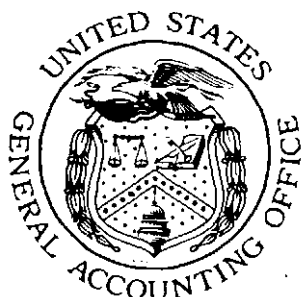


BY THE COMPTROLLER GENERAL
**Report To The Subcommittee On The
Handicapped, Senate Committee On
Labor And Human Resources**
OF THE UNITED STATES

How Federal Developmental Disabilities Programs Are Working

The Developmentally Disabled Assistance and Bill of Rights Act of 1975 supports four programs intended to directly or indirectly benefit the "developmentally disabled"-persons whose handicap is attributable to mental retardation, cerebral palsy, epilepsy, autism, or severe dyslexia and whose disability originated before age 18, is expected to continue indefinitely, and is so severe as to prevent such persons from functioning normally in society.

All four programs have problems which must be addressed by either the Congress or HEW. Some of the problems such as, the need for performance standards, regulations, and guidelines are applicable to individual programs. While others such as, the lack of monitoring and specific direction were found to exist in all four programs.



HRD-80-43

FEBRUARY 20, 1980



COMPTROLLER GENERAL OF THE UNITED STATES
WASHINGTON, D. C. 20548

B-197416

The Honorable Jennings Randolph
Chairman, Subcommittee on the
Handicapped
Committee on Labor and
Human Resources
United States Senate

Dear Mr. Chairman:

Pursuant to your June 24, 1978, request and later discussions with your office, we have made a comprehensive examination of the overall administration and operation of four developmental disability programs--State Formula Grant, State Protection and Advocacy, Special Projects, and University-Affiliated Facilities. These programs were designed to improve and coordinate services to the developmentally disabled and to protect their rights. This report describes how these programs operated during the 3-year period covered by Public Law 94-103 and discusses what the Congress and the Department of Health, Education, and Welfare should do to bring about improvements.

As requested by your office, we did not take the additional time to obtain written comments from program officials or from the Department of Health, Education, and Welfare. However, the information in this report has been discussed with Rehabilitation Services Administration officials, and their comments have been included where appropriate. Also, as agreed with your office, we are making the report available to the appropriate congressional committees, agency officials, and other interested parties.

Sincerely yours,

A handwritten signature in dark ink, which appears to read "Thomas B. Heath". The signature is written in a cursive, flowing style.

Comptroller General
of the United States

COMPTROLLER GENERAL'S
REPORT TO THE SUBCOMMITTEE
ON THE HANDICAPPED
SENATE COMMITTEE ON LABOR AND
HUMAN RESOURCES

HOW FEDERAL DEVELOPMENTAL
DISABILITIES PROGRAMS ARE
WORKING

D I G E S T

Numerous projects and activities have been funded under programs to help the "developmentally disabled," but whether these persons' conditions have been significantly bettered as a result is largely unknown.

Developmentally disabled persons, numbering approximately 2 million, have disabilities which originated before the age of 18, are expected to continue indefinitely, and constitute a substantial handicap to their ability to function normally in society. Five conditions have generally been accepted as constituting a developmental disability: mental retardation, cerebral palsy, epilepsy, autism, and severe dyslexia.

Because the Congress believed these persons were being overlooked by other disability programs, in 1975 it continued and expanded efforts to better their conditions with programs supported under the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103). Four major programs discussed in this report were intended to ameliorate their plight:

- State Formula Grant Program in which each State shares Federal funds to establish comprehensive statewide service networks to meet the needs of the developmentally disabled.
- State Protection and Advocacy Program to establish and guard their rights, assuring that they obtain quality services needed for maximum physical, psychological, and social development.

--Special Projects Program to fund projects which demonstrate new or improved techniques for delivering services and to assist in meeting their special needs.

--University-Affiliated Facilities Program to strengthen staff resources to serve these disabled persons.

For the 3 years and 3 months period Public Law 94-103 was in effect, a total of \$179 million was allocated for these four programs.

All of these programs have funded projects and activities to help the developmentally disabled. However, the Department of Health, Education, and Welfare (HEW) had not developed criteria or standards to measure program performance or made any indepth reviews of the programs for overall impact on the conditions of the persons they were meant to serve.

At the request of the Senate Subcommittee on the Handicapped, GAO examined the operation and administration of the four developmental disabilities programs and found that all the programs had problems which must be solved. The State Formula Grant Program is particularly burdened. Many of its problems are so fundamental and pervasive that major improvements are needed, beginning with a clear congressional definition of what this program should accomplish.

Although the State Protection and Advocacy Program is too new to gauge its impact, early indications are that this program offers new hope for the developmentally disabled. This program contains clout--a key ingredient that is lacking in the Formula Grant Program. Designated State agencies for this program have legal authority to push for actions and obtain services for the developmentally disabled. This enables the disabled to go outside established service delivery systems and assure that their rights are protected. However, the program also has some problems, not the least of which is lack of funds.

For the most part, the Special Projects Program is not unique or special. Contrary to program goals, many projects were strikingly similar to projects funded under the Formula Grant Program. This was particularly true of regional projects--many of which were narrowly scoped, not designed for widespread application or replication, and were providing conventional services instead of developing unique or innovative techniques for service delivery. Much of this occurred because program funds were often used to continue projects started under nondevelopmental disability programs.

The main problems with the University-Affiliated Facilities Program are that it is funded from numerous sources with no fixed pattern, has vague mission statements, and has varying and incompatible guidelines. It is a classic example of trying to serve more than one master, resulting from various supporters having different perceptions and expectations about what the program should be accomplishing.

All four programs need closer monitoring and more specific direction from HEW if they are to be effective and viable forces in improving the conditions of the developmentally disabled.

To improve the State Formula Grant Program, the Congress needs to delineate what it wants the program to accomplish. In addition, the Secretary of HEW needs to direct the Commissioner of the Rehabilitation Services Administration to

- develop uniform standards to help program administrators, State Councils, and others evaluate program performance;
- formulate standards to measure the performance of State Councils;
- encourage States to establish more effective and accountable grant review mechanisms;

- provide States with more specific guidance for reporting program expenditures;
- assure that the States develop and use appropriate monitoring and evaluation tools to assess their programs; and
- increase HEW regional monitoring and evaluation efforts.

To improve the State Protection and Advocacy Program the Secretary should direct the Commissioner of the Rehabilitation Services Administration to

- formulate specific regulations and guidelines;
- assist States in accessing other funds for their programs;
- require the States to establish a mechanism for coordinating the advocacy activities of this program with the Formula Grant Program; and
- establish standards to measure program performance.

The Secretary should also improve the Special Projects Program by requiring the Commissioner of the Rehabilitation Services Administration to

- review all projects currently being funded under this program and discontinue support to those which are not, or do not hold promise of fulfilling legislative objectives;
- fully inform the Congress on how program funds are spent and what has been accomplished;
- strengthen grant review procedures;
- increase program monitoring and evaluation, including site visits to projects; and

--establish a system to follow up on project accomplishments and dissemination of project results.

Further, the Secretary of HEW should assure that the Commissioner of the Rehabilitation Services Administration establishes goals, objectives, and performance standards for the University-Affiliated Facilities Program supported with developmental disabilities funds and periodically evaluate supported facilities.

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ABBREVIATIONS

GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
RSA	Rehabilitation Services Administration
UAF	University-Affiliated Facilities

CHAPTER 1

INTRODUCTION

The Nation's commitment to care for and attend to the problems and needs of the mentally retarded and others having related disabilities is manifested in a myriad of human service programs at the national, State, and local level. Programs providing a broad spectrum of services at each life stage are now available for this once-neglected population. Yet, segments of the disabled population still are not getting the services they need--they are not able to join the network of available services. Most vulnerable are the developmentally disabled.

THE DEVELOPMENTALLY DISABLED: WHO ARE THEY?

Developmental disabilities describes a group of handicapping conditions which often require services resembling those needed by retarded persons. Categorically, five conditions are generally accepted as constituting a developmental disability: mental retardation, cerebral palsy, epilepsy, autism, and severe dyslexia. To be considered as developmentally disabled, a person's disability must

- have originated before age 18,
- be expected to continue indefinitely, and
- represent a substantial handicap to his/her ability to function normally in society.

The Department of Health, Education, and Welfare (HEW) has estimated that 10 million people are afflicted with one or more of these disabling conditions, with mental retardation (numbering about 6 million) far outdistancing the other groups. However, to consider all 10 million to be developmentally disabled would be erroneous, since many probably do not meet the other three conditions of eligibility--especially the substantially handicapped factor.

While the actual number of developmentally disabled persons is unknown, HEW has estimated that 2 million people are developmentally disabled. Generally included are the moderately, severely, and profoundly retarded (about 10 percent of all retarded); epileptics whose seizures cannot be controlled, most cerebral palsy and autistic cases, and those suffering from severe dyslexia.

People with developmental disabilities often require special lifelong services from several agencies. Because they are more difficult and costly to serve, the developmentally disabled tend to be overlooked or excluded in the plans and programs of general and specialized service agencies.

ATTEMPTS TO PROVIDE FOR A NEGLECTED POPULATION

Although programs for the developmentally disabled have existed for decades, it was in the early 1960s that the Federal Government provided the initial impetus for a renewed emphasis on the needs of this neglected population. The first to be helped were the mentally retarded. The key legislation was the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963--Public Law 88-164.

Public Law 88-164

In 1963 the Congress created the first Federal categorical construction program for the mentally retarded. Public Law 88-164 provided Federal funds to (1) build research centers for preventing and combating mental retardation, (2) construct public or nonprofit clinical facilities (i.e., university-affiliated facilities) which would provide inpatient/outpatient services, demonstrate how specialized services could be provided, and provide clinical training for physicians and others working with the retarded, and (3) encourage States to build community facilities for the retarded.

Public Law 88-164 resulted in millions of dollars being spent and hundreds of facilities constructed to help the retarded. But there were shortcomings, such as:

1. Construction was the primary focus--few funds were available for services.
2. Services were fragmented because of a general lack of coordination among the various service programs.
3. Poverty areas where facilities and services were scarce were often neglected.
4. Operational (core) support to cover basic administrative expenses of the newly constructed university-affiliated facilities was inadequate.

5. The programs were mainly for the mentally retarded. Excluded were disability groups, such as cerebral palsy and epilepsy, which have service needs similar to those of the retarded.

Recognizing these deficiencies, the Congress amended Public Law 88-164, which expired in 1970. The result was the second landmark legislation in the history of programs for the developmentally disabled--Public Law 91-517.

Public Law 91-517

Several notable changes occurred under the new legislation, which was enacted on October 30, 1970. Construction gave way to planning and services as major areas of emphasis. The previous authority to construct community facilities was replaced by a broad new Federal/State grant-in-aid program to help States develop and implement a comprehensive plan to meet the needs of the disabled. The States' share of funds under a formula grant could be used for services, planning, administration--and to a lesser degree for construction.

The 1970 Act provided for States to commingle funds with those of other programs to develop a network of services for the disabled. With few restrictions and only broad guidelines, States were permitted great latitude in spending funds under this program.

Public Law 91-517 tried to overcome the shortcomings of the prior legislation by emphasizing coordination of services, getting services into poverty areas, and filling in existing service networks. Through separate project grants it also provided core support for the University-Affiliated Facilities Program (UAF).

The new law also broadened the target population to include cerebral palsy, epilepsy, and other neurological conditions closely related to mental retardation. A new term--developmental disability--was adopted to describe this new target group.

PUBLIC LAW 94-103; SOMETHING OLD AND SOMETHING NEW FOR THE DEVELOPMENTALLY DISABLED

The Developmentally Disabled Assistance and Bill of Rights Act, enacted in October 1975, continued support of the State Formula Grant and University-Affiliated Facilities

programs. Two new programs were added to benefit the developmentally disabled: a State Protection and Advocacy Program and a Special Projects Program.

State Formula Grant Program

More than half (54 percent) of the Federal funds under Public Law 94-103 were allocated to 50 States and 6 territories for the State Formula Grant Program. State shares under this program were to be used for planning, Administration, delivering services, and constructing facilities for the developmentally disabled. During the 3 years and 3 months Public Law 94-103 was in effect, almost \$98 million of the \$179 million allocated went for expanding and revising the State Formula Grant Program created under the prior developmental disabilities legislation.

Planning is a major priority of the State Formula Grant Program. States develop a plan for a coordinated and integrated service delivery system which is supposed to spread from the State to local levels, provide technical assistance to poverty areas, and involve agencies and consumers at all levels. The key organization in the planning process is a State Planning Council composed of members of each principal State agency, local agencies, nongovernmental organizations, and consumers. The Council acts as the strategist for developing and implementing the program. Through its approved State Plan, the Council establishes goals and priorities for developing a comprehensive network of services for the developmentally disabled, including a plan to eliminate inappropriate placements and improve the quality of care of the disabled in institutions.

Five percent (or \$50,000, whichever is less) of each State's allotment was to be used to administer the State Formula Grant Program. Here, the key organization is a designated State agency that is responsible for administering the implementation of the State Plan and assuring that program funds are properly spent and accounted for. The designated State agency selects from Council strategies the best way to achieve goals and objectives according to the State Plan.

Using program funds for constructing facilities was further discouraged under Public Law 94-103--a maximum of 10 percent could be used.

Funds could be used for a wide range of diversified services for the developmentally disabled. Funds were to be commingled with those of other programs to facilitate the development of comprehensive services. Without imposing a set pattern of services on any one State, funds were to be integrated with both specialized and generic services of several State agencies, such as health, welfare, education, and rehabilitation. Program funds were supposed to fill service gaps and expand the existing service network--not supplant already available funds. Accessing the existing service network is a fundamental tenet of the State Formula Grant Program.

The Federal share of expenditures under this program was limited to 75 percent (except in poverty areas, where it could increase to 90 percent).

State Protection and Advocacy Program

One of two new programs authorized under Public Law 94-103 is the State Protection and Advocacy Program--designed to establish and guard the rights of the developmentally disabled and assure that they have quality services needed for maximum physical, psychological, and social development. It was the smallest of the four developmental disability programs, with just under \$8 million (4 percent of all funds appropriated for the program) allocated to the States and territories during the 3-year period.

To continue receiving State Formula Grant Program funds, each State had to establish a protection and advocacy system by October 1977. Federal funds were made available to design and set up a system independent of any service-providing State agency. These systems were to be backed by legal and administrative authority. States were given much flexibility in implementing their respective systems.

University-Affiliated Facilities Program

Public Law 94-103 provided basic core support to 37 university-affiliated facilities. This \$16 million program (over the 3 years) was to assist facilities with meeting the costs of operating demonstration facilities and providing interdisciplinary training to strengthen staff resources to serve the developmentally disabled. An additional \$1 million was awarded to some facilities to initiate feasibility studies and establish satellite centers for services in areas not covered under the university-affiliated facility network.

Funding sources (such as Maternal and Child Health Services) were expected to provide the largest share of the program's resources and basically determine how a particular facility operates. The developmental disabilities program, however, expanded the role of the university-affiliated facilities beyond what was mandated by other programs. HEW guidelines encouraged facilities to

- make training and other services available for the developmentally disabled;
- serve all age groups;
- provide a wide range of training opportunities (including graduate and undergraduate programs, short-term workshops, general orientation experiences, etc.);
- develop data on service and staff needs;
- provide a setting of interdisciplinary training where various disciplines learn together and share their experiences;
- coordinate their efforts with State and local agencies to remain responsive to service needs of the developmentally disabled;
- provide technical assistance and work with State Planning Councils; and
- serve the substantially handicapped.

Special Projects Program

Public Law 91-517 allowed up to 10 percent of the State formula grant moneys to be used by HEW for projects of national significance. These projects were to demonstrate new or improved techniques for delivering services and assist with meeting the special needs of the disadvantaged developmentally disabled. Under Public Law 94-103 this authority was replaced with a new Special Projects Program which retained the projects-of-national-significance element but also added a discretionary grant authority for regional projects.

Close to \$57 million was made available under this program during the 3-year period, making it second only to the

State Formula Grant Program as the largest of the four programs under Public Law 94-103. HEW regional offices were allocated \$38 million and HEW headquarters kept the remaining \$19 million for projects of national significance. Special project funds were to go to public or nonprofit organizations to improve service quality, demonstrate established and new programs to improve services, increase public awareness about the developmentally disabled, coordinate community resources, provide technical assistance and training, and gather and disseminate information.

PROGRAM ADMINISTRATION

Administration of the four programs under Public Law 94-103 is a shared responsibility among national and State/local officials. Key organizations in the programs include HEW headquarters and regional office personnel, a National Advisory Council, State Planning Councils, Council staff, designated State agency personnel, and officials of the university-affiliated facilities.

National level

Overall program administration was the responsibility of the Developmental Disabilities Office, which was organizationally located in the Office of the Assistant Secretary for Human Development, HEW headquarters. When the law was passed in 1975, the Developmental Disabilities Office had 33 full-time staff positions--26 professional and 7 administrative/clerical. In May 1978, a reorganization reduced the staff to 16 people, of which 13 were professionals. The change also relegated the Office to a bureau status within the Rehabilitation Services Administration (RSA), one step further removed from the Assistant Secretary.

While the Developmental Disabilities Office was primarily responsible for promulgating regulations and guidelines for the developmental disabilities programs and for monitoring and evaluating these programs nationally, it relied on the 10 HEW regional offices to assist in the day-to-day administration of the programs. Developmental disabilities staff in the regional offices had remained relatively constant since Public Law 91-517. In January 1979 regional staff consisted of 31 people--including 22 professionals. This represented an average of slightly more than two professionals per regional office to administer the developmental disabilities programs.

A third key organization was the National Advisory Council on Services and Facilities for the Developmentally Disabled. The Council was created to advise HEW on regulations, to evaluate the developmental disability programs, to monitor program implementation, and to review grant applications for projects of national significance. The Council was comprised of 25 members representing major Federal agencies, State and local governments, institutions of higher learning, and organizations providing services to the disabled.

State/local level

Governor-appointed planning councils along with a council staff and a designated State agency share responsibilities for carrying out the State Formula Grant Program in each State. Planning council roles include establishing goals and objectives, identifying service gaps, setting priorities for allocating program funds, and establishing mechanisms for monitoring and evaluating the program. Councils are to employ adequate staff to help carry out their responsibilities on a day-to-day basis. Each State is also to designate an agency to provide proper and efficient administration of the program.

A second State agency appointed by the Governor is responsible for administering each State's protection and advocacy system. This agency is to be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities.

Under the University Affiliated Facilities Program the facility director and staff are responsible for program administration; technical assistance is available from HEW regional personnel.

HEW regional officials control funds and direct their share of special project funds, with little involvement at the State or local level. However, applicants for funds under the Special Projects Program were required to submit a copy of their application to the appropriate State planning council for review and comment before being approved or rejected by HEW.

SCOPE OF REVIEW

This report represents our second major effort to review the developmental disability programs. In 1974 we apprised the Senate Subcommittee on the Handicapped, Committee on Labor

and Public Welfare, of the results of our review of programs under Public Law 91-517 (the predecessor to Public Law 94-103).

Shortly before Public Law 94-103 was to expire, the Senate Subcommittee, on June 24, 1978, requested a similar review of programs under that legislation. Like our first review, this evaluation was a broad-based and comprehensive examination of the overall administration and operation of each of the four developmental disability programs. As requested, our work was directed at assessing the administration and operation of existing Federal programs and not at evaluating which Federal strategies would be most appropriate for improving the conditions of developmentally disabled individuals. Our review concerned such questions as:

- How are the programs being implemented?
- Are the programs producing desired results and achieving intended purposes?
- What modifications are needed to make the programs more effective?

Our fieldwork, conducted between October 1978 and April 1979, centered on Public Law 94-103 even though that law expired and was replaced by the current developmental disabilities legislation (Public Law 95-602) in November 1978. This report can help determine whether any changes are needed in the current programs.

We reviewed the legislation, regulations, and guidelines for the four developmental disability programs, examined numerous project files, and conducted interviews with program officials. At the Federal level, we interviewed HEW headquarters and regional officials and reviewed their program files. We met with representatives of 12 special interest groups to obtain their comments on program accomplishments and problems. (See app. I.)

Most of our efforts involved the Formula Grant, Protection and Advocacy and University-Affiliated Facilities programs in four States: Ohio, Pennsylvania, Washington, and California. We also reviewed HEW administrative activities for these programs and the Special Projects Program at headquarters and in regional offices in Regions III, V, IX, and X. Because each State may operate differently, we cannot conclude that our findings are necessarily representative of the nationwide programs. However, the funding coverage was

extensive, despite the relatively few locations visited, and we believe our findings present an accurate overview of the developmental disability programs. Appendix II shows our coverage of each program.

In reviewing the State Formula Grant Program, we (1) interviewed the Chairperson and selected members of the planning councils, the Council staff, and officials of the designated State agency, (2) reviewed and scheduled pertinent data from State records pertaining to every service project awarded by the sampled States from their fiscal years 1976-78 formula grants, (3) visited five project sites in each of the four States, reviewing project files and interviewing project officials, and (4) reviewed HEW audit reports pertaining to the Ohio and Washington formula grant programs.

We interviewed State officials for each of the four Protection and Advocacy Programs and reviewed agency records. We visited all seven university-affiliated facilities receiving core support in the selected States. In addition to determining how these grants were used, we also solicited officials' comments and reviewed facility records to ascertain program accomplishments and problems. At the national level, we interviewed officials of the National Association of University-Affiliated Programs and obtained pertinent data on the facility network.

In reviewing the Special Projects Program, we interviewed HEW officials in Washington, D.C., and selected regional offices. We also examined agency files pertaining to special projects and projects of national significance awarded during the review period.

CHAPTER 2

FUNDAMENTAL PROBLEMS HAMPER

STATE FORMULA GRANT PROGRAM

The State Formula Grant Program, largest of the four developmental disability programs, has many problems. Foremost is a basic disagreement about how to run the program; specifically, whether the program should be planning or service oriented.

Compounding the problem are other program weaknesses, such as roles and responsibilities of key organizations, the coordination of and commitment to program goals, the availability of vital planning data, the distribution and control of program funds, and the monitoring and evaluation of programs.

While some progress has been made in meeting the needs of the developmentally disabled, overall program performance was virtually impossible to measure. Standards to gauge whether the program is good or bad have not been established. Moreover, the problems identified are so fundamental and pervasive that they tend to overshadow program accomplishments.

CONFLICTING VIEWS REGARDING PROGRAM IMPLEMENTATION

The State Formula Grant Program, established about 9 years ago, has been the cornerstone for developmental disability programs. It has received over \$195 million in Federal funds since 1970 and has attained a certain prominence not shared by the other programs. Often, it is referred to as the developmental disability program--excluding the other programs. However, problems exist in how the State Formula Grant Program should be implemented. The disagreement is whether it should be a planning or a service program.

The basic goal of the State Formula Grant Program has not changed--funds received by the States are used to improve the quality, scope, and extent of services for persons with developmental disabilities. This was the program's broad mandate under Public Law 91-517, Public Law 94-103, and Public Law 95-602--the current developmental disabilities legislation. How this mandate was to be accomplished has been the center of much confusion and controversy.

In the early years of the developmental disabilities legislation the States emphasized service delivery. Funding of small, fragmented service projects to fill unmet needs

(i.e., gap filling) of the developmentally disabled was commonplace. Planning was subordinate to direct assistance. Recognizing that scarce funds could be used better if States designed comprehensive service networks, the Congress opted for a planning, advocacy, and coordination focus for the program and enacted Public Law 94-103.

Under Public Law 94-103, the major priority in the State Formula Grant Program was the development of a plan for a coordinated and integrated service-delivery system. The program was expected to use other funding sources to implement State plans. However, program funds are to be made available for direct services, although the legislation did not stipulate how much should go for services and how much should be spent on planning and related activities. It stated that funds were to be used to fill gaps in existing service structures and to expand services where needed.

The planning versus services controversy was a serious problem in at least two of the four States. In Ohio, 8 of the 11 Planning Council members interviewed said "this was a bone of contention and a barrier to successful implementation of their program." In Pennsylvania, the Executive Director of the Planning Council said that a basic disagreement between the Council staff and the State agencies regarding program focus has hindered the two from working together. Furthermore, Pennsylvania's decision to use all of its 1978 State Formula Grant funds for planning, influencing, and advocacy prompted one of the State's major disability organizations to request that the Formula Grant Program be discontinued.

Officials of 8 of 12 national special interest groups stated that the primary emphasis should be on "hands-on" 1/ services, with some planning. The National Task Force on Definition of Developmental Disabilities 2/ highlighted the planning versus services issue as a major problem in its October 1977 report to HEW. The Task Force repeatedly encountered people in the field of developmental disabilities who expressed concern about this matter. According to its

1/A term used to describe assistance or services provided directly to a person.

