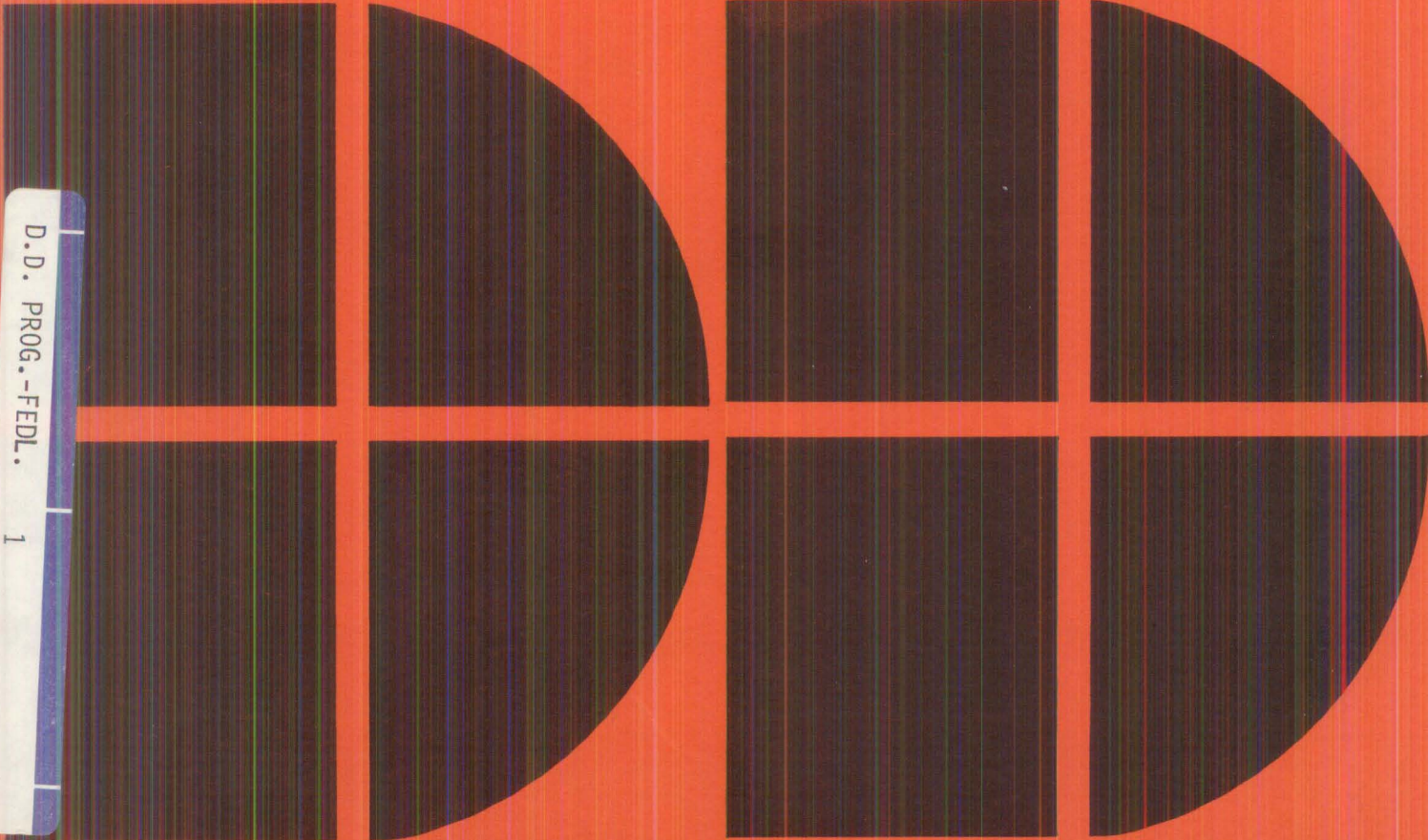


GC4006 Programs
Development and Assistance
Project

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

R. Strand

Developmental Disabilities



D.D. PROG.-FEDL.
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THE DEVELOPMENTAL DISABILITIES PROGRAM

By Tom Stripling, Technical Coordinator

A training module to an understanding of the Developmental Disabilities Program. Discussions include State Councils and State Designated Agencies, the National Advisory Council on Developmental Disabilities and the Developmental Disabilities office, University Affiliated Facilities and the 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 original Act entitled, the Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-517). Individuals and groups at the local and national levels advocated for legislation to benefit individuals with handicapping conditions as early as 1920. However initial achievements toward the present developmental disabilities program were not accomplished until the 1950's. These early initiatives were piecemeal and exploratory focusing primarily on issues in health, education and rehabilitation services.

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 President's Panel on Mental Retardation was influential in the passage of two major pieces of legislation. The first piece of legislation responding to the President's concerns was 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 States to improve prenatal care for economically and socially disadvantaged women, as well as to provide infant care services for children "at risk" of mental retardation because of poor economic and social environments. More important to the current discussion, the Act authorized funds for grants to States to conduct comprehensive mental retardation planning on a coordinated intra-agency basis. Each State was required to document its problems in serving the mentally retarded and its intentions or inability to resolve these problems.

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

Part A of Title I of Public Law 88-164 was entitled Grants for the 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 in 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, appropriated funds to assist in the construction of clinical facilities that would provide, as nearly as possible, a complete range of inpatient and outpatient services for individuals with mental retardation. These facilities would act as demonstrations for specialized services in the 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 aspects of Public Law 88-156 and can be seen as a forerunner of the developmental disabilities program.

These two Acts did much to direct the nation's focus onto the health welfare, and livelihood of individual with mental retardation. 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 relate with these 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) were important accomplishments on behalf of the mentally retarded. The Medicare-Medicaid Act is a mechanism for Federally funded medical services for the poor, aged, and disabled. The Mental Retardation Amendments of 1967 supported part of the cost of the 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 program gained formal recognition 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 umbrella three major disability groups (mental retardation, cerebral palsy and epilepsy) and theoretically, other disabilities 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 accomplishment. The Act (Public Law 91-517) was amended in 1975 with the passage of the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103). This module will present the developmental disabilities concept by discussing the program as it exists currently under the two pieces of legislation. The 1975 amendments did not change the direction of the program, but rather enhanced the original provisions 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".

A. Definition of Developmental Disabilities

The original Act defines a "developmental disability" to mean any neurological condition closely related to mental retardation, which originated prior to age 18,

was likely to last a lifetime and represented a substantial handicap to the individual. Mental retardation, cerebral palsy and epilepsy were singled out as developmental disabilities, and any other conditions closely related to mental retardation. The Secretary of the Department of Health, Education and Welfare was empowered to name any other neurological conditions as eligible under the program. However, by 1975 the Secretary had not seen fit to name any additional disabilities as eligible under the program.

The 1975 amendments to the developmental disabilities legislation retained the requirements that the disability must originate prior to age 18, be a substantial handicap and continue for a lifetime. Mental retardation, cerebral palsy, and epilepsy were maintained while autism was included along with dyslexia (a learning disability) if it was attributable to mental retardation, cerebral palsy, epilepsy and autism. This new definition, also, maintained the requirement that developmental disabilities could be any condition which results in similar impairment of general intellectual functioning or adaptive behavior or requires treatment and services similar to those required for individuals with mental retardation.

This new definition, however, changed the Secretary's role in naming additional disabilities to be included under the program. The Secretary was required to conduct or have conducted an indepth study of the definition and make recommendations to the Congress as to whether it should be changed. The results of this study were to be reported by the Secretary to the Congress by the end of fiscal year 1977 (September 30, 1977). This timetable coincides with the timetable of the current legislative authority (PL94-103) which ends on September 30, 1978. The results of the study and the recommendations of the Secretary could be used in any attempts to re-enact the legislation for fiscal year 1979 beginning October 1, 1978.

The Secretary awarded a grant to ABT Associates, Inc., of Cambridge, Massachusetts in November, 1976. ABT Associates would staff a national

task force appointed under the Secretary's authority to study the definition. This task force was charged with analyzing the current definition, requesting recommendations from the field-at-large and recommending actions to the Secretary. At this writing the task force has completed its work and submitted two recommendations to the Secretary.

The majority report concludes that: for purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:

- 1) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- 2) is manifest before age 22;
- 3) is likely to continue indefinitely;
- 4) results in substantial functional limitations in three or more of the following areas of major life activity:
 - a. self-care,
 - b. receptive and expressive language,
 - c. learning,
 - d. mobility,
 - e. self-direction
 - f. capacity for independent living, or
 - g. economic self-sufficiency; and
- 5) reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are:
 - a. of lifelong or extended duration and
 - b. individually planned and coordinated.

The minority report reflects the basic agreement which existed among task force members concerning the elements of the recommended definition: age of onset, chronicity, severity, functional limitations, impairments, service needs and categories of diagnostic conditions. The major area of disagreement, however, was in specifications of impairments and categories of conditions. The minority report substitutes the following language for the wording "mental and physical impairment or a combination of mental and physical impairments":

"Is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy, or autism because such

condition results in similar impairment of general intellectual functioning or adaptive behavior and requires treatment and services similar to those required for such persons."

The task force has completed its work. There is no sure way to predict how the Secretary will view the two reports. Each report has its particular rationale supporting the differences in direction, therefore providing the Secretary with flexibility in deciding the issue.

This study's significance is related directly to the future direction of the program. Suffice it to say that regardless of the decision by the Secretary to recommend one report over the other or a combination of the reports the decision remains with the Congress as to which definition will stand. Advocates should realize that their state program will be affected by any change in definition and select some strategy for dealing with any change in definition.

The remaining sections of this module present the four principle aspects of the developmental disabilities program. These aspects will be discussed in term of goals and services, eligibility criteria and application process, funding and their relationships with other programs. The discussions will focus on the program as it currently exists with limited reference to variations brought about by the 1975 amendments. All sections are followed by some questions which highlight the materials presented in the section.

