basis of a pilot program mechanism of 1 to 3 years. This practice is designed to establish projects with enough time to

demonstrate value and effectiveness in addressing a particular priority. Once the pilot program period has lapsed, successful projects should be maintained by generic and/or private funding.

State Councils or State Agencies can be influential in supporting their successful project in attempts to secure continuation funds. They can be convinced by monitoring reports and the evaluation that the pilot program merits continuation. The grantee should encourage active Council/Agency support for continuation funding if they are so inclined. This support is significant in that often the generic funding sources with State or Federal dollars are members of the Council. However, if the funding source is not present on the Council, the Council can be encouraged to approach the funding source in support of the project.

Unfortunately, too many State Councils and Administrative Agencies have been remiss in assisting proven projects to secure continuation funding. This has resulted in accusations that the pilot project mechanism is not helpful to individuals with a developmental disability since by the time a project proves valuable, the funds have been expended, and there is no funding source willing to continue it. Successful community programs which are initiated, need to be maintained if they are to actively prevent institutionalization. The potentials are too very real for returning individuals to institutions because community programs have no secure funding. The problems of continued funding for pilot projects should be focused upon by State Planning Councils as an administrative priority. If Councils fail to find ways to secure continuation funding for successful pilot projects then it should reconsider funding at all.

Habilitation Planning

The 1975 amendments to the Developmental Disabilities program initiated a

new concept mandating "Habilitation Plans." This concept simply requires of each recipient of Developmental Disabilities funds the development of individual habilitation plans for each person receiving direct care services. Potential grantees should become aware of the provisions of a habilitation plan so that they may develop a system of plans which will comply with the legal requirements.

Habilitation plan requirements have five characteristics:

- 1) The plan must be written;
- 2) The plan must be developed jointly by the program personnel, the individual with a disability or his/her parents or guardian;
- 3) The plan should contain long-term goals and intermediate objectives stated in sequence with the methods for attaining such goals and objectives (Also the plan must indicate the objective criteria and evaluation procedure for assessing whether the goals and objectives are being achieved. It also states who is the program coordinator for that particular plan.);
- 4) The plan must state the specific habilitation services to be provided and the agency delivering the service, including the date services begin and end;
- 5) The plan shall specify the roles and objectives of all parties in the implementation of the plan.

Each individual's habilitation plan must be re-evaluated, and modified if necessary, at least once a year. The agency conducting the review should have primary responsibility for services to that individual. In the case of a single agency project this would not present any problems. However, some projects may incorporate many different agencies with specific involvements. In this instance, it must be established which of the agencies has primary

responsibility for services to each individual enrolled in the project.

The habilitation plan is designed as a monitoring tool documenting the effects of a program on individuals served. It provides a monitoring tool to safeguard an individual's involvement in a program. Because the plan must be reviewed and up-dated periodically, the chances of any individual becoming abused, lost, or forgotten are lessened. The initial plan and all subsequent up-dates must be dated and included as a separate part of the individual's case records. The plan is for action focused upon the program goals and objectives for the individual.

The reason for mentioning habilitation plans, in relation to the planning process, is to emphasize that this plan is as significant as the State plan. If a State fails to develop a plan, then there are no funds. Similarly, if there is no habilitation plan then the grantee cannot receive funding. In addition, the monitoring of the habilitation plan will document the benefits an individual has received from participating in the program. This review linked with program and budget monitoring will provide a more complete assessment of the value of any project.

Conclusion

The information of this section is designed to increase the reader's programmatic understanding of how Developmental Disabilities funds can be secured for those who need them. This section indicates the fundamental grant structure used by most States, however, the actual process in any State must be identified and employed when submitting an application.

Before proceeding to the next section, please take a few minutes to answer the highlight questions that follow.

Worksheet--Section III

- 1) Fundamentally, any individual who fulfills the definition of developmental disabilities is eligible to benefit from a service funded by Developmental Disabilities.