2/The Task Force was established to comply with section 301(b) of Public Law 94-103, which mandated that a study be conducted concerning the definition of developmental disability, and the nature and adequacy of services provided under other Federal programs for persons with disabilities not included in the definition.

report, many people view the primary mission of the State Formula Grant Program as a service provider to a targeted population. These people, while recognizing other funding sources exist that provide needed services to the disabled, were concerned that no single agency is responsible for delivering services specifically to the developmentally disabled.

The Task Force said others believe that the program should be directed to planning and advocacy, with a mandate to mobilize existing resources to take care of the developmentally disabled. Proponents of this position told the Task Force that not enough money exists in the Formula Grant Program, that the funds could be better used for other programs and to demonstrate model services which generic agencies are reluctant to support.

Officials of HEW's Developmental Disabilities Office acknowledged that a problem with program implementation existed which can be traced to imprecise and unclear congressional intent in this area. In an attempt to clarify the issue, officials of the Office contend that they have tried to convince the States that more money should be used for planning and less for services. They contend that the formula grants should be used to get the developmentally disabled into service systems used by other people. The Office's position is that program funds are not to be used to create a separate channel of funds just for the developmentally disabled since this would segregate them from others and their avenues for services. They believe the biggest payoff will come from good planning and using available resources and funds--not small, isolated service projects which temporarily fill service gaps.

As long as the developmental disabilities legislation allows funds to be spent for both planning and services, we believe that the State Formula Grant Program will continue to experience implementation problems. The new legislation (Public Law 95-602) may alleviate some confusion and controversy surrounding this issue. Under the current State Formula Grant Program, at least 65 percent of a State's allotment must be used for services. Thus, for the first time States have some specific guidance regarding the direction of their programs.

ROLES OF KEY ORGANIZATIONS UNCLEAR; WHO IS TO DO WHAT?

Managing the Formula Grant Program at the State level has been a persistent problem, with key organizations questioning and debating their functions. We observed role relationship

problems concerning who (1) prepares the State Plan, (2) sets program goals, priorities, and strategies, (3) allocates and controls program funds, (4) gathers and analyzes planning data, and (5) monitors and evaluates program performance.

Public Law 91-517 provided little guidance to Planning Councils, Council staff, and designated State agencies to carry out their respective responsibilities. Likewise, HEW regulations were ineffective in this matter. States were left on their own to determine roles and relationships among their key program organizations.

Public Law 94-103 tried to differentiate roles by directing Councils and their staffs to perform functions relating to plan approval, monitoring and evaluation, and reviewing other agencies' plans affecting the developmentally disabled; and, by inference, charging the State agencies with responsibility for administering the Formula Grant Program. While this was an improvement, the language of the law lacked specificity and key role relationships remained confused.

Comments by Council members

Our discussions with 38 members (about one-half the Planning Council members in the four States) showed that there was still confusion regarding Council, Council staff, and State agency roles. We asked each member to identify who was primarily responsible for carrying out nine major program activities in their State:

- Preparing the State Plan.
- Reviewing project applications.
- Approving projects for funding.
- Approving other program expenditures.
- Setting priorities, strategies, and goals.
- Gathering various planning data.
- Reviewing other State agency plans.
- Administering the program.
- Evaluating the program.

In Ohio, all officials could not agree on any of the nine activities. However, a majority concurred on two. Seven of the 11 members interviewed said that the State agency administers the program and seven agreed no one evaluates it. Responses to the other activities were scattered, indicating a general lack of agreement by the Council as to who does what.

Although the eight Pennsylvania Council members we interviewed concurred that priority, strategy, goal-setting, and gathering of planning data were done by the Council, their responses to the other seven activities were mixed. Four Council members cited unclear roles as a major problem to program success. The Pennsylvania Council's concern about clarifying roles and responsibilities was evident from our review of Council minutes. Many discussions centered on who should prepare the State Plan and who should monitor its implementation. In its September 1978 meeting, the Council discussed the need for the Congress to clarify roles and responsibilities and suggested sending Council staff to Washington, D.C., to help solve their dilemma.

Similar to Ohio, the 11 Council members we interviewed in Washington did not agree on any of the activities. At least half said the Council sets priorities and reviews other State plans, and the State agency administers the program. But their perceptions about who performs other major activities varied widely. Three Council members identified role clarification as a major problem to program implementation.

In California, we interviewed eight Council members, with similar results. Complete accord was reached on none of the activities, although over half the members said the Council sets priorities, evaluates the program, and approves program expenditures other than for projects. Two members cited lack of clarity about roles and responsibilities as a major deterrent to program operations.

For years the Developmental Disabilities Office has contracted for technical assistance through the Special Projects Program to help Councils carry out their responsibilities. As part of a continuing 6-year project, one grantee received over \$1.5 million under Public Law 94-103. We asked the 38 Council members whether their programs had benefited from this project. Twenty were not aware of the project. Of those who were aware of the project, four indicated that the project was useful, but could not provide specifics on how it assisted their programs; two said it was not helpful; and the others did not know if the project improved their programs.

Who controls the funds?

If there were any doubts about program officials not knowing what they were supposed to do, these were dispelled when HEW received feedback on its proposed regulations for Public Law 94-103. Most comments concerned respective roles and responsibilities of the Planning Councils, their staffs, and the designated State agencies. Many role-relationship matters were questioned, but major areas of disagreement involved developing and preparing the State plan, awarding project grants, and controlling the annual State allotment.

Who controls the funds has been a particularly troublesome and unsettling matter and varies from State to State. In Ohio, the Planning Council determined priorities and specified how its funds were spent.

In Pennsylvania, controlling program funds has been a problem between the Planning Council and the State agency. The State agency claimed the Council has no funds of its own, cannot authorize expenditures under the Formula Grant Program, and has no authority to enter into contracts (i.e., service projects). In the past, the Council, the designated State agency, and other State agencies have controlled program funds at one time or another.

In Washington, the designated State agency determined how program funds were spent, particularly which projects were funded. The Planning Council was primarily an advisory group and until recently had almost no say in selecting and awarding service grants.

In California, program funds are spent as mandated by a State law--the Lanterman Act. The Planning Council directly controls only the 25 percent allotted to it and has little authority over the balance. Most program funds, by law, are turned over to local area boards for planning and related purposes and to the designated State agency which awards service projects.

These differences in handling and controlling program funds are not necessarily bad since they provide the States with a degree of flexibility in this area. The problem is one of accountability. If Planning Councils designate priorities for spending but the designated State agency actually spends the money, who should be responsible for program funds? Public Law 94-103 did not address this matter, and it caused the States some problems.

Federal guidance too late

Even though Public Law 94-103 did not explicitly address roles and responsibilities and fund accountability, we believe many of the problems encountered by State officials could have been alleviated if HEW regulations and guidelines for the State Formula Grant Program had been prompt. HEW issued regulations for the program 16 months after Public Law 94-103 was passed, to be effective 3 months later. Program guidelines further clarifying the law and the regulations were not issued until September 1977 (almost 2 years after the legislation was enacted).

HEW regulations and guidelines clarified many of the role-relationship difficulties experienced by the Planning Councils, Council staff, and the State agencies. Regarding preparation and development of State plans, the regulations stated that Council should supervise the development of and approve the Plan, and the State agency should prepare the Plan. Regarding control over program funds, Council should not control individual grant (project) applications because it is a State agency function. The regulations clarified that Council could earmark funds to achieve specific objectives outlined in the State Plan, although day-to-day administration of the program and program funds was the responsibility of the State agency.

HEW guidelines further clarified a Council's responsibility, with assistance from its staff, for gathering planning data and reviewing other plans to enable it to set goals, priorities, and strategies. This arrangement was intended to provide the parameters for how and where program funds should be spent, which basically is the State agency's role. The guidelines also stated that the State agency is responsible for administering the program and assuring that funds are properly spent and accounted for. The monitoring and evaluation were to be shared responsibilities between the Council and State agency, with Council having overall supervision of State Plan implementation and establishing methods for monitoring and reviewing. Actual review of program activities, including evaluations of projects, was delegated to the State agency.

The current developmental disabilities legislation, Public Law 95-602, clarifies the problem concerning who should prepare the State Plan. It stipulates that this is a joint responsibility of the Planning Council and designated State agency. However, the legislation does not address the other role-relationship problems. As of November 1979, HEW had

not issued regulations or guidelines to supplement the new law. As a result, we could not determine whether these same problems will continue.

COORDINATION AND COMMITMENT
TO PROGRAM OFTEN LACKING

A fundamental tenet of the State Formula Grant Program is the development of coordinated, integrated, and comprehensive service networks to provide for the lifelong or extended needs of the developmentally disabled. State Planning Councils, responsible for developing strategies to create these networks, cannot do the job alone. Federal and State agencies responsible solely for the care of the developmentally disabled do not exist. Therefore, it is incumbent on the Planning Councils to request help from many Federal, State, and local agencies and organizations whose diverse interests and services may not specifically include the developmentally disabled, but whose resources are vital to achieving the goals of the State Formula Grant Program.

Are Planning Councils effective?

How well Planning Councils are able to obtain support and commitments from others determines whether or not they are effective. Some contend the Councils are performing well, others do not. Council members had mixed feelings about the effectiveness of their State Councils as evidenced by their responses to some questions. The following table lists responses from the 38 Council members interviewed in the four States.

<u>Question</u>	<u>Responses</u>	<u>Frequency</u>
1. Has your Council had any significant impact on influencing others to provide services to the developmentally disabled?	Yes	16
	No	15
	Don't know or no response	7
2. To what extent has public interest and expressed concern for the developmentally disabled in your State been increased as a result of the Formula Grant Program?	Little, if any	16
	Some	11
	Don't know or no response	11
3. Are the developmentally disabled receiving more and better services as a result of the Formula Grant Program?	Yes	6
	Yes, but not necessarily due to this program	17
	No	2
	Don't know or no response	13
4. Has the program resulted in better planning for the needs of the developmentally disabled?	Yes	17
	Some	7
	No	8
	Don't know or no response	6
5. How effective has your Council been in bringing together other agencies to plan and provide for the developmentally disabled?	Very effective	3
	Good to moderately effective	14
	Not effective	12
	Don't know or no response	9
6. Is enough being done by your Council and others to promote and inform people about the program and the cooperation needed to make it effective?	Yes	6
	No	28
	Don't know or no response	4
7. How successful has the program been in stimulating other agencies to take actions toward deinstitutionalization?	Very successful	2
	Moderately successful	18
	Not successful	10
	Don't know or no response	8

The table shows that Council members' perceptions vary about how well their Councils have performed key functions. They did not feel that their Councils should be commended in any area, although they rated themselves relatively high in planning and stimulating other agencies to work toward deinstitutionalization. They rated the Councils low in promoting the program and informing people about the cooperation needed to make it effective.

In discussing Council effectiveness, representatives from the 12 special interest groups interviewed generally agreed that State Planning Councils are needed. Commenting on the impact of the program on expanding and improving the quality of services to the developmentally disabled, seven representatives said that the impact has been significant, two said it has been moderate, and three said it has been small, with credit belonging to others and not the Council. With one exception, all groups said public interest and concern for the developmentally disabled has increased. Regarding the extent and quality of coordination among program officials, the consensus was that the program needed

improvements. Most representatives rated the program's coordination from fair to poor.

While concurring that Councils have had their problems, developmental disability headquarters' and regional officials generally felt that the Councils were performing well and should remain as a key element of the State Formula Grant Program. They believe systematic planning is important, and the Councils are a good mechanism to achieve this. No one else would look out for the developmentally disabled, and funds now going to the program, if taken away from the Councils, would be spread among other programs--none of which specifically target the developmentally disabled.

As part of its analyses of the 1978 State Plans, an HEW consultant noted that nearly two-thirds of the States cited lack of coordination as a major program problem. The consultant also pointed out that many Councils are not taking their coordination responsibilities seriously. The consultant's analysis indicated that nearly one-third of the Councils considered coordination unimportant, and one Council undertook coordination without involving other agencies. Nine State Councils saw no role for themselves in coordination or had no idea how to initiate or maintain it. Only one saw coordination as an implementation tool for obtaining other kinds of benefits.

In summary, the Planning Councils appear to have an erratic record of successes and failures. Some have been effective catalysts for the Formula Grant Program, others have not. The following sections discuss some problems the Councils have had to deal with.

Inadequate coordination at Federal level sets poor example for States

Councils' attempts to use and coordinate activities of a variety of health, education, rehabilitation, and other social service programs are hindered by a lack of coordination within these programs at the Federal level. Federal agencies do not set a good example for the States because they do not have an effective interagency coordinating mechanism to bind their programs together and provide an incentive for State-level coordination in the Formula Grant Program.

Councils must deal with differing State agency program regulations, standards, clientele, and reporting requirements--many of which are established and dictated at the Federal level. Often these act as built-in disincentives to the State

agencies since they have little to gain by working together. As one HEW regional official told us, other programs are not anxious to serve the developmentally disabled because the severely disabled are not "goal-makers"--they are never healed, and they do not show great signs of progress which look good in accomplishment reports.

Our work at HEW headquarters and four HEW regional offices indicated that little effort is put forth by developmental disability officials to coordinate the Formula Grant Program with other Federal programs. Furthermore, 10 of the 12 special interest groups we interviewed considered the extent and quality of coordination among Federal agencies to achieve Public Law 94-103 goals as fair or poor.

Council clout not commensurate
with its responsibilities

Charged with important responsibilities but given little authority and money, Councils have had to rely on cajoling, influencing, and encouraging others to provide for the developmentally disabled.

Throughout our review, the Council's lack of power was repeatedly cited as a major deterrent to its effectiveness. Twenty of the 38 Council members believed they did not have authority to carry out their mandates, while two others indicated they were not sure because they felt their Councils never exerted any authority. Many who felt their Councils had enough authority appeared to take a narrow view of their Council's role. Their responses frequently addressed advisory responsibilities only.

Council Executive Directors generally agreed that Councils need more power. One Director viewed this as the number one problem to program effectiveness. In another State, the Council's priority was to establish a legislative base--a law which will provide State funds to give the Council added impetus to plan, influence, and evaluate other programs for the developmentally disabled. Another Director said one of Council's most important functions is to oversee the implementation of the State Plan; however, to do the job it needs more power.

It became apparent after many interviews with Council members and other program officials that personalities, politics, and the ability of Councils to cajole and influence others to work together determined whether Councils are able to effectively carry out their coordination roles. Some

believe the Congress is unrealistic in its expectations regarding coordination, particularly the program's size compared to other major programs it is supposed to coordinate with. According to program officials, money is influential, and the State Formula Grant Program having a small amount of money has limited clout. The implications were that the program is too small to demand much respect from other programs.

Those who said Councils need more clout suggested changes should start with Council's responsibility for reviewing State plans of other major Federal/State programs. Currently, the Congress mandates that Councils review and comment on other plans "to the maximum extent feasible." In practice, this generally meant the Councils and their staffs, if they reviewed these other plans at all, were reviewing them after they had been finalized by the respective agencies. In essence, these reviews were academic since Councils had little if any input and their own plans were not coordinated efforts.

In its January 1977 regulations, HEW recognized the potential benefits to be gained by allowing Councils to review and comment on other plans before approval--stating this would enhance the Councils' planning efforts. However, HEW said such a potentially burdensome arrangement was not authorized since it might impose on other agencies whose programs do not call for this type of effort.

It seems unrealistic and probably inappropriate to expect other agencies to give Councils full authority to review their plans, except on an after-the-fact basis. Yet, if the Councils are to plan effectively for the developmentally disabled, better mechanisms will have to be developed.

Program lacks visibility

While it is difficult to make a direct correlation, we believe the relatively low profile of the State Formula Grant Program hinders coordination and commitment to the program. Not only does its small size (in funding) work to its disadvantage, but also visibility of key program organizations is not good.

At the national level, the program's stature appears to have slipped. The National Advisory Council on Services and Facilities for the Developmentally Disabled, created several years ago to advise HEW about various aspects of the developmental disability programs, was abolished by the new

legislation--Public Law 95-602. Furthermore, in May 1978 a major reorganization within HEW reduced the Developmental Disabilities Office to a bureau status and resulted in a substantial reduction in Office staff--from 33 full-time positions when Public Law 94-103 was passed, to 16 positions.

The implications of these changes are speculative at this point. On the surface, however, we see the developmental disability programs losing some visibility. More important, specific focus on the developmentally disabled as a unique target group might suffer since it appears they will be absorbed to some degree in broader rehabilitation programs under the HEW reorganization.

It is too early to say what the impact will be at the State level. In reviewing the organizational structures of the four States, we observed that the Planning Councils appeared to serve as advisers to the Governors, but did not have cabinet-level status which would enable them to affect statewide policy and action on behalf of the developmentally disabled.

In evaluating the 1978 State Plans, an HEW consultant noted that another key organization in the Formula Grant Program--the administering State agency--often lacked status in the State. HEW guidelines suggested that the administering agency be placed in an organizational position which allows it to operate at a level with other State agencies with which it and the Council must collaborate on behalf of the developmentally disabled. According to the consultant's study, the highest position the agency can occupy in State government is in the office of the Governor. Nationwide, only one administering agency occupied this position. About 30 percent of the agencies were one or less levels removed from the Governor's office, and presumably possessed authority at least equal to that of other State agencies. Most of the remaining administering agencies were at least two levels removed. This presumably placed them in a position slightly below or in some cases equal to other major agencies.

The visibility issue became more clouded where confusion existed about which of these groups--the Council or the administering agency--represented the State Formula Grant Program. In Ohio and Pennsylvania, for example, this was not evident. We noted that delineation of the roles and responsibilities of the two groups was not clear. Also, since the administering agencies were attached to one of the major

State service agencies, it was not clear which group was actually running the program. We found that Council members also were confused, as some viewed the Formula Grant Program as an adjunct to the State agency with no clear cut autonomy of its own.

Council and Council staff turnovers
are disruptive to the program

Frequent changes in Council membership and Council staff have been a disruptive force and a major factor obstructing program effectiveness in three of the four States reviewed. Only in Washington had there been a reasonable degree of stability and continuity over our 3-year review period.

Twenty-three of 27 Council members from the other three States said changes in Council staff and Council have caused problems in their programs. Some of the problems cited were:

- Old programs were indiscriminately scrapped and replaced with new programs.
- Council effectiveness suffered as active members (i.e., contributors) left.
- Program continuity suffered.
- Progress was thwarted.
- More personality conflicts resulted with new members.
- Appointment of replacements was not timely.
- Replacements were not adequately trained or versed in the ways of the Council.

During the 3 years, Ohio had two Executive Directors and two acting Executive Directors. At the close of our fieldwork, the Council was once again searching for an Executive Director. Ohio's Council also experienced a drastic change in membership in early 1978 when many were replaced or dropped, as Council size was reduced from 31 to 21 members.

Disagreements among Council, Council staff, and designated State agency officials in Pennsylvania resulted in several key people dropping their involvement with the program. In 1976 Council size was reduced from 40 to 17 members. At the close of our fieldwork, the Council was searching for a replacement for the Executive Director. These appeared to be major reasons why the Pennsylvania program was struggling.

We noted in the State Plan that one of the Council's top priorities was establishing responsibilities between itself and the State agencies. It seems this should have been accomplished long ago.

California's program also has experienced significant changes in personnel since the passage of Public Law 94-103: two reorganizations of the Council, a reorganization and re-assignment of personnel and responsibilities among the State's developmentally disabled health and welfare agencies, creation of an independent Council staff, and the resignation of the Executive Director. Council members and others told us these changes reduced the short-term effectiveness of California's program, since new people had to become familiar with the program and new working relationships had to be developed.

Council member turnover (particularly among consumer representatives) and changes in Council staff were observed as national problems by an HEW consultant. In its February 1979 report to HEW, the consultant noted that turnovers in Council membership create vacancies and inconsistent follow-through of ideas and actions. The report also said Council staff turnover hinders Council functioning and coordination.

During our review of the Special Projects Program, we found that many projects both nationally and regionally were awarded for technical assistance to Council members. An HEW official stated that one reason so many technical assistance projects are needed is because of the high turnover of Council members and the need to train new members.

Passive participation reduces Council effectiveness

The proliferation of Federal, State, and local service programs and the plethora of standards, eligibility requirements, target groups, and other administrative criteria make coordination imperative if the developmentally disabled are to be included in these programs. Public Law 94-103 recognized this by mandating that Councils include key people from all the major State agencies, as well as representatives from local and nongovernment organizations and a contingency of consumers. HEW guidelines further emphasized the importance of coordination, but also stressed that effective participation by all Council members, particularly State agency members, was vital to program success.

A study by an HEW consultant dated February 1979 concluded that States most successful in fostering coordination

were those in which agency officials in key management positions actively participated in Council activities. These Councils were successful because these people were able to make policy decisions for their agencies.

In the four States visited, Council effectiveness was impeded by what we term passive participation. While the States met the legal composition requirements and attendance at Council meetings was generally good, involvement in major Council activities by some members was poor. Even in Pennsylvania, where the Council requires State agency heads to attend all meetings, we found that this did not guarantee active participation by these members.

Our review of Council records in three of the four States (excluding Pennsylvania) showed an average attendance record of 60 to 87 percent for Council meetings. However, attendance by State agency heads was generally much lower. On an average, members from these agencies attended only 44 percent of the meetings. Frequently, they sent representatives or designees in their place. At the other extreme, consumer members went to 82 percent of the meetings. The next table summarizes our review of attendance records for Council meetings:

	<u>Ohio</u>	<u>Washington</u>	<u>California</u>	<u>Total</u>
1. Period reviewed	10/77 thru 9/78	10/76 thru 9/78	10/76 thru 9/78	
2. Number of Council meetings held	7	12	24	43
3. <u>State agency attendance</u>				
(a) Meetings attended by APPOINTED Council members	25%	34%	61%	44%
(b) Meetings attended by DESIGNEES	60%	23%	28%	34%
(c) Total meetings attended by member or designee	<u>85%</u>	<u>57%</u>	<u>89%</u>	<u>78%</u>
4. <u>Local/nongovernment attendance</u>				
(a) Meetings attended by APPOINTED Council members	69%	54%	72%	61%
(b) Meetings attended by DESIGNEES	12%	2%	--	4%
(c) Total meetings attended by member or designee	<u>81%</u>	<u>56%</u>	<u>72%</u>	<u>65%</u>
5. <u>Consumer attendance</u>				
(a) Meetings attended by APPOINTED Council members	82%	66%	89%	82%
(b) Meetings attended by DESIGNEES	--	--	--	--
(c) Total meetings attended by member or designee	<u>82%</u>	<u>66%</u>	<u>89%</u>	<u>82%</u>
6. <u>Average attendance--all members</u>				
(a) Meetings attended by APPOINTED Council members	58%	53%	79%	66%
(b) Meetings attended by DESIGNEES	25%	7%	8%	10%
(c) Meetings attended by members or designees	<u>83%</u>	<u>60%</u>	<u>87%</u>	<u>76%</u>

Fourteen of the 38 Council members we interviewed cited lack of coordination as the major barrier to successful implementation of their Formula Grant Programs. Following are some of the reasons Council members provided for the apathy and lack of commitment to their programs:

--Outside job or business pressures did not allow some members to spend much time on Council activities.

--Protection of special interest and competition among the State agencies did not provide a climate to foster coordination.

--Some consumers found it inconvenient to attend out-of-town meetings.

--Council members disagreed on program emphasis. Some, particularly the consumers, wanted direct services, while others viewed the program as planning oriented.

--Some members advocated only for their own constituents, not exclusively the developmentally disabled.

--Some members simply were disinterested and had no confidence in the Council as a vehicle for service improvement.

While it was beyond the scope of our review to delve deeply into these problems and all the ramifications on Council effectiveness, we noted that one potential danger of passivity was the possibility of a few members taking over Council functions and running the program. We do not believe this is a healthy situation.

Quality, not quantity, is more important
in consumer representation on Councils

Public Law 94-103 requires Council membership to include at least one-third consumers--persons with developmental disabilities, or their parents or guardians. The new legislation, Public Law 95-602, requires one-half the Council members to be consumers.

In discussing with program officials the adequacy of consumer representation and consumer impact on program coordination, we found that it is more important to have constructive, participating members than large numbers of consumers on the Councils. Twenty-three of the 32 Council members who voiced an opinion told us that one-third consumer representation is adequate. Officials of the Developmental Disabilities Office indicated that increasing the number of consumer members is not the answer to more effective and responsive Councils.

