

**THE
DEVELOPMENTAL
DISABILITIES
ACT**

a View and Review

DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Social and Rehabilitation Service

Rehabilitation Services Administration

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FOREWORD

This publication combines a discussion of the provisions *of* the Developmental Disabilities Services and Facilities Construction Act P.L. 91-517 together with examples of developmental disability programs carried out in the last three years.

It is intended to serve as a basic pamphlet helpful to the grant applicants and recipients as well as to the parent, consumer, and professional seeking a wider knowledge of developmental disability programming.

DISCRIMINATION PROHIBITED-Title VI of the Civil Rights Act of 1964 States: "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal assistance." Therefore, the developmentally disabled grants program, like every program of activity receiving financial assistance from the Department of Health, Education, and Welfare, must be operated in compliance with this law.

THE DEVELOPMENTAL DISABILITIES ACT-

A VIEW AND REVIEW

When the Developmental Disabilities law went into effect on October 30, 1970 it emphasized a major step forward in providing for better and quicker services to the mentally retarded and others with disorders of neurological origin requiring similar care and treatment.

After the more than three years in which the law has been in operation 11 is time for us to evaluate the impact of the activities on behalf of the developmentally disabled which were made possible by this law.

The Act, P.L. 91-517. provides for services to an estimated 8.700,000 children and adults who have a developmental disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological handicapping condition found by the Secretary of the Department of Health, Education, and Welfare to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals AND the disability originates before such individual attains the age of eighteen, continues or can be expected to continue indefinitely, and constitutes a substantial handicap to such individual.

The bill marked a new approach in the Federal Government's efforts to provide a better life for the developmentally disabled by transferring power to the State and local levels where people involved in the problems of providing services to individuals with developmental disabilities could aid in the problem-solving process. The law amends Public Law 88-164 and authorizes appropriations for an extensive list of services under two titles: Title I covering formula grants and projects of national significance; and Title II covering grants for interdisciplinary training programs in institutions of higher learning, and for university-affiliated facilities to house these programs.

WHAT THE ACT DOES

The Act authorizes grants for:

- Developing and implementing a comprehensive and continuing plan;
- Providing services to the developmentally disabled;
- Constructing facilities for the housing of services;

- Training specialized personnel for services and research;
- Developing or demonstrating new or improved techniques of services;
- Constructing "university-affiliated facilities" to house the interdisciplinary training of professional personnel; and
- Administering and operating demonstration and training facilities.

FORMULA GRANT PROGRAM

Title I, Part C of the Act authorizes formula grants to States for planning, administration, services, and construction of facilities; and the system of formula grants to the States accounts for 90% of the expenditures under Title I (Up to 10% of the formula-grant money may be set aside to fund projects of national significance.)

Formula-grant money is allocated to the States on a formula basis; it then becomes State money and is administered by one or more State agencies.

Prime Concepts of Formula Grants

- The Federal money supports a wide range of diversified services in terms of lifetime human needs of the developmentally disabled. The Act provides for the comingling of funds under this program with those of other State programs. The comingling facilitates the development of comprehensive services for the developmentally disabled through the combination and integration of both specialized and generic services of several State agencies, yet it does not impose a set pattern of services on any one State. Such diverse State agencies as health, welfare, education, and vocational rehabilitation may be participants in the program.
- Comprehensive planning for needed services and facilities thus providing for more efficient and effective utilization of existing human and fiscal resources at all levels.
- Development of new or innovative programs to fill gaps in existing services and to extend the reach of currently available services to new groups of individuals.
- Integration of services and resources of all State, regional, and local agencies assisting the developmentally disabled.
- Development of strategies at the State level for the successful implementation of the program.

(Use of the Federal funds must not bring about a decrease in the levels of State and local efforts in providing services to persons with developmental disabilities. To the extent feasible, the program should stimulate an increase in efforts.)

Authorization Level

FY 1971	S60	million
FY 1972	\$105	million
FY 1973	\$130	million
FY 1974	\$32.5	million

The amount actually appropriated by Congress in any fiscal year has been less than the authorized level.