True _____ False _____

- 2) An agency or organization applying for Developmental Disabilities funds must be _____ or _____.

- 3) What kind of facility must sponsor a UAF "satellite center?"

- 4) What does RFP stand for?

- b) List three potential funding sources of a UAF.

A. _____
B. _____
C. _____

- c) Grant writing requires preplanning in what two areas?

A. _____
B. _____
C. _____

- 7) The "time-line" indicates in a comprehensive manner all the project activities which occur _____ and _____

- 8) Evaluation has what two dimensions?

A. _____
B. _____

- 9) Some Councils and State Agencies have been lapse in securing _____
_____ for projects to continue after its Developmental
Disabilities grant expires.
- 10) All applications that receive funds must develop a _____
_____ for all individuals participating in the
project.

IV. Planning Process

This section is devoted totally to the State plan required of each participating State annually prior to the awarding of any formula grant funds. Mention in Section I was given to the mutual responsibilities of the State Council and the State Agency. This discussion will explore this mutual responsibility, as well as include a third equal party who is responsible for participating in the process: the advocate.

The State plan requirements, as mandated by Public Law 94-103, are designed to provide a framework for a comprehensive planning process. This design reflects the emphasis of the Developmentally Disabled Assistance and Bill of Rights Act upon adequate planning for services. The specific requirements number 30 and cover a broad range of activities. They are noteworthy here so that the discussion can be directed toward specific issues.

The requirements are:

- 1) designate the State Planning Council;
 - designate the State administrating agency;
- 2) Describe the quality, extent, and scope of services being provided, or to be provided under other State plans affecting the disabled; including programs such as education of the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health;
 - describe how funds from the Act will augment and supplement rather than duplicate or replace services eligible for Federal assistance under other State programs;
- 3) set forth priorities, policies and procedures for the expenditure of funds

under this Act;

- 4) contain assurances to the Secretary of the Department of Health, Education, and Welfare that Developmental Disability funds will be used to strengthen services to the disabled;
- and there will be reasonable State financial participation in implementing the State plan;
- 5) describe the quality, extent, and scope of treatment, services, and habilitation being provided in implementing the State plan;
- 6) provide that services and facilities furnished under the plan comply with standards as to the scope and quality of services and the maintenance and operation of facilities;
- 7) meet U.S. Civil Commission requirements for establishing and maintaining personnel standards;
- 8) provide that the State Planning Council be adequately staffed and identified staff be assigned to the Council;
- 9) provide that the State Council will review and evaluate at least annually, its State plan;
- 10) provide that the State administering agency will submit reports as required by the Secretary;
- 11) provide that special financial and technical assistance be given to areas of urban or rural poverty in providing services;
- 12) describe methods to be used to assess the effectiveness and accomplishments of the State in meeting needs of developmentally disabled individuals;
- 13) provide for the development of a construction program for facilities to serve the developmentally disabled;

- based on a state-wide inventory of existing facilities and a survey of needs and meeting the requirements of the Secretary for furnishing needed services to persons unable to pay;
- 14) set forth the relative need for projects included in the construction program, and assign priorities based on financial resources available for maintenance and operation, and that construction will be conducted in accordance with standards prescribed by the Secretary;
- 15) specify the per centum of the State's allotment to be devoted to construction, not more than 10% of the allotment for any fiscal year;
- 16) provide to every applicant for a construction project an opportunity for fair hearings;
- 17) provide for fiscal control and fund accounting necessary to assure proper disbursement of funds paid to the State;
- 18) provide assurances that financial support exists to complete the construction project, and to maintain and operate;
- 19) provide assurances that all laborers and mechanics employed in the construction project will be paid wages in accordance with the Bacon-Davis Act;
- 20) contain a plan to eliminate inappropriate institutionalization, and to improve the quality of care and surroundings of persons for whom institutional care is appropriate;
- 21) provide for early screening, diagnosis, and evaluation (including maternal care, developmental screening, home care, infant and preschool stimulation programs, and parent counseling and training) of developmentally disabled infants and preschool children, particularly those with multiple handicaps;