Because they have a more personal interest and because they tend to be more zealous in their efforts to help the disabled, consumer members can be a very influential and motivating force on Councils, according to program officials. In some respects, they can be the strongest feature of the Council because they have insights into the real world of the disabled that other members may not have. However, program officials contended that consumers can be disruptive to Council effectiveness if they get too involved in their own interests and are not responsive to the broader role expected of them.

Several Council members stated that consumer members often view their role inappropriately--that instead of advocating for the broader developmentally disabled population,

some are only concerned about their particular constituent disability groups. This point was also made in a 1977 national survey of Council member characteristics conducted by the University of North Carolina.

Program officials also had these criticisms of consumer Council members:

- Consumer involvement in the State Plan preparation is minimal.
- Consumers are generally untrained and not knowledgeable about Council operations and service networks.
- Consumers often do not have managerial and organizational skills.
- Some consumer members are so severely handicapped they are not able to perform effectively.

ARE DEVELOPMENTAL DISABILITY STATE PLANS
AN EXERCISE IN FUTILITY AND NONUTILITY?

The legislation intended State Plans to serve as Councils' planning and strategy documents for meeting the needs of the developmentally disabled. While the State Plans articulated what Councils knew about developmental disability populations, service needs, and capabilities of agencies to help the disabled, they also had substantial information gaps and did not serve as a basis for measuring program performance.

Basic to State plan preparation is the accumulation of various data requested by HEW to show the extent, quality, and scope of services provided to the developmentally disabled. With this information, together with data on the number of people in the target population, Councils should be able to identify service gaps, to develop strategies to fill unmet needs, and to apply their resources in the most effective and efficient manner.

The States reviewed gathered a tremendous amount of information, as evidenced by the size of their 1978 Plans--which ranged between more than 200 pages (California) to over 700 pages (Ohio). But how valuable this information was in identifying service gaps and providing Councils with the framework to set long-range goals, annual objectives, and priorities is questionable.

A fundamental problem with all four Plans was that the reported statistical and other data were often inaccurate, incomplete, and not a true measure of the extent, quality, and scope of services provided or not provided to the developmentally disabled. Basic to these deficiencies was the definition of the target population, particularly the term "substantially handicapped." Not only were the terms interpreted differently by States, but more important from a data-collecting standpoint, other State agencies generally did not use these terms in their programs. Therefore, the data on the numbers of developmentally disabled, services provided, and service gaps must be qualified to the extent that much of this information simply was not available and had to be estimated.

HEW lauded the Councils for their work in collecting much of the requested information. In reviewing the 1978 State Plans, an HEW consultant reported that, overall, 61 percent of the almost 300 items of information requested was reported. We question the necessity for some of the data, however. Our review showed only one-third of the requested data was explicitly required by law and/or HEW regulations. The rest was either not required (i.e., nice to know) or only implicitly required, according to the consultant's study.

A significant finding in the consultant's study was that nearly 40 percent of the States did not use their State Plan data to justify their program goals and objectives. Furthermore, only about 9 percent based their goals, objectives, and priorities on data showing service needs and gaps. Knowledge and expertise of Council members and others, along with mandates of Public Law 94-103 and implementing regulations, were the bases for program direction in many of the States--not data from the State Plans.

Executive Directors and Council members in the four States reviewed stated that preparation of these voluminous Plans was wasteful, that few people use them, and that they are not very useful for implementing and monitoring their Formula Grant Programs. One Executive Director branded much of the statistical and tabular data as useless because there was little agreement as to what constitutes a substantial handicap and information on that target population simply is not available or is incomplete.

Another Executive Director said its Council does not have sufficient data on the extent, quality, and scope of services to enable it to identify service gaps. In fact, until recently other agency State Plans had not been reviewed to get this information. Definitional and data collection problems experienced by the State's major service agencies made it impossible to obtain the required data. A committee of that State's Planning Council concluded that too much of the Council's planning was not based on factual data gathering and that the Council was setting priorities and strategies in a vacuum. To correct these problems, the Council contracted for several studies in 1978 to improve its data base.

Program officials in one of the four States considered their State Plan a meaningless document not widely used and prepared solely to meet Federal requirements. State officials placed little confidence in the statistical data collected and said their program was not aimed solely to the substantially handicapped since criteria had not been developed to define that specific a target population. In their State, the blind and the deaf were included among the developmentally disabled.

One State Plan included a statement that said the inability to collect data on the developmentally disabled and their service needs severely hampered the Council's planning efforts. The Executive Director of that State's Council said much of the required information was not available because State agencies gathered data based on their own eligibility standards and did not segregate services received by the developmentally disabled.

In questioning 38 Council members about how their Councils assess program effectiveness, only one cited the State Plan as a basis for such evaluations. Most said their Councils do not evaluate their Formula Grant Programs because they have no criteria for measuring success or failure. Apparently the Councils do not find their plans useful as a basis for assessing their programs.

IT IS DIFFICULT TO TELL HOW PROGRAM FUNDS ARE USED

HEW, responsible for overall administration and accounting of program funds, can only speculate how States are actually using their allocations because State financial reports are inaccurate, incomplete, and inconsistent. Without additional, more detailed information, HEW cannot adequately monitor the use of program funds.

Public Law 94-103 authorized States to spend their allocations for administration, planning, construction, and services. The law did not specify the types of expenses to be included in these categories, nor did it instruct the States regarding the nature, type, and frequency of financial reports to show how program funds were being used. Only three conditions were imposed on the States:

1. No more than 5 percent, or \$50,000 (whichever is less), of each allotment could be spent on administration of the program.
2. No more than 10 percent could be used for construction.
3. At least 10 percent of the fiscal year 1976 allotment and 30 percent of the fiscal year 1977 and 1978 allotments were to be used for deinstitutionalization activities--i.e., eliminating inappropriate placements in institutions or improving conditions of those appropriately placed in institutions.

HEW monitors expenditures and controls funds through financial status reports, which are required to be submitted by each State each quarter. These reports list program expenditures and obligations by the four major expense categories cited in the legislation. Some States use a fifth category (deinstitutionalization) to identify how much they spent for this legislative-mandated activity. In most instances, however, expenditures under this category fell under the category of services, so this is how we treated these costs. The next table shows reported expenditures and obligations by the four States during the 3-year review period.

<u>State</u>	<u>Expense category</u>	<u>FY 1976</u>	<u>FY 1977</u>	<u>FY 1978</u>	<u>Total for 3 years</u>	<u>Percent</u>
Ohio	Administration	\$ 117,391	\$ 128,669	\$ 16,650	\$ 262,710	6
	Planning	22,812	16,301	181,095	220,208	5
	Services	1,626,198	1,270,859	1,217,096	4,114,153	89
	Construction	-	-	-	-	-
	Total	<u>\$1,766,401</u>	<u>\$1,415,829</u>	<u>\$1,414,841</u>	<u>\$ 4,597,071</u>	<u>100</u>
Pennsylvania	Administration	\$ 125,877	\$ 50,000	\$ 46,955	\$ 222,832	4
	Planning	298,389	265,400	357,431	921,220	17
	Services	1,517,174	1,233,221	1,278,909	4,029,304	74
	Construction	160,121	135,850	-	295,971	5
	Total	<u>\$2,101,561</u>	<u>\$1,684,471</u>	<u>\$1,683,295</u>	<u>\$ 5,469,327</u>	<u>100</u>
Washington	Administration	\$ -	\$ 6,682	\$ -	\$ 6,682	1
	Planning	58,897	74,713	103,095	236,705	18
	Services	410,758	282,714	274,508	967,980	72
	Construction	40,000	41,322	41,000	122,322	9
	Total	<u>\$ 509,655</u>	<u>\$ 405,431</u>	<u>\$ 418,603</u>	<u>\$ 1,333,689</u>	<u>100</u>
California	Administration	\$ 455,416	\$ 301,317	\$ -	\$ 756,733	10
	Planning	1,118,540	495,437	514,710	2,128,687	29
	Services	1,071,224	1,364,860	1,619,501	4,055,585	54
	Construction	-	-	-	-	-
	Unobligated (note a)	244,850	150,414	161,803	557,067	7
	Total	<u>\$2,890,030</u>	<u>\$2,312,028</u>	<u>\$2,296,014</u>	<u>\$ 7,498,072</u>	<u>100</u>
Four-State total	Administration	\$ 698,684	\$ 486,668	\$ 63,605	\$ 1,248,957	7
	Planning	1,498,638	851,851	1,156,331	3,506,820	18
	Services	4,624,354	4,151,654	4,390,014	13,167,022	70
	Construction	200,121	177,172	41,000	418,293	2
	Unobligated	244,850	150,414	161,803	557,067	3
	Grand Total	<u>\$7,266,647</u>	<u>\$5,817,759</u>	<u>\$5,812,753</u>	<u>\$18,898,159</u>	<u>100</u>

a/The unobligated funds shown for California represent moneys reported as not used and reverting back to the Federal Treasury. Subsequent to the completion of our fieldwork, State officials told us that only \$58,463 of the fiscal year 1978 amount was actually returned, that the other \$103,340 has been obligated. We did not determine how this amount was prorated among the four categories.

The quarterly reports did not call for any further details on program expenditures. Essentially, the data in the table were all HEW had regarding how funds were spent. After analyzing the reported data of the four States, we determined that the financial data, at best, outlined program expenditures, but could be misleading if taken at face value.

Administration expenses

States did not uniformly report administration costs. There were two reasons for this: (1) the 5-percent-or-\$50,000 limitation was ignored and (2) HEW guidance regarding what should or should not be included under the expense categories was not available during the first 2 years.

As the table on page 33 shows, three of the four States reported administration expenses in excess of the limitation for at least 1 or 2 years. Over the 3-year period administration expenses amounted to 7 percent of the allotments for the four States. While HEW guidelines specifying types of expenses allowed or not allowed were not issued until September 1977, this was no excuse for exceeding the limit. The limitations were clearly stipulated in the law.

The problem was basically one of misinterpretation and a resultant misclassification of planning expenses as administration. Ohio and Pennsylvania, for example, included salaries and benefits of Council staff as administration costs. California officials could not tell us why over \$750,000 was categorized as administration during the first 2 years. One reason they gave was that fiscal accounting procedures changed three times during the period and the people in charge may have inconsistently classified expenditures under the program. In our limited review, we noted that two planning-and-resource-development-type projects totaling \$69,106 were inappropriately charged to administration.

By 1978, all four States were properly classifying administration expenses as costs associated with the designated State agency to operate the Formula Grant Program.

Planning expenses

HEW guidelines interpret planning to entail all expenditures related to Council activities, including efforts by other planning groups such as regional boards. We found that States did not uniformly apply this criteria for their planning expenses. As mentioned, some planning expenses were understated by amounts improperly designated as administration. We did not make the in-depth analysis of State records that would be needed to determine exactly how much was misclassified.

However, to get an inkling of how much the States actually spent or obligated for planning, we arbitrarily reduced all the overstated administration costs to the \$50,000 limit and put the balance in planning. The adjusted figures, not shown in the table on page 33, indicate the four States allocated between 8 percent and 37 percent of their program funds for planning; the average for the four States was 23 percent. While probably not precise, we believe these revised planning figures better show how program funds were actually used.

On the surface, California apparently spent a proportionately higher portion of its Federal funds on planning than the other States--particularly Ohio, which reported an average of 5 percent compared to California's 29 percent. Our review of the types of expenditures charged to planning showed this is misleading. Inconsistencies between what was considered as planning by Ohio versus what California called planning accounted for much of the disparity.

Ohio's planning expenses essentially consisted of Council staff salaries and benefits, plus miscellaneous Council costs, such as travel and lodging for Council meetings. California included not only these costs but also substantial amounts to support the operations of 13 area planning boards located throughout the State. For example, almost \$900,000 of California's fiscal year 1976 planning expenses were expenses of these area boards. Also included in California's planning figures were numerous Council-awarded projects totaling over \$250,000 for the 3-year period. Similar expenses in Ohio were classified as services.

The reported data were also misleading for trend analyses. California is a good example. The reported information indicated that, over the 3-year period, planning was deemphasized and more money was put into services. However, inconsistencies in the way the data were reported accounted for these discrepancies. In 1976 California categorized area board expenses as planning, but in 1978 these expenses were listed as services. California's reported expenses are misleading, and any conclusions drawn from their data would be invalid because uniform criteria was not applied to the expense categories over the 3-year period.

Similar reporting inconsistencies existed in the other States. But inconsistencies were only one factor explaining variances among the States and differences in reported expenses in individual States. To identify all contributing factors of the reporting discrepancies and to arrive at accurate figures for planning and other expenses would require a detailed financial audit. This was beyond the scope of our review.

Construction expenses

Categorizing expenditures for construction resulted in no reporting problems. As the table on page 33 shows, the States allocated very little of their Federal funds to construction. Overall, only 2 percent of the program funds received by the four States went for construction--well below the 10-percent

legislative limit. Washington, which applied an average of 9 percent of its funds for construction, appeared to have gone over the 10-percent limit in fiscal year 1977, but we attributed this to reporting errors.

Services

HEW regulations stipulated that States must make part of their annual allotments available to other public and non-profit agencies, institutions, and organizations to improve the quality, extent, and scope of services to the developmentally disabled. Although neither the law nor HEW set a minimum or maximum for services, the 10- and 30-percent requirement relating to deinstitutionalization could be construed as a restriction on how service moneys should be spent. (See p. 32.) In practice, however, we found that this restriction was academic--States merely identified a portion of their service expenditures as deinstitutionalization. As a result, all four States met the requirement.

This restriction was meaningless since no criteria was established by HEW to specify what should be considered deinstitutionalization. Just about anything which sought to improve services could, theoretically, be termed deinstitutionalization. Further, neither HEW nor the States accumulated data showing how many developmentally disabled were deinstitutionalized as a result of the Formula Grant Program. The new legislation does not have this requirement.

The table on page 33 shows that all four States reviewed allocated at least half their formula grant allotments to services, with three showing over 70 percent of their Federal funds in this category. The national average was 68 percent for services, according to a Developmental Disability Office report.

In all four States the term "services" in the financial reports meant projects or subgrants awarded to public and non-profit groups and organizations designed to meet a myriad of goals and objectives set out in the State Plans. What the reports did not show, however, were the types of projects funded and what project funds were used for. Information on types of projects was particularly important since, on the surface, the reported financial data appeared to be inconsistent with the primary intent of the Formula Grant Program. With most funds going for services, the implication was that the States were running service-oriented programs, contrary to the planning emphasis intended by the law. Our review showed that this was not entirely true.

Types of projects

To better understand how much reported services directly benefited the developmentally disabled, we reviewed State records for projects awarded during the 3 years. For the sake of analysis, we classified projects as either direct or indirect service. Direct service projects were those providing identifiable "hands-on" services to people, regardless of the number of people served. Indirect services included planning, model building, and resource-development-type projects in which "hands-on" services were not provided or intended and immediate benefits to the developmentally disabled were not in evidence. Some projects were a combination of direct and indirect services--e.g., the primary purpose was model building but some people were given "hands-on" services. We classified these as direct service projects.

Of the \$13.1 million reported as services by the four States, \$4.9 million (38 percent) went to projects we classified as indirect. We believe this is a conservative estimate, for two reasons. First, the criteria we applied to the combination direct/indirect service projects overstated the number of projects and amounts actually going for direct services. In Ohio, for instance, 16 of the 93 projects, totaling \$1.2 million (29 percent of the total project dollars) were combination projects--all of which we categorized as direct services. Second, California included several projects in its planning figures. Thus, our data for that State's indirect service projects are understated because, had we reviewed these projects, we probably would have classified most, if not all, of them as indirect services. As a result, California had the smallest percentage of indirect service dollars--17 percent--compared to Washington's 61 percent, Pennsylvania's 51 percent, and Ohio's 38 percent. The following table summarizes the results of our analysis of direct and indirect service projects in the four States.

State	Program funds awarded	Projects awarded	Direct service projects				Indirect service projects			
			Funds	Percent	Number	Percent	Funds	Percent	Number	Percent
Ohio	\$ 4,114,153	93	\$2,538,513	62	58	62	\$1,575,640	38	35	38
Pennsylvania	4,029,304	88	1,962,888	49	45	51	2,066,416	51	43	49
Washington	967,980	60	381,025	39	24	40	586,955	61	36	60
California	<u>3,960,924</u>	<u>113</u>	<u>3,271,123</u>	83	<u>87</u>	77	<u>689,801</u>	17	<u>26</u>	23
Total	<u>\$13,072,361</u>	<u>354</u>	<u>\$8,153,549</u>	a/62	<u>214</u>	a/60	<u>\$4,918,812</u>	a/38	<u>140</u>	a/40

a/Average.

Note: As shown in the table on page 33, California reported \$4,055,585 for services over the 3-year period. In reviewing State projects files, we could account for \$3,960,924--\$94,661 less than what was reported. This explains why the total figure for the four States (\$13,072,361) does not agree with the total services figure shown in the table on page 33.

Project expenditures

State financial reports submitted to HEW provided no specifics on what service funds were used for. We found that a substantial portion was used for salaries of project personnel--63 percent, according to our analyses of available data in the project records. The next table summarizes our analysis of project costs by major expense categories:

Expense category	Ohio	Pennsylvania	Washington	California	Total	Percent
Salaries	\$2,242,363	\$2,648,510	\$589,952	\$1,682,862	\$ 7,163,687	63
Travel	141,748	125,850	45,303	142,149	455,050	4
Overhead	115,848	43,917	35,669	150,248	345,682	3
Rent, equipment, and supplies	740,614	368,165	138,867	261,010	1,508,656	13
Consultant fees	475,027	164,401	95,807	81,202	816,437	7
Other (note a)	128,781	575,461	62,382	25,152	791,776	7
Not spent (note b)	<u>269,772</u>	<u>103,000</u>	<u>---</u>	<u>---</u>	<u>372,772</u>	<u>3</u>
Total	<u>\$4,114,153</u>	<u>\$4,029,304</u>	<u>\$967,980</u>	<u>\$2,342,623</u>	<u>c/\$11,454,060</u>	<u>100</u>

a/Project records in all four States had insufficient information to show a complete account of what was included in the "other" category. From the information that was available, we determined that these expenses included such things as printing, postage, legal fees, telephone, and duplication charges.

b/The figures shown for the "not spent" category represent funds not used by the grantees. These were either returned to the State or left with the grantees. We would have had to perform a financial audit to determine exact amounts left and returned.

c/Reported services expenses shown on page 33 were \$13,167,022 for the four States. This is \$1,712,962 higher than the total service expenses shown above (\$11,454,060). Because fiscal year 1978 expenses for California were not available at the time of our fieldwork and California project records for fiscal year 1976 and 1977 projects were incomplete, we were not able to analyze the total service costs (\$4,055,585) for California's projects.

Our analysis showed that, overall, 58 percent of the salaries were paid to coordinators, administrators, project directors, secretaries, bookkeepers, and other personnel who normally would not provide "hands-on" services. The salary expenses for these types ranged from 46 to 65 percent in the four States.

While the large number of indirect service projects partially explains why salary expenses for indirect service personnel were so high, we also found numerous direct service projects supporting people not providing "hands-on" services. Of the 214 direct service projects awarded by the four States, salary data were available for 167 projects. (See table on p. 38.) Our analysis showed that 100 (60 percent) of these direct service projects were supporting salary costs of indirect service personnel from formula grant funds. We determined that 775 people with salaries totaling \$3.9 million were employed under the 167 direct service projects. Indirect service personnel numbered 226, with salaries totaling \$1.2 million--almost one-third of the total outlay for salaries under direct service projects.

QUESTIONABLE PRACTICES IN AWARDING SERVICE PROJECTS

Our review in the four States disclosed several questionable practices in the review and approval of project grants. These related to:

- Council input to project selection.
- Sufficiency of controls regarding conflicts of interest, duplication, competition, and client eligibility.
- Non-Federal matching requirements.
- Dispersion of projects.
- Disability groups served.
- Poverty area projects.
- Grantee assurances regarding affirmative action and individual habilitation plans.
- Appeal mechanisms.

Council input to project selection

State Planning Councils are responsible for monitoring and evaluating the implementation of their State Plans. Since much of that implementation involves service projects, we believe the Councils should be familiar with how projects are selected. This is not to suggest that Councils make the awards, since HEW clearly assigns this responsibility to the designated State agency. As a minimum, however, Councils should have adequate assurances that grant review and approval procedures result in the selection of projects which best meet Council goals and priorities.

We found that Councils' input to project selection generally ended once they had established goals, objectives, and priorities--through the State Plan. While some Council members participated in the grant review process by virtue of their membership on review panels, the Councils as a whole generally divorced themselves from these proceedings.

Through interviews with Council members, we found many either did not know how projects were awarded or did not agree on the methodology used. Some said awards were made on a "buddy system," or were given to grantees that prepared the most complete application package. Others said grantees with previous program experience got the awards. Seventeen (some from each State) of the 38 Council members interviewed said they simply did not know how projects were awarded or what criteria was applied. Very few said that only those projects which were in concert with State Plan goals and objectives were the ones receiving grants.

Sufficiency of controls

The States' systems for reviewing and approving projects generally addressed conflicts of interest, duplicate projects, competition, and client eligibility; but, controls to safeguard against irregularities in these areas were not always adequate.

Of the four States reviewed only California expressly prohibits, by law, potential project recipients from involvement in the review and approval processes. In the other States controls to prevent conflict of interest situations, overt or implied, were less exacting and did not prohibit awarding projects to reviewing officials or their associates. Reviewing officials were requested or expected to take a nonparticipative role in decisions to fund or reject proposals from their organizations.

Explicit or intentional conflict of interest situations are difficult to detect. However, in reviewing the project records we identified 49 projects (14 percent of the 354 projects awarded in the 3 years) which, on the surface, could be construed as potential conflicts of interest. These were projects awarded to agencies, organizations, and affiliations of Planning Council members in Ohio, Pennsylvania, and Washington. None of the California projects appeared to involve conflicts of interest, indicating that the State law was implemented effectively.

Public Law 94-103 and the implementing regulations prohibited awarding program funds only to consumer members and their organizations. While it is not improper for agencies and organizations of nonconsumer Council members to receive grants under this program, doing so creates suspicion about how program funds are spent. Some Council members we interviewed said projects were awarded under a "buddy system" and that this was discrediting the State Formula Grant Program.

Safeguards to prevent awarding projects which duplicate or replace other funds (i.e., supplanting) generally consisted of relying on the integrity of grantees and familiarity by Council and State officials of what services were being rendered by other agencies. All four of the States asked potential grantees to provide assurances in their proposals that their projects were coordinated to avoid duplication and supplanting of funds.

Competition for program funds was often lacking. Information available from State records for 284 of the 354 service projects showed that 119 projects (42 percent) were awarded without competition. Insufficient information on the remaining 70 projects did not allow us to make determinations regarding competition. The table below shows that the extent of competition varied significantly among the four States:

<u>State</u>	<u>Projects analyzed</u>	<u>Compe- titive</u>	<u>Percent</u>	<u>Noncom- petitive</u>	<u>Percent</u>
Ohio	93	60	65	33	35
Pennsylvania	47	29	62	18	38
Washington	60	4	7	56	93
California	<u>84</u>	<u>72</u>	86	<u>12</u>	14
Total	<u>284</u>	<u>165</u>	<u>a/58</u>	<u>119</u>	<u>a/42</u>

a/Average.

In the absence of legislative or regulatory mandates to award projects competitively, each State decided for itself the types of awards it would make. As the previous table showed, Ohio and Pennsylvania chose to mix their projects--some competitive, some noncompetitive. Washington elected to make its awards noncompetitive, for the most part. Except for 12 projects awarded to specific grantees in poverty areas, California chose to make its awards competitive.

In their grant review processes none of the four States appeared to be giving top priority to the most severely handicapped individuals.

Our site visits to 20 direct service projects (5 in each State) showed that many whose disabilities did not fall within a strict definition of developmental disability were served.

We found that of the 1,183 people served by the 20 projects, 612 (52 percent) either (1) did not fit one of the categorical groups in the Federal definition (e.g., cerebral palsy or epilepsy), (2) were diagnosed as mildly or borderline retarded, or (3) were not classified as to type or degree of disability. Among those served were persons whose primary disability was diagnosed as learning disorders, emotional problems, hearing impairments, tubular sclerosis, muscular dystrophy, spina bifida, blindness, and deafness.

No officials interviewed used the Federal definition of developmental disability to the letter. Some applied their State's definition, which in the case of Washington included hearing disorders and in Pennsylvania included the learning disabled. Others appeared to use no limiting criteria or very liberal criteria.