Allotments

1. Formula for making State allotments. The formula for allotments to States includes factors which are widely used in determining State allocations:

- Population
- Per capita income
- Need for services and facilities for the developmentally disabled.

2. Minimum allotment. The minimum allotment to all States, District of Columbia, and Puerto Rico is \$100,000 in each fiscal year.

3. Reallocation of funds. Funds allocated to a State for a fiscal year and not required for the program in that year shall be available for reallocation to other States.

4. Maximum allocation for construction. The ceiling on the portion of allotted funds which a State may use for construction projects is established by the Secretary. It may not exceed 50 percent of the State's allotment.

Use of Funds

Formula grant money allotted to States may be used for:

1. Planning for the delivery of services and for the construction of facilities. Each State program operates under a Federally-approved comprehensive plan reviewed and revised annually by the State Planning and Advisory Council. The plan must provide for technical assistance to poverty areas and intensive involvement of agencies and consumers at all levels.

2. Work of the State Planning and Advisory Council. The State Planning and Advisory Council sets the pace and direction for the development and growth of the program through its members drawn from each of the principal State agencies, local agencies, non-governmental organizations and citizens groups concerned with developmental disabilities, consumers of services (at least one-third of the membership of a State Council must represent consumers).

3. Administration by one or more designated State agencies which must administer or supervise the plan. Formula-grant money along with State funds must provide for adequate administration of the program which operates through two mechanisms:

The State Planning and Advisory Council
The Designated State Agencies.

It is usual for one or more State agencies to be designated to supervise or administer the State plan. It is also allowable for an interdepartmental agency such as a commission or board to be designated to administer or supervise the administration of ALL portions of the plan. In the case of construction it is somewhat different; only a single State agency must be designated as the sole agency for administering or supervising the administration of grants for construction under the State plan.

4. **Delivery of Services.** Use of formula-grant money by the States for support of services is designed to fill gaps in the existing service structure in the State and for expansion of services to groups of the developmentally disabled not now receiving services.

"Services for persons with developmental disabilities" means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habitation or rehabilitation of an individual affected by such a disability. The term "services" includes:

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

5. **Construction.** Federal funds may be used to assist in the construction of facilities for the developmentally disabled to house the services listed above. Under terms of the legislation "construction" means:

- a. the construction of new buildings; the acquisition, expansion, remodeling and alteration of existing buildings;
- b. initial equipment for such buildings;
- c. architect's fees.

6. **State Plan Requirements.** There are further stipulations besides those already mentioned before a State can qualify for an allocation of formula-grant funds. The State plan must:

- a. describe how other pre-existing State-Federal programs provide for the developmentally disabled and how the new program will complement and augment, but not duplicate, these programs. At least nine specific programs must be taken into account:
- vocational rehabilitation
 - public assistance
 - social services
 - crippled children's services
 - education for the handicapped
 - medical assistance
 - maternal and child health
 - comprehensive health planning
 - mental health
- b. show how needed services and facilities for the mentally retarded and other developmentally disabled will be provided;
- c. show forth policies and procedures to insure effective expenditures of funds under the plan;
- d. contain assurances that:
- the funds will be used to strengthen services;
 - part of the funds will be made available to local groups or agencies;
 - Federal funds will be used to supplement, rather than supplant, non-Federal funds that would otherwise be available;
 - the State itself will bear a reasonable share of the non-Federal cost of implementing the plan;
- e. provide for the maintenance of standards with respect to the scope, quality, and administration of facilities and services under the State plan;
- f. require administering State agencies to make reports and keep records;
- g. provide that special financial and technical assistance will be given to urban and rural poverty areas in securing services and facilities;
- h. describe the methods that will be used to assess the effectiveness of State programs under the plan;
- i. develop a program for the construction of facilities based on an inventory of existing facilities and survey of need;
- j. provide for the determination of priorities for meeting needs for services and construction of facilities.

Regulations and Standards

The Secretary is required to issue general regulations to cover:

The kinds of services and categories of persons which may be included in the formula grant program.

Standards as to the scope and quality of services.

- The general manner in which a State shall determine priorities for services and facilities, with special consideration for poverty areas.
- General standards of construction and equipment.