- 22) provide for counseling, program coordination, follow-along services, protective services, and personal advocacy on behalf of developmentally disabled adults;
- 23) support the establishment of community programs as alternatives to institutionalization using, to the maximum extent feasible, the resources and personnel in community agencies to assure full coordination and the provisions of appropriate supplemental health, educational, or social services;
- 24) assure that the human rights of all individuals will be protected while receiving treatment, services or habilitation in programs funded under this Act;
- 25) provide for a Design for Implementation including methodology for implementation of the State plan, priorities for expending funds, detailed plan for the use of funds, specific objectives to be achieved, list of programs and resources to be used, and method for periodic evaluation of the design's effectiveness;
- 26) provide for maximum use of volunteers in accordance with the Domestic Volunteer Service Act of 1973;
- 27) provide for the implementation of an evaluation system in accordance with they system to be designed by the Secretary;
- 28) provide to the maximum extent feasible, an opportunity for prior review and comment by the State Planning Council of all State plans of the State which relate to programs affecting persons with developmental disabilities;
- 29) provide for the protection of interests of employees affected by deinstitutionalization; and

30) contain additional assurances and information as the Secretary may find necessary to fulfill the provisions of this Act;

All of the above requirements have been further described in regulations and guidelines promulgated by the Secretary of Health, Education, and Welfare, through the Developmental Disabilities Office. Both these documents are available through the State Council's staff and the regional Developmental Disabilities office, upon request.

Mutual Responsibilities

The mutual responsibilities of the State Council and the State Agency are designed to encourage cooperation between the governmental and nongovernmental, the public and private sectors who are involved with service delivery for individuals with a disability. The situation also creates a natural monitoring system because each one's responsibility is contingent upon activities of the partner. This is best explained as follows:

- 1) the Council sets the direction for the plan;
- 2) the Agency writes the plan;
- 3) the Council reviews and submits the plan;
- 4) the Agency implements the plan; and
- 5) the Council and Agency monitor and evaluate the implementation of the plan.

There is also a third responsible partner to this planning process and that is the individuals with a developmental disability and/or their advocates. Through the various steps of the plan the participation of the general public is necessary if the final product is to speak to the real needs of those it intends to serve. Certainly it is the intent of every Council and Agency that their State plan be reflective of the people it will serve. However, their

efforts could be significantly enhanced through the conscious involvement of disabled individuals. The Council and Agency should conduct planning sessions which are open to the public. However, it is the responsibility of the public to take advantage of these public forums and other opportunities to share with Council, the Agency, and other interested individuals.

Data Collection

The collection of data and information germane to the State plan by the State Council and Agency is a major intercept point for public involvement. The State plan requirements emphasize the need to know the statutes of the entire service delivery system, including all those Federal/State programs that affect the disabled.

Review of State Plans

As mentioned earlier, this review of State plans is a mandated responsibility of the Council (See Section III). The State Council must identify all the State plans affecting the disabled and develop a collaborative effort with each responsible State agency for the plans identified. The Act suggests some State plans the Council should review. They include: vocational rehabilitation, public assistance, medical assistance, social services, education of the handicapped, mental retardation, mental health, maternal and child health, and crippled children and comprehensive health planning. Additional State plans which the Council may wish to review are: transportation, housing, recreation, community development, and advocacy.

The reader will recall that one category of membership in the State Council consists of State agencies' representatives of those programs that impact the disabled. These representatives can be instrumental in acquainting the Council and the Agency with the processes that lead to the development of

the respective State plans. This information will provide a framework by which the Council can understand at which points it should exchange information and/or comment on different aspects of each State plan.