The lack of specificity in the Federal definition encourages flexible eligibility standards. States have not been provided a uniform working definition with objective and measurable classifications of severity and functional limitations to determine who is or is not eligible for services. Program funds are modest, and legislative intent appears to limit the target population to a select group of handicapped individuals. Consequently, we believe closer attention needs to be given in the grants review process to use program funds judiciously and support only those projects mainly targeted for the substantially handicapped.

The Congress has already taken action to expand the definition of developmental disability by passing Public Law 95-602.

Non-Federal matching requirements

Public Law 94-103 requires that the non-Federal share of project costs be at least 25 percent (10 percent for efforts in poverty areas). The legislation is not clear regarding matching requirements for individual projects, however. HEW has interpreted the legislative mandate to mean that each project does not have to contribute the 25- or 10-percent match, that as long as the State total of all non-Federal program funds--regardless of source--equals or exceeds these percentages the requirement is satisfied.

Although all four States reported non-Federal matching funds equal to or in excess of the legislative requirement, none of the States required the match from individual project grantees. Consequently, about 3 of every 10 projects failed to put up at least 25 percent (10 percent for poverty area projects) of the total costs of their projects. The extent to which projects met or exceeded the match in each State is shown in the next table--a summary of our review of 323 projects for which this information was available:

<u>State</u>	<u>Projects analyzed</u>	<u>Projects with 25/10% match</u>		<u>Projects without 25/10% match</u>		<u>Projects with no match</u>	
		<u>Num-ber</u>	<u>Percent</u>	<u>Num-ber</u>	<u>Percent</u>	<u>Num-ber</u>	<u>Percent</u>
Ohio	93	73	78	20	22	9	10
Penn-							
sylvania	88	72	82	16	18	15	17
Washington	58	50	86	8	14	0	0
California	<u>84</u>	<u>35</u>	42	<u>49</u>	58	<u>28</u>	33
Total	<u>323</u>	<u>230</u>	a/71	<u>93</u>	a/29	<u>52</u>	a/16

a/Average.

Not requiring every grantee to absorb a portion (e.g., 25 percent) of their project costs is not only inequitable but also can work as a disincentive to project success. For some projects the non-Federal match may be a hardship, especially if required in cash; however, in-kind services can be substituted according to the legislation. Furthermore, one of the tenets of the State Formula Grant Program is to provide seed money with the intent the project will subsequently be carried on with other funds. If at least a portion of these other funds cannot be raised initially, it is questionable whether the project can sustain itself later. Most important, however, is the inherent lack of incentive to succeed when grantees do not have an investment in their projects or are at minimum risk to perform well.

Dispersion of projects

Projects were widely dispersed throughout the States of Washington and California during each of the 3 years under review. In Pennsylvania, projects were scattered during the first 2 years but fiscal year 1978 projects tended to be clustered in or near the State Capital, as 55 percent of the projects and 79 percent of the dollars were awarded to grantees in the Harrisburg area.

In Ohio the State Capital area increasingly drew the projects, with 34 percent awarded to Columbus grantees in 1976, about 68 percent in 1977, and 75 percent in 1978.

Public Law 94-103 and HEW regulations were basically silent on the matter of geographic distribution of projects, except efforts were to be made to award some projects in poverty areas. We noted that California appeared to make a concerted effort to equalize projects throughout the State.

If the program is to be planning oriented, we do not believe wide distribution of projects is as important as it would be if the program is to be service oriented. Conceivably, the expertise and resources could be available in one area so it may not be necessary to spread program funds throughout the State. We believe the important thing is to fund projects and use those resources which best accomplish program goals and objectives, regardless of location. On the other hand, centralizing projects apparently has given some the impression that the program is not really serving the developmentally disabled statewide. We believe the Planning Councils should allay these perceptions where they become impediments to program success.

Disability groups served

In awarding projects, all four States funded many projects not linked to any specific disability group. Our analysis, summarized below, showed that 200 (56 percent) of the 354 projects were awarded to grantees having no specific disability affiliation.

Primary disability affiliation	Number of projects awarded				Total	Percent
	Ohio	Pennsyl- vania	Wash- ington	Cali- fornia		
Mental re- tardation	52	29	9	27	117	33
Cerebral palsy	2	9	3	7	21	6
Epilepsy	6	1	1	2	10	3
Autism	-	-	-	1	1	}
Dyslexia	-	-	-	-	-	
Learning disabled	-	2	-	-	2	
Blind	-	2	-	-	2	
Hearing im- pairment	-	-	1	-	1	
None	33	45	46	76	200	56
Total	<u>93</u>	<u>88</u>	<u>60</u>	<u>113</u>	<u>354</u>	<u>100</u>

As our analysis shows, mental retardation projects received much of the grants going to groups associated with the five categorical disabilities specified in the developmental disabilities legislation. It should be pointed out that mental retardation prevalence is higher than the other disabilities, so this is not surprising. We noted only one project which was geared to the autistic, yet this was one of the major disabilities specifically intended to be served. This contrasts with the five projects awarded to groups whose primary affiliation was a disability not included in the legislation--the learning disabled, blind, and hearing impaired.

While we are not suggesting that project funds be divided proportionately or equally among the various disabilities, we believe State grant review processes need to take into account that some groups are being neglected and perhaps should be receiving a greater share of the funds.

Poverty area projects

HEW regulations stipulated that special consideration should be given to activities located in areas of urban and rural poverty. However, the regulations did not explain special financial and technical assistance in terms of the number of projects or funds to be expended. Our discussions with program officials in four HEW regional offices indicated that adherence to this requirement was not monitored. Neither the regional offices nor HEW headquarters compile data showing how many projects or how much money is getting into poverty areas.

Lacking further guidance, States awarded projects in poverty areas to varying degrees. Our review of project records in the four States showed the percentage of projects going to State-designated poverty areas ranged from a low of 8 percent in Washington to 41 percent in Pennsylvania. The average for the four States was 24 percent:

<u>State</u>	<u>Total projects</u>	<u>Poverty area projects</u>	
		<u>Number</u>	<u>Percent of total</u>
Ohio	93	26	28
Pennsylvania	88	36	41
Washington	60	5	8
California	<u>a/84</u>	<u>12</u>	14
Total	<u>325</u>	<u>79</u>	<u>b/24</u>

a/Includes fiscal year 1976 and 1977 projects only.

Information not available for fiscal year 1978 projects.

b/Average.

Overall, the States appeared to be doing a fairly good job of getting services to poverty areas. However, without criteria regarding how many projects or what portion of a State's allotment should go to poverty areas, we could not determine whether the States are meeting the intent of the law.

Affirmative action

As a condition of receiving Federal funds under the Formula Grant Program, Public Law 94-103 required each recipient to take affirmative action to hire and advance in employment qualified handicapped individuals. The four States reviewed gave only superficial attention to this mandate. Furthermore, HEW did little to make sure this requirement was being met.

In the four States compliance with the affirmative action mandate often consisted of the States merely putting a standard clause in their application forms sent to potential grantees regarding actions to hire and advance the handicapped. As the next table shows, however, even this token compliance was in evidence in only about half the projects we reviewed.

<u>State</u>	<u>Projects analyzed</u>	<u>Projects with an affirmative action clause</u>		<u>Projects without an affirmative action clause</u>	
		<u>Number</u>	<u>Percent</u>	<u>Number</u>	<u>Percent</u>
Ohio	93	23	25	70	75
Pennsylvania	88	73	83	15	17
Washington	60	60	100	0	0
California	<u>84</u>	<u>11</u>	13	<u>73</u>	87
Total	<u>325</u>	<u>167</u>	a/51	<u>158</u>	a/49

a/Average.

Our discussions with State officials and our review of project records indicated no additional attempts were made by program officials to assure grantees' compliance. None of the States maintained statistics showing how many handicapped individuals were hired or advanced in employment. During our visits to 20 direct service projects we found that five of the grantees had no affirmative action plan and made no attempts to hire or advance the handicapped. Three others had affirmative action plans but made no attempt to implement their plans.

Except for its regulations, HEW did nothing to ensure compliance with the affirmative action mandate. In fact, one Regional Director we interviewed was not aware of the requirement. HEW officials in the other three regional offices said they did not have sufficient resources to monitor this and that they relied on the States to ensure compliance. Neither HEW headquarters nor any of the four regional offices required the States to report on their adherence to this mandate, and no statistics were available to show how many handicapped were hired or advanced in employment by recipients of program funds.

Individual habilitation plans

Public Law 94-103 required that an individual habilitation plan be prepared for each person receiving services

under fiscal year 1977 and 1978 service projects. The plans were supposed to be tailored to the service needs of the individual and identify specific services to be provided, when they would be provided, and who would provide them. The plans were to be reviewed by service providers at least annually.

Similar to the compliance check for affirmative action, State agencies generally incorporated in their project application forms sent to prospective grantees a clause concerning the grantee's assurance that individual habilitation plans would be prepared for each client served. Our review of State records for 84 direct service projects, excluding fiscal year 1978 California projects for which information was not available, indicated these assurances were given for about three of every four projects:

<u>State</u>	<u>Projects analyzed</u>	<u>Projects with the assurance</u>		<u>Projects without the assurance</u>	
		<u>Number</u>	<u>Percent</u>	<u>Number</u>	<u>Percent</u>
Ohio	22	18	82	4	18
Pennsylvania	20	14	70	6	30
Washington	8	1	12	7	88
California	<u>34</u>	<u>28</u>	82	<u>6</u>	18
Total	<u>84</u>	<u>61</u>	<u>a/73</u>	<u>23</u>	<u>a/27</u>

a/Average.

During our site visits to 20 projects, we noted only one grantee that had no habilitation plans for any of its clients. Eleven others had plans for each client and these appeared to be complete, reasonable, and reviewed periodically, as required. The remaining eight grantees maintained plans for only some of their clients or had plans which were incomplete or not updated--or they told us the plans were being maintained by referral agencies or other service providers.

While compliance with this mandate appeared good, we question whether strict adherence to the requirement is needed--or desirable. Requiring such plans has become fashionable with many Federal programs besides the developmental disabilities programs. The detailed requirements of each program are not uniform, which means several plans could conceivably be prepared for a single individual if he/she receives services under several programs. This does not seem reasonable to us, as the paperwork could be quite burdensome. It would seem that a single, all-purpose plan could be developed by the primary service provider to satisfy the needs of all the programs.

Appeal mechanisms

Of the four States reviewed only California had established a formal appeal mechanism to handle complaints of applicants whose projects were not funded. Rejected applicants were provided the opportunity to testify and offer additional information to a State-level review committee which either sustained or reversed the initial decision. During the 3-year period we reviewed, this mechanism was used only once.

All four States, including California, contacted rejected applicants to inform them their projects would not be funded. The feedback varied from simple acknowledgments that the applicant's proposal was considered but not selected to substantive letters telling the rejected applicant how many proposals were received; how many were funded; what the grant review process entailed; what criteria was used to grade the proposals; and specific reasons why the proposal was not accepted. Washington's feedback to rejected applicants was particularly informative.

To maintain credibility and to encourage rejected applicants to continue their efforts to help the developmentally disabled and to apply again for Federal funds, we believe the grant review process should provide meaningful feedback to rejected applicants. Further, the system should have an appeal mechanism, preferably independent of the initial review team, so the rejected applicant is given every reasonable opportunity to have its proposal thoroughly studied.

LITTLE ATTENTION IS GIVEN TO MONITORING AND ASSESSING PROGRAM PERFORMANCE

How well the State Formula Grant Program is responding to the purposes of the legislation, nationally or within individual States, is largely unknown. Uniform standards to gauge performance do not exist, making monitoring and evaluation of the program highly subjective. Strapped with elusive program concepts and scarce resources to oversee the program, HEW merely maintains a Federal presence, relying on each State to monitor and determine the worth of its own program. The States, lacking direction and pressure to account for their activities, have done little to assess their programs.

Monitoring and evaluation at the State level

State developmental disability Councils establish goals and objectives, identify service gaps, and set priorities for allocation of State Formula Grant Program funds. To ensure that their plans are carried out and program funds are properly spent and accounted for, the law requires Councils to establish methods for monitoring and evaluating the program, including reviews of its own activities.

A review of the 1978 State Plans by an HEW consultant concluded that most Councils have not developed monitoring and evaluation capabilities and strategies. The Plans we reviewed for the four States contained much rhetoric on proposed evaluation and monitoring activities. But our discussions with program officials indicated that Councils spend most of their time developing plans and strategies, with little time devoted to supervising, monitoring, and evaluating program implementation.

Most (63 percent) Council members we interviewed said their Councils have done little, if anything, to measure program performance. Those who indicated the Councils make some effort to assess program results cited informal mechanisms (such as personal observations) as the primary means for evaluating programs. Most cited a lack of criteria to carry out this responsibility as the major problem. During our 3-year review period, HEW did not issue measurement criteria to evaluate the program, although it prepared draft performance standards in March 1979. However, these were expected to change as a result of the new developmental disabilities legislation.

Ironically, Councils rarely have had to account for their activities even though they have major program responsibilities and are a key organization in the State Formula Grant Program. While State Plan regulations and guidelines require various information on Councils, they do not ask for details on Council activities. An official of the Developmental Disabilities Office told us that HEW has not systematically reviewed Council activities, citing a lack of formalized and uniform evaluation instruments to do so.

Self-imposed or independent evaluations of Council activities likewise have rarely been made; and those which have been done have not included a critical examination of Council performance. Of the four States we visited, only California had established a mechanism to periodically review

Council activities. A California law requires an independent evaluation of Council effectiveness every 3 years. However, criteria had not yet been developed for the evaluation.

In the four States, monitoring and evaluation of service projects, where most program funds are expended, were done sporadically, were often perfunctory, and frequently relied on grantees' integrity. In reviewing State project files, in discussions with program officials, and during our site visits to 20 direct service projects, we noted:

- While periodic financial and project activity reports were required from the grantees, these frequently were late, or not done at all, and often were so general in nature as to prohibit any effective monitoring of project expenditures and accomplishments.
- Effective fiscal control over project funds was not always exercised. For example, grantees often were allowed to carry funds over from year to year, making accountability of funds for individual grants difficult. Also, some grantees were permitted to keep unspent Federal funds after the projects were completed.
- Much reliance was placed on grantees' financial reports to insure that funds were used in accordance with approved project budgets. Often these reports did not provide details for selected items of cost, so it was difficult to determine how the funds were used.
- Information on the number and types (ages, degree of disability, etc.) of people served was not routinely compiled by State officials. Further, data in the project files showing this information were often incomplete.
- Generally, Council members did not participate in site visits to obtain a firsthand knowledge of how program funds were spent and what was being accomplished. Further, indications were that Councils were not consistently apprised of project results.
- Frequency of site visits by Council staff, State agency officials, and independent evaluators varied among the States and even within individual States over the 3-year period. Sometimes all or most projects were visited; other times few if any projects were visited.

- Courtesy visits often were made instead of indepth evaluations where accomplishments were compared with approved goals.
- Grantee self-evaluations were frequently incomplete and subjective, not providing meaningful information to effectively gauge performance and progress toward meeting goals. Reports often listed activities conducted under the project without showing how these activities had met objectives.
- No cost-benefit or overall impact studies were made by States to give an overview of project accomplishments individually or in aggregate. On the indirect service projects no attempt was made to determine the extent to which project results were disseminated or used by others. We found that, more often than not, there was little or no sharing of project findings with others.

Allotments to the States are inadequate for funding all applicants seeking funds under the State Formula Grant Program. Therefore, it is imperative that Councils and the designated State agencies give greater attention to their monitoring and evaluation responsibilities to insure that funded projects are effective and provide maximum benefits to the program. Based on our findings, the States have much to do to provide these assurances.

Monitoring and evaluation at the Federal level

The Congress entrusted HEW--specifically the Developmental Disabilities Office--with broad oversight and accountability responsibilities for the State Formula Grant Program. While it had formulated regulations, issued guidelines, and provided for technical assistance to steer program implementation, HEW has given little attention to monitoring and assessing program performance. Our review showed that the Developmental Disabilities Office:

- Has never made a comprehensive review which measured accomplishments against program goals and expectations, even though the program has been in existence since 1970.
- Has yet to formulate an official evaluation system for the program even though it was mandated by the Congress to do so by October 1977.

- Has imposed minimal reporting requirements on the States to evidence program performance.
- Has sketchy data showing how States have spent program funds. In only one year (fiscal year 1975) have as many as one-half the States submitted final expenditure reports. Over the 7-year period ended with fiscal year 1977, on the average only one of every four required expenditure reports had been submitted.
- Has basically delegated monitoring and evaluation responsibilities to the regional offices, but has provided little guidance for carrying out these activities. Initial program administration review guidelines are to be available to the regional offices sometime during fiscal year 1980.

State Plans, prepared by each State as a condition to receiving a formula grant allotment, have been a primary monitoring tool for HEW. While these plans are fairly good indicators of what States propose to do, they are poor measures of actual performance. HEW officials review the State Plans primarily as a compliance check to make sure all required information and issues are addressed. We found little evidence to show that HEW makes followup reviews to determine how well the plans are being implemented. For example, attendance by HEW officials at Council meetings where major program decisions are made are the exception rather than the rule. Only one of the four regional offices we reviewed regularly sent a representative to the meetings.

Periodic financial and program performance reports are also required of the States, but their value as effective management tools is also questionable. Used primarily by regional officials to monitor State programs, we found these reports were not always updated, sometimes were not even prepared, were rarely supplemented with site visits by HEW officials to obtain firsthand knowledge of program operations, and required HEW to rely heavily on State officials' integrity to depict program accomplishments. One regional official stated that the reports were virtually meaningless as management tools. The reports did not appear to be used as a vital source for a national overview of program direction, accomplishments, and accountability.

HEW officials at headquarters and in four regional offices generally cited insufficient staff and other resources as the major deterrent to doing more program monitoring and evaluation. However, we did not view lack of

resources as the major reason why more or better program assessments were not made. We believe the absence of uniform and generally accepted criteria to gauge program performance is the major problem.

Neither Public Law 94-103 nor the implementing regulations specified criteria to assess the program. The Director, Developmental Disabilities Office, told us that imprecise and unclear congressional intent has made it difficult to outline exactly what is expected of the program.

Without specific objective standards to judge program performance, we believe it is virtually impossible to assess the program nationally or in individual States. To say the program is good, bad, or indifferent is a subjective judgment based on what one expects from the program. Program goals are so broad and nebulous and program concepts so elusive that traditional measures of performance (such as the number of people served) do not seem appropriate.

To illustrate, one of the fundamental goals of the program is to develop a comprehensive plan for a statewide network of services for the developmentally disabled and to influence service providers to improve and expand the scope of services to the disabled. Progress toward meeting this goal is rarely quantifiable to provide an objective criteria to evaluate success. Even if it can be shown that the developmentally disabled are receiving more or better services, it is not easy to relate this accomplishment specifically to the Formula Grant Program. Other programs may have influenced these actions as much as or more than any influence of the developmental disability Council.

In the absence of specific measurement standards, we found HEW Regional Offices applying their own criteria. Two of the four regions judged program success according to how well the Council and the administering State agency worked together and what success they had using funds from other agencies. Another region's criteria was how well the Council implemented its State Plan. The fourth region considered a State's familiarity with the law and regulations, knowledge of the State's developmental disabilities population, and public awareness of the needs of the target population as the main ingredients of a good program. Officials in all four regions stated that they recognized the subjectivity of these judgments but acknowledged little else could be done without specific performance standards.

CONCLUSIONS

The State Formula Grant Program, after 9 years of operation and nearly \$200 million in expenditures, is beset with many problems:

- Basic disagreements regarding program focus exist. Some program officials believe the program should be planning oriented, others believe it should be service oriented.
- Key State officials are confused about their roles and responsibilities. Who should control funds has been a particularly troublesome matter.
- Coordination and commitment to the development of comprehensive and integrated statewide service networks are often lacking.
- State Planning Councils' authority is not commensurate with their responsibilities.
- Small program size deters coordination and commitment from larger programs.
- Turnovers of Council members and staff have been disruptive to program continuity and effectiveness.
- Passive participation by some Council members and self-serving interests by others impede program effectiveness.
- State Plans, the Councils' main planning and strategy documents, are of dubious value.
- States' expenditure reports offer little insight into how program funds are actually used.
- Program credibility is endangered by questionable practices in awarding service projects.
- How well the States are responding to congressional expectations is largely unknown, since uniform standards to gauge program performance do not exist.

RECOMMENDATION TO THE CONGRESS

Because of the intrinsic and pervasive nature of many of the problems with this program, we recommend that the Congress clearly delineate what it wants the program to

accomplish. Once this is done the Secretary of HEW should be in a position to establish specific and attainable goals against which the program can be measured.

RECOMMENDATIONS TO THE SECRETARY OF HEW

We recommend that the Secretary of HEW direct the Commissioner of RSA to:

- Develop uniform evaluative standards to help program administrators, Planning Councils, and others to gauge program performance.
- Formulate standards to measure the performance of State Planning Councils and to hold them accountable for their activities.
- Encourage States to establish grant review mechanisms which provide adequate safeguards and assurances that service projects: will not duplicate other efforts, will be awarded competitively, will not supplant other available funds, will abide by affirmative action and habilitation plan requirements, and will not result in conflicts of interest. States should also be encouraged to set up formal appeal mechanisms to handle complaints of rejected project applicants.
- Provide States with more specific guidance for reporting expenditures of their formula grants so these reports are more meaningful and informative. Detailed instructions for classifying the types of expenses to be included as administration, planning, and services should also be provided.
- Assure that the States develop and use appropriate monitoring and evaluation capabilities for their programs and particularly for service projects.
- Increase regional monitoring and evaluation efforts.

CHAPTER 3

THE STATE PROTECTION AND ADVOCACY PROGRAM:

NEW HOPE FOR THE DEVELOPMENTALLY DISABLED

Official recognition that the developmentally disabled deserve appropriate treatment, services, and habilitation, has given the disabled new hope. Although it is a new program, the State Protection and Advocacy Program can vitalize the developmental disability programs and provide clout-- something that does not exist in the other programs. With an evaluative group independent of any State service or administering agency, the developmentally disabled have an outside way to determine whether their rights are being violated.

For the State Protection and Advocacy Program to reach its potential, however, this new program must overcome some already noticeable weaknesses, not the least of which is funding. Not only is it the smallest (in funding) of the four developmental disability programs, but it has also had difficulties acquiring additional funds to support and expand its operations. Two-thirds of the funds supporting this program come from authorizations under Public Law 94-103.

Possible duplication could also be a problem, since there are numerous groups and agencies within a State having advocacy roles. Cooperation and coordination between the new Federal program and the advocacy organizations will require closer attention. HEW guidance, which has been weak, will also have to be strengthened if this program is to be effective.

THE PROGRAM LOOKS PROMISING-- BUT IT IS TOO EARLY TO TELL

An integral part of the developmental disability programs is respecting individual rights. As required by Public Law 94-103, starting with fiscal year 1978, a State cannot receive a formula grant allotment unless it has in effect a system to protect and advocate the rights of the developmentally disabled. Furthermore, the system must have legal and administrative authority and be independent of any State agency providing services to the disabled. States were allowed much discretion in the types of systems they wanted to develop.

Both the new State Protection and Advocacy Program and the older State Formula Grant Program have advocacy roles, but the new program has clout--a key ingredient which makes it distinctive. While Planning Councils advocate by influencing, cajoling, and encouraging agencies to include the developmentally disabled in their programs, State Protection and Advocacy Program officials can compel agencies to provide services when benefits have been denied or rights of the developmentally disabled have been violated. While court cases may be a rarity, the threat of legal action is always present.

Some HEW regional officials stated that the State Protection and Advocacy Program is effective because it can force agencies to provide mandated services. One Regional Director said that the program is potentially the best and most cost effective of the four developmental disability programs. Two other directors indicated it is still too early to tell how effective the program will be.

Undoubtedly, the program offers new hope for those that are unable to obtain needed services, but the program is new. It has not yet proved to be an effective advocate for the developmentally disabled. Our review of these programs in the States visited provides some insight into the program's direction.

Program planning

Nearly \$5 million (the first 2 years of funds) was provided for the States to plan and design statewide systems for protection and advocacy. October 1, 1977, was the legislative deadline to have the systems in place and ready for implementation. Fiscal year 1978 funds totaling \$3 million were to be used by the States for program implementation.