Worksheet--Section I

- 1) The President's Panel on Mental Retardation began in _____.
- 2) The Panel was influential in the passage of what two pieces of important legislation for the mentally retarded?
 - A. _____
 - B. _____
- 3) Which 1963 legislation enabled States to initiate comprehensive mental retardation planning on an intra-agency basis?

- 4) Name the three parts of Public Law 88-164 that affected planning and services for the mentally retarded.
 - A. _____
 - B. _____
 - C. _____
- 5) What are two pieces of legislation on behalf of the developmentally disabled?
 - A. _____
 - B. _____
- 6) What are the three qualifying characteristics in the definition of developmental disabilities?
 - A. _____
 - B. _____
 - C. _____
- 7) What are the five disabilities included in the 1975 amendments to the definition?
 - A. _____
 - B. _____
 - C. _____
 - D. _____
 - E. _____

8) When was the definitional study mandated?

9) What possible effects would a change in definition have on your State program(s)?

II. Goals and Services

This section will identify and explain the goals and services of the developmental disabilities program. To accomplish this task it is necessary to splinter the discussion into four distinct areas. 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.'s); and the
- D. Protection and Advocacy Systems.

Each aspect will be discussed separately, however, the common thought will be to demonstrate how each aspect can further the goal of establishing 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 on Developmental Disabilities. The Governor must also designate a State agency to administer the program. 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 establishing the program in State law.

The State Planning Councils are mandated to be advocates on behalf of all individuals with a developmental disability, while the State Administrating 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 Annual 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 which represent programs in the State 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's, 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 to the State Plan could be arranged 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 organizational arrangements. Unfortunately none 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 by the 1975 amendments. Second, the political and social environments of each State have their own unique effect 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 or their parents or guardian; 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 parent or guardian, who are not officers of any entity, or employees 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 by individuals with a disability in this program which has a goal to improve conditions for them. The emphasis for individuals with a disability to be members of the Council is not

decreasing the role of parents but rather encouraging individuals with a disability to advocate on their own behalf.

The category of governmental agencies representatives should consist of individuals capable of speaking on and deciding for their respective agencies. These individuals should represent the major programs in a State which concern or impact on the developmentally disabled. Such programs may include, but are not limited to: vocational rehabilitation, education, mental health, maternal and child health, crippled children's services, public assistance, medical assistance, transportation, social services 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 non-involvement of such governmental agency representatives has been the naming of a delegate by the member. This practice maintains a communication link between the agency and the Council. However, the Council is at a disadvantage without the direct involvement of the person who has authority to make commitments on behalf of the agency/program.

The final category of 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 individuals with a disability. These members should represent a cross section of the private sector in the State.

This triangle of Council membership typifies the major participants in any human services 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 mandates for services. Membership appointments are usually

staggered terms which require some reappointments or new appointments by the Governor each year. Generally Councils offer nominations to the Governor for his consideration in filling any vacant positions. Individuals who are interested in becoming Council members should inquire of the State Council as to the process for being nominated and appointed. Sometimes it is equally affective to correspond 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 bring to 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 Councils 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 so informed.

Council Staff

Public Law 94-103 mandates that the State Planning Council have adequate staff 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, 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 the Civil Service merit system of the State, i.e., classification or unclassified 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 and/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 and Activities

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

These funds may be used in four areas; administration, planning, services and construction. In the area of services, funds may 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 needs, the Developmental Disabilities program is not intended to be 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 service delivery system concept associated with this program is oriented toward the provision of grant funds to a grantee for a pilot project that in turn provides direct care services to a population specified in an approved grant application.

Therefore, to use Developmental Disabilities program funds for services, it is essential to receive a project grant. Project grants are awarded on the basis of priorities established in the annual State plan (See page 71). 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 the priority areas listed in the current State Plan.

The Council does not have the responsibility for awarding grant funds.

The 1975 amendments clearly set that responsibility on the State Agency. However, since this responsibility had been the Council's under the original Act, some Councils are still heavily involved with awarding grants. Other Councils have retained screening committees which assist State Agencies in the awards process and still others have nothing to do with awarding funds.

In this discussion concerning services, it might be beneficial to explore some potential 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. However an important consideration must be presented before this discussion continues.

Demonstration Funds

The formula grant funds available for services are not intended for general long-term support. Rather the funds are designed to be used for short-term demonstration projects. Unlike vocational rehabilitation, medicaid, or Title XX,

developmental disabilities funds are extremely limited (\$150,000 is the base grant award). Compared to generic service funds used to support the majority of human services year after year, developmental disabilities funds are for demonstration of project ideas which will satisfy a service needs areas on a short-term basis. In this manner developmental disabilities funds can be used to fill gaps identified between generic programs. For example, severely disabled individuals have been excluded from traditional vocational rehabilitation services because they could not be assessed as to their degree of employability. The nature of this problem appears to be twofold. Not only do rehabilitation counselor have inadequate training to enable them to properly assess the severely disabled, but severely disabled individuals have not had the benefit of schooling and such to enable them to demonstrate their employment potential. In attempting to resolve this difficulty some developmental disabilities funds have been used to establish prevocational training projects. These projects attempt to demonstrate to vocational rehabilitation counselors that with some preparation severely disabled individuals can be raise to a level of self actualization that will enable their employment potential to be assessed. As these projects demonstrated the value of prevocational training the next objective was to encourage vocational rehabilitation agencies to extend funding to continue this effort on behalf of the severely disabled.

This example can be cited for any number of generic services programs that find a gap in services to the developmentally disabled population. As needs (gaps) are identified developmental disabilities funds can initiate demonstration projects which if successful can prove to a generic program that an investment of funds could resolve the needs.

Community Residential Alternatives

Advocates should review the State Plan for priorities and the Design for Implementation (See Section IV) 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 that requires the State Plan to 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 use of community resources. The State Council must commit at least 10% of its funds for Fiscal Years 76, 77 and 78 toward these efforts.

Advocates should encourage the State Council and State Agency to direct their "deinstitutionalization" efforts towards establishing new community residential alternative and/or improving existing alternatives. Certainly the efforts of the Council in this area need not be exclusively the workings of the developmental disabilities program. Councils may influence other State agencies to join 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 to establish residences by providing staffing funds during the first year of the project.

Another example of how the developmental disabilities program 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 and from the nearest programs. The home does own a vehicle, but unfortunately, it is

not large enough to transport all the individuals at one time.

The Council in cooperation with a State Agency could initiate discussions with the local school department to extend existing services from urban to rural areas. The school department formulates a proposal to increase services by the establishing 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 to begin is within the next few months, so the only remaining problem concerns the transportation of individuals to and from 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, which 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 the 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 public forum for individuals with a disability, nongovernmental agencies' representatives, and State agencies' representatives. Second, the designated State Administating Agency must work

cooperatively with the State Council to accomplish the goals of the program. Third, formula grant funds are awarded to a State on the basis of an approved annual State plan and are then distributed as demonstration projects based on identified priorities documented in the State plan. Fourth, advocates are encouraged to participate in the program either as appointed members of the Council, or as conduits of data and information about conditions confronting disabled individuals (Section IV), or as applicants for grants to address an identified priority of the Council (Section III).

The next discussion will focus on the National Advisory Council on DD and the Developmental Disabilities office.

B. National Advisory Council on Developmental Disabilities :

The National Advisory Council on Services and Facilities for the Developmentally Disabled (NAC) was established by the original developmental disabilities act (Public Law 97-157) 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 development 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, the 1975 amendments expanded the NAC to 25 members. Members are divided into two categories. Sixteen appointed members including persons with a disability, and/or their parent 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 represent the major Federal/State programs which affect the developmentally disabled. They include:

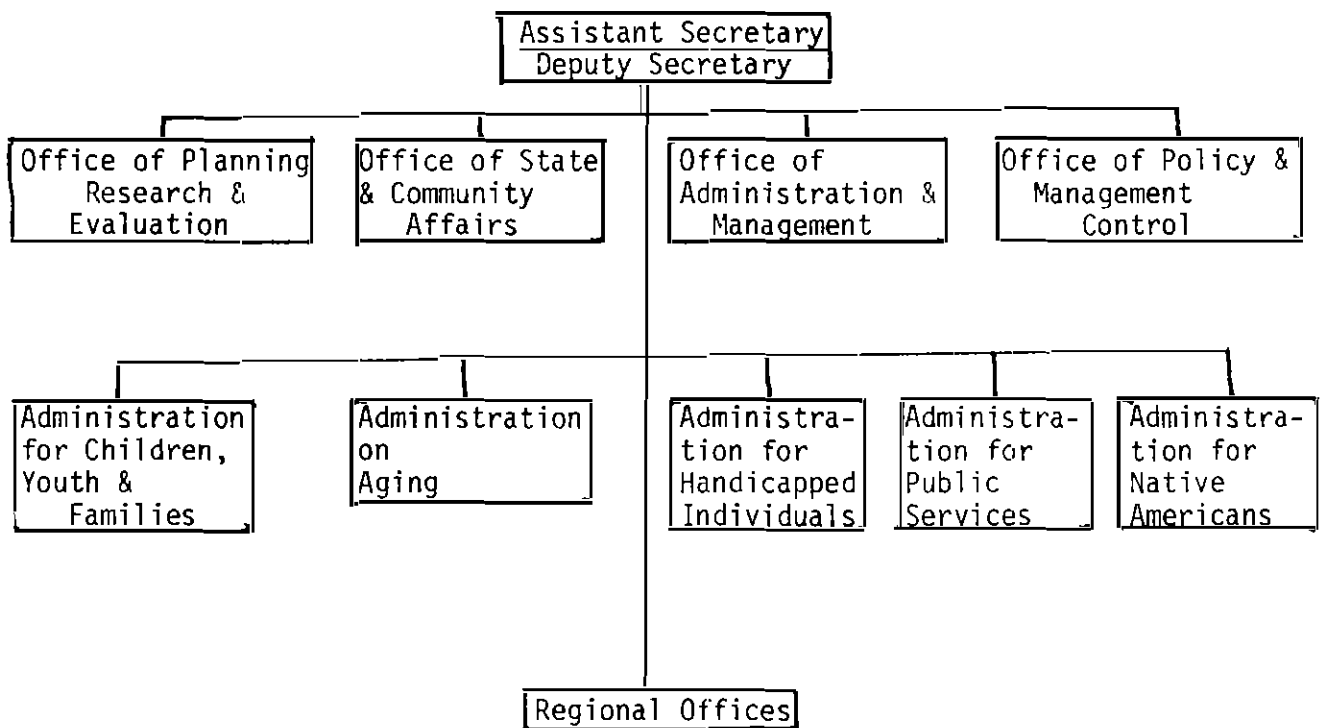
Deputy Commissioner,	Bureau of Education of Handicapped
Commissioner,	Rehabilitation Services Administration
Administrator,	Social and Rehabilitative Services
Director,	National Institute of Child Development and Human Development
Director,	National Institute of Neurological Diseases and Strokes
Director,	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 responsibility for the program to the Assistant Secretary for the Office of Human Development Services. Within this office is the Administration for Handicapped Individuals, within which is located the Developmental Disabilities Office. The DDO is the federal agency established to administer the developmental disabilities program.