It is critical to establish a strong working relationship on the Council among its State agency representatives and the other members. These relationships can decide whether a meaningful and constructive exchange will exist concerning the review and comment of State plans. Without a strong working relationship among the members, the Council will sacrifice any natural advantage that the Council's forum can create due to the membership components. (Remember that the Council's membership typifies the triangle of the human service delivery system: those who need services, those who administer the State's responsibility for services, and those who provide services.)

In most States the process for review and comment of State plans has not been formally developed into a systematic yearly routine. Rather, at best, the reviews have been informal and staggered. A State Council may decide to discuss only a particular number of plans this year and follow the next year with another set of plans. Generally this action is the result of two factors: unfamiliarity and staff.

Unfamiliarity

The mandate to review all State plans affecting the disabled is an original provision of the Developmental Disability Act that was continued by the 1975 amendments. Unfortunately, the State Councils have not been extremely successful in implementing this requirement, although many individual attempts have been articulated. The review requires a great deal of familiarity with the concept of State plans. Persons who have never before seen a State plan are quickly confused by the regulations, format and process, regardless of the

plan's content. Therefore, it becomes essential to become familiar, not only with the content of particular State plans, but with the regulations, format and processes that are pertinent to each State plan reviewed.

State agencies responsible for State plans affecting the persons with a developmental disability are not sure what it all means to participate in this Council process. State agencies can have very mixed feelings about allowing the Council a role as reviewer and commentator. Likewise, the Council membership is not quite sure what their role means to themselves, particularly since they are unfamiliar with this kind of activity.

State agencies must understand the potential effects of this review. State Councils must understand that their role of review and comment is not an approval or disapproval responsibility. State agencies must interact with the Council to see if the Council can offer reliable and creative comments. As well, the Council must interact with the State Agencies to see if they (the State Agencies) are sincerely interested and committed to the cause of improving the well-being of individuals with a developmental disability. Each party must become articulate, constructive and supportive of each other and the potentials for program change.

Staff

Another barrier that has delayed the review of State plans is that State Councils generally have not been staffed adequately to accomplish the review of 5 to 10, or even 2, State plans, particularly if no procedure exists to complete the review. Often the staff is either not available (man hours) or is itself unfamiliar with any procedures which could be a facilitating resource.

In the area of community residential alternatives data collection would need to inventory the available resources, i.e., number, type, location,

potential of existing alternatives. It would be beyond the scope of this module to list all the data and information that would be needed to complete such an inventory. However, any information concerning existing facilities, as well as data concerning those who require alternatives, and resources and constraints to community residences would be helpful to the planning process. Any and all information should be directed to the Council and Agency. They will appreciate the input and participation regardless of the utility of the information.

Priorities

State Plan priorities are established after all the data and information collected by the Council and Agency has been analyzed. Priorities are those needs that have been selected as the most important. Priorities can take either of two directions: administrative or fundable. Administrative priorities are those needs which can be addressed (satisfied) through administrative action, therefore not requiring the commitment or expenditure of funds, Developmental Disabilities or otherwise. Usually this type of priority is directed toward a State law, regulation, policy, or procedure that either needs to be expanded, improved, or removed. For example, some States have restrictions on the minimum size of community residential settings eligible for "cost reimbursement" as a principle funding mechanism for community residential settings, then the priority could be simply the drafting and acceptance of a new policy or law. There would be no need to commit or spend funds to make this change, but rather, negotiations.

Fundable priorities, however, are those needs which definitely require the specific commitment and expenditure of funds in order to satisfy the need. A good example would be the need to establish a day care program for children

with a disability not yet in school, but whose parents do work. The solution to the need simply is the commitment of funds to start a day care program.

These optional types of priorities provide the Council with a broad range of actions that could be initiated to meet a need. The Council need not limit its discussion or implementation of remedies simply to funding. It provides a stimulus for advocates to encourage the Council to pursue areas of policy and procedure that affect disabled individuals, in addition to service-gap problems.