Eligible Participants in Programs

State, regional, and local public and nonprofit agencies and organizations are eligible for participation in programs under this Act.

Appropriations

Appropriations for the formula-grant portion of the developmental disabilities program were:

FY 1971	\$11,215,000
FY 1972	21,715,000
FY 1973	21,715,000 (President's Budget)
FY 1974	32,500,000 (less 5%)

Federal Share

The Federal share of support varies according to the type of program to be supported as indicated in the following chart:

Program	Non-Poverty Areas	Poverty Areas
Services, Planning, and Administration	75% of eligible expenditures for services, planning and administration activities funded during fiscal years 1971 and 1972. 70% of such expenditures funded during fiscal years 1973 and 1974.	Up to 90% of eligible expenditures for services, planning and administration projects for the first 24 months during which the project is funded. Up to 80% of such expenditures for the next 12 months during which the project is funded.
Construction	Up to 66-2/3% of eligible construction costs.	Up to 90% of eligible construction costs.

Obligations

Over the three-year period from 1971 to 1973 obligations of the formula-grant funds have been:

Planning Administration

<u>Fiscal Year</u>	<u>Services</u>	<u>Construction</u>	<u>Totals</u>
1971	\$ 9,187,929	\$1,914,921	\$11,102,850
1972	17,575,891	2,666,704	20,242,595
1973	<u>18,391,532</u>	<u>1,910,028</u>	<u>20,301,560</u>
Totals	\$45,155,352	\$6,491,653	\$51,647,005

The Act is seen as providing for an expanded capacity for diagnosis, treatment, and training, with the desired goal of successfully integrating the developmentally disabled into the larger community.

Accomplishments

Formula-grant program accomplishments by the States since the enactment of P.L. 91-517 have concentrated on:

- identifying the developmentally disabled populations
- protecting current and future client needs
- increasing and coordinating currently available public and private services
- undertaking innovative pilot projects
- building needed new facilities.

In order to attain the ultimate goals of the Act formula-grant projects undertaken in some of the areas are briefly reviewed here:

1. **Identification of Clients and Coordination of Services.** Many States are concentrating on the problem of adequately identifying their developmentally disabled citizens and offering them comprehensive and coordinated services. As the President's Task Force on Coordination for the Mentally Retarded stated in 1963. "The mere existence of an array of essential services is not enough. To be worthwhile and productive, they must be brought within easy reach of all citizens at the time they are needed."

- *Colorado* has been coordinating the work of agencies and developing resource groups to identify and provide the most appropriate services for their developmentally disabled clients.
- *Kansas* is emphasizing utilization of professionals for consultation, referral, and follow-up of the developmentally disabled clients.
- The *Ohio* Department of Mental Health and Mental Retardation is joining with the State Advisory Council and Ohio State University in a computerized tracking system for the developmentally disabled.
- *Louisiana* is establishing a similar system utilizing generic health, social, and education agencies throughout the State.
- The United Cerebral Palsy Association of Tarrant County, *Texas*, in coordination with local radio stations, newspapers, 85 schools, and

878 churches, is establishing with State funding a Central Registry of the Cerebral Palsied in the county

2. **Transportation.** Missouri, New Jersey, Alabama, and Iowa focused during 1973 on developing multi-purpose transportation systems suitable for the needs of the developmentally disabled.

3. **Advocacy.** With the goal of having a trained advocate for each developmentally disabled person in the Slate, several States are exploring advocacy programs. They are training advocate volunteers to become familiar, with the treatment needs of their clients and to act as a liaison between their clients and the professionals serving them in order to insure that necessary changes in the treatment are made.

- *Ohio* has developed plans fur an advocacy system directed by a joint board drawn from members of the Epilepsy Foundation, the United Cerebral Palsy Association, and the Ohio Association for Retarded Children. Private agencies interested in participating would refer their staff members to this board for (raining to become supervisors of local programs. These supervisors, in turn, could then train local volunteers. These training sessions for supervisors would be conducted through a university-affiliated facility.
- The *Nebraska* and *Colorado* Associations for Retarded Children are developing State-wide training programs for advocates. also.
- *Kansas* has proposed a follow-along service to provide lifetime counseling and advocacy to developmentally disabled persons.
- The *District of Columbia* is utilizing the Information Center for Handicapped Children for training advocates.