The table on page 59 shows that the States reviewed spent about \$543,000 of their \$1.5 million on system design and planning. Although program funds for the first 2 years were available for this purpose, only California used its funds exclusively to design and plan its protection and advocacy system. The others applied at least a portion of their allocations to get a headstart on program implementation:

State	Fiscal year	Public Law 94-103		Application of funds		
		funds awarded	Planning	Implementation	Unexpended	
Ohio	1976	\$ 84,974	\$ 84,974	\$ -	\$ -	
	1977	140,896	91,405	49,491	-	
	1978	134,932	-	134,932	-	
Total		<u>\$ 360,802</u>	<u>\$176,379</u>	<u>\$184,423</u>	<u>\$ -</u>	
			(49%)	(51%)		
Pennsylvania	1976	\$ 96,288	\$ 93,141	\$ 3,147	\$ -	
	1977	152,333	-	152,333	-	
	1978	160,881	-	160,881	-	
Total		<u>\$ 409,502</u>	<u>\$ 93,141</u>	<u>\$316,361</u>	<u>\$ -</u>	
			(23%)	(77%)		
Washington	1976	\$ 26,506	\$ 26,506	\$ -	\$ -	
	1977	41,934	-	41,934	-	
	1978	41,272	-	41,272	-	
Total		<u>\$ 109,712</u>	<u>\$ 26,506</u>	<u>\$83,206</u>	<u>\$ -</u>	
			(24%)	(76%)		
California	1976	\$ 142,897	\$ 18,985	\$ -	\$123,912	
	1977	228,635	228,000	-	635	
	1978	216,907	-	216,907	-	
Total		<u>\$ 588,439</u>	<u>\$246,985</u>	<u>\$216,907</u>	<u>\$124,547</u>	
			(42%)	(37%)	(21%)	
Four-State totals	1976	\$ 350,665	\$223,606	\$ 3,147	\$123,912	
	1977	563,798	319,405	243,758	635	
	1978	553,992	-	553,992	-	
Total		<u>\$1,468,455</u>	<u>\$543,011</u>	<u>\$800,897</u>	<u>\$124,547</u>	
			(37%)	(55%)	(8%)	

The transition from planning to implementation went reasonably well in Pennsylvania and Washington--less than one-fourth of their Federal allotments were reported for planning. Pennsylvania's Developmental Disabilities Planning Council assigned an Advocacy Task Force the job of recommending the statewide structure to operate its system. Most of Pennsylvania's planning money went for consultant services to inventory advocacy organizations throughout the State and to train advocates and draft legislation to obtain State funds to support advocacy activities.

Washington already had a statewide advocacy system in place, developed with HEW discretionary funds starting in 1972. Although Washington reported its first year's funds under Public Law 94-103 as planning, these could be categorized as implementation. The funds were used to expand the existing protection and advocacy system.

Ohio and California encountered problems in putting their systems in place. In Ohio, the Planning Council sought control over the new program by establishing its own group and supporting it with formula grant moneys, in addition to the funds received under the Federal protection and advocacy authority. A second group challenged the Council's selection, alleging conflicts of interest and mismanagement of funds. A court battle ensued and, later, an HEW audit. Over \$200,000 intended for the program was tied up in courts until September 1978--almost 1 year after HEW had approved the system design. The money was eventually awarded to the challenging protection and advocacy group, but the legal arguments delayed program implementation.

California's efforts to establish a protection and advocacy program floundered from the start. Only \$19,000 of its \$143,000 first-year allotment was spent. This went for consultant services to assist the Planning Council with developing a system. Several options were presented. Indecisiveness, however, resulted in California allocating nearly all of its second year's funds for additional planning and startup costs. Although HEW approved the State's advocacy plan in November 1977 (more than 1 month after the deadline), it was not until May 1978 that the Governor appointed a State agency to operate the program.

Program implementation

The table on page 59 shows that Washington and Pennsylvania designated over 75 percent of their funds for implementation, Ohio slightly over 50 percent and California only 37 percent. Over 20 percent of California's allocation was never used.

All four States designated private, nonprofit organizations to operate their protection and advocacy programs. However, their programs differed not only in mode of operation but also in the extent to which they exercised their authority to pressure service agencies to provide for the developmentally disabled. Following are outlines of each program's operation.

The Ohio Protection and Advocacy Association is aggressive. The Association battled to win designation as Ohio's official group for statewide advocacy, it litigated for formula grant funds, and it will probably aggressively pursue the rights of the developmentally disabled. According to its Executive Director, the Association's main mission is to train people to advocate more effectively for the developmentally disabled. Concomitant with this is the fostering of self-reliance in the disabled--encouraging them to be their own advocates. Most conventional advocacy activities were intended to be carried out by a statewide network of 21 citizen advocacy groups and over 100 local affiliates of the State's four consumer groups representing cerebral palsy, autism, mental retardation, and epilepsy.

If conventional advocacy fails, negotiation with appropriate service agencies is the next step. As a last resort, the Association has indicated it will pursue legal action to secure services for the developmentally disabled. The Association views itself as an advocate for the disabled, urging agencies to abide by the laws and render services where needed and mandated.

The Association envisions its role as the focal point in Ohio for all developmental disability advocacy activities. Its goals are to provide central direction and technical assistance by

- establishing standards and regulations for advocacy services;
- monitoring advocacy agencies;
- providing legal backup resources, drafting legislation, and testifying at public hearings;
- disseminating informational materials; and
- providing training to advocates, parents, and professionals.

Pennsylvania's Developmental Disabilities Advocacy Network is the coordinating agency providing central direction and linkage among all agencies and advocacy organizations concerned with protecting the rights of the developmentally disabled. It serves as a clearinghouse for complaints, relying on established advocacy groups and individual advocates to

solve problems. It provides resources to citizen and volunteer advocates on an as-needed basis by disseminating information, technical advice, and training.

A major component of the Network is a center and regional intake and referral mechanism which receives complaints or requests for help. A public awareness program invites collect calls to the central office or any of the three regional offices. Through commitments from the State's five major consumer groups (epilepsy, mental retardation, cerebral palsy, autism, and learning disabilities), 140 local units serve as advocacy substations, and from a statewide pool of volunteer advocates, the Network operates an individualized subsystem in which an advocate works with a client to meet his/her needs. Recruiting and training a large force of specialized advocates is a primary goal of the Pennsylvania protection and advocacy group.

The Network retains legal services, as needed, at both the central and field locations. However, much of its legal advocacy was carried on by several legal groups which received support from the State Formula Grant Program and others. Probably the most significant of these is a public interest law firm which works for legal reform and was heavily involved in several class action lawsuits.

California's program is barely beyond the planning phase, having initiated operations in September 1978. Almost all of its implementation funds are being used to initiate 11 advocacy projects throughout the State: five personal advocacy, three legal advocacy, and three workshop projects. These projects are to address identified advocacy problems, but they are not designed to set up a network of advocacy services--which appears to be a longer range goal.

Unlike Ohio and Pennsylvania, which have not been reluctant to use their legal powers, California's Protection and Advocacy Program was not set up to pursue expedient legal action on behalf of the developmentally disabled.

Washington's Troubleshooters Office, the designated agency for statewide protection and advocacy, is a pioneer human and civil rights organization. Similar to the Ohio and Pennsylvania programs, Troubleshooters functions as a central clearinghouse for statewide advocacy activities. In addition, one of Troubleshooters main functions is to train advocates for its affiliated offices, which were located in over half the State's counties at the time of our review.

Troubleshooters home office recruits and trains advocates for these affiliated offices. Advocates are taught how to pursue consultative, administrative, and legal remedies on behalf of the developmentally disabled, their parents, and advocates. Training is the primary link and method for coordinating all advocacy functions in the State. Troubleshooter offices are to serve as the protective and advocacy agents for their local areas. The home office provides ongoing technical assistance, including demonstrating how other funds can be acquired for startup costs for local affiliates. Most calls for assistance were handled by local troubleshooters.

Troubleshooters prides itself in not being a referral service. It does not believe in merely sending a client to a provider. Franchised advocates were expected to contact the appropriate service agency and follow through to make sure action was being taken. Emphasis was also placed on self-advocacy, encouraging the disabled to acquire what is rightfully theirs. While it had developed working relationships with various legal services, Troubleshooters chose to work within the service delivery system. It has yet to resort to litigation to achieve results.

Program accomplishments

Gauging program performance was difficult because the State Protection and Advocacy Program is just emerging from the planning stage. However, program performance reports covering first-year operations provided some insight. The following table shows the number and types of people served, and services rendered in the four States reviewed varied widely. While such discrepancies make comparisons difficult, some of the other data present a fairly good service profile:

<u>People and services</u>	<u>Ohio</u>	<u>Pennsylvania</u>	<u>Washington</u>	<u>California</u>
Number of services provided	1,562	209	3,269	524
Number of people served	1,487	170	2,451	524
Average number of services	1.1	1.2	1.3	1.0

Ages

17 and over	86%	53%	50%	49%
6 - 16	13	36	33	31
5 and under	1	7	17	6
unknown	-	4	-	14

Primary disability

Mental retardation	78%	30%	53%	37%
Cerebral palsy, epilepsy, autism, and dyslexia	16	33	25	23
Multiple Handicap	2	7	-	14
Other	4	30	22	26

Client location

Urban	62%	49%	73%	72%
Rural	12	40	24	4
Institutions	25	4	2	10
Other	1	7	1	14

Requester

Service providers	75%	13%	25%	20%
Family or friend	21	55	56	44
Client	4	32	19	22
Unidentified	-	-	-	14

Type of service

Encouragement and support	24%	10%	20%	13%
Information	20	10	34	48
Training	15	54	4	14
Referral	13	4	25	7
Legal	2	2	4	7
Public speaking and workshops	-	16	-	-
Negotiation	6	4	11	9
Social activities	12	-	-	-
Locating advocate	8	-	-	-
Other	-	-	2	2

Adults appeared to be the chief beneficiary of services, outranking other age groups in all four States. In Ohio, for example, adults received 86 percent of all services rendered. Consistently ranked at the bottom were preschoolers. All four programs appeared to be serving people not falling within the categorical definition of developmentally disabled, as shown on the preceding table under the "other" category of primary disability. In Ohio and Washington the programs were subsidized with nondevelopmental disability funds, so program officials did not feel compelled to limit their services to a select group. This was not the case in California and Pennsylvania, however, because these programs were entirely supported by developmental disability funds.

Clients in urban areas were receiving the largest share of services in every State, although rural areas were reasonably represented in Pennsylvania and Washington. People in institutions received a fairly large share of the services in Ohio. Requests for services generally came from families, friends, or the disabled themselves. The exception was in Ohio, where approximately three-fourths of the requests were initiated by service providers.

Types of services varied considerably, although training, information, and encouragement and support ranked high in most of the States. Legal services ranked low in every State, indicating this last-resort measure had been used discriminately.

It appears some States have active programs and are serving quite a few people, while others are serving relatively few. Again, the program is new and many people probably had not been exposed to it. All four States have instituted public awareness campaigns to publicize their programs.

PROBLEMS NEEDING ATTENTION

While the Protection and Advocacy Program looks promising, it has problems. The inability of some programs to acquire additional money, the potential for duplicate advocacy activities, and the lack of guidance and direction from HEW threaten program success.

Acquiring additional funds

Two-thirds of the funds going for program implementation came from authorizations under Public Law 94-103. If this

program is to expand with little or no increases in Federal developmental disability funds, State protection and advocacy systems will have to do a better job of soliciting support from others.

Approximately \$3 million in Federal funds was apportioned among the States and territories in fiscal year 1978 to implement their protection and advocacy programs. This represented only 5 percent of all funds authorized that year under Public Law 94-103, making the State Protection and Advocacy Program the least funded of the four programs. On an average, States received \$55,743 each to carry their programs through the first year of implementation. California received the largest award with \$216,907; 19 States and territories received the minimum of \$20,000. The other States we reviewed received the following: Ohio--\$134,932, Pennsylvania--\$160,881, and Washington--\$41,272.

With relatively little money being allotted for the program, other funds become vital if States are to establish effective statewide advocacy programs. A consultant study made for HEW reported that an additional \$3.1 million had been acquired by the States and territories. However, one-third were not able to acquire additional funds--they relied solely on their share of the \$3 million Federal funds from Public Law 94-103 (California was among this group).

Difficulties with acquiring funds become even more apparent when one looks at the sources which supplement the Federal protection and advocacy funds. The following table shows that 84 percent of the \$6.1 million in operating funds came from the Federal Government--with two-thirds coming from the State Protection and Advocacy and Formula Grant Programs. Generally speaking, State, local, and private organizations have not been very supportive. Of the four States in our review, the two largest--California and Pennsylvania--were operating solely with Federal developmental disability funds. Ohio and Washington were able to garnish some additional support from State and private sources. Ironically, financial support from local groups, where much of the grassroots advocacy is expected to take place, was almost nonexistent. The entire grassroots amount shown in the table (\$35,520) went to one State.

	<u>All States and territories</u>	<u>Per- cent</u>	<u>Ohio</u>	<u>Per- cent</u>	<u>Pennsyl- vania</u>	<u>Per- cent</u>	<u>Washing- ton</u>	<u>Per- cent</u>	<u>Cali- fornia</u>	<u>Per- cent</u>
<u>Federal</u>										
Public Law 94-103/ Protection and Advocacy	\$3,010,096	49	\$134,932	31	\$160,881	55	\$ 41,272	25	\$216,907	100
Public Law 94-103/State Formula Grant	1,109,213	18	159,145	36	133,000	45	-	-	-	-
Other Federal (e.g., CETA, Title XX, and WIN programs)	1,044,786	17	109,586	25	-	-	112,643	67	-	-
Subtotal, Federal	5,164,095	84	403,663	92	293,881	100	153,915	92	216,907	
<u>Non-Federal</u>										
State	577,265	9	32,500	8	-	-	-	-	-	-
Local	35,520	1	-	-	-	-	-	-	-	-
Private	334,212	6	-	-	-	-	13,367	8	-	-
Subtotal, non- Federal	946,997	16	32,500	8	-	-	13,367	8	-	-
Total	\$6,111,092	100	\$436,163	100	\$293,881	100	\$167,282	100	\$216,907	100

Our review indicated that the more aggressive programs (such as Ohio's and Washington's) have been at least moderately successful in obtaining additional funding. Particularly noteworthy is Washington's tapping of Comprehensive Employment and Training Act funds to enable them to hire and train additional troubleshooter advocates. Sixty-three percent of Washington's program was funded through this program.

If the State Protection and Advocacy Program is to thrive and not just survive, Federal support will have to be increased and/or program officials will have to partake in fundraising efforts. Some States have already proven that fundraising is possible.

Potential duplication

Protection and advocacy did not have their roots in the Federal program--advocacy groups have existed for years. This has been both advantageous and disadvantageous to the Federal Protection and Advocacy Program. One of the advantages is that the Federal program does not have to start from the beginning if a State already has local advocacy organizations and State agencies have established protection and advocacy as one of their functions. Duplication of advocacy efforts, however, poses a potentially serious problem.

Before implementing its program, Pennsylvania inventoried advocacy services available throughout the State. It found that, in addition to five State agencies and 136 local chapters of primary consumer disability groups, a number of local organizations throughout the State provided some type of advocacy service. Besides these, the Planning Council identified numerous groups which were either providing or planning to offer protective and advocacy services for the developmentally disabled. Pennsylvania was not unique in this respect. The other three States reviewed, and undoubtedly every State in the country, have many individuals and organizations advocating for the disabled.

Protection and advocacy has also been a prominent goal in some State Formula Grant programs. Ohio's Planning Council, for example, had been funding protection and advocacy projects for several years, beginning with a community awareness project in 1973. Since that time, the Ohio Council has supported at least nine other advocacy projects from its formula grant funds. Pennsylvania, Washington, and California have likewise

used some of their formula grant dollars for these types of projects. From their fiscal year 1976 through 1978 formula grants, these States supported at least 33 advocacy projects costing \$1.7 million:

<u>State</u>	<u>Number of projects</u>	<u>Funds from State Formula Grant Program</u>
Ohio	10	\$ 636,736
Pennsylvania	7	698,229
Washington	2	43,951
California	<u>14</u>	<u>355,703</u>
Total	<u>33</u>	<u>\$1,734,619</u>

An HEW consulting group, after reviewing the 1978 State plans for protection and advocacy systems nationwide, concluded that failure to use and coordinate existing advocacy efforts in the States is a problem. The group mentioned that cooperative agreements between Planning Councils and designated State agencies for protection and advocacy were generally lacking.

Each designated protection and advocacy agency reviewed recognized the importance of having a coordinated network, but the extent to which it established links with local and other advocacy groups could not be readily determined. However, cooperation between the State Formula Grant and Protection and Advocacy Programs ranged between good and poor. In Ohio, the turmoil created by the earlier confrontations between the Planning Council and the protection and advocacy agency apparently has left a lasting impression--coordination between the two groups is nonexistent. State Formula Grant money now supporting Ohio's Protection and Advocacy Program was won in a court battle. Continued support after these funds run out is not expected, according to the agency's executive director.

In Washington, the designated protection and advocacy agency requested that the Planning Council inform it of any advocacy projects awarded under the State Formula Grant Program and that grantees coordinate their projects with Troubleshooters. This had not been done. Furthermore, Troubleshooters had no input into formula grant project review and selection. The Planning Council, however, attempted to track Troubleshooters' activities through a monitoring board which was to report to the Council at each of its meetings.

In California, coordination between the State Formula Grant and Protection and Advocacy Programs was sporadic and informal. The Planning Council was notified about the projects awarded by the protection and advocacy agency in 1978, but this exchange of information was one-sided. Formula grant projects were not made known to the designated protection and advocacy agency initially, although it has requested copies of future grants.

Of the States required, Pennsylvania appeared to be closest to setting up a mechanism to coordinate advocacy efforts to the two Federal developmental disability programs. The designated protection and advocacy agency provided input into the State Formula Grant project review process, and in fact administered some advocacy projects supported with formula grant funds.

We found a potentially serious duplication problem that must be dealt with if scarce developmental disability funds are to be spent efficiently and effectively. Considering the myriad of advocacy activities, duplication and mistargeting of funds are inevitable unless the protection and advocacy program develops an effective coordinating mechanism. Although this program is still new and time may alleviate coordination problems, coordination needs to be monitored closely. If coordination does not improve--particularly between the protection and advocacy agencies and the Planning Councils--the only recourse might be to mandate coordination.

HEW guidance is minimal

With only a very broad mandate and little guidance from HEW, States have been given full authority to design and operate the type of protection and advocacy systems they want. Not only has this made program accountability difficult to enforce and program performance virtually impossible to measure, it has left the States operating in a vacuum.

Public Law 94-103 requires every State to have a protection and advocacy system if it is to continue receiving funds under the State Formula Grant Program. Other than this broad mandate and stipulations regarding the implementation deadline and type of agencies prohibited from operating the new program, the legislation offered no further direction for the State Protection and Advocacy Program. The Congress relied on HEW to guide the States with developing and implementing their individual programs, and HEW has been of little help.

HEW provided the States with no substantive regulations or guidelines to clarify the intent and mechanics of the new program. HEW regulations issued 16 months after the program was authorized merely restate the law, virtually word for word. HEW's position, stated in a preamble to the regulations, says:

"It is the Department's belief that approaches may be utilized in order to achieve the substantive goal of establishing an independent agency to pursue the rights of the developmentally disabled. The Department believes it desirable to give States flexibility in the development of such a system."

The result has been that HEW regional offices, given responsibility to oversee States' administration of their programs, have been provided no standards to measure performance and little, if any, authority to compel States to adhere to congressional intent. Furthermore, the States were left with money to set up systems without guidance.

The four regional directors we interviewed said guidance from HEW headquarters has been virtually nonexistent. The directors have had to provide direction based on their own impression of program intent.

Lacking standards and staff to administer the State programs, regional offices have had to rely on the designated State agencies to perform self-evaluations and report program accomplishments and problems to them. Much reliance is placed on the integrity of designated protection and advocacy officials to properly manage their programs and the funds allotted to them. The audit is essentially the only control exercised over Federal funds. Except for the audit of Ohio's program, in which allegations of mismanagement of funds were largely substantiated by HEW, no programs have been audited by HEW since the program's inception.

Protection and advocacy officials in the selected States generally were dissatisfied with guidance furnished by the regional offices. Ohio and Pennsylvania program officials stated that the regional offices have provided little substantive assistance, and they indicated they have been given freedom to operate whatever types of programs they want. A Washington Troubleshooters' official stated that the regional office's lack of authority to make major program decisions makes them of questionable value. In California, the protection and advocacy official stated that the lack of criteria for spending program funds had not been clarified by its regional contact.

CONCLUSIONS

If it reaches its potential, the State Protection and Advocacy Program could be the most potent and effective mechanism to insure that the developmentally disabled receive the benefits, services, and rights they are entitled to. Two factors which distinguish this program from others--independence and power--also are the key to its success. Being independent of other administering or service agencies, the State Protection and Advocacy Program gives the developmentally disabled a way to work outside established service delivery systems to contest their rights. More importantly, where needed services are not being provided, program advocates can intercede on behalf of the disabled and compel others to furnish such services.

To ensure program success, HEW needs to lend its support through better leadership and guidance--HEW has not provided substantive direction for the program. It has permitted the States maximum flexibility and discretion to operate the types of programs they choose. Basically, HEW has taken a "wait and see" attitude. We believe this is a mistake. Program accountability demands that HEW take a more active role and provide the States needed guidance.

Funding appears to be a major problem. Nationally, two-thirds of the program funds have come from the developmental disabilities legislation. While some States have successfully acquired funds from other Federal programs and from non-Federal sources, many have not. If it is intended that States are to establish broad-scale programs with (1) coordinated links among the various advocacy groups throughout the State, (2) monitoring capabilities to examine the many service programs, and (3) effective legal and administrative mechanisms to follow through on rights violation cases, it would appear more financial support will be needed. This is where HEW can help.

Whether increased funding does or does not come from the developmental disabilities legislation, we believe HEW should assist States by showing them how to access other funds. Washington and Ohio in our sample are examples where efforts to garnish additional support have been successful. HEW should take advantage of these and other experiences to assist States to expand their programs and make them something more than just another information and referral effort.

Potential duplication also could endanger the effectiveness of the State Protection and Advocacy Program. Consumer groups, concerned citizens, and numerous other advocacy groups exist in every State. A top priority for the new program should be the establishment in each State of a coordinated network of advocacy services so that duplication is avoided or kept to a minimum.

Particular attention should be directed to the two tandem Federal programs, the State Formula Grant Program and the State Protection and Advocacy Program, both of which have advocacy roles. We believe that these two programs must set the example for coordination throughout the State. If they cannot work in unison, the pattern is set for other advocacy groups and organizations to fragment their efforts. At minimum, these two major developmental disability advocates should be aware of what each is doing--their respective roles and activities must be delineated. For both to be effective, they must interact in a positive and supportive way.

RECOMMENDATIONS TO THE SECRETARY OF HEW

We recommend that the Secretary of HEW direct the Commissioner of the Rehabilitation Services Administration to:

- Formulate specific program regulations and guidelines.
- Assist States with acquiring other funds.
- Require the States to establish a mechanism(s) whereby the Planning Councils and the Protection and Advocacy agencies coordinate their activities to prevent duplication and ensure efficient and effective utilization of program funds.
- Establish standards by which program performance can be measured.

CHAPTER 4

SPECIAL PROJECTS PROGRAM:

IS IT REALLY SPECIAL?

The Congress intended the Special Projects Program to be special. Unlike the narrowly focused and often service-oriented formula grant projects, special projects were to deal with issues and needs on a broad scale, and were to demonstrate new methods to better serve the developmentally disabled.

The Special Projects Program is still relatively new, so it might be premature to judge the program's success. However, our initial impression is that many of the projects we reviewed--particularly the regional projects--bear a striking similarity to projects funded under the State Formula Grant Program. Sixty-one percent of the projects, accounting for 48 percent of the dollars spent, appeared to focus on direct "hands-on" services for specific target groups, not models or demonstrations for widespread replication.

While many of the nonservice projects went for exemplary services and models, the heaviest concentration was in technical assistance and training for officials of the other three developmental disabilities programs. The indication is that much of the special project funds are supporting consultant services to help HEW's developmental disabilities officials administer and monitor the programs.

We also observed that Federal developmental disability grant award procedures have weaknesses regarding competition, Planning Council input, feedback to rejected applicants, affirmative action, grantee contributions, and the quality of project designs. Postaward monitoring and project evaluations by program officials are also inadequate. Much reliance is placed on grantee self-evaluations which often are not critical examinations of project results. A key element of the program--dissemination of project findings--also received little attention. Generally, it is difficult to determine what impact the program has had.

LEGISLATIVE BACKGROUND

The Special Projects Program is new because separate authority and funding for the types of activities envisioned in this program did not exist in the developmental disability legislation until passage of Public Law 94-103. The concept,

however, is not unique. Under Public Law 91-517 and several widely varying pieces of legislation not directly related to developmental disabilities, HEW had access to funds for putting in place regional and national projects as models for State and local agencies. These funds were to provide HEW with a ready mechanism for initiating innovative activities to expand or otherwise improve services to the disabled. Unlike projects under the State formula grant authority, which were intended to serve local needs, these special projects were to have more far-reaching benefits.