Design for Implementation

When priorities, administrative or fundable, have been established the State Agency is required to develop a Design for Implementation (DFI). The Design specifies the methodologies to be used to address the identified priorities. The Design will indicate for each priority the strategy, the available funds (if appropriate), the timeframes for action, and the expected outcome.

The Design must be included in the State plan when submitted for approval. This gives the Council the opportunity to review the Design and comment to the State Agency. Some individuals are concerned that the Agency will use its responsibility to prepare the Design as a method of controlling the program. They stipulate that regardless of the priority areas, the Agency can pick and choose which ones it will be concerned with during the fiscal year.

Others believe that the Design represents a critical monitoring element in the formula grant program. They believe that through the Design, advocates can observe the sincerity and willingness of the Agency to implement the program.

No one can forecast accurately how effective the Design for Implementation will be. Certainly each opinion concerning the Design is possible. However,

until the Design is perfected and monitored no conclusions can be drawn on its effectiveness. Advocates should pay close attention to the Design to observe how it will affect the implementation of the State plan. If there are suggestions concerning the Design for any of the priorities, they should be forwarded to the State Agency for its consideration.

Community Residential Alternatives

There are specific State plan requirements that address the priority of community residential alternatives. They are all directed towards the increasing use of community settings and resources to remedy the needs of persons with a developmental disability.

Specifically the requirements concern maximizing the use of existing community programs, eliminating inappropriate institutionalization, supporting the development of community services and providing financial and technical assistance to urban and rural poverty areas. Advocates should key into these provisions and verify the State Council's involvement. If the State plan neglects to indicate any Council intention in any of these areas, then advocates should present their concerns to the Council and Agency and urge actions be taken in compliance with these provisions.

There are a host of activities that could be implemented in compliance with a community focus. A complete module could be devoted to a discussion of the goals, objectives, and strategies of developing community services, i.e., residential and programmatic. For our purposes it is sufficient to state that provisions do exist for the State Council and the State Agency to actively pursue the development of community services. It is the responsibility of individuals with a disability and their advocates to acquaint the Council and Agency with their desire for these services and to insist on their

establishment. Without personal involvement individuals with disabilities are subject to receiving services they do not desire or need. Through the State planning process the opportunity exists for achieving recognition of the needs of individuals with disabilities. Every effort should be expended to insure that the State plan is reflective of the conditions and desires of the individuals it is intended to service.

Conclusion

Prior to the next section, entitled Funding, take a few moments to consider the questions that follow. They focus upon information of this section and place emphasis on some critical issues.

Worksheet--Section IV

1) Who are the three participants in the development of the State plan?

- A. _____
- B. _____
- C. _____

2) What does a State receive after the approval of the annual State plan?

3) List the five responsibilities of the Council and the Agency concerning the State plan.

- A. _____
- B. _____
- C. _____
- D. _____
- E. _____

4) List four State plans that affect individuals with developmental disabilities that must be reviewed by the Council?

- A. _____
- B. _____
- C. _____
- D. _____

5) Which members of the Council should be most influential in assisting the Council review other State plans?

6) What are two types of priorities?

_____ and _____

7) What must the State Agency prepare which indicates the methodology to be used in addressing a priority listed in the State plan?

8) List three provisions of the State plan requirements which are concerned with community residential alternatives.

- A. _____
- B. _____
- C. _____

9) What two factors have contributed to the unsuccessful attempts to review State plans affecting the disabled?

_____ and _____

10) Give an example of a fundable priority and an administrative priority.

V. Funding

Mentioned numerous times throughout this module, is that upon submission and approval of an annual State plan on Developmental Disabilities each State is allotted a formula grant. The amount of each formula grant is based upon:

- 1) the population;
- 2) the extent of the need for services and facilities for persons with a developmental disability; and
- 3) the financial need of the State.