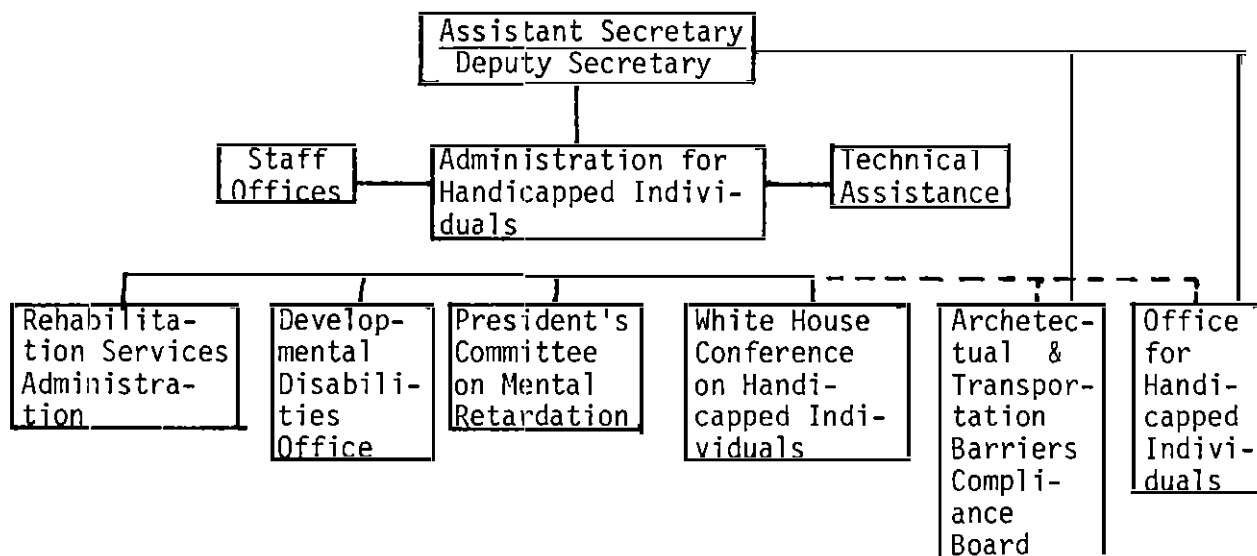
Organizational Chart: Office of Human Development Services



The Administration for Handicapped Individuals is newly formed, therefore it is difficult to state exactly what functions it will conduct. Currently programs included under this administration are functioning as they did prior to this new

reorganization. The most significant development of this Administration has been the naming of the Commissioner of Rehabilitation Services Administration (RSA) as the Administrator of this office, thereby placing Developmental Disabilities under the leadership of RSA which was the case back in 1970. The amendments to the original Act in 1975 had changed that order to place DDO equal to RSA.

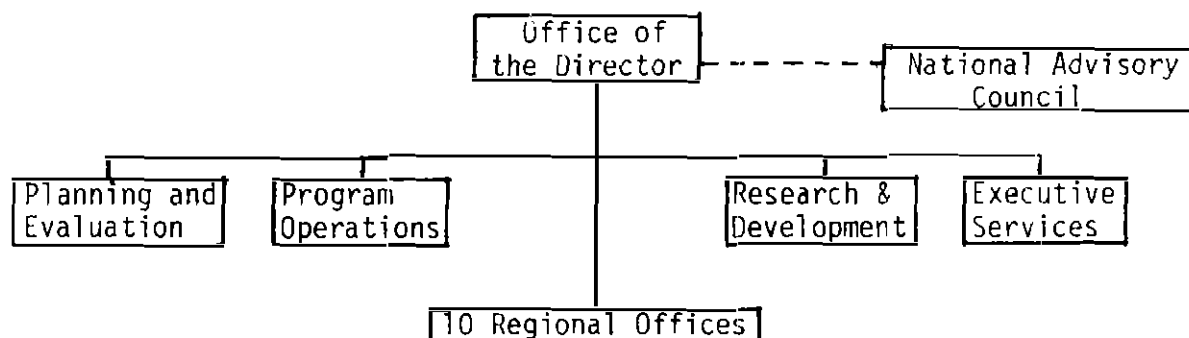
Organizational Chart: Administration for Handicapped Individuals



The Developmental Disabilities Office is responsible for two principle activities. First, the operation, management, regulation and monitoring of the overall developmental disabilities program. Second, the provision of technical assistance to the National Advisory Council as it requires to fulfill its duties and functions. This division places the Developmental Disabilities Office in a similar role to that of the state designated agency. The DDO administers the overall program including the state formula grants, the protection and advocacy program, the university affiliated facilities program and special

project funds. While, at the same time, acting as the designated agency for the National Council including staffing, funding and liaison with the Department of Health, Education and Welfare. The DDO is divided into five units to accomplish its responsibilities:

Organizational Chart: Developmental Disabilities Office



The office of the Director is responsible for the central organization of the entire office. The Director is the liaison between the office and the rest of Department of Health, Education and Welfare, therefore responsible to the Administrator for Handicapped Individuals, who in turn is responsible to the Assistant Secretary. At the same time, the Director is the Executive Secretary of the National Advisory Council. The Planning and Evaluation Division conducts analyses of the target population, the needs and resources, and prepares short-range and long-range plans. The Program Operations Division takes responsibility for the State formula grants and the protection and advocacy systems. The Research and Development Division is responsible for the special projects funds and the university affiliated facilities program. The Executive Services Division is responsible for budgets, personnel, public information and the day-to-day management of the entire program.

In addition to the central office, there exists a regional office of DDO in each of the 10 regions of the Department of Health, Education and Welfare. These offices are staffed by a director and some support staff (varying with each region). It is the responsibility of the regional director to maintain a liaison between the DDO and each State Developmental Disabilities Program, as well as, a liaison with any UAF's and special projects operating in a region. This liaison effort consists of technical assistance, information, program monitoring, fiscal reporting, and most importantly, the review and approval of annual State Plans. (See Appendix 10 for Regional offices).

Services and Activities

The Federal level is not designed for the provision of direct care services, but towards the implementation, management and accounting of the entire program. The National Advisory Council is a policy review and recommendations board that collaborates with the Developmental Disabilities Office, and therefore with the Department of Health, Education and Welfare, on the proposal of regulations and guidelines to facilitate the implementation of the program. Such regulations and guidelines concern areas like state plan requirements, the design for implementation, administration of the State Plan, employees' protection, construction programs, volunteers, roles, responsibilities and functions of the state administrating agency and the state council, just to name a few.

Besides these efforts the National Advisory Council conducts discussions and negotiations with the federal agencies which are responsible for various programs impacting the developmental disabilities population. This aspect has been strengthened in recent years particularly because of the new membership composition of the National Council. (See page 23)

The Developmental Disabilities Office has concentrated recently on the issues of state planning and monitoring of the state formula grant program. State planning has become a significant priority in that it is envisioned as the area most central to the measuring of the effectiveness of the entire program. DDO has been also investing efforts into the potentials of the university affiliated facilities' program especially since the 1975 amendments introduced the concept of satellite centers. (See page 34)

Special Projects and Projects of National Significance

There are funds authorized through Section 145 of the Developmental Disabilities Act which allows the Secretary after consultation with the National Advisory Council to make specific project grant awards 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. Each year the National Council and the Developmental Disabilities Office set priorities for the distribution of these funds. These priorities must be agreed to by the Secretary before any proposals are requested. Requests for Proposals (RFP) are published annually. These RFP's are announced in the Federal Register and circulated through the Regional DDO's and State Councils. Applicants must conform with regulations and guidelines for the preparation of the application forms and the procedure for submission, 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 the submission of the proposal to the Regional 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 are very applicable to community residential alternatives. This means that these funds could be used to demonstrate

a new type of community residential alternative or to demonstrate a process for establishing residential alternatives using new funding resources. The major idea is that the applicability of these funds depends on some demonstration aspect.

Advocates interested in these possibilities must express their ideas to the Secretary of HEW and/or the National Advisory Council, so that they could consider the rationale for establishing the use of these special project funds in that area as a priority. If the priorities do fall in line with an advocate's goals for establishing community residential alternatives, or any other areas, than careful planning will be needed to complete the required application forms. These forms are available through the State Councils or through the Regional Developmental Disabilities Offices. Completed application forms must be submitted to the Regional office

The Regional office reviews applications for technical, programmatic and budget aspects. This review is completed at the Regional office and submitted along with the application to the central office for final approval or denial.

C. University Affiliated Facilities

This concept originated with the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. (Public Law 88-164) Part B of that Act entitled Project Grants for Construction of University Affiliated Facilities for the Mental Retarded, appropriated \$5 million. These U.A.F.'s, as they became known, provided two activities. First, they were demonstration facilities for the provision of services for persons with mental retardation. Second, they conducted interdisciplinary training programs for personnel needed to render specialized services for persons with mental retardation.