Public Law 94-103 combined the special projects authority of the prior developmental disability legislation with similar provisions from two nondevelopmental disability programs: the Public Health Service Act and the Vocational Rehabilitation Act. No longer did the support of such projects have to depend on funds from the developmental disabilities formula grant program and nonrelated programs.

Almost \$57 million was made available to the Special Projects Program making it the second largest of the four developmental disabilities programs. These moneys were divided between HEW headquarters and 10 regional offices, with the only stipulation that at least 25 percent of the funds were to be used for projects of national significance. The law further specified that the funds be used for projects which met one or more of the following nine objectives:

1. Demonstrations of programs to expand or improve services.
2. Public awareness and public education to alleviate barriers confronted by the developmentally disabled.
3. Coordination of community resources.
4. Demonstrations of the provision of services to the developmentally disabled who are economically disadvantaged.
5. Technical assistance.
6. Training specialized personnel to provide services or research.
7. Development of model projects for services.
8. Gathering and disseminating information.
9. Improving the quality of services.

Guided by these nine objectives, both the projects of national significance (i.e., national projects) and other special projects (i.e., regional projects) had basically the same mission: improve the scope and quality of services to the developmentally disabled by providing guidance and demonstrations to more effectively and efficiently carry out the purposes of the other three developmental disability programs. Only in their breadth of coverage were the two types of projects different. National projects, awarded by the Developmental Disabilities Office, were to provide a national or multiregional perspective to program issues and problems. Regional projects, awarded by the 10 HEW regional offices, were to be more conducive to statewide or regional activities--although like the national projects their results also might be disseminated or replicated.

HOW PROGRAM FUNDS
WERE DISTRIBUTED

Records maintained by the Developmental Disabilities Office showed that over the 3-year period regional projects received 67 percent of the total funds--\$38.2 million of the \$56.9 million awarded under the program. Of the 715 grants awarded, 609 were for regional projects (this includes all 10 HEW regional offices) and 106 for national projects.

However, as the next table shows, funds for regional projects decreased each year as national projects took an increasingly larger portion of the total funding. By the third year, national projects accounted for 50 percent of the program dollars, a substantial jump from the first year when only 20 percent of program dollars went for national projects. (Note: HEW failed to meet the award deadline for some fiscal year 1976 national projects. As a result, over \$1 million which would have gone for such projects was returned to the Federal Treasury. This is why the minimum 25-percent requirement for national projects was not met that year.)

Fiscal year	National projects			Regional projects			Total	
	Number of grants	Amount	Percent	Number of grants	Amount	Percent	Number of grants	Amount
		(millions)			(millions)			(millions)
1976	27	\$ 4.6	22	296	\$16.2	78	323	\$20.8
1977	29	5.2	28	201	13.2	72	230	18.4
1978	50	8.9	50	112	8.8	50	162	17.7
3 years	106	\$18.7		609	\$38.2		715	\$56.9
Percent	15	33		85	67		100	100

Note: Various statistical and other data presented in the balance of this chapter will be expressed in terms of the number of grants or the number of projects we reviewed. The number of grants represents all awards made to the various grantees receiving funds under the Special Projects Program. The number of projects represents the number of grantees, and will always be less than the number of grants since many grantees received more than one award during the period. In reviewing project records at the Developmental Disabilities Office and at four HEW regional offices, we found it easier to compile some data by the number of grants and some by the number of projects. This explains why our numerical totals vary from one analysis to another, depending on whether we compiled the data by grants or projects. For example, the prior table shows our analysis by the number of grants.

Except for the mandated 25-percent minimum for national projects, neither the legislation nor implementing regulations specified how program funds were to be divided between national and regional projects. The Developmental Disabilities Office decided to keep national project funds close to the minimum the first 2 years in order to continue regional projects previously funded under Public Health Service and Vocational Rehabilitation programs. As mentioned, special project authority under these programs was replaced by the developmental disabilities legislation. This is the major reason why regional projects received the larger share of the program's funds, initially.

Because project awards, the duration of projects, and project recipients varied so dramatically, we found that it was not feasible to profile a typical project. On the average, grants for national projects were substantially larger than for regional projects. Our review of the 106 national grants showed the average award was \$176,069--almost triple the size of the average regional grant, which was \$62,469, based on our review of the 309 grants given by four HEW regional offices. The dollar range also varied substantially, for both the national and regional projects. The largest single award was \$1.5 million for a national telecommunications project, and the smallest a \$591 grant for a regional rehabilitation project. The next table summarizes our analysis of grants for all national projects and projects awarded by the four regional offices we visited.

<u>Type</u>	<u>Number</u>	Grants awarded during fiscal years 1976-78			
		<u>Amount</u>	<u>Average</u>	<u>Highest</u>	<u>Lowest</u>
National	106	\$18,663,307	\$176,069	\$1,499,825	\$7,922
Regional:	309	19,302,814	62,469	288,664	591
Region III	97	6,195,056	63,867	288,664	5,646
Region V	86	7,498,933	87,197	217,798	591
Region IX	52	2,328,200	44,773	123,844	3,958
Region X	74	3,280,625	44,333	142,461	1,361

Most projects were awarded on a continuing basis; that is, most were supported with program funds for several years. Although the duration of projects varied, both national and regional projects generally went on for 3 years with Federal aid. Few were funded for just 1 year. This meant that many grantees received program funds far exceeding the average amounts shown in the preceding table, which were based on awards made annually.

The Developmental Disabilities Office appears to have made an effort to distribute program funds widely. In a cursory review of developmental disability program reports for fiscal year 1976 and 1978 grants, we noted that every State had at least one national or regional project. The average was 10 grants, although some had substantially more than the average. For example, six had at least twice as many as the average State, as follows.

<u>State</u>	<u>Number of grants</u>
New York	43
Oregon	36
District of Columbia (note a)	31
California	23
Pennsylvania	22
Maryland	21

a/Although not a State, the District of Columbia was a major recipient of program funds and is therefore included in the analysis.

Regarding the type of grantee, we again found no particular pattern. In reviewing 146 projects funded by the four regional offices, we noted that nonprofit, private organizations had the most projects (47 percent of the total), but universities, particularly university-affiliated facilities,

got the largest portion of the dollars (39 percent of the total). The next table shows the number of projects and dollars awarded among the grantee categories.

<u>Type of grantee</u>	<u>Number of projects</u>	<u>Funds awarded</u>	
Nonprofit, private	69 (47%)	\$ 5,544,170	(35%)
Universities	38 (26%)	6,174,269	(39%)
Public	37 (26%)	3,843,856	(24%)
Other	<u>2 (1%)</u>	<u>281,635</u>	<u>(2%)</u>
Total	<u>146</u>	<u>\$15,843,930</u>	

National projects were almost evenly split between universities (45 percent) and nonprofit, private organizations (49 percent)--with public agencies receiving the smallest share (6 percent).

ARE SPECIAL PROJECTS SPECIAL?

The Congress indicated the Special Projects Program was to be special. It divorced national projects' authority from the State Formula Grant Program, stipulated specific objectives for these projects, targeted the multihandicapped as project beneficiaries, and created a new program and heavily funded it. Unlike the narrowly scoped formula grant projects, the special projects were supposed to deal with issues and needs on a broad scale, so that "hands-on" services and programs at the grass roots level could be improved. In contrast with the local and one-State focus of the formula grant projects, special projects were to address multi-State, regional, and national needs.

While judging program performance would be somewhat premature since the Special Projects Program is still relatively new, our initial impression is the program has yet to establish itself as something unique or special. This was particularly evident in our review of regional projects which often resembled the types of projects we observed during our review of the State Formula Grant Program. Many of the special projects either appeared to have a direct service focus or were limited in scope.

Similarities between special and State formula grant projects

We reviewed 146 projects totaling \$15.8 million awarded during the 3 years covered by our review at four HEW regional

offices. We determined that 89 projects (61 percent) and \$7.7 million (48 percent) were directed at activities designed to provide "hands-on" services to the developmentally disabled. These projects appeared to supplement the State Formula Grant Program and did not appear to offer anything which could not have been funded by that program.

In at least one region a regional official told us that these discretionary grants were nothing more than extensions of the formula grant projects. The official justified this action on the basis that the formula grant allotments were insufficient to carry out an effective program in some States. This practice apparently is limited to the regional projects, since we found no instances of national projects providing "hands-on" services.

Another similarity between the special and formula grant projects was their scope of coverage. Generally, formula grant projects served local or statewide service needs, as intended. Many special projects reviewed, which should have a broader scope, were likewise narrowly focused to a single State or, in some instances, to specific areas of a State.

Three of every four regional projects we reviewed appeared to respond to issues and needs of either a single State or certain geographic regions of a State. Only 35 of the 146 projects and 37 percent of the dollars were awarded for national, regional, or multi-State projects. The next table highlights the types of projects funded during the 3 years reviewed:

<u>Project type</u>	<u>Number of projects</u>	<u>Amount</u>	<u>Percent</u>
National	2	\$ 68,400	1
Regional	29	5,290,526	33
Multi-State	4	382,812	3
Single State	71	5,606,847	35
Other (e.g., city)	<u>40</u>	<u>4,495,345</u>	<u>28</u>
Total	<u>146</u>	<u>\$15,843,930</u>	<u>100</u>

National projects had a better record in this regard because 70 percent of the 106 grants appeared to have a national perspective.

It can be argued that, while special projects may immediately benefit only a particular target area (e.g., one State or county), the issue or need addressed in the

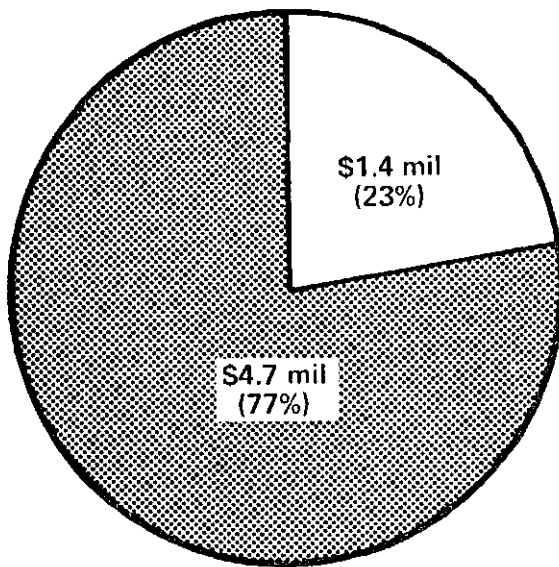
project probably has broader implications and could have a regional or national impact--when replicated or used by others. This may be true, but many of the projects reviewed did not appear to be designed for such widespread application. For example, many of the regional projects were not models or demonstrations of innovative services or techniques. Instead, they appeared to offer conventional services (such as training and community living arrangements) geared to targeted populations within their particular service area. Further evidence indicating these projects were not special was the general lack of dissemination of project results. (See p. 93 for further discussion.)

Public Law 94-103 also intended that special projects expand and improve services for the multihandicapped. We noted the target group for most projects was the multi-handicapped, although many projects were focusing on specific disability groups, such as mental retardation and cerebral palsy. Again, the national projects had the better record, with only 17 percent of the grants targeted for specific disability groups and not the multihandicapped. Forty percent of the regional projects (one-third of funding) went for particular disability groups, with the mentally retarded being the primary beneficiary.

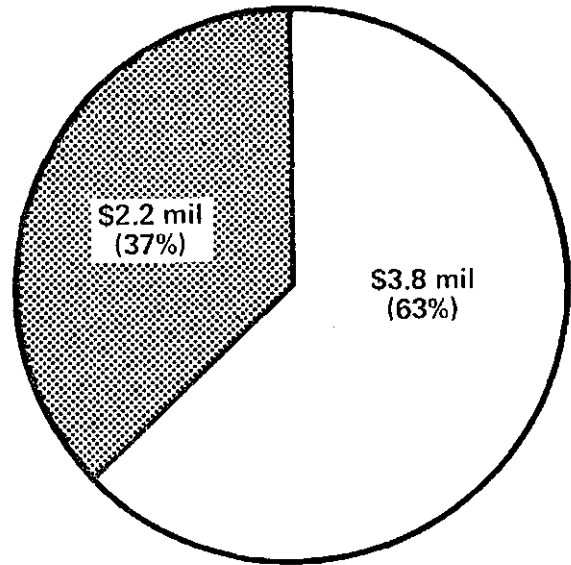
Impact of nondevelopmental disability projects

We noted a substantial portion of the regional funds were used to continue support of projects originally started with HEW discretionary grants under Vocational Rehabilitation and Public Health Services programs. Authorized funding for these projects was discontinued when Public Law 94-103 was passed.

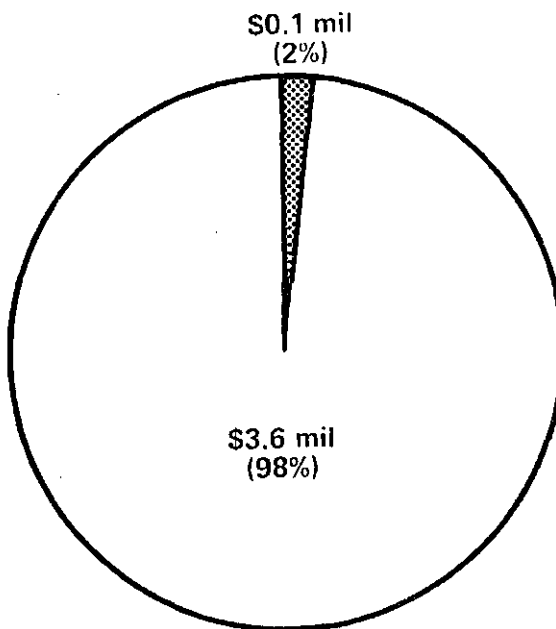
As the series of charts on page 82 depict, the amount and percentage of special project funds going for these non-development disabilities projects was quite high initially and tapered off dramatically by the third year, but over the 3-year period accounted for 44 percent of the \$15.8 million in program funds we reviewed in the four selected regional offices.



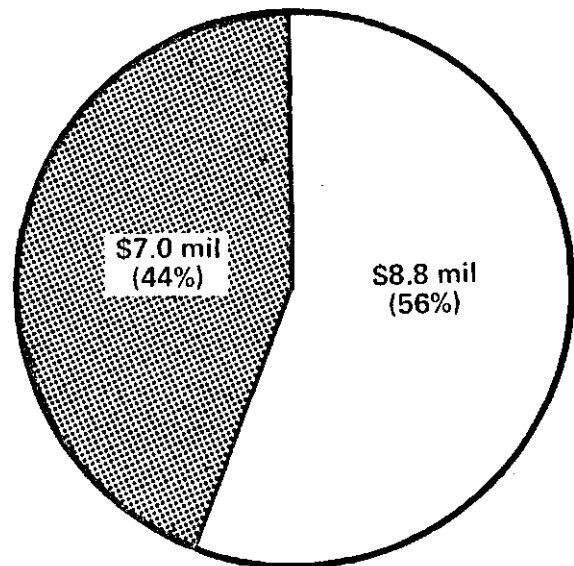
1976



1977



1978



3 Years

NOTE: Shaded areas denote amount and percentage of developmental disabilities special project funds awarded to continuation projects previously supported by Vocational Rehabilitation and Public Health Service Funds.

As the diagrams show, developmental disabilities funds available for new projects were substantially reduced because regional officials continued support for the older projects, many of which were already in their third, fourth, and fifth year of funding. Of the 146 projects we reviewed, 84 projects totaling \$7 million were carryovers from prior non-developmental disabilities legislation.

Recognizing the different purposes of the Special Projects Program and the two older nondevelopmental disabilities programs, the Developmental Disabilities Office instructed the regional offices to continue funding continuation projects only if they clearly supported goals of the new program and related to one or more of the nine objectives cited in the developmental disabilities legislation. (See p. 75.)

To comply with the developmental disabilities objectives, regional officials labeled many of the older projects as demonstration, training, and service improvement projects. However, we found many of these projects primarily focused on direct services. Special project funds were frequently used to place clients in group homes, to support sheltered workshops, to fund various vocational enrichment programs, and to provide a myriad of other "hands-on" services. Even on some of the new projects we found a service orientation, although not as widespread as with the older projects.

We determined that, of the 84 continuation projects, 72 appeared to have a direct service thrust. Further, 17 of the 62 new projects also appeared to be service oriented. Looking at just this one aspect of direct versus indirect service, it was obvious that the Special Projects Programs, at least with respect to the regional projects, were not following the course set by the developmental disabilities legislation. As can be seen, the continuation projects had a significant impact on the direction of the program.

According to an official of the Developmental Disabilities Office, one major reason why regional offices were not allotted any program funds for new projects in fiscal year 1978 was that many projects were too service oriented and did not support the concepts of the Special Projects Program. As this official told us, no policy implications were forthcoming from the regional projects. The Developmental Disabilities Office viewed many of the projects as extensions of the State Formula Grant Program which could be more easily done through the State Planning Councils. In fact, it has recommended shifting a substantial portion of future special projects funds to the formula grant program.

Special projects frequently
used to help administer other
developmental disabilities programs

The Congress authorized HEW to fund special projects for a variety of activities. (See p. 75 for the nine program objectives.) Three of the nine program objectives concern service demonstrations, which indicates that special consideration should be given to projects designed to formulate model programs and service techniques which can be replicated by others. The remaining objectives, broadly categorized, relate to public awareness, coordination, training, gathering/disseminating information, improving service quality, and technical assistance.

Neither the legislation nor implementing regulations prioritized project activities to indicate which types should be emphasized or what portion of the program funds should be made available for each. It was left to the discretion of HEW to decide which projects would best accomplish the purposes of the developmental disabilities legislation.

Our analysis of 122 special projects (60 national and 62 regional) that were funded for \$27.5 million, showed about one-fourth of the projects and program funds went for demonstrations or models. The heaviest concentration, however, was in technical assistance, where one-third of the national projects (39 percent of the dollars) and 18 of the 62 regional projects (42 percent of the dollars) were for this purpose. Our analysis excluded the 84 Vocational Rehabilitation and Public Health Service projects since these generally were not comparable to the new projects under the Special Projects Program.

Training projects and projects designed to gather and disseminate information on the developmentally disabled also ranked high, together accounting for about a quarter of the project dollars. The next table highlights our analysis of project allocations by program objective.

Type	National projects			Regional projects			All projects	
	Number	Amount		Number	Amount		Number	Amount
Demonstrations	15	\$ 5,029,810 (27%)		17	\$2,477,195 (28%)		32	\$ 7,507,005 (27%)
Public awareness	5	886,921 (5%)		4	209,098 (2%)		9	1,096,019 (4%)
Coordination	3	354,835 (2%)		3	297,442 (3%)		6	652,277 (2%)
Technical assistance	20	7,290,452 (39%)		18	3,703,442 (42%)		38	10,993,894 (40%)
Training	4	625,505 (3%)		15	1,597,232 (18%)		19	2,222,737 (8%)
Gather/disseminate	12	3,791,399 (20%)		3	227,522 (3%)		15	4,018,921 (15%)
Improve service quality	1	684,385 (4%)		2	306,246 (4%)		3	990,631 (4%)
Total	60	\$18,663,307 (100%)		62	\$8,818,177 (100%)		122	\$27,481,484 (100%)

Central and regional offices have made extensive use of special project funds to carry out their administration and monitoring responsibilities for the other three major developmental disabilities programs. Citing inadequate resources to do this in-house, developmental disabilities officials often employed consultants to assist State Developmental Disability Planning Councils, University-Affiliated Facilities, and State Protection and Advocacy officials with implementing their programs.

We found that, of the 57 technical assistance and training projects, 32 went to consultants to guide developmental disability program officials in the areas of planning, advocacy, program administration, and evaluation. In addition, the primary beneficiary of 7 of the 12 national projects for gathering and disseminating information were officials administering the other three major developmental disabilities programs. The next table profiles a sampling of the consultant projects geared to help HEW carry out its administrative responsibilities.

<u>Project type</u>	<u>Title</u>	<u>Number of grants</u>	<u>Project amount</u>
National	Management Training For Key Staff Of State Protection And Advocacy Agencies	1	\$ 99,546
	Management Training Program For State Developmental Disability Councils	1	99,303
	Advocacy And Planning For Developmental Disability Consumer Council Members	3	306,785
	Technical Assistance To Developmental Disability Councils	3	1,512,971
	Federal Program Information And Assistance	3	818,499
Regional	Technical Assistance - Public Education	3	304,692
	Planning And Evaluation Project: Developmental Disability Consortium	3	265,000
	University-Affiliated Program Consortium	3	352,798
	Influencing Strategies For State Developmental Disability Councils	3	180,478
	University-Affiliated Facilities Consortium Media Project	2	152,489
	Regional Developmental Disabilities Training And Technical Assistance Center	3	278,960
	Coordination And Delivery Of Training And Technical Assistance Center	2	247,688
	Training And Technical Assistance Through A Bi-Regional Resource Team	2	278,798

In its January 1979 Annual Evaluation Report, the National Advisory Council on Services and Facilities for the Developmentally Disabled pointed out that some technical assistance and training projects have not been very helpful. The Council suggested there is a need for an overview of the total training and technical assistance needs, activities, strengths, and weaknesses. We also believe the Developmental Disabilities Office needs to determine what benefits have been realized from these projects.

OBSERVATIONS ON GRANT AWARD
PROCEDURES AND POSTAWARD
PROJECT EVALUATIONS

To obtain insights about HEW's management of the Special Projects Program, we reviewed several aspects of the grant review and award process and inquired about project evaluations after awards were made.

How projects were selected

Formal independent review panels were utilized during the 3-year period to evaluate proposals for national projects. Panel members had expertise by virtue of their prior involvement in comparable or identical activities. We did not review their qualifications but have no reason to question their credibility.

Using a scale of 0 to 100, the panels rated grantee applications against five factors:

1. Quality of the application (20 points).
2. Technical approach and methodology (30 points).
3. Applicant qualifications (30 points).
4. Relevance of project objective to program goals (10 points).
5. Reasonableness of the proposed budget (10 points).

Our cursory review of panel ratings for a sampling of the applications showed that grants went to applicants scoring the highest average grade.

Panel recommendations were submitted to the Developmental Disabilities Office which, by law, was to consult with the National Advisory Council before awards were made. The Council reported this was done for only 1 of the 3 years (fiscal year 1977 projects). Time constraints the first year and the untimeliness of the Council's meeting the third year prevented the Council from having much input into the final decisionmaking process these other 2 years.

Regional projects were selected in a less formal manner. For the first year, regional directors were allowed much discretion in how their special project allotments would be spent. The Developmental Disabilities Office provided some

guidance for project selection but left procedural aspects of grant review and approval to the regional offices. In the four regions visited, review and approval were done in-house, with no formal independent panels like those established for the national projects. Directors devised their own procedures and developed project priorities based on perceived regional and State needs. Neither the central office nor the National Advisory Council were involved in the final decisions for the first year of projects.

The Developmental Disabilities Office exerted more control over the 1977 regional projects. It required the regions to establish formal review procedures, including the use of independent panels of experts from outside HEW. The central office specified the methodology to be used for screening applications, and regional recommendations for funding had to be submitted to the Developmental Disabilities Office for a second screening. In consultation with the National Advisory Council, the central office determined which projects should be funded.

Regional offices received no new special project funds for 1978. The Developmental Disabilities Office applied the funds which would have been available to the regions to national projects. Earlier we mentioned dissatisfaction with the types of regional projects being funded as a primary reason for the central office not allotting the regions funds for new projects the third year.

Extent of competition

Excluding the 1976 regional projects, which basically were chosen at the discretion of HEW regional officials, mechanisms for creating a competitive atmosphere for special projects were established. We already mentioned the creation of independent review panels, which was one attempt to make awards competitive. Another method employed by HEW was the announcement of grant notices in the Federal Register and the Commerce Business Daily.

In our review of 1 year of responses to the solicitations, we found that, on the average, nine applications for regional projects were received for each project awarded. The response ratio for national projects was about 2-1/2 to 1. While this indicated a fairly good competitive environment, particularly for the regional projects, we noted that only applications for new projects were solicited in this manner. Grant award procedures did not require applications for continuation projects to go back through the independent panel

screenings. Instead, they were to be reviewed by central and regional program officials. According to program officials, once a grantee was initially selected through the competitive process, funding was practically automatic for 3 years. Since most projects continued from year to year, this meant that a substantial portion of each year's program funds were awarded noncompetitively.