In any fiscal year, no State will receive an allotment of less than \$150,000, which is \$50,000 greater than the limit set by the original Developmental Disabilities Act, Public Law 91-517.

Federal Share and State Match

When a State is awarded a formula grant it is required to match those funds by 25% of the total. The Council may, however, match only 10% of the total for those portions used to provide services to urban and rural poverty areas. The State can take several options to fulfill the match requirement. First, the State can commit the total match with State revenue. Second, the State can commit part of the match in State revenue and require that each grant recipient match their grant by a certain percentage to complete the total match. Third, the State can provide an "in-kind contribution." From the Office of Human Development's Grants Administration Manual (1/1/77) the definition of "in-kind contribution" means "changes for real property and equipment, the value of goods and services directly benefiting the grant program and specifically identifiable to it and represents the value of non-cash contributions provided by the grantee." The State may not use any Federal funds it receives, except when specific Federal funds permit it, for matching,

i.e., community development block grants and general revenue sharing.

Federal Authorization

For allotments made to each State as a formula grant, the Congress authorized to be appropriated \$40,000,000 for Fiscal Year 1976, \$50,000,000 for Fiscal Year 1977, and \$60,000,000 for Fiscal Year 1978. The actual amounts allocated for those fiscal years is less than the amounts authorized. The Fiscal Year 1978 budget submitted by the President and approved by the Congress has the following accounting of funds:

Developmental Disabilities:

	1976	1977	1978
	Actual	Estimate	Estimate
State Grants	30,959*	33,089*	41,608*

(*figures in thousands of dollars)

Uses of Formula Grant Funds

A State Council and State Agency must collaborate when deciding the budget for any fiscal year. The fiscal year for the Federal government begins on October 1st and continues until September 30th. There arises a problem with this fiscal year since the probability is great that a State's fiscal year does not conform with the Federal. Often States are on a July 1st to June 30th fiscal year or possibly something else. This difference is remembered while discussing the Federal and State systems.

Funds may be used in four ways; administration, planning, services, and/or construction. For the purpose of construction a State is restricted to using no more than 10% of the total formula grant, if the specific construction requirement of the State plan has been approved. For the purpose of administration a State is restricted to using up to 5% of the total allotment, or \$50,000, whichever is the least, to pay no more than one half of the

expenditures. There are no such restrictions on the use of funds for planning or services.

Accounting Procedures

Each State is required to develop acceptable standard accounting procedures for its administration of funds, as well as for grantees who are awarded Developmental Disabilities funds. All fiscal records must be kept, at least, seven (7) years in the event the General Accounting Office of the Congress is requested to perform an audit.

Maintenance of Effort

The State plan must contain an assurance that funds received through the Developmental Disabilities program will not supplant State, local, and other nonfederal funds otherwise available for services and activities indicated under the plan. Funds are to be used to increase the amount of funds otherwise available for services.

Payments

Each State receiving a formula grant is allotted four quarterly grant awards which are forwarded to the State in equal amounts. The actual transfer of funds is a much slower process which requires that a State has completed the necessary accounting reports for the previous quarters.

The Secretary of Health, Education, and Welfare is authorized to withhold payments from any State which he finds in significant noncompliance. Noncompliance can refer to poor accounting procedures, non-fulfillment of the intention of the approved State plan, and/or failure to comply with regulations of the program.

Special Projects

Section 145 of Public Law 94-103 authorizes Special Projects to be awarded by the Secretary of Health, Education, and Welfare, in consultation with the National Advisory Council. At least 25% of the amount allocated for Special Projects must be devoted to projects of national significance. In Section III of this module, a full discussion on Special Projects can be found.

The authorization level for Special Projects is considerably higher than the actual expenditures for Fiscal Year 1976 and the estimates of Fiscal Year 1977 and Fiscal Year 1978. The chart is as follows:

<u>Special Projects</u>	<u>1976</u>	<u>1977</u>	<u>1978</u>
Authorization*	\$18,000	\$22,000	\$25,000
Allocation*	\$13,065	\$19,937	\$11,017

(*figures in thousands of dollars)

There is no requirement for a match from applicants of these funds.