The first Developmental Disabilities Act incorporated the U.A.F.'s into its program by providing funds to the U.A.F.'s to cover their administration and operation expenses. In return the U.A.F.'s were required to interface with the state Developmental Disabilities Councils on the resolution of service needs and/or the provision of technical assistance to the Councils in fulfilling their responsibilities.

Services and Activities

U.A.F.'s offer multiple services in a variety of service delivery models. Some U.A.F.'s are geared towards children or adults, although most are concerned with both population groups. The services provided include, but are not limited to:

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

There are ~~two~~ important aspects to remember about the provision of services

by a U.A.F. Not only do services cover a wide range but they are provided as a total concept by a multi-disciplinary team. This means that an individual may receive a cluster of services provided by 4 or 5 or 6 different professionals from a variety of disciplines. Such as:

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

Although U.A.F.'s have fundamentally a medical/educational base, they are becoming more and more involved with community agencies. U.A.F.'s are increasingly providing services which are followed up by community agencies. This is lending to a possible partnership between U.A.F.'s and community agencies. To further enhance this partnership is the training aspects of the U.A.F.'s.

U.A.F. Training

As mentioned above U.A.F.'s provide inter-disciplinary training for personnel required to deliver specialized services to individuals with a developmental disability. This training function requires that the professional staff of the U.A.F., who represent various disciplines, hold an academic position at the affiliated university/college. So that as the professional provides services to individuals, he/she may take the opportunity to provide instructions to students. The students enrolled in a U.A.F. must have a mix of academic and practicum training. Students have classes for a set period of time and then have practicum placements in a U.A.F. activity with supervision provided by the staff professional.

Originally training was directed towards graduate level students,

i.e., masters and doctoral students. However increasingly U.A.F.'s have expanded their training to include undergraduate and in-service students. Thus increasing the role of the U.A.F. as it interfaces with community agencies. The provision of in-service training has particularly increased the liaison between U.A.F.'s and community agencies.

Unfortunately there are only forty-six U.A.F.'s, and the vast majority of them are merely programs and not facilities. This number has created a barrier to the liaison between U.A.F.'s and Developmental Disabilities Councils and community agencies. Therefore, it has become necessary to define the role of U.A.F.'s and State Councils and community agencies. The definition of roles has centered on the ability of U.A.F.'s to respond to the multiple needs of any agency or area. It was decided that U.A.F.'s could collaborate with States in priority areas mutually identified and within fiscal and manpower resources. This arrangement is based on a needs assessment and has proved successful and yet, burdensome to accomplish.

U.A.F.'s find that demands are excessive and they easily interrupt program activities, such as service delivery and training because limited resources are being stretched beyond their intended use.

Regardless of the awkwardness of this arrangement, some very creditable accomplishments have and continue to occur at the State level. U.A.F.'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, U.A.F.'s have and continue to provide specialized direct care services to individuals 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.

These forty-six U.A.F.'s are located in thirty different states. These facilities represent a nationwide network of services, training and research. The experiences of more than a decade (1964 - 1977) have shown U.A.F.'s to be a sound concept and an effective mechanism for serving the needs of persons with a developmental disability. However there is a simple problem to consider. How is the best way to expand the U.A.S. program to better service state council, community agencies and individuals?

The Question of a Satellite

The passage of the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) recognized the fact that a U.A.F. 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 regulations, 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 U.A.F. resources to those areas either unserved or underserved by existing U.A.F.'s. The satellite center is intended to be attached to one or more U.A.F.'s who would receive supplemental funding from the Secretary of Health, Education, and Welfare for establishing and operating such a satellite center.

There have been many questions concerning the nature of the satellite centers, so it might be beneficial to discuss some of the more apparent issues that have emerged.

There are two divergent theories surrounding the definition of a satellite. Some believe that the satellite center was intended only to be a physical plant and programmatic extension of a parent U.A.F.

As such the satelliet 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 U.A.F.

The other theory suggests that a satellite center in a community unserved by a U.A.F. should be administered by itself in accord with the community, and not be a U.A.F., which has no direct 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 envolve into a multi-faceted U.A.F., thereby slowly decreasing the level of involvement of a parent which was needed during the initial years.

An Issue

This brings up a most significant issue: can a satellite center evolve into a free standing U.A.F.? This issue brings about the greatest disagreement. As stated above, one group considers the satillite center to be onlv a service extension of the parent U.A.F. 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 U.A.F. resources; which are services, training and research. If the satellite must start with

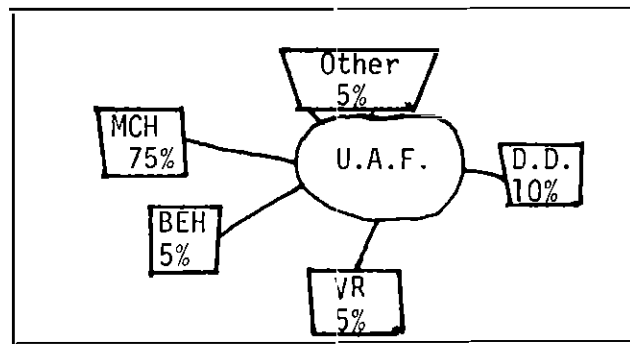
limited resources and a potential for growth that is understandable, and perhaps a wise development strategy. But ultimately the satellite center should develop in response to the needs of the community it serves. If the community needs staff training either "in-service" or "pre-service", than why couldn't the satellite center develop resources to meet this need? The alternatives would be either no one meets the additional needs, or the parent U.A.F. would have to address these needs or the development of another entity. None 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 U.A.F.'s. Reliance upon a U.A.F. 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. U.A.F.'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 U.A.F.'s receive funding from the old Maternal and Child Health funds which are administered by the Bureau of Community Health Services. On the average, most U.A.F.'s receive less than 15% funding from the developmental disabilities program which are restricted to administration and operational expenses.

In addition, the Bureau for Education of the Handicapped, vocational rehabilitation, private foundations, state and other grant funds do contribute to the U.A.F. program. (In some cases, there are large investments of State and local funds.) 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 the satellite centers seems fruitless if other funding sources

do not approve of the concept as stated in Public Law 94-103. All of these funding sources must act collectively if the satellite center concept is to become operational.

U.A.F. Funding*



(*percent of investment not intended to equal 100%)

So the fate of the satellite center concept is a serious question. Most believe that the concept will be instituted. Certainly the need for the resources has been documented over and over again. The U.A.F. 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, U.A.F.'s are a multi-faceted resource for State and local agencies and organizations. U.A.F.'s are committed to working with State Planning Councils to identify areas where U.A.F. resources can be applied. The services component of a U.A.F. may not be particularly germane to the establishment and operation of a community residential alternative. However, U.A.F.'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.

U.A.F.'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 to 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.

U.A.F.'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.

U.A.F.'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 U.A.F. in developing community services, contact the State Planning Council or the U.A.F. 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 Systems

The Developmentally Disabled Assistance and Bill of Rights Act

(Public Law 94-103) introduced a new Title II called, "Establishment and Protection of the Rights of Persons with Developmental Disabilities".

This Title II has four elements:

- Section 201 - Rights of the Developmentally Disabled;
- Section 202 - Habilitation Plans;
- Section 203 - Protection and Advocacy of Individual Rights; and
- Section 204 - Studies and Recommendations

Each section deals with a specific finding, procedure, process and study in the area of protection and advocacy of human rights for persons with developmental disabilities. The locus of these provisions clearly demonstrates Congress' intention to mandate the right to treatment, services and habilitation for persons with developmental disabilities.

The Rights of Persons with a Developmentally Disability

This section has language in it which speaks for the entire Congress and therefore for all Americans. It states that the Congress makes the following finding with respect to the rights of persons with developmental disabilities. The findings are:

1. "Persons with developmental disabilities have a right to appropriate treatment, services and habilitation for such a disability."
2. "The treatment, services and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty."
3. "The Federal Government and the States both have an obligation to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that -
 - (A) does not provide treatment, services and habilitation which is appropriate to the needs of such persons; or
 - (B) does not meet the following minimum standards:
 - a) Provision of a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program.
 - b) Provision to such persons of appropriate and sufficient medical and dental services.

- c) Prohibition of the use of physical restraints on such persons unless absolutely necessary and prohibition of the use of such restraints as a punishment or as a substitute for a habilitation program.
 - d) Prohibition on the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment or habilitation of such persons.
 - f) Permission for close relatives of such persons to visit them at reasonable hours without prior notice.
 - g) Compliance with adequate fire and safety standards as may be promulgated by the Secretary.
4. "All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable possible outcome for those served, and -
- (A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services, which are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 17, 1974, as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;
 - (B) in the case of other residential programs for persons with developmental disabilities, which assure that care is appropriate to the needs of the persons being served by such programs, assure that persons admitted to facilities of such programs are persons whose needs can be met through services provided by such facilities, - and assure that the facilities under such programs provide for the humane care of the residents, are sanitary, and protect their rights; and
 - (C) in the case of non-residential programs, which assure the care provided by such programs is appropriated to the persons served in the programs."

Essentially these findings are major areas of concern now specifically noted in legislation as the responsibility of the Federal and State Governments. The scope of this responsibility includes all programs, residential and non-residential, which receive public monies. This section does not explain how the Federal and State Government's are to implement and assure these findings. The next two sections of Title II provide these answers. First, Section 202 mandates individual habilitative plans for persons with developmental disabilities. Second, Section 203 mandates

State protection and advocacy systems for such persons. Both of these sections adequately require procedures and processes to assure the findings of Section 201.

Habilitation Plans

Section 202 requires that each State participating in the formula grant part of the program assure the Secretary of Department of Health, Education and Welfare that all persons receiving services under the formula grant funds have an individualized written habilitation plan. Furthermore, requirements include assurance that every agency, program and project funded with developmental disabilities funds provide services on the basis of written habilitation plan for each individual served.