Planning Council reviews of regional projects

Public Law 94-103 requires that State Developmental Disability Planning Councils be provided the opportunity to review special project applications. To assure that these projects are consistent with State Plan objectives for the formula grant program, Planning Councils were supposed to receive a copy of all applications for regional projects in their State and were to provide HEW with their comments on the proposals.

We found applicants did not always coordinate with the Planning Councils, that Councils sometimes did not provide comments, and occasionally projects were funded despite disapproval by the Councils. Our analysis involved 146 projects awarded by four regional offices.

For 52 (36 percent) of the projects, regional developmental disability records indicated Councils were not given an opportunity to review and comment on the proposals. Of the 94 proposals which were submitted to the Councils, the Council did not respond to 36. Thus, 88 of the 146 projects were funded with no evidence of Council input. Council feedback on two proposals suggested that the projects would not be useful. For one of the projects, two Councils said the proposed benefits were not worth the cost. Yet in both instances the projects were funded.

Feedback to rejected applicants

There appears to be no uniformity regarding feedback to applicants whose proposals are rejected. One regional office provides minimal feedback, merely informing applicants they have been rejected. It relies on the applicant to follow up, at which time the applicant is told why his/her proposal was not funded. At the other extreme, two regional offices sent letters of rejection and cited reasons why the proposals were not funded. Among the reasons given were: (1) measurable objectives lacking, (2) no provision for disseminating project results, (3) low competitive rating, and (4) no allowance for contingencies or alternative actions if problems occur in carrying out the project.

Neither the Developmental Disabilities Office nor any of the regions we visited had created a mechanism to handle appeals for rejected applicants. Appeal procedures were not required by the legislation or implementing regulations.

Affirmative action compliance

Our review of regional project records showed little attention was given to the requirement that the handicapped be hired and advanced in employment by recipients of program funds. Only 15 of the 146 projects evidenced affirmative action plans. Since we did not visit any of these projects, we could not determine how much the handicapped were hired or advanced. HEW had not accumulated information in this regard.

Grantee contributions to project costs

Public Law 94-103 does not require recipients of special project funds to have an investment in their projects, although Developmental Disabilities Office policy is that grantees contribute at least 10 percent of the costs. Almost one out of every five projects was funded entirely with Federal developmental disabilities money or provided less than the suggested grantee contribution. Furthermore, in discussing non-Federal matching practices with developmental disability officials, we found that amounts cited by grantees were not ordinarily confirmed or verified by them.

Quality of project designs

While most projects appeared to be well designed and reasonable in view of funding and time limitations, we believe some were not. Using the following criteria, we noted 11 projects totaling \$1 million which probably should not have been funded, or at least should have been more closely scrutinized:

- Clarity of purposes and objectives.
- Relevance of project goals to program goals.
- Definition of major project tasks.
- Orderly and systematic achievement of project results.
- Realistic and definitive timetables.

Two of the projects we questioned were also criticized by State Planning Councils. Two others were funded because an HEW regional official was intrigued by the concepts being proposed. One project was funded to supplement a university-affiliated facility's budget, and according to the regional official, the project's objectives were "pie in the sky" and unclear. All of the questioned projects were regional.

We also scrutinized project designs to see whether they included measurable objectives and evaluation components to gauge project performance. While the national projects appeared to be adequate in this regard, many regional projects were not. Twenty-five (17 percent) of the regional projects did not contain objectives in the specificity needed to measure success. Furthermore, 42 of the 146 projects (29 percent) did not include an evaluation component. We believe program officials and the review panels should have given more attention to this matter--that some basic measuring tool should be a condition for funding all projects.

Project monitoring

Postaward fiscal and programmatic project evaluations by developmental disability central and regional officials were a rarity. The officials appeared to be more concerned with reviewing project applications and dispersing program funds than in checking on project performance and accomplishments.

Developmental Disabilities Office guidelines require that each project be visited at least twice a year for monitoring and evaluating performance. These evaluations, coupled with grantee performance reports, are to serve as the basis for continuing or terminating projects. As pointed out before, most special projects were continued for 3 years or longer, yet our review disclosed that program officials rarely conducted critical, indepth onsite evaluations of the projects. Central and regional officials acknowledged they have been remiss in this responsibility, but cited lack of resources (people and funds) for not doing the job.

Program officials rely on grantee self-evaluations to track project performance. Basically, monitoring by central and regional officials is limited to scanning financial and performance reports required to be submitted periodically by grantees. Fund accountability is particularly weak. Grantees initially submit budgets showing how they propose to spend the developmental disability funds. Once the funds are released, program officials have little knowledge about project expenditures, except about the data reported by project officials.

Since they do not audit expenditures and rarely visit the project site, they must rely on grantee integrity and the threat of audit to guard against misuse of project funds. As with the formula grant projects, program officials have little knowledge about how project funds are actually spent since grantees have provided little specific data on expenditures.

We found that many evaluations do not compare results with objectives, so they are of dubious value. We determined that 68 (47 percent) of the 146 regional projects had not been subjected to an indepth critical evaluation which measured project performance against what was proposed.

When we compared project accomplishments to goals and objectives for 138 projects (some national, most regional) which were completed or nearly completed, we found that a number of projects were only partially successful and a few failed:

<u>Our evaluation</u>	<u>Number of projects</u>	<u>Percent</u>
Project was total success	88	64
Project was partially successful	29	21
Project failed	3	2
Information insufficient to make a judgment	<u>18</u>	<u>13</u>
Total	<u>138</u>	<u>100</u>

One measure of project accomplishments not reflected in the above analysis is the extent that project results, both successes and failures, were made available to others. We believe that sharing knowledge and experiences from these projects is of paramount importance. Not only does this allow for more effective use of scarce program funds, but it also can alleviate needless duplication of research and experimentation by others.

In discussing this matter with central and regional developmental disability officials, we noted that new proposals are not routinely checked against projects funded in the past. A proposed project could duplicate a past project and the reviewing officials would not know about it, except by personal knowledge. Projects funded by one regional office were not coordinated with those funded or being considered by another office. One regional official said the Developmental Disabilities Office is expected to spot duplicate projects when

it screens the regional projects before they are approved. Except for two readily available catalogs profiling some of the special projects which have been funded, we observed no mechanism in either the central or regional offices which provided a check for duplication.

Also largely unknown is how much projects have been replicated or project results disseminated for use by others. Neither the central nor regional program officials routinely follow up to see whether grantees share project results or how frequently project experiences are utilized by others. These officials contended it was beyond their capability to ensure dissemination of project results and that they relied on grantees to do this.

With approximately 1 of every 3 developmental disability dollars being spent on special projects, we believe that program officials should assure that these funds are being used effectively and that the results are needed, used, and disseminated to others.

CONCLUSIONS

For the most part, the Special Projects Program has not exhibited itself as unique or special. Much of the \$57 million for the first 3 years of this program appeared to support projects which bear a striking similarity to projects funded under the State Formula Grant Program. This was especially true of the regional projects, many of which were narrowly scoped, not designed for widespread application or replication, and intended to provide direct "hands-on" services to the developmentally disabled. Approximately 60 percent of the 146 regional projects we reviewed were continuations of projects previously funded under Vocational Rehabilitation and Public Health Service programs. The goals of these projects did not parallel the precepts of the Special Projects Program.

Because of the predominance of Vocational Rehabilitation and Public Health Service projects and because many of the new projects funded to meet Public Law 94-103 objectives were still in process, it may be premature to judge the Special Projects Program as good or bad. Our initial impressions, however, were that:

- Many projects could have been funded under the State Formula Grant Program, assuming funds had been available.

- A heavy concentration of program funds, nationally and regionally, went for technical assistance--

informational and training projects to help the Developmental Disabilities Office administer the other three developmental disability programs. Projects addressing other program objectives received less attention.

- The program needs to be better managed by improving grant review procedures, more effective project monitoring and evaluation, and systematically following up on the dissemination of project results.

RECOMMENDATIONS TO THE
SECRETARY OF HEW

We recommend that the Secretary of HEW direct the Commissioner of RSA to:

- Review all projects currently funded under the Special Projects authority and discontinue support to those which are not, or do not hold promise of fulfilling one or more of the objectives of the developmental disabilities legislation.
- Fully inform the Congress on how program funds are distributed between national and regional projects and among the nine program objectives. Information should also be provided on how effective the projects have been in improving the operations of the other developmental disability programs.
- Strengthen grant review procedures so that grants
 - are reviewed by appropriate State Planning Councils;
 - are awarded competitively, including a requirement that continuation projects compete for grant funds;
 - are awarded consistently with affirmative action requirements;
 - are not awarded unless the projects have built-in evaluation components and assurances that project results will be disseminated; and
 - are not awarded for projects that duplicate other efforts.
- Increase monitoring and evaluation efforts.
- Establish a mechanism to routinely follow up on project accomplishments and the dissemination of project results.

CHAPTER 5

UNIVERSITY-AFFILIATED FACILITIES PROGRAM:

IS IT LIVING UP TO EXPECTATIONS?

The University-Affiliated Facilities Program (UAF) has a lot to offer but lacks a clear central focus. From the beginning, the program has been funded from numerous sources with no fixed pattern, vague mission statements, and varying guidelines. This has placed facilities in a precarious "can't win" situation and is an example of trying to serve too many organizations.

Determining whether the program is living up to expectations is not easy because perceptions about what the program should be doing are so varied. The facilities reviewed appeared to be responding to their broad, but rather nebulous mission mandates regarding interdisciplinary training, exemplary service models, research, and technical consultation. But, individual programs differed greatly in complexity, major programmatic thrust, types and numbers of people trained, disciplines represented, and people served, that we could not unequivocally say whether one was better than the other or one was moving toward program goals better than others.

More important, there was a lack of measurement criteria for evaluating the overall program or individual facilities. Although the University-Affiliated Facilities Program has been in existence for over 15 years, HEW has yet to formulate specific standards to gauge program success. The program continues to lack coherence and consistency, and a lot of questions about the program's value remain unanswered.

Funds provided to facilities through the developmental disabilities legislation undoubtedly help the program, especially since they pay various administration and operation costs and free other funds for training, service, and other activities. But, the developmental disability funds also bring expectations which do not always coincide with mandates of other funding authorities. Consequently, the program has achieved only sporadic success in (1) being responsive to the needs of the disabled adult, (2) establishing links with the service community, (3) training parents and nonprofessionals, (4) addressing the needs of the more substantially handicapped, and (5) providing more diversified training and service experiences.

Despite its shortcomings, the University-Affiliated Facilities Program is a contributor to the overall service network for the developmentally disabled. But HEW needs to state program goals and objectives more clearly, combine varying mandates, and formulate a national mission and purpose for the program. The development of standards and measurement criteria is important because it would provide the needed framework within which program strengths and weaknesses can be assessed and determinations regarding program expectations can be made for the program, overall, and for individual facilities.

HISTORICAL OVERVIEW

The University-Affiliated Facilities Program began in 1963 under Public Law 88-164--the Congress authorized funds to construct university-affiliated clinical facilities to:

1. Train physicians and other specialized personnel to serve the mentally retarded.
2. Demonstrate new techniques to diagnose, treat, educate, train, and care for the mentally retarded (exemplary or model services).
3. Provide inpatient and outpatient clinical services to the retarded.

Thus, in their first charter UAFs were clinical and training facilities that provided services, trained staff, and researched new service techniques to help the mentally retarded.

Subsequent legislation, regulations, and guidelines ^{1/} have imposed additional mandates and expectations on the UAF Program. One significant change involved clientele. Originally intended for only the mentally retarded, by law UAFs had to include programs for persons with handicaps caused by cerebral palsy, epilepsy, autism, and other conditions related to or requiring services similar to those needed by the retarded (the developmentally disabled). Subsequent legislation also required that the clientele include complex cases (the substantially handicapped), and adults.

^{1/}In lieu of formal guidelines never issued by HEW, the April 1972 draft guidelines directed UAFs on how to use Federal developmental disability funds and set forth various program expectations.

Another major change concerned training. Developmental disabilities legislation introduced the term interdisciplinary training as a key element of the UAF Program. It emphasized that the UAF programs should include doctors, social workers, pediatricians, therapists, and many other disciplines, who should work together as a team learning what each has to offer in terms of services. Students from various academic backgrounds and professionals in the service community were to be provided a setting where all could learn together under the tutelage of a faculty made up of representatives of all appropriate disciplines.

Program guidelines said UAFs were expected to develop a staff for the complete range of services needed by the developmentally disabled. This meant providing a variety of training opportunities, including graduate and undergraduate programs for students; and workshops, seminars, and orientations for professionals, paraprofessionals, parents, trainers of parents, and others concerned about improving services for the disabled.

In the past, the UAF's service mission expanded. While training has been the intended focus of the UAF Program since it began, facilities were not limited to activities solely in the academic setting. Program guidelines said that UAFs, when developing model service programs, were to use facilities and services of the community and regions within which they operated. This was intended to provide a dimension of reality to their training programs, something not always present in the well-supported services of the facility.

The guidelines instructed UAFs to build better connections with State and local service delivery systems, particularly with the State Developmental Disabilities Planning Councils. UAFs were to pursue activities consistent with the developmental disability State Plans. They were also called upon to provide more direct services as part of their overall training mission.

Finally, the expanded role of the UAF Program included research activities. While they were not expected to get involved with basic or generic research, UAFs were to use applied research techniques to improve their training and service programs. Also implied in the program guidelines were such activities as identifying service and staff needs and designing evaluation tools for training and services.

After the impetus provided by the 1963 legislation, the UAFs were to seek funding sources to operate their training and service programs. From the beginning, UAFs have been funded from numerous sources with no fixed pattern. In HEW two programs have played a significant role--Public Health Service's Maternal and Child Health Service (a major contributor) and the Office of Education's Bureau of Education for the Handicapped (a key supporter).

A third source of Federal funding is the developmental disabilities program. Unlike the programmatic support from the other Federal programs and from State and local sources, the developmental disabilities UAF Program provides what might be termed core support. The Congress intended this to cover basic administrative and other essential costs associated with program initiation and maintenance. This then frees other funds for training, service, research, and related activities. More important, the developmental disability support was supposed to provide a central focus to the UAF Program by combining various mandates and expectations of its diverse backers.

THE EFFECT OF DEVELOPMENTAL DISABILITY CORE SUPPORT APPEARS TO BE MINIMAL

The developmental disability core grants from Public Law 94-103 enabled UAFs to spend other funds on training, services, and related programmatic activities, but generally did not achieve the concomitant expectations of the core support guidelines. At seven facilities, attempts had been made to satisfy varying mandates and missions imposed by different funding sources. The result was that individual facilities mirrored the directives of their primary supporters and differed significantly in programmatic thrust, complexity, disciplines represented, and responsiveness to the developmental disability mandates.

A profile of seven facilities we visited

To determine the impact of the developmental disability core grants and to obtain firsthand knowledge of program operations, we visited 7 of the 37 UAFs receiving core support under Public Law 94-103. Programs were conceptually tied together through four basic elements: training, service, research, and technical consultation. However, individual facilities were so diverse that no two facilities were alike.

The following table profiles the facilities visited and provides an outline of their dissimilarities.

Name of affiliated university

<u>Profile elements</u>	<u>California</u>	<u>UCLA</u>	<u>Southern California</u>	<u>Ohio State</u>	<u>Cincinnati</u>	<u>Temple</u>	<u>Washington</u>
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First year of operation	1973	1969	1966	1967	1967	1972	1963
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Primary academic affiliation	Pediatrics	Child Psychiatry	Pediatrics	Medical	Pediatrics	Human Services	Pediatrics
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Program forte	Genetics Research	Psychology	Nutrition, Education	Psychology, Special Education	Special Education	Human Development	Special Education
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Number of student disciplines	6	12	12	16	20	14	13
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Number of trainees	24	55	147	212	261	121	(b)
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Primary funding source	University	State	Federal: Maternal and Child Health	Federal: Maternal and Child Health	Federal: Maternal and Child Health	Federal: Developmental Disability Core Grant	Federal: Maternal and Child Health
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Programmatic Balance (note a):							
--Training	35%	50%	(b)	38%	40%	(b)	66%
--Services	25%	30%	(b)	32%	47%	(b)	11%
--Research	25%	10%	(b)	28%	11%	(b)	23%
--Technical consultation	15%	10%	(b)	2%	2%	(b)	-

a/Percentages are based on best available information: Faculty/staff hours; program expenditures; or Director's estimate.

b/Not available.

Is developmental disability core support too small to be effective?

On an average, the core grants accounted for about 7 percent of the total fiscal year 1978 income for the seven sampled facilities. Only in the Temple and California cases were the grants significant portions of the facilities' operating budgets. The table on page 101 shows these UAFs had comparatively few financial resources in contrast with the million dollar operations of the other facilities. Overall, the Federal Government was the principal supporter of the UAFs, contributing 58 percent of their total income. Maternal and Child Health, alone, contributed 1 of every 3. dollars and was the major financier of four programs. Of the seven, only Temple did not receive Maternal and Child Health assistance.

The table shows the diverse funding patterns of each UAF. It should be noted that no single source was the major contributor for all the facilities. Also, the State Formula Grant Program provided little support. Only Ohio State and Temple of the seven UAFs we reviewed were receiving funds through the developmental disability planning Councils.

Along with the financial support comes varying mandates and expectations. Maternal and Child Health funds, for example, must be used to support trainees interested in service in the child health field. Only certain disciplines are supported, and students must be full time and studying at least at the post baccalaureate level. Likewise, only certain faculty positions can be funded. Similarly, other grantors, such as the Bureau of Education for the Handicapped, also impose restrictions on the UAFs as to how their funds should be used.

The core grants were supposed to relieve UAFs of various administrative and operational costs associated with operating a facility, and thus free other funds for training, service, and related missions. The developmental disabilities legislation provided minimal guidance for spending these core funds. It stated that they were to assist UAFs in meeting the cost of administering and operating (1) demonstration facilities for providing services for the developmentally disabled and (2) interdisciplinary training programs for personnel needed to render specialized services for the developmentally disabled.

Source of income	Name of affiliated university															
	California		UCLA		Southern California		Ohio State		Cincinnati		Temple		Washington		All seven UAFs	
	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent	Amount	Per- cent
Federal:																
Public Law 94-103/																
Core Grants	\$ 92,102	27	\$ 184,866	5	\$ 92,102	8	\$ 150,143	7	\$ 111,239	5	\$ 92,102	34	\$ 251,467	5	\$ 974,021	7
Public Law 94-103/																
Special Projects	-	-	99,303	3	-	-	290,000	14	66,328	3	-	-	80,739	2	536,370	4
Bureau of Education																
For Handicapped	17,000	5	30,000	1	25,000	2	213,885	10	33,963	1	38,000	14	955,675	20	1,313,523	9
Maternal and Child Health	43,090	12	460,003	12	772,291	69	903,375	43	980,072	42	-	-	1,748,293	36	4,907,124	33
Services	-	-	-	-	-	-	159,596	7	-	-	-	-	570,758	12	730,354	5
Various	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Total--Federal	152,192	44	774,172	21	889,393	79	1,716,999	81	1,191,602	51	1,130,102	48	3,606,932	75	8,461,292	58
State:																
Developmental Disability Councils	-	-	-	-	-	-	184,044	9	-	-	49,714	18	-	-	233,758	2
Various	38,000	11	2,868,000	79	133,531	12	-	-	231,690	10	-	-	187,212	4	3,458,433	23
Total--State	38,000	11	2,868,000	79	133,531	12	184,044	9	231,690	10	49,714	18	187,212	4	3,692,191	25
Local	35,278	10	-	-	100,000	9	136,178	6	692,116	29	7,281	3	89,207	2	1,060,060	7
University	119,892	35	-	-	-	-	84,249	4	243,941	10	86,363	31	918,543	19	1,452,988	10
Total--all sources	\$145,362	100	\$2,642,172	100	\$1,122,924	100	\$2,121,470	100	\$2,359,349	100	\$273,460	100	\$4,801,894	100	\$14,666,631	100

\$ 92,102	27	\$ 184,866	5	\$ 92,102	8	\$ 150,143	7	\$ 111,239	5	\$ 92,102	34	\$ 251,467	5	\$ 974,021	7
-	-	99,303	3	-	-	290,000	14	66,328	3	-	-	80,739	2	536,370	4
17,000	5	30,000	1	25,000	2	213,885	10	33,963	1	38,000	14	955,675	20	1,313,523	9
43,090	12	460,003	12	772,291	69	903,375	43	980,072	42	-	-	1,748,293	36	4,907,124	33
-	-	-	-	-	-	159,596	7	-	-	-	-	570,758	12	730,354	5
152,192	44	774,172	21	899,393	79	1,716,999	81	1,191,602	51	\$130,102	48	3,606,932	75	8,461,392	58
38,000	11	2,868,000	79	133,531	12	-	-	231,690	10	-	-	187,212	4	3,458,433	23
38,000	11	2,868,000	79	133,531	12	184,044	9	231,690	10	49,714	18	187,212	4	1,692,191	25
35,278	10	-	-	100,000	9	136,178	6	692,116	29	7,281	3	89,207	2	1,060,060	7
119,892	35	-	-	-	-	84,249	4	243,941	10	86,363	31	918,543	19	1,452,988	10
\$345,362	100	\$3,642,172	100	\$1,122,924	100	\$2,121,470	100	\$2,359,349	100	\$273,460	100	\$4,801,894	100	\$14,666,631	100

Although formal guidelines were never issued by HEW, Developmental Disabilities officials stated that they considered their April 1972 draft guidelines to be the program's mandates. These guidelines specify how the funds should be spent and commission UAFs to expand their activities beyond the mandates and expectations of their other supporters.

The guidelines imply the core grants should pay all or some of the salaries and related expenses of key facility personnel, i.e., directors, administrators, program coordinators, and others who determine how the facility should operate. Also, salaries of support staff and various operational costs (such as supplies, building maintenance, utilities, printing and duplicating, and housekeeping staff) could be paid. Ineligible for core support are faculty salaries, trainee support, and services.

In reviewing funds used by the seven UAFs during fiscal years 1976-78, six allocated at least 75 percent of their core funds for personnel costs. The Cincinnati UAF used only one-third of the funds for salaries, spending the greater portion for facility operating costs. This UAF was also the only one not using developmental disability funds to pay any of its key personnel. The number of key people paid a full or partial salary from the core grants at the other UAFs varied from 3 to 10 during the period. These positions generally were occupied by people responsible for key segments of the facility programs (i.e., directors and UAF management). Three of the UAFs had improperly allocated a portion of their core grants to salaries of five faculty and service personnel.

According to the guidelines, the core grants, by paying the salaries of key UAF people, were intended to move the UAF programs in directions not necessarily mandated by other programs. For example, UAFs were to include the disabled adult in their programs. Developmental disabilities in addition to mental retardation and complex cases were also to be targeted. Training experiences were to be more diversified, extending to all academic levels and to parents and paraprofessionals. Attention was to be given to community outreach and research.

Increased expectations from the developmental disabilities legislation were not met with increased funds to expand the UAF training and service programs. The core grants could not be used specifically for programmatic activities, instead,

it apparently was hoped that by funding key positions the UAFs would broaden their missions, utilizing resources available from other funding sources.

UAF directors interviewed said that the core grants have had a significant influence on program direction. But, they added every UAF must operate a program that reflects the mandates of their funding sources. For example, if the Bureau of Education for Handicapped contribution is large, a classroom training program will result. If the Maternal and Child Health grant is large, or the UAF is located in a children's hospital, the program will be for children.

Most of the directors felt the core grant, however small, acts as a vital bonding agent to unite fragmented funding sources and mandates, and directs the use of funds toward the developmental disability goals. Only one director indicated that his program would not be hampered if the core support did not exist. The others said their programs would continue, but would not be the same. One said his program would revert to a narrow focus within pediatrics. Another said several faculty and disciplines would be dismissed. Coordination (inside and outside the UAF) would be more difficult, according to another director. While two directors felt there would be no major redirection in their programs, they indicated a further entrenchment of Maternal and Child Health influence would result. Finally, one director believed that undergraduate programs might be phased out of his facility.

The Director of the American Association of University-Affiliated Programs was even more emphatic about the vitalness of the developmental disability support. He compared core support to a person's blood--it is a small percentage of total body weight, but removing it would cause certain death. According to the Director, the dollars themselves are not important; it is the fact that they represent a central focus and specific ideals that other funding sources, with their diverse interests, would not continue.

We are not convinced, however, that the core support has had such a dramatic impact on the UAF Program. In reviewing the activities of the sampled facilities, we observed that movements toward the developmental disability expectations have been started but full success is far from reality. The next few sections highlight our observations of training, service, research, and technical consultation activities conducted by the seven facilities visited. Where information was available from other UAFs, we also included this.