University Affiliated Facilities:

The funds authorized for this level of the program were:

<u>UAF's</u>	<u>1976</u>	<u>1977</u>	<u>1978</u>
Authorizations*	\$15,000	\$18,000	\$21,000

(*figures in thousands of dollars)

The Secretary of Health, Education, and Welfare has specific guidelines from the Act on how these funds may be discussed. For Fiscal Years 1976 and 1977, no less than \$5,000,000 dollars shall be made available for the purposes of administering and operating UAF's. While for Fiscal Year 1978, no less than \$5,500,000 may be available.

In reference to the satellite studies, the Act requires that \$750,000 be

available for feasibility studies. After all these allocations have been completed, the Act stipulates that at least 40% of the remaining funds be available for the establishment and operation of satellite centers.

The actual expenditures for Fiscal Year 1976 were \$4.144 million, while the estimates for Fiscal Years 1977 and 1978 are \$5.250 and \$5.500 million respectively.

Conclusion

The information in this section is provided so that the reader can achieve a focus on the size of the Developmental Disabilities program in total. For example, the amount authorized in Fiscal Year 1976 for the entire program was \$73,000,000, but the actual expenditures were far below that level at \$48,168,000. This discrepancy is not unusual in any Federal program. It indicates the variance between what is envisioned as potential and that which can be realistically achieved.

Advocates should learn from this discrepancy the need to encourage programs to strive for their greatest potentials. Certainly this position must be focused upon the Federal system, but even more so at the State level, from which the majority of individuals with a disability receive benefits.

Worksheet--Section V

- 1) Each State that received approval of its annual State Plan is allotted a _____

- 2) What is the percentage of the Federal share for any project providing services to urban or rural poverty areas?

- 3) What are two forms of match available to any agency applying for Developmental Disabilities funds?
A. _____
B. _____
- 4) A State may only commit _____ of its formula grant for construction projects.
- 5) Developmental Disabilities funds are limited to _____ or _____, whichever is less, for the 1/2 of the total administrative costs.
- 6) The Secretary of Health, Education, and Welfare is authorized to _____ payments from any State which he finds in compliance.
- 7) At least 25% of the funds available for Special Projects must be set aside for _____ of _____
- 8) What is the term used for funding levels stated in an act?

- 9) What is the minimum allotment a State could receive in any fiscal year?

VI. Relationships With Other Programs

The principle focus of the Developmental Disabilities program is on planning for services, rather than the promulgation of direct services funded by the formula grant. Compared to some of the larger programs like vocational rehabilitation, special education programs, and social security the Developmental Disabilities program is far from being a money program. Rather the concept is one which intends to stimulate and facilitate the use of generic programs in remedying the problems that confront individuals with a developmental disability.

The philosophy behind the creation of the Developmental Disabilities program was that already there exists numerous services for the disabled. However, these services are not coordinated enough to form a comprehensive services delivery system. Therefore, if some structure could be devised that could focus on encouraging and developing coordination and cooperation among existing Federal, State, and local resources then considerably greater service capabilities would be realized.

It is from this philosophical viewpoint that the review of all the State plans affecting the disabled became a critical mandate of the State Councils. Since the State plan process is a research, analysis, and planning sequence that constitutes a commitment between the Federal and State agencies over how a program will be administered and what the program will provide, the State plan is a key to understanding the availability of services affecting the disabled. Through a review of all these State plans the Council should be equipt to consider improving coordination and cooperation in those areas of mutual involvement. Besides cooperation with what now exists, the review affords an opportunity to the Council to ponder future areas of cooperative activities among these programs.