Each habilitation plan must be written and individualized to each person's specific needs. The plan must contain a statement of the long-term habilitation goals and the intermediate habilitation objectives relating to the attainment of such goals. The objectives should be stated in sequence and be expressed in behavioral or other terms that provide measurable indices of progress. Each plan must be clear as to the objective criteria and evaluation procedure and schedule for determining the effectiveness of the plan. Specific attention during the evaluation is to be directed towards describing how the objectives were achieved with regard to the suggested strategies mentioned in the original plan.

Every plan developed for an individual involved with a developmental disabilities funded program shall be developed jointly by the person with developmental disabilities, and where appropriate, parent /advocate or guardian, and the representative of the program primarily responsible for delivering or coordinating services to the individual. The plan must attest

to the procedure for developing the plan and must name a program coordinator who will be responsible for the implementation of the plan.

This section describes the habilitation plan as containing statements of specific habilitative services to be provided, the agency or agencies to provide the services, the qualifications of staff to provide the services and finally the initiation and duration of the services. The plan is completed by indicating the role of all parties implementing the plan and the schedule for at least annual revision of the plan.

All states who want to be certified for receipt of the federal formula grant funds must comply with this requirement by giving assurances to the Secretary of DHEW as required in the Act and the regulations in their State plan. These assurances state that D.D. funds will be distributed to any agency that does not have a habilitation planning procedure for each client served.

Protection and Advocacy of Individual Rights

Section 203 contains the provisions of the Protection and Advocacy Systems now required in each State participating in the formula grant program as a provision of the State Plan. This system has been the focus of much attention since it was mandated to be in existence by October 1, 1977. The elements of the Protection and Advocacy Systems appear simplistic for State to comply with by the deadline. The provisions are that not later than October 1, 1977:

- (1) The state will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and
- (2) Such system will:
 - a) have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the State, and

- b) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities."

Two major issues surrounding these provisions concern the independence of the system and its suggested powers. Since the January 27, 1977 regulation* stated that the Governor designate the responsible agency for the system all the issues centered on the Governor of each State. The issue of independence has two sides. Government, is concerned particularly about who or what will account and control the system if the responsible agency cannot be a service provider. While the private sector is suspicious of the conflict of interest any protection and advocacy system might have if it is housed under a governmental agency. This issue has been and continues to be debated. It will take some time before an analysis can be done regarding the pros and cons of the issue.

A second issue which surfaced during the discussions about the Protection and Advocacy Systems concerned the scope of the power of the system. Governors were not enthusiastic about designating an agency to turn around and bring suit against the State. The past has seen numerous class action suit brought against States for the right to treatment. Governors were not interested in seeing these new Protection and Advocacy Systems bring additional litigation against the States.

This issue is not whether to litigate or not, but rather where is the emphasis on litigation for this system. The law states that the system must have "authority to pursue legal, administrative and other appropriate remedies....." It needed to be understood by all parties just how to decide how to pursue a remedy. Did Congress intend that legal advocacy be first priority, administrative advocacy second priority and other appropriate remedies be the last ditch efforts? Or did Congress intend appropriate remedies be the goal and

* 45CFR Part 1386.70

legal and administrative advocacy be the instruments?

Unfortunately, this debate too is continuing like the debate regarding independency of the agency. There doesn't appear to be any statical way to settle the score because too few systems are prepared to initiate remedial actions at this writing. However, it can be conjunctured that Congress's intent was closer to the later explanation. That remedies be persued where most appropriate. In translation to a policy statement it could be stated as "Advocacy action to remedy any situation under the jurisdiction of this system will be pursued at the lowest appropriate level. If a remedy can be obtained through administrative advocacy prior to court action than it is appropriate if the desired outcome is obtainable".

Currently 48 States have had their Protection and Advocacy plan approved by the central Developmental Disabilities Office. These plans were developed by a variety of governmental and non-governmental agencies. There results (plans) are the essence of the various Protection and Advocacy Systems. Advocates should obtain a copy of the State's Protection and Advocacy plan to be able to understand the system in the State. These plans are on pre-printed forms and should show consistency in format and information. Persons with developmental disabilities are encouraged to participate in the Protection and Advocacy System to help insure that the system can function with an awareness of persons with developmental disabilities.

Studies and Recommendations

This is the final section of Title II. It simply is in response to some confusion over the most appropriate standards for assure quality in service delivery. Section 204 requires the Secretary of Health, Education and Welfare to conduct or arrange to have conducted a review and evaluation of the standards

and quality assurance mechanisms applicable to residential facilities and community agencies under the Rehabilitation Act of 1965, Title XXIII, XIX and XX of the Social Security Act and any other Federal law administered by the Secretary of Department of Health, Education and Welfare. The review and evaluation is to be conducted on their effectiveness in assuring the rights of persons with developmental disabilities. In addition the review must indicate the effectiveness of these standards in insuring that services rendered are consistent with current concepts of quality care for treatment, services and rehabilitation of such persons.

This study is to recommend standards and quality assurance mechanisms based upon performance criteria for measuring and evaluating the developmental progress of a person. These recommendations are to be utilized by the Secretary to implement changes in the current standards and regulations concerning quality assurance.

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 Services

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 program services or funds. Rather, the developmental disabilities program awards grants to public and/or private nonprofit agencies and organizations, who in turn use the funds to provide direct care services to individuals and/or their families.

Agency or Organization

The criteria for any agency to receive developmental disabilities funds 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 (See Page 5) 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 developmental disabilities funds for a day care program. As a contingent of funding the agency had to describe the target population in the program. The agency has targeted the program for individuals 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 II, pages 31-33) there are multiple funding sources that must be accessed. It would be beyond this module to discuss the eligibility criteria involved for each potential 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, or private nonprofit agency or organization, however, there will be additional stipulations to consider (See definition of UAF, page 31).

UAF Satellite Center

The statute requires that 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 be a description of the kind of facility needed to meet the identified needs of the geographical area to be served. This description will influence the kind of applicants sought for the center, but most likely

the applicant will have to be a public or private nonprofit agency.

Application Process Model

The process model which follows will mirror the one most employed at the State level. There are many variations, however, the fundamentals will remain the same. This process model will also conform, with that process employed at the Federal level, although specific mention will be made of critical variations in the State and Federal processes.

Request for Proposals

When priorities are established in the State plan, the State Agency will solicit grant proposals from any nonprofit private or public agency to address any of the identified priorities. Generally the State Agency will publish newspaper advertisements called "Requests 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 be awarded a particular 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 use the RFP process, (i.e., newspaper advertisements) personal contact with the agency will insure that you are informed of the RFP's being published.

At the Federal level, RFP's are announced in the Federal Register and 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 State may publish since there is not 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 agency 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 amounts indicated in the State Plan.

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, the population(s) to be served, the content and methodology of the proposal, the personnel involved, the budget, the project monitoring and evaluation procedures, and a statement on continuation funding of the project at the conclusion of the developmental disabilities grant.

Grant writing is a process requiring preplanning in two ways. First, the program content and the methodology must be organized so that they 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 arranging the budget on a "time-line", which corresponds to the accomplishment of goals and objectives. Budget projections should coincide with projected activities. This way the expenditure of funds can be monitored according to the grant's 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. As a general practice 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, thereby, informing the funding sources when the project will actually operate.

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. In this way the problem might be addressed 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 process of identifying a grant's weaknesses and/or strengths, as they develop during the grant period. Monitoring also allows the grantee, the State agency and the council to react appropriately to these findings with strategies for implementing the grant. 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. Public Law 94-103 mandates the Council and Agency to develop evaluation tools for grants management.

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 why some were successful and others not.

In addition to the monitoring reports, the evaluation of a project usually includes a final report by the grantee giving a self-assessment on 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, 1976)

Continuation Funding

The final consideration for potential grant applications 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 and 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 not 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 Agencies fail to find ways to secure continuation funding for successful pilot projects then it should reconsider funding at all.

Conclusion

The information of this section is designed to increase the reader's programmatic understanding of how Developmental Disabilities funds can be

secured. This section indicates the fundamental grant structures used by most States, however, the actual process for any State must be identified and used by grantees 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?

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

A. _____
B. _____
C. _____

- 6) 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 to a discussion of the State plan required of each State participating in the formula grant program. Mention in Section II was given to the mutual responsibilities of the State Council and the State Agency (See page 12) for the State Plan. This discussion will focus on this mutual responsibility in specific detail. Emphasis will include suggestions about the potential role advocates can play in this State Plan process.

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 on adequate planning for services. The specific requirements number 30 and cover a broad range of areas. They are noteworthy here so that the discussion can be directed toward specific issues. A State Plan for the provision of services and facilities for persons with developmental disabilities must -

- 1) designate a State Planning Council as perscribed by law;
 - designate a State administrating agency as perscribed by law;
 - designate a single State agency for construction programs as perscribed by law,
- 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, etc.;
 - describe the needs to be met, and individuals to be served (such as type and severity of disabilities, age groups, economic status)

- describe how funds from the Act will compliment 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 in various political subdivision of the State in order to improve the quality, extent and scope of such services;
- give assurances that part of the funds available through this program will be made available to other public or nonprofit private agencies, institutions and organizations;
- 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 or to be provided in implementing the State plan;
- 6) provide that services and facilities furnished under the plan comply with standards perscribed by regulations, including standards as to the scope and quality of services and the maintenance and operation of facilities;
- 7) include provisions, meeting such requirements as the U.S. Civil Service Commission may perscribe, relating to the establishment and maintenance of personnel standards on a merit basis;
- 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 and submit appropriate modification to the Secretary;
- 10) provide that the State administrating agency will submit reports as required by the Secretary, and will keep such records and affort such access

thereto as the Secretary finds necessary to assure the corrections and verification of such reports;

- 11) provide that special financial and technical assistance be given to areas of urban or rural poverty in providing services and facilities;
- 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 prescribed by 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, however, not more than 10% of the allotment for any fiscal year maybe committed;
- 16) provide to every applicant for a construction project an opportunity for a hearing before the State agency;
- 17) provide for such fiscal control and fund accounting as maybe 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 the facility;
- 19) provide assurances that all laborers and mechanics employed in the construction project will be paid wages consistent 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 the 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 for 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 (Title 45 Code of Federal Regulations, Chapter IV, Part 410) 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.