Training

UAF Programs should include a provision for interdisciplinary training: an integrated educational process involving interdependent contributions of several disciplines to increase understanding of attitudes, values, and methodology of participating disciplines. While the developmental disabilities guidelines strongly support this concept, they do not provide standards to address such matters as disciplinary mix, i.e., how many and what types of disciplines should interact to make the training effective.

In the table on page 99, the number of disciplines involved in the UAF Programs visited ranged between 6 and 20. However, in practical training and service settings, interdisciplinary teams rarely approached this degree of interaction. While the Cincinnati UAF, with 20 disciplines represented in the program had between four and eight generally interacting on a case, the other UAFs usually had fewer disciplines working together.

The guidelines expanded the UAF training mission to include disciplines other than those normally found in the health-oriented and education-based programs of Maternal and Child Health and the Bureau of Education for the Handicapped. Specialists were to be developed in other disciplines, such as physical education, recreation, sociology, anthropology, music therapy, law, and administration.

To determine which disciplines predominated nationally and at selected UAFs, we analyzed trainee records compiled by the American Association of University-Affiliated Programs for 1977-78 trainees. The records contained information on six of the seven UAFs we visited. According to the American Association, a trainee is one who is receiving systematic, continuous training in a broad range of professional functions at a UAF.

Based on information from 33 UAFs, health and education disciplines dominated the UAF scene, undoubtedly the result of the strong backing provided the UAF Program by Maternal and Child Health and the Bureau of Education for the Handicapped. The national reports showed a total of 58 disciplines and 3,319 trainees (for which data were collected) in the 33 UAFs. Significantly, six health and education disciplines accounted for 60 percent of all trainees, as shown in the next table.

<u>Discipline</u>	<u>Number of Trainees</u>	<u>Percent</u>
Special education	664	20
Nursing	355	11
Dentistry	306	9
Medical social work	244	7
Speech pathology	227	7
Nutrition	<u>206</u>	<u>6</u>
Other disciplines (52)	2,002	60
	<u>1,317</u>	<u>40</u>
Total	<u>3,319</u>	<u>100</u>

By contrast, the developmental disability-influenced disciplines account for only a small portion of the trainees. As shown in the next table, only 6 percent of 3,319 trainees had disciplines specifically mentioned in the developmental disability program guidelines.

<u>Discipline</u>	<u>Number of Trainees</u>
Physical education	65
Developmental disabilities	47
Recreation	34
Music therapy	27
Administration	11
Social anthropology	10
Law	<u>3</u>
Total	<u>197</u>
Percent of all trainees (3,319)	<u>6</u>

Overall, the UAFs we visited had the same poor trainee record for disciplines encouraged by the developmental disability guidelines. However, as the next table shows, two UAFs made significant strides in getting these disciplines in their programs.

<u>UAF</u>	<u>Total</u>	<u>Number of trainees</u>	
		<u>Developmental disability discipline</u>	
California	24	0	
UCLA	55	0	
Southern California	147	0	
Ohio State	212	31	(15%)
Cincinnati	261	4	(2%)
Temple	121	16	(13%)
Washington	(a)	(a)	
Total	<u>820</u>	<u>51</u>	(6%)

a/Not available.

Unlike the Maternal and Child Health mandate to train graduate candidates, the developmental disability guidelines encourage a broad range of training opportunities, including undergraduate programs. Short-term workshops and orientation experiences are encouraged as opposed to the full-term course program. Reports on 33 UAFs show a wide range of training opportunities being provided. Of the 3,498 trainees for which data were collected (includes the 3,319 previously discussed) 38 percent were undergraduates. A summary of trainees by academic level is shown in the next table.

<u>Academic level</u>	<u>Number of trainees</u>	<u>Percent</u>
Undergraduate	1,349	38
Masters	1,305	37
Doctoral	514	15
Professional	275	8
Other	<u>55</u>	<u>2</u>
Total	<u>3,498</u>	<u>100</u>

Extensiveness of training, as measured by hours of classroom, clinical, research, and community-based experiences, also varied but indications were that greater emphasis was placed on long-term training. As the next table shows, almost three of every four trainees in the 33 reporting UAFs were exposed to 41 or more hours of training experiences.

<u>Training hours</u>	<u>Number of trainees</u>	<u>Percent</u>
1-40	913	26
41-160	1,035	30
161-500	905	26
Over 500	<u>645</u>	<u>18</u>
Total	<u>3,498</u>	<u>100</u>

Regarding type of training, clinical experiences predominated in the 33 facilities. This was true at every academic level, as the next table shows.

<u>Academic level</u>	<u>Type of training</u>		
	<u>Classroom</u>	<u>Clinical</u>	<u>Research/ Community</u>
	<u>-----(percent)-----</u>		
Undergraduate	20	65	17
Masters	20	63	19
Doctoral	5	55	40
Professional	10	69	22

(Note: Dual mode training may result in some training counted twice, thus resulting in percentages over 100.)

The UAFs we visited varied in some respects from these profiles. For example, the California and UCLA facilities provided programs almost exclusively for graduate professional students. Also, over 60 percent of the trainees at the Temple (84%), UCLA (93%), and California (64%) UAFs received 161 or more hours of training--far above the overall average of 44 percent for the 33 facilities. Finally, classroom training was more in evidence at Ohio State and Southern California UAFs than at other facilities.

The UAF directors indicated they were not given enough freedom to operate their training programs. Disciplines needed approval by their departments, advisory committees, or their principal funding source. The directors recognize that more diversified training opportunities would enhance their programs. They told us they could use additional funds to expand their community outreach and adult programs, for example. However, since these are activities encouraged by the developmental disability guidelines, the directors said this is where the funds will be taken.

The Director of the American Association of University-Affiliated Programs contended that what is needed is a parallel adult funding authority that would provide for adults the way Maternal and Child Health provides for children. He suggested that Vocational Rehabilitation could be placed in the UAF Program to fulfill this role.

Services

UAFs are intended to be a part of the total service delivery system. While their main mission is not the provision of services, UAFs are expected to enhance their interdisciplinary training programs by providing opportunities for observation and practice in settings (i.e., their *OWN* clinics or community facilities) where direct services are provided.

Responding to the mandates of their primary funding sources, UAFs have been accredited with notable achievements in their service programs, particularly in the areas of diagnosis, treatment planning, and medical care. However, they have not been as successful in fulfilling their developmental disability expectations. Instead of serving all age groups, as intended, UAFs have concentrated on child and adolescent care. Our analysis of available data on new clients served by 18 facilities, including the seven we visited, showed 91 percent of the clients were aged 17 or under. Of the seven, only Temple was noticeably responsive to the adult population. The next table summarizes our analysis by age of new clients served in fiscal year 1978.

Age groups of clients served	Name of affiliated university								Total
	California	UCLA	Southern California	Ohio State	Cincinnati	Temple	Washington (note b)	11 Others	
0-5	169 (69%)	64 (30%)	(a) (a)	103 (45%)	223 (44%)	- -	170 (58%)	2,577 (50%)	3,306 (48%)
6-17	28 (11%)	120 (56%)	(a) (a)	100 (44%)	284 (55%)	107 (44%)	122 (41%)	2,200 (43%)	2,961 (43%)
Over 18	50 (20%)	30 (14%)	(a) (a)	26 (11%)	6 (1%)	134 (56%)	4 (1%)	343 (7%)	593 (9%)
Clients served	<u>247</u>	<u>214</u>	(a)	<u>229</u>	<u>513</u>	<u>241</u>	<u>296</u>	<u>5,120</u>	<u>6,860</u>

a/Data not readily available. UAF officials told us there were no adults served, that most patients were under the age of 10.

b/Data were not readily available for all clients served. The 296 represents new clients served only in the facilities' Experimental Education Unit, one of two major components of the UAF. Also, data at the facility were not recorded for same age groupings as above. The figures shown for the over 18 category could be slightly understated since the UAF recorded 7 clients served in its 13 to 18 age grouping.

The developmental disability legislation directs the UAFs to serve other disabilities, such as cerebral palsy, epilepsy, autism and dyslexia, along with mental retardation. Services were also to be provided to the substantially handicapped. Data compiled nationally and at our selected UAFs did not categorize clients according to the five classifications in the developmental disabilities legislation, although some data were available on mental retardation clients. Therefore, it was impossible for us to determine what efforts had been made to serve all types of developmentally disabled.

Determining what emphasis was placed on serving the more complex cases was difficult because of insufficient data and the absence of a uniform definition for substantially handicapped. Based on retardation levels of 6,100 clients served at 17 UAFs (including all of our sampled facilities except the Southern California UAF, for which comparable data were not available), we noted only 1 of every 4 clients was either moderately, severely, or profoundly retarded. The Temple UAF had the highest percentage of clients in these categories. Our analysis, summarized in the table on the next page, suggests that the UAFs have made some attempts to include the substantially handicapped in their programs, but much more needs to be done.

The developmental disability guidelines encourage UAFs to use community facilities in place of their own clinics, whenever feasible, so trainees have the opportunity to see the problems encountered by agencies serving the disabled. The UAF directors told us that they use community facilities whenever possible or practical. We noted much of the services were being provided in the UAF clinics where special lab equipment, a more controlled environment, more effective feedback and follow through, and faculty and student availability exist.

Research

The Director of the American Association of University-Affiliated Programs told us that research is the most neglected of the four major UAF program areas. We believe there are two reasons for this. First, UAF funding generally goes for training and services, with little left over for research. Second, and more basic, is an apparent disagreement of UAF's research mission.

Retarda- tion levels of clients served (note a)	Name of affiliated university						
	<u>Califor-</u> <u>nia</u>	<u>UCLA</u>	<u>Ohio</u> <u>State</u>	<u>Cincin-</u> <u>nati</u>	<u>Temple</u>	<u>Wash-</u> <u>ington</u> (note b)	<u>Others</u> <u>Total</u>
No re- tarda- tion	28 (19%)	51 (26%)	4 (7%)	235 (59%)	7 (3%)	141 (48%)	2,612 (55%) 3,078 (51%)
Mild	- -	51 (26%)	21 (37%)	59 (15%)	33 (13%)	13 (4%)	823 (17%) 1,000 (16%)
Moderate	1 (1%)	38 (19%)	7 (12%)	43 (11%)	60 (25%)	101 (34%)	486 (10%) 736 (12%)
Severe	- -	19 (9%)	3 (5%)	16 (4%)	92 (38%)	30 (10%)	324 (7%) 484 (8%)
Profound	2 (1%)	5 (2%)	4 (7%)	9 (2%)	45 (19%)	- -	163 (4%) 228 (4%)
Unknown (Note c)	120 (79%)	36 (18%)	18 (32%)	35 (9%)	4 (2%)	11 (4%)	345 (7%) 569 (9%)
Clients served	151	200	57	397	241	296	4,753 6,095

a/Based on intelligence.

b/Data were not available for all clients served by this UAF. Tabular data show levels of retardation for clients served in only one of the facility's two major components, the Experimental Education Unit. Also, this UAF did not differentiate between severe and profound cases of retardation. We classified them all as severely retarded for purposes of presentation.

c/Not yet diagnosed.

Public Law 94-103 does not address UAF research specifically. Instead, in defining what a UAF is, it talks in terms of demonstration facilities providing interdisciplinary training programs to render services. The new developmental disabilities legislation, Public Law 95-602, lacks additional information, although it does say that UAFs are to conduct applied research programs to produce more efficient and effective methods for service delivery and training. Also, the developmental disability guidelines are rather sketchy in describing the UAFs' research objectives:

1. Develop data regarding service and manpower needs.
2. Design methods to evaluate training and service programs.
3. Accumulate and evaluate clinical information on clients served.

We do not take issue with the research expectations cited in the guidelines. They are commendable goals. But, is this what was intended? Should UAFs be doing other types of research, and specifically what type of activity constitutes research? We do not believe these questions have been addressed sufficiently.

In April 1976, the American Association of University-Affiliated Programs issued a report "Perceptions of and Expectations for Future Role and Mission of University-Affiliated Facilities." The report summarized what various groups associated with the UAF Program believed the program was all about and what purpose it served. One of the matters addressed was the UAF's research mission. The perceptions and expectations voiced by such people as UAF directors, chairpersons and staff of the State Planning Councils, and HEW regional directors, varied significantly. Some felt the UAFs should not be limited to applied research, that some biological research should also be conducted. Some said emphasis should be on clinical research. Others believed it was more in the UAF's mission to do behavioral and social science research.

The research activities at seven UAFs we visited showed some of all types, including basic research at two of the facilities. However, in discussions with UAF officials and review of project records having research activities, we concluded that most research is inseparable from training,

services, and technical consultation. At all facilities, research appeared to be a by-product of other UAF missions. For example, many of the demonstration projects being conducted had an element of research, but basically were intended to serve as training devices.

One area where the UAFs could do a better job is disseminating their research results. In the seven UAFs we reviewed, the findings generally were not shared outside the UAF network. If development of new knowledge and discovery of new applications for service delivery are to be totally effective, we believe this information should be shared with the service community.

Technical consultation

The developmental disability guidelines stress the importance of UAFs' maintaining close relationships with the State Planning Councils to assure implementation of the State Plans under the Formula Grant Program. In effect, UAFs should actively participate in the planning process for improving services to the developmentally disabled. UAFs should provide technical assistance to the Councils, public and private agencies, service providers, and others who can benefit from their knowledge.

While data were not readily available showing the extent to which UAFs are providing technical assistance nationally, our review at seven facilities showed much activity in some areas, not so much in others. The UAFs were very active in continuing education, in-service training (versus pre-service training of students) of professionals, and a myriad of other community outreach efforts. Workshops, seminars, conferences, and various types of orientation programs were being conducted by all the UAFs we visited. The in-service training and continuing education programs were generally short lasting from 1 hour to several days.

Attendees generally consisted of professionals, such as nurses, physicians, administrators, therapists, school teachers, and various other service providers. The number of participants varied from facility to facility, from a few hundred to several thousand annually. To a lesser extent, parents of the developmentally disabled were also targeted for these training sessions. UAF involvement with paraprofessionals appeared to be minimal, although we noted some facilities were developing programs for these groups through local community colleges.

Technical assistance was provided to numerous organizations and groups, such as hospitals, community facilities, local service groups, State agencies, colleges, and professional and private organizations. We noted, however, that relationships between the UAFs and the State Planning Councils appeared to be sporadic. In two facilities, it appeared to be an on-again, off-again relationship. Occasionally, the Councils would involve the UAFs in their planning efforts and would award them grants (under the Formula Grant Program) to carry on particular projects.

The table on page 100 shows that only two of the facilities were getting funds from the Councils. Only two of the seven UAFs, Cincinnati and Washington, had a representative on the planning Councils, although some directors told us they send a UAF representative to the Council meetings.

MORE ATTENTION NEEDS TO BE GIVEN
TO PROGRAM DIRECTION, IMAGE
BUILDING, AND MEASUREMENT CRITERIA

Since it began, the UAF Program has had to respond to mandates and expectations of several funding sources, without central direction. As a result, the program lacks uniform standards to measure performance.

Program lacks effective
central direction

HEW has not established a coherent national policy for the UAF Program which provides a central focus to the varying mandates and expectations of its many financial backers. Hamstrung by nonuniform and somewhat contradictory guidelines of its supporters, UAFs do not fit the image of any one program and are in a constant struggle to live up to varying expectations, while at the same time trying to clarify their exact role.

In its 1976 Annual Evaluation Report, the National Advisory Council On Services And Facilities For The Developmentally Disabled observed that the most serious problem with the UAF Program were the lack of clearly defined roles, goals, objectives, and program direction--particularly in relation to the developmental disabilities program. The Council called for direct and specific HEW leadership in this regard.

During our fieldwork, we saw no evidence of the strong central direction and leadership that the Council suggested. An example was the failure of HEW to approve official guidelines for the UAF Program. The 1972 draft guidelines which the Developmental Disabilities Office provisionally enforced, did not provide the type of concrete and pragmatic guidance needed to direct the program. Several vital matters are not addressed in the guidelines: types and amounts of training to be provided, how UAFs should be balanced programmatically, and how the developmental disability core grants should be used to mesh the varying mandates of other funding authorities.

The UAF Program also lacked any regulations to specifically clarify what the UAFs should be doing. Basically, the HEW regulations reiterated the broad mandates of Public Law 94-103. The regulations did reemphasize, however, that priority consideration should be given to facilities demonstrating an ability to provide services in the community rather than within the institutional setting. We found no evidence to indicate this requirement was ever considered in the funding of UAFs.

In late 1977, the Developmental Disabilities Office developed a long range strategy for guiding the future of the UAF Program. The strategy addressed several key issues:

1. Issuance of a policy statement with respect to Program missions and objectives.
2. Development of a unified and coordinated inter-agency grant application process to alleviate conflicts among varying funding sources.
3. Development of UAF standards and quality assurance mechanisms.
4. Determine manpower needs.
5. Require closer coordination between the UAF and State Formula Grant Programs by getting Planning Councils more intimately involved in UAF application processes.

This long range strategy was never approved by HEW. The UAF Program remained in limbo.

Officials of the Developmental Disabilities Office indicated to us that HEW has no firm long range plans for the UAF Program. This was also confirmed in our discussions with HEW regional personnel. No additional facilities are anticipated. UAFs which are supported with developmental disability funds are the same ones which have been supported for years. This predetermined funding strategy allows no new facilities to enter the UAF network.

Officials of the Developmental Disabilities Office told us they do not have the resources to properly monitor the program, that they rely on the regional offices to do this. Regional officials said they had inadequate staff and travel funds to effectively monitor the UAFs in their regions. They also cited insufficient guidance from the central office regarding UAF evaluations and program administration as another reason for little monitoring. Several national and regional projects have been awarded to consultants who are to provide guidance and technical assistance to the UAFs. These projects may provide valuable assistance to the UAFs, but we question whether consultants should be planning the UAF Program.

Program needs to
improve its image

In its April 1976 report on perceptions and expectations of the UAF Program, the American Association of University-Affiliated Programs said UAFs should attempt to integrate with and complement the service delivery network to become an integral part of the comprehensive service delivery system. Our review indicated that UAFs have only partially succeeded in this regard.

As part of our review of the State Formula Grant Program, we asked Planning Council members whether UAFs in their States have been active contributors to the service system. Of the 38 members interviewed, 10 said UAF contributions were poor. They said UAFs

- could be more selective in their training, that some is not needed,
- do not follow up on their training,
- are not getting out into the community and providing direct services,

- are not communicating with the Planning Council,
- are self-serving, and
- are contributing nothing.

Fourteen gave UAFs a fair to good appraisal. They cited the following as examples of what UAFs have done:

- Helped the Planning Council reorganize.
- Informed the Councils about their activities.
- Did a good job training professionals.
- Provided good diagnostic services.

Significantly, 14 of the 38 members interviewed either had no idea what the UAFs were contributing or had no perception about what UAFs should be doing.

For some, the UAFs have an "ivory tower image." The Director of the American Association of University-Affiliated Programs felt this image is the result of (1) facilities being attached and closely associated with universities, (2) service providers feeling threatened by involvement with professionals and intellectuals, and (3) UAFs not always being able to respond to the short-term immediate needs of the service community. This image is fostered by a general reluctance of the UAFs to go outside their facilities and work directly with service providers.

We believe UAFs must improve their image within the service community by demonstrating they want to become a full partner in the service network.

Standards needed to measure program performance

Conceptually, UAFs are linked through their interdisciplinary training and exemplary service missions. Realistically, UAFs do not have specific criteria and standards to objectively measure program performance overall, or for individual programs. The UAF Program is characterized by a great deal of autonomy and diversity. Individual facilities vary considerably in complexity, programmatic thrust, disciplines represented, and the nature and extent of their

training, service, and related activities. In short, UAFs have had considerable freedom in operating their programs.

Greater precision in defining the mission of the UAF Program and delineating what constitutes an acceptable program are needed if progress toward meeting goals is to be measured and individual programs are to be held accountable for their operations. There currently exists no effective mechanism for gauging overall program performance or for comparing one UAF against another to retain the good ones or, if they exist, to seek out those that are not doing well. Consequently, the same UAFs continue to be supported, regardless of performance.

Changes under Public Law 95-602

The current developmental disabilities legislation requires that UAF standards conditionally be established before core support is continued under this program. HEW nominally complied with this mandate by issuing general standards in August 1979. However, as stipulated, these were not to be construed as performance standards which could be used to measure quality and quantity of program and individual facility "achievements. HEW does not have adequate information to develop such standards, but has contracted with a consultant to produce performance standards.

To give more specific direction to the UAF Program, the new legislation officially mandates several activities not cited in previous developmental disabilities legislation. Public Law 95-602 specifically addresses the need to focus on persons of all ages and those who are substantially handicapped. The legislation also implies a continuing and active relationship between UAFs and Planning Councils. Finally, to have a closer network of various Federal programs supporting the UAFs, the legislation calls for a joint review of UAF applications by all Federal agencies providing funds to a UAF.

CONCLUSIONS

It is too early to tell what impact the new requirements of Public Law 95-602 will have on the UAF Program. However, the key will be the development of definitive performance standards to provide a much needed framework within which program strengths and weaknesses can be assessed and determinations regarding program expectations can be made in general and for individual UAFs.

HEW has not issued guidelines for the UAF Program, developed specific regulations to make UAFs accountable for their activities, and established a national policy or strategy for the program.

The UAF Program lacks coherence and consistency primarily because perceptions and expectations about what it should be accomplishing are varied. This creates an unsettling situation which must be corrected if the program is to be recognized as a vital part of the overall developmental disability service network.

RECOMMENDATIONS TO THE SECRETARY OF HEW

We recommend that the Secretary of HEW assure that the Commissioner of RSA establishes goals, objectives, and performance standards for the UAF Program supported with developmental disabilities funds and periodically evaluates the supported facilities.

SPECIAL INTEREST GROUPS

CONTACTED BY GAO

1. Association for Children with Learning Disabilities (Derwood, Maryland)
2. Epilepsy Foundation of America (Washington, D.C.)
3. National Association for Retarded Citizens (Washington, D.C.)
4. National Society for Autistic Children (Washington, D.C.)
5. Spina Bifida Association/Washington Area (Washington, D.C.)
6. United Cerebral Palsy Association (Washington, D.C.)
7. Council for Exceptional Children (Reston, Virginia)
8. American Association on Mental Deficiency (Washington, D.C.)
9. National Association of State Mental Retardation Program Directors, Inc. (Arlington, Virginia)
10. National Advisory Council on Services and Facilities for the Developmentally Disabled (Washington, D.C.)
11. North Carolina Developmental Disabilities Council, National Conference on Developmental Disabilities (Washington, D.C.)
12. National Institute on Child Health and Human Development, Mental Retardation and Developmental Disabilities Branch (Bethesda, Maryland)

EXTENT OF COVERAGE IN GAO REVIEW
OF THE FOUR PROGRAMS AUTHORIZED
UNDER PUBLIC LAW 94-103

<u>STATE FORMULA GRANT PROGRAM</u>	Funds <u>allocated</u> (Fiscal years 1976-78)
Total program	\$ 97,688,395
GAO-selected States:	18,940,686
--California	7,498,072
--Pennsylvania	5,469,327
--Ohio	4,597,071
--Washington	1,376,216
GAO coverage of total program	<u>19.4%</u>
 <u>STATE PROTECTION & ADVOCACY PROGRAM</u>	
Total program	\$ 7,850,000
GAO-selected States:	1,468,455
--California	588,439
--Pennsylvania	409,502
--Ohio	360,802
--Washington	109,712
GAO coverage of total program	<u>18.7%</u>
 <u>UNIVERSITY-AFFILIATED FACILITIES PROGRAM</u>	
Total program	<u>a/\$</u> 15,964,759
GAO-selected facilities:	2,826,417
--California, Southern California, UCLA	999,274
--Temple	261,679
--Ohio State and Cincinnati	840,279
--Washington	725,185
GAO coverage of total program	<u>17.7%</u>

APPENDIX II

APPENDIX II

Funds
allocatedSPECIAL PROJECTS PROGRAM

Total program	\$ 56,864,465
GAO-selected projects:	34,507,237
--Projects of national significance	18,663,307
--Region III	2,794,313
--Region V	7,440,793
--Region IX	2,328,199
--Region X	3,280,625
GAO coverage of total program	<u>60.7%</u>

ALL FOUR PROGRAMS

Total for the 4 programs	\$178,367,619
GAO-selected States, facilities, projects	57,742,795
GAO coverage of total program	<u>32.4%</u>

a/Includes core support only--not feasibility and satellite center funds.

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