4 **Domiciliary Services (Deinstitutionalization/Institutional Reform).** *Alabama* is developing twelve group homes as alternitives to institutions, while *New Jersey* has planned community-centered, semi-independent living arrangements for developmentally disabled persons. The Greater Omaha Association for Retarded Children, using a grant from *Nebraska*, is establishing developmental hostels to serve retarded and handicapped children currently institutionalized. Each hostel will offer physical therapy, recreation, education, and t raining in social skills as well as day care.

With Slate funding the Sioux City chapter of the *South Dakota* Association tor Retarded Children has created a half-way house to provide group living for employed, developmentally disabled men,

5. **Prevention/Early Treatment.** *Rhode Island* is funding a collaborative program for children age birth to three years through the Association of Home Health Agencies, the Meeting Street School, the Trudeau Memorial Training Center, and the Child Development Center,

Home development programming for children with physical disabilities is provided by the Meeting Street School and the Child Development Center. while the Trudeau Center provides a multi-sensory stimulation program on site for children under age two, and a day care center for two-and three-year

olds who have already received home training from the two above-mentioned agencies. The Association of Home Health Agencies working with public health nurses acts as a liaison between the clients and the other agencies involved and supervises parental follow-through.

The *Connecticut* Office of Mental Retardation has developed an enrichment mother-child treatment program aimed at preventing retardation through remedial training for two- to four-year olds and their mothers in high risk poverty areas. Through the Wheeler Clinic in Plainville, Connecticut is funding another early prevention program beginning with prenatal counseling among high-risk populations and moving on to an early identification and stimulation program for developmental problems in which the parents and a multi-disciplinary team become involved.

6. Services. The following list shows the kinds of services being provided by the States and the proportion of funds allocated to provide them in FY 1973.

<u>Services</u>	<u>Percent</u>
Diagnosis	5.2
Evaluation	4.6
Treatment	7.4
Personal Care	5.2
Day Care	7.9
Domiciliary	13.2
Special Living Arrangements	8.5
Training	10.2
Education	5.6
Sheltered Employment	7.0
Recreation	4.2
Counseling	6.1
Protective and Socio-legal	2.3
Information and Referral	5.4
Follow Along	4.0
Transportation	3.0
	<u>99.8</u>

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

Title I, Part C of the Act provides for up to 10% of the formula-grant money to be set aside for projects of national significance.

Approval of Grants

Applications for special projects are received, reviewed, approved, and funded directly by the Federal Government.

Types of Projects

The funds reserved by the Secretary may be used for projects of national significance which will

- demonstrate new or improved techniques in the delivery of services,
- assist in meeting special needs of the disadvantaged for services and facilities,
- be of special national significance in carrying out purposes of this title.

The fifteen projects of national significance presently underway deal specifically with advocacy, technical assistance, and deinstitutionalization/institutional reform. They are designed to serve as models for the States in developing strategies in these fields. They are:

1. **Advocacy.** In response to President Nixon's directive of November 16, 1971, to Federal agencies to "take steps to strengthen the assurance of full legal rights for the retarded," the Division of Developmental Disabilities has funded two projects in the area of advocacy.

The first of the two Federal advocacy projects is a review study. It is a joint effort on the part of the Rehabilitation Services Administration, the Office of Education, and the National Institute of Mental Health to stimulate, monitor, and evaluate ongoing advocacy projects. Eleven organizations national and community-oriented—that have been working in the area of advocacy have had their work reviewed and evaluated,

The second project of national significance advocacy program has been financed under the co-mingled funds of the Division of Developmental Disabilities and the Bureau of Education for the Handicapped and supports the development of a comprehensive National Legal Center for Law and the Handicapped located at the University of Notre Dame, Indiana. The Center has been organized to examine and promote the legal rights of handicapped persons. Its primary function is to provide aid to the handicapped through knowledge, understanding, and implementation of the law. The goal of the Center's activities is to secure the legal rights of all handicapped persons to treatment, education, and social services.