There are three very important terms that are critical to understanding the nature of the state plan requirements as they pertain to the need for services. The terms are:

- Quality: The plan shall provide that services and facilities furnished under the State Plan for individuals with a developmental disability will be in accordance with standards set forth in section 1386.17 of the regulations.
- Extent: The plan shall identify the kinds of needs that exist, those to be met, and individuals to be served (such as type and severity of disabilities, age groups, economic status), the geographical location, distribution, and accessibility of services, and other relevant factors.
- Scope: The plan shall describe the scope of services to be provided, taking into account Federally - aided State and local programs involved, manpower, and financial resources, and other factors, directed toward the alleviation of developmental disabilities or toward the social, personal, physical or economic habilitation or rehabilitation of individuals with a disability.

These terms direct the planning effort towards substantive areas which are

linked to the questions "What good did the service delivery system do to those involved with it?" "How close to an ideal service system is the existing system?" "How many needs are served given the basic needs of the individuals with a disability?" The answers to these questions should be of utmost importance to advocates concerned about the Council and its understanding of the needs of the State developmental disabilities population.

Mutual Responsibilities

The mutual responsibilities of the State Council and the State Agency are designed to encourage cooperation between, governmental and nongovernmental the public and private sectors, all involved with service delivery for individuals with a disability. The situation creates a natural monitoring system because each one's responsibility is contingent upon activities of the other party. 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 party to the planning process. Individuals with a developmentally disability and/or their advocates and any interested individuals may participate in this planning process. Through the various steps of the plan the participation of the general public is necessary if the final product is to address the real needs of those it intends to serve. Certainly it is the intent by 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 positive involvement of disabled individuals, parents, providers, and the general public. The Council and Agency generally conduct

planning sessions which are open to the public. However, it is the responsibility of the public to take advantage of any public hearings and other opportunities to share data and information with the Council and the State Agency.

Data Collection

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

Review of State Plans

The review of all State plans which relate to programs affecting individuals with a developmental disability is a mandated responsibility of the Council (See State Plan requirement 28). The State Council must identify all the State plans affecting the disabled and develop a collaborative working 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. Basically any program operating in the State regardless of the funding source could fall under the review of the State Council. The intent is that the Council needs to familiarize itself with the State's service delivery system and all the potentials for services to individuals with a disability. Certainly this review is an extensive task, therefore, requiring some decisions by the Council regarding

which State plan it wishes to review in any given fiscal year.

The reader will recall that one category of membership for the State Council consisted of State agencies' representatives for 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 provide information and/or comments on different aspects of a State plan.

It is critical in the process to establish a good working relationship on the Council among the State agency representatives and the other members. These relationships can determine whether a meaningful and constructive exchange will exist on the Council concerning the review and comment of State plans. Without a working relationship among the members, the Council will sacrifice any natural advantage that the Council's forum could create due to its membership components. NOTE: 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 the early years of the program, the review of the state plans was informal and staggered in most States. Initially Councils were unsure of what kinds of information they should research in their review of a state plan. However, these reviews have improved in recent years since the developmental disabilities State plan guidelines have directed State to consider certain information relative to population, services, providers, resources and utilization of the program by individuals with a developmental disability.

There are, however, two factors to consider in assessing the review of State plan.

Unfamiliarity

The mandate to review all State plans affecting individuals with a disability is an original provision of the developmental disability act in 1970 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 degree of familiarity with the concept of State plans as well as a knowledge of the various federal/state programs which have state plans. Persons who have never seen a State plan are quickly confused by its regulations, format and process, regardless of the plan's content. Therefore, it is essential to become familiar, not only with the content of a particular State plan, but with the regulations, format and processes that are used to develop a State plan.

Council members have an additional challenge in fulfilling this review requirements. The Council must attempt to identify its role in this review. Members must be mindful that the review does not have along with it any approval or disapproval authority. The review should result in an increased working knowledge of what a program is or is not doing for individuals with a developmental disability. This knowledge should result in Council suggestions as to how a program could initiate, increase and/or improve services to the developmentally disabled. The Council must negotiate with a program rather than demand. The Council must cooperate with an agency rather than dictate to the agency. State agencies responsible for these various state plans are not sure what it means to participate in this Council review. Therefore the Council needs to assure State agencies that it can offer reliable and constructive comments and suggestions. At the same time the Council must

interact with the State agencies to see if they (the State agencies) are interested and committed to the improvement of services and facilities for individuals with a developmental disability.

Staff

Another facet that has affected the review of State plan is the staff to the Council. Often staff is unavailable (man hours) or is unfamiliar with any procedure which could facilitate the review.

If the Council members are unfamiliar with State plans, they naturally look to staff to fill this gap. Unfortunately, many Councils have one or two staff members dividing the entire work load. Therefore, some Councils have not conducted thorough reviews because they chose not to commit excessive staff time to the review at the expense of other things to do. The biggest contributing factor to this problem has been that some Council's staff are still writing the developmental disability State plan. This is an enormously time consuming task which is the proper responsibility of the State agency (See page 11). If Council staff are made to author the State plan then this decreases their time available for review of State plans.

In those States where staff are available to review State plans, the major problem confronting the Council is "How to review the State plan?" There have been numerous attempts to systematize and simplify the review. Some States have developed formats which give staff specific information requirement to key on during the review. This idea has been further strengthened by the information requirements of the State plan (See State plan requirements, page 59).

Regardless of the available staff, the familiarity of the Council to State plans, there are two consistent problems that must be dealt with if the review is to prove beneficial. First, State plan review of this type is not a general

practice. Therefore, State plans do not share the same requirements for information. Thus making comparisons extremely difficult. A typical problem of this sort is that not all State plan count their populations along the same definitional or demographic lines. For example, education program do not usually count the mental retarded, cerebral palsied, epileptic and autistic. Rather they might count the trainable retarded, the learning disabled, students with speech and hearing problems, etc. If the program doesn't count the developmental disabilities population than some other comparisons must be developed.

The second problem to be considered relates to the presentation of the review information to the Council members, to the State agency, to anyone else. If the prime reviewers of the State plans are staff than their presentation of their research findings to the Council can be a problem. The problem lies in how information can be presented to the Council members so they can make use of it. The special problem is that Council members must be oriented to the State plan process, information and potentials. So that the Council members can use the information creatively this orientation is critical.

Suffice it to say that this State plan review process is a difficult one to implement. Councils must press themselves to understanding State plans, regulations, formats and procedures. Councils must have an understanding of the various programs so that they can make reasonable suggestions to a program concerning services to the developmentally disabled. The Council must become increasingly educated through orientation, information analysis and consumer inputs.

Role of the General Public

It is beyond the scope of this discussion to list all the data and information that is needed to satisfy the State plan requirements. Generally, information concerning the population (age, sex, race, location, poverty levels, disabilities, degree of severity) the services (sources, match, distribution) are all vital to the State plan. The State agency and the Council will look to a variety of sources to satisfy their informational needs. One natural source of information is the general public.

The general public includes individuals with a disability, parents, guardians, advocates, providers and any interested persons. The Council and State agency will look to the general public for their information on needs, services, resources and constraints. This information is of significant importance for two reasons. First, the resulting plan will affect services to the disabled, therefore, they should participate in the plans developments if it is to better address their needs. Second, the Council and State agency will provide opportunities for the general public to make input into the plan. However, the general public must demonstrate its degree of interest by making the input. The Council and State agency will provide the opportunity, but the general public must take advantage of this situation. If they chose not to participate it doesn't change the time table by which the plan must be developed. The plan will proceed with or without input from the general public.

The role of the general public in the planning process is an important one. However, its importance can be missed if the general public fails to participate, or if the opportunities provided for this input are not really opportunities.

The direction of all this planning process, state plans review, Council and State agency activities, and general public input is towards the establishment of priorities for the coming fiscal year.

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 types: 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". A priority could be simply the drafting, negotiating and acceptance of a new policy or law. There would be no need to commit or spend funds to make this change.

Fundable priorities, however, are those needs which definitely require the specific commitment and expenditure of funds. 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 indicates 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 to the Regional office for approval. This gives the Council the opportunity to review the Design and comment to the State Agency on its proposed strategies. Some are concerned that the State 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 concentrate actions on during the fiscal year.

Others believe that the Design of Implementation represents a unique 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 priorities. It should be remembered that the State Council must agree to the plan developed by the State Agency before it can be submitted to the Regional Office. At this time the Council should seriously review the plan and begin negotiating with the State Agency for any changes they (the Council) believes should be made. The State Agency should expect the Council to question some aspects of the plan and therefore prepare for some negotiations. Through this process the Council and Agency can resolve any final problems before involving the regional office.

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 tried 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 and State agency involvement. If the State plan neglects to indicate any intentions in these areas, then advocates should present their concerns to the Council and Agency and urge that actions be taken to comply with these provisions.

There are a host of activities that could be implemented 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 and develop 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.

[illegible]

V. Funding

The fact has been established 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 of the State;
- 2) the extent of the need for services and facilities for persons with a developmental disability within the State; 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 established by the original Developmental Disabilities Act, Public Law 91-517. (See Appendix 1)

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 funds used to provide services to urban and rural poverty areas. The state can exercise several options in fulfilling the match requirements. First, the State can match the total with State (public) dollars. Second, the State can match part of the total with State dollars and then 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 Services' Grants Administration Manual (1/1/77) the definition of "in-kind contribution" means "charges 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 Federal funds to match other federal funds. The only

exceptions to this rule are community development block grant funds and general sharing funds.