This goal of cooperation and coordination with other programs affecting the individuals with a disability can be seen in various examples. For instance, in terms of community residential alternatives, the use of Developmental Disabilities funds to rehabilitate a facility into a group home would not be as effective as if funds from the Department of Housing and Urban Development, which are for that specific purpose, were used. If Housing and Urban Development funds had been used then perhaps the Developmental Disabilities funds might have been committed to staffing costs or equipment.

There are numerous examples of how generic funds could be used in cooperation with Developmental Disabilities funds in order to provide specific services. It is not the intent of this section to list all the possibilities. However, it is the intent of the module to propose facts which an individual or group of individuals can implement at the most appropriate time, in a most appropriate manner, for the benefit of individuals with a developmental disability.

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WORKSHEET ANSWERS

Section II

- 1) State Planning Council and State Administrative Agency
- 2) A) those who need services
B) those who deliver services
C) those who administer a State's responsibility for services
- 3) any public or private nonprofit agency involved with service delivery, higher education, advocacy or other activities concerned with individuals with a disability
- 4) any individual named by the Council member to represent hem/her at Council meetings because of scheduling conflicts.
- 5) any of the following:

A) Vocational Rehabilitation	E) Transportation
B) Public Assistance	F) Education
C) Maternal and Child Health	G) Medical Assistance
D) Mental Health	H) Social Services
- 6) Advocates
- 7) appointed members and ex-officio members
- 8) definition of Developmental Disabilities and standards and quality assurance mechanisms
- 9) Office of Human Development
- 10) A) Training
B) Service
C) Research
- 11) satellite centers

WORKSHEET ANSWERS

Section III

- 1) True
- 2) public or private, nonprofit
- 3) university affiliated facility (UAF)
- 4) request for proposals
- 5) Developmental Disabilities
Maternal and Child Health
Bureau of Education for the Handicapped
State and local funds
Private foundations
Grants
- 6) Program content and methodology
Budget
- 7) simultaneously and sequentially
- 8) dimension of objectivity
dimension of quality
- 9) continuation funding
- 10) habilitation plan

WORKSHEET ANSWERS

Section IV

- 1) State Agency, State Council, and Advocates
- 2) A formal grant
- 3) A) Council sets direction;
B) Agency writes plan;
C) Council reviews and submits plan;
D) Agency implements plan;
E) Council and Agency monitor and evaluate plan.
- 4) A) Vocational Rehabilitation
B) Special Education
C) Public Assistance
D) Medical Assistance
E) Social Services
F) Housing
G) Maternal and Child Health
H) Transportation
I) Vocational Education
J) Mental Health
- 5) State agencies' representatives
- 6) Administrative and fundable
- 7) Design for Implementation
- 8) A) Deinstitutionalization and institutional reform;
B) Maximize the use of existing community resources;
C) Support the development of community services;
D) Provide technical and financial assistance to urban and rural poverty areas.
- 9) Unfamiliarity and Staff
- 10) Fundable priority is any service or planning effort.
An administrative priority is any activity that requires remedy or negotiation.

WORKSHEET ANSWERS

Section V

- 1) Formula grant
- 2) 90
- 3) cash or in-kind
- 4) 10%
- 5) 5% or \$50,000
- 6) withhold
- 7) Projects of National Significance
- 8) Authorizations
- 9) \$150,000

The Federal Programs Information and Assistance Project is a consolidation of two grants of national significance awarded by the Developmental Disabilities Office of the Department of Health, Education and Welfare. The grants were developed through the efforts of the four national voluntary agencies representing each of the developmental disabilities. These four agencies, Epilepsy Foundation of America, National Association for Retarded Citizens, National Society for Autistic Children and United Cerebral Palsy Associations, Inc., are jointly participating in the Project. The National Association for Retarded Citizens has responsibility for administering the grants.



Epilepsy
Foundation
of America



National
Association
for Retarded
Citizens



National Society
for Autistic
Children



United
Cerebral Palsy
Associations, Inc.