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 of funds:

Developmental Disabilities: Authorizations

	<u>1976</u> Actual	<u>1977</u> Estimate	<u>1978</u> Estimate
State Grants	30,959*	33,089*	41,608*

(*figures in thousands of dollars)

Uses of Formula Grant Funds

It was already noted in Section II that Developmental Disabilities funds maybe used for administration, planning, services and construction. This division of funds must be based on each individual State program. It is generally a collaborative effort of the State Council and Agency that decides how funds will be utilized. There are two limiting factors which affect the use of funds.

First, a State may commit no more than 10% of its formula grant to construction programs. Second, a State may commit no more than 5% or \$50,000, which ever is less, to administer the program. There are no such restrictions on the use of funds for planning or services.

Fiscal Year

The federal fiscal year begins on October 1st and concludes on September 30. These dates were established by "The Congressional Budget and Impoundment Control Act of 1974". The importance of these dates is twofold. First, States must have their State plan approved prior to the start of the fiscal year or they will not receive a formula grant. Furthermore, until the plan is approved any expenses incurred may not be paid by the formula grant funds once it is received. For example, if the state plan is not approved until December 1, than once the formula grant is received, it may not be used for expenses made between October 1 and December 1.

Second, formula grant funds must be expended or committed to expenditures during the fiscal year within which the funds were awarded. Simply this means that funds awarded for the fiscal year starting October 1, must be committed or expended by September 30. Formula grants cannot be carried over the end of the fiscal year.

This does not mean that once funds are committed, i.e. awarded to a grant, that they can't then be expended past the fiscal year. In fact, this is generally the case. Although the decision was made before September 30, the grantee can expend those funds according to the grant award regardless if that is beyond the fiscal year. An important point to remember is that if by chance a grantee is unable to utilize the awarded funds for the purpose for which they were awarded and the fiscal year has ended, the State Council and Agency cannot make any additional commitment for these unused funds. They could extend the original grant so to use the remaining funds, but they could not make a new award to another grantee. This is because the fiscal year has closed.

Accounting Procedures

Each State is required to develop acceptable standard accounting

procedures for the 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.

Each State must require periodic fiscal reports from grantees. The format is determined by the State. The most practical application of this requirement is that the federal government requires each State to report quarterly on its use of Developmental Disabilities funds. Therefore most States have designed quarterly reporting for their grantees.

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 to States

Each State receiving a formula grant is allotted four quarterly grant awards which are forwarded to the State in equal amounts. These quarterly allotments can be in staggered amounts if the State plan documents that the expenditure of funds by the State is on a staggered basis. The actual transfer of funds is a slow process which requires that a State has completed the necessary accounting reports for the previous quarters. The federal government does delay the transfer of the last 10% of the formula grant until they receive final State awarding.

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)

University Affiliated Facilities:

The funds authorized for this level of the program were:

<u>U.A.F.'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 U.A.F.'s. While 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.

In 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 of 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.

The importance of this focus is to reinforce an earlier observation that Developmental Disabilities is not designed as a funding program. The comparison of funding levels with some other programs makes the point even stronger.

Authorization Levels FY76

Vocational Rehabilitation (Title I)	-	\$720,000,000.
Vocational Education (Title I)	-	422,690,000.
Social Services (Title XX)	-	\$2,393,540,000.
Medicaid (Title XIX)	-	2,200,000,000.
Developmental Disabilities	-	\$73,000,000

Advocates should realize that the generic programs are far larger than

the Developmental Disabilities program. Advocates should concern themselves with the use of Developmental Disabilities funds to stimulate the larger programs to increase their use by individuals with a developmental disability.

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 noncompliance.
- 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 continually funded by the formula grant. Compared to some of the larger programs like vocational rehabilitation, special education, and social security the developmental disabilities program is far from being a money program. (See Authorization Levels page 82). The concept is intended to stimulate and facilitate the use of generic programs, like those mentioned above, in remedying the problems that confront individuals with a developmental disability, their families, and their communities.

The philosophy behind the creation of this program was that already there exists numerous services for the disabled. Unfortunately, these services are not coordinated enough to form a comprehensive services delivery system. Individuals with a disability of certain severity or multiplicity were not being adequately served. While those with less severe disabilities were not receiving integrated services, but piecemeal or inappropriate services. Therefore, if some structure could be devised that could focus on encouraging and developing coordination among existing programs, and stimulating new programs, 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 becomes of such critical importance. Since the State plan review process is a research, analysis, and planning sequence that constitutes an investigation into the nature of a service delivery system. These State plans are legal contracts between the Federal and State agencies on how a program will be administered, what services will be provided, and who will be eligible for services. Through a review of these state plans the

Council should be equipt with valuable information considering how to initiate and coordinate services.

These reasons make the developmental disabilities program useful in stimulating cooperation among any federal programs involving disabled persons. Of particular interest is how developmental disabilities can be used to access generic services programs. Developmental Disabilities Councils can be forums for discussion leading to the initiation, expansion and improvement of services.

There are numerous examples of how generic funds can be used in cooperation with developmental disabilities funds. All the services fundable under this program can be used in cooperation with any of the programs listed under the Review of State plans (See page 65) to demonstrate service techniques, utilization and applicability.

The roles of the Council and State Agency are designed along the goal of integrating the various aspects of the generic service system. In accomplishing this goal the developmental disabilities program became the potential linking mechanism. Advocates are challenged to articulate their needs to this program and to work within the program to improve the welfare and livelihood of disabled persons.

APPENDICES

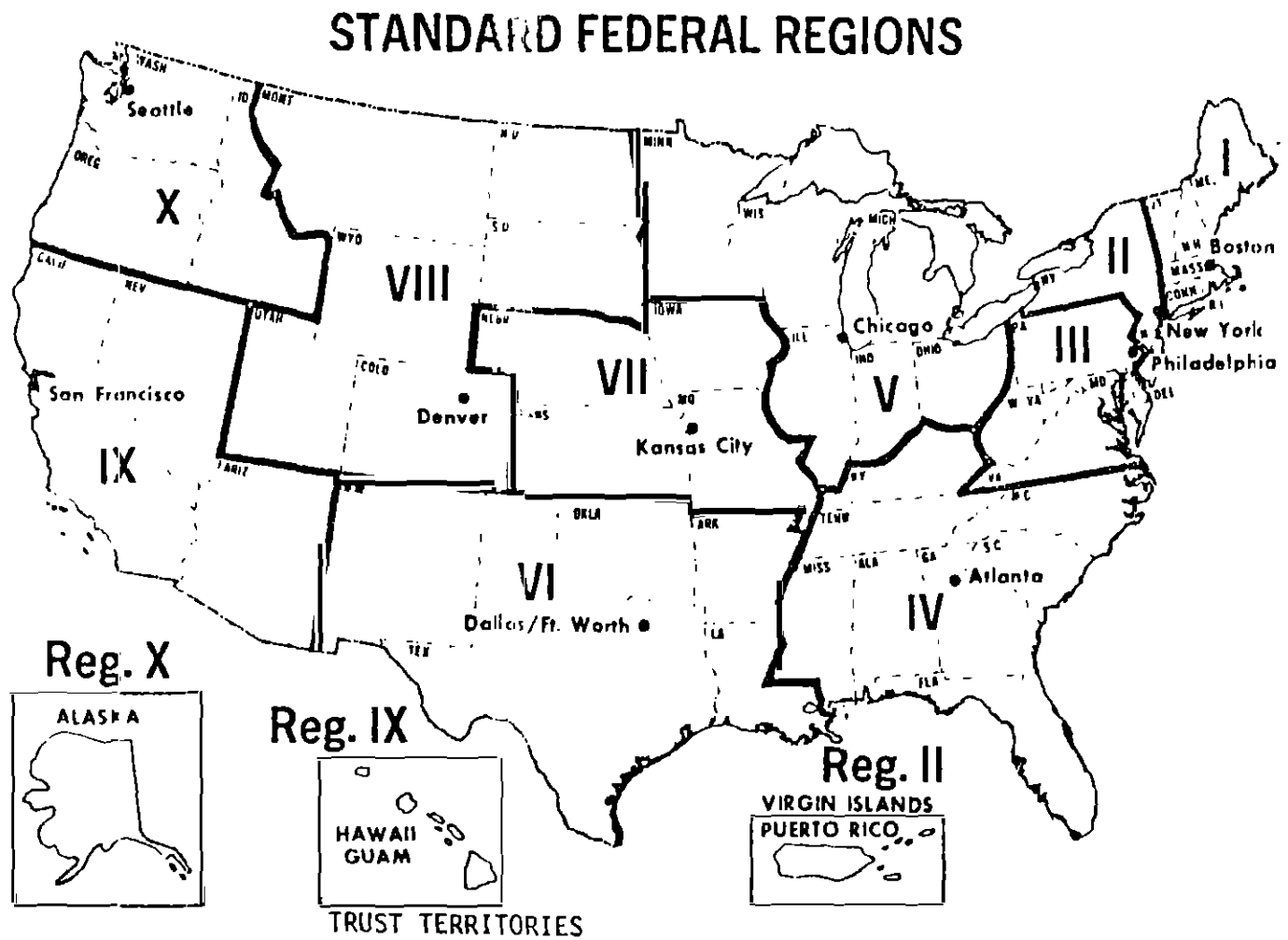
Appendix 1
 DEVELOPMENTAL DISABILITIES PROGRAM
 FISCAL YEAR 1978

	State Formula Grants	Protection and Advocacy Grants
<u>STATES</u>		
Alabama	641,472	60,491
Alaska	150,000	20,000
Arizona	277,927	26,808
Arkansas	358,926	33,999
California	2,296,014	216,907
Colorado	282,801	27,761
Connecticut	345,905	33,495
Delaware	150,000	20,000
District of Columbia	150,000	20,000
Florida	1,013,516	97,299
Georgia	713,464	69,439
Hawaii	150,000	20,000
Idaho	150,000	20,000
Illinois	1,296,855	122,020
Indiana	736,324	69,107
Iowa	424,866	37,144
Kansas	299,210	28,072
Kentucky	613,106	56,917
Louisiana	605,562	58,073
Maine	178,230	20,000
Maryland	470,757	44,175
Massachusetts	717,164	69,228
Michigan	1,173,207	109,930
Minnesota	542,290	49,581
Mississippi	440,326	42,593
Missouri	676,952	64,265
Montana	150,000	20,000
Nebraska	223,404	20,440
Nevada	150,000	20,000
New Hampshire	150,000	20,000
New Jersey	824,234	78,868
New Mexico	172,498	20,000
New York	2,124,527	209,427
North Carolina	875,460	83,582
North Dakota	150,000	20,000
Ohio	1,409,145	134,932
Oklahoma	410,037	38,833
Oregon	290,893	28,209
Pennsylvania	1,676,518	156,966
Rhode Island	150,000	20,000
South Carolina	462,382	44,872
South Dakota	150,000	20,000
Tennessee	678,845	64,600
Texas	1,612,424	155,140
Utah	173,387	20,000
Vermont	150,000	20,000
Virginia	684,380	64,196

STATE:

Washington	416,918	40,269
West Virginia	387,247	34,015
Wisconsin	667,286	61,127
Wyoming	150,000	20,000
American Samoa	50,000	20,000
Guam	50,000	20,000
Puerto Rico	713,541	67,220
Trust Territories	50,000	20,000
Virgin Islands	50,000	20,000
TOTAL	30,058,000	3,000,000

Region I John F. Kennedy Bldg. 20th Floor Boston, MA 02203 (617) 223-5746	Robert Briggs
Region II 26 Federal Plaza 38th Floor P.O. Box 602 New York, NY 10007 (212) 264-5763	John Conti
Region III 3535 Market Street Box 13716 Philadelphia, PA 19108 (215) 596-1224	Elizabeth Schoenfeld
Region IV 50 Seventh Street, NE Atlanta, GA 30323 (404) 881-2382	John Smith
Region V 300 South Wacker Drive 15th Floor Chicago, IL 60606 (312) 353-8416	Robert Vogt
Region VI 1507 Pacific 5th Floor Dallas, TX 75201 (214) 749-3574	Marvin Layne
Region VII 601 East 12th Street 3rd Floor Kansas City, MO 64106 (816) 374-5211	William Ferguson
Region VIII 9017 Federal Office Bldg. 1961 Stout Streets Denver, CO 80202 (303) 837-2135	Howard Rosen
Region IX 50 United Nations Plaza San Francisco, CA 94102 (415) 556-7774	Martha Hislop
Region X Arcade Bldg. 1321 Second Avenue (MS 622) Seattle, WA 98101 (206) 442-5462	R.S. Justice



University Affiliated Facilities

Center for Developmental and Learning Disorders

University of Alabama at Birmingham
1720 Seventh Avenue South
Birmingham, AL 35233

University Affiliated Program
Children's Hospital of Los Angeles
University of Southern California
4560 Sunset Boulevard
Los Angeles, CA 90027

University Affiliated Facility
The Neuropsychiatric Institute
Univ. of California, Los Angeles
760 Westwood Plaza
Los Angeles, CA 90024

Division of Clinical Genetics
and Developmental Disabilities
Department of Pediatrics, College
of Medicine
Univ. of California, Irvine
Irvine, CA 92664

John F. Kennedy Child Development Center
University of Colorado Medical Center
4200 East Ninth Avenue
Denver, CO 80220

Developmental Training Center
Indiana University
2853 East Tenth Street
Bloomington, IN 47401

University Hospital School
University of Iowa
Iowa City, IA 52242

Kansas University Affiliated
Facility Central Office
c/o Bureau of Child Research
University of Kansas
Lawrence, KS 66045

Mailman Center for Child Development

University of Miami
1601 N.W. 12th Avenue
P.O. Box 520006, Biscayne Annex
Miami, FL 33152

Georgia Retardation Center
4770 North Peachtree Road
Atlanta, GA 30341

Athens Unit of Georgia Retardation Center
850 College Station Road
Athens, GA 30601

Kansas University Affiliated
Facility/Parsons
Parsons State Hospital and
Training Center
2601 Gabriel
Parsons, KS 67357

Riley Child Development Center
Indiana University Medical Center
1100 West Michigan Street
Indianapolis, IN 46202

Developmental Evaluation Clinic
Children's Hospital Medical Center
300 Longwood Avenue
Boston, MA 02155

Eunice Kennedy Shriver Center for
Mental Retardation, Inc.
Walter E. Fernald State School
200 Trapelo Road
Waltham, MA 02154

Institute for the Study of Mental
Retardation and Related Disabilities
University of Michigan
130 S. First Street
Ann Arbor, MI 48108

Kansas University Affiliated
Facility/Kansas City
c/o Children's Rehabilitation Unit
Univ. of Kansas Medical Center
Rainbow Boulevard at 39th St.
Kansas City, KS 66103

Kansas University Affiliated
Facility/Lawrence
John T. Stewart Children's Center
University of Kansas
352 New Haworth Hall
Lawrence, KS 66045

Illinois Institute for Develop-
mental Disabilities
1640 West Roosevelt Road
Chicago, IL 60608

Human Development Center
University of Kentucky
Medical Annex #3
763 Rose Street
Lexington, KY 40506

John F. Kennedy Institute
Johns Hopkins University
707 North Broadway
Baltimore, MD 21205

Mental Retardation Institute
New York Medical College
Valhalla, NY 10595

Division for Disorders of
Development and Learning
The University of North Carolina
at Chapel Hill
Biological Sciences Research
Center
Chapel Hill, NC 27514

UAF Program of South Carolina
c/o Human Development Center
Winthrop College
Rock Hill, SC 29733

Center for Developmental Disabilities
University of South Carolina
503 Main Street
Columbia, SC 29208

Child Development Clinic
St. Louis University
1401 S. Grand Boulevard
St. Louis, MO 63104

University of Missouri-Columbia
University Affiliate Facility
Univ. of Missouri Medical Center
TD-4 West, Room 127
Columbia, MO 63201

Meyer Children's Rehabilitation
Institute
Univ. of Nebraska Medical Center
444 S. 44th Street
Omaha, NE 68131

Institute of Child Study
Kean College of New Jersey
Union, NJ 07083

Rose F. Kennedy Center
Albert Einstein College of Medicine
Yeshiva University
1410 Pelham Parkway South
Bronx, NY 10461

Child Development and Mental
Retardation Center
University of Washington
Weattle, WA 98195

Waisman Center on Mental
Retardation and Human Development
University of Wisconsin
2605 Marsh Lane
Madison, WI 53706

University Affiliated Program for
Child Development
Georgetown University Medical
Center
3800 Reservoir Road, N.W.
Washington, DC 20007

The Nisonger Center for Mental
Retardation
Ohio State University
1580 Cannon Drive
Columbus, OH 43210

Center on Human Development
University of Oregon
Eugene, OR 97403

Crippled Children's Division
Child Development and Rehab-
ilitation Center
University of Oregon Medical School
3181 S.W. Sam Jackson Park Road
Portland, OR 97201

Developmental Disabilities Center
Temple University
Ritter Hall Annex, 9th Floor
Philadelphia, PA 19122

St. Christopher's Hospital
2600 N. Lawrence Street
Philadelphia, PA 19133

Woodhaven Center
2900 Southampton Road
Philadelphia, PA 19154

University Affiliated Cincinnati
Center for Developmental Disorders
University of Cincinnati
Elland and Bethesda Avenues
Cincinnati, OH 45229

Developmental Disabilities Center
for Children
Louisiana State University
Medical Center
1100 Florida Avenue
New Orleans, LA 70119

University Affiliated Center
for Developmentally Disabled
Children
The University of Texas Health
Science Center at Dallas
Southwestern Medical School
Department of Pediatrics
5323 Harry Hines Blvd.
Dallas, TX 75235

Child Development Center
University of Tennessee
711 Jefferson Avenue
Memphis, TN 38105

Exceptional Child Center
Utah State University
Logan, UT 84322

University Affiliated Program
Center for Human Development
Ohio University
Administrative Annex
Athens, OH 45701

Organizational Office of UAF's

American Association of University Affiliated Programs (AAUAP)
110 17th St. N.W. Suite 908
Washington, DC 20036
Seldon Todd, Executive Director
(202) 333-7880

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WORKSHEET ANSWERS

Section I - Questions on Pages 9 and 10

- 1) 1961
- 2) A) Maternal and Child Health and Mental Retardation Planning Amendments (PL 88-156)
B) Mental Retardation Facilities and Community Mental Health Centers Construction Act (PL 88-164)
- 3) Maternal and Child Health and Mental Retardation Planning Amendments
- 4) A) Grants for the Construction of Centers for Research on Mental Retardation
B) Project Grants for Construction of U.A.F.
C) Grant for Construction of Facilities for the Mentally Retarded
- 5) A) Developmental Disabilities Services and Facilities Construction Act (PL 91-517)
B) Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103)
- 6) A) prior to age 18
B) substantial handicap
C) lasting a lifetime
- 7) A) Mental Retardation
B) Cerebral Palsy
C) Epilepsy
D) Autism
E) Dyslexia, attributable to those listed above
- 8) in PL 94-103 in 1975
- 9) Self-analysis will suffice for this answer.

WORKSHEET ANSWERS

Section II - Questions on Pages 47 and 48

- 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 him/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 Services
- 10) A) Training
B) Service
C) Research
- 11) satellite centers

WORKSHEET ANSWERS

Section III - Questions on Pages 57 and 58

- 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 - Questions on Pages 75 and 76

- 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 - Questions on Page 84

- 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, Inc., and United Cerebral Palsy Associations, Inc. as well as the National Conference on Developmental Disabilities, 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, Inc.



United
Cerebral Palsy
Associations, Inc.



National
Conference on
Developmental
Disabilities