2. **National Conference of State Planning and Advisory Councils.** Approximately 1000 members of State Planning and Advisory Councils, the National Advisory Council, and representatives of other public and private non-profit groups interested in developmental disabilities convened in Washington in November 1972 to promote communications, coordination, and cooperation among the State Councils and the National Advisory Council. The conference provided an opportunity for an exchange of technical information, a discussion of the relationship between local, State and Federal programs, and an examination of the topics of national concern.

3. **Individualized Data Base.** Under the aegis of the Pacific State Hospital in California a two-purposed data project is in operation; namely, data collection and data processing. Data collection not only aids in casefinding, but the

computerized system makes possible the tracking of the developmentally-disabled clients. The pilot project was originally set up in western states; now other states are requesting participation.

4. **The Developmental Disabilities Technical Assistance System (DD/TAS)** was established at the University of North Carolina and is delivering requested technical assistance and consultation to the State and Regional Developmental Disability Councils.

5. **Deinstitutionalization/Institutional Reform.** President Nixon's two major national goals in regard to mental retardation are: to reduce by half the occurrence of mental retardation in the United States before the end of the century and to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful living in the community. In line with these goals, programs are being funded in the areas of deinstitutionalization and institutional reform by both the Federal Government and the States.

To aid in the development of projects of national significance, grants were made available to each State Developmental Disabilities Planning Agency. The grants covered up to 90% of the costs of one year's planning activities.

6. **Joint Commission on Accreditation of Hospitals.** A grant to the Accreditation Council for Facilities for the Mentally Retarded (Joint Commission on Accreditation of Hospitals) is enabling the organization to survey all public and private institutions for the retarded by 1976.

7. **Community Alternatives to Institutional Reform.** Pilot projects are being carried on in 14 States to demonstrate methods of reducing populations of State institutions for the mentally retarded. The purpose of these model projects for deinstitutionalization is to help States devise more effective methods of meeting the needs of developmentally disabled persons who are currently inappropriately placed in institutional settings or at the risk of being unnecessarily institutionalized.

NATIONAL ADVISORY COUNCIL

The Council advises the Secretary on regulations, and studies and evaluates the effectiveness of programs in carrying out the purposes for which they were established. Provision has been made for the Council to receive technical assistance and be furnished necessary data.

UNIVERSITY AFFILIATED FACILITIES

Title II of the Act provides for a new program of Federal support for interdisciplinary training programs in institutions of higher learning as well as for the construction of facilities to house these programs.

Training Programs

Purpose

Grants are authorized to cover the costs of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to persons with developmental disabilities.

Authorizations

FY 1971	\$15 million
FY 1972	17 million
FY 1973	20 million
FY 1974	4.25 million

Appropriations-UAF Services

FY 1971	0
FY 1972	\$4.25 million
FY 1973	4.25 million
FY 1974	4.25 million

Approval of Grant

Applications are reviewed, approved, and funded in the Regional Offices of SRS.

Federal Share

Up to 75% of approved grant.

Priorities

Priority consideration is given to projects in which arrangements have been made with a junior college to participate in the program proposed in the application.

Maintenance of Effort

The application must be supported by reasonable assurance that the grant will not result in a decrease in the level of effort at State and local levels in providing services to persons with developmental disabilities and in the support of training of persons to provide services to the developmentally disabled.

UAF Construction Program

Authorizations

FY 1971	\$20 million
FY 1972	20 million
FY 1973	20 million
FY 1974	no authorization

Appropriations

FY 1971	0
FY 1972	0
FY 1973	0
FY 1974	0

Planning Grants for Construction

Although P.L. 91-517 provides that in any fiscal year an amount not to exceed 2% of the construction appropriation would be available to cover part of the costs of the planning of approved projects for construction under the UAF construction program there have been no appropriations for UAF construction, so this provision is inoperative.

UAF Accomplishments

The university-affiliated program, originally a construction program, provided construction support to twenty centers including six additional facilities at different campus locations. From the beginning UAF training operations have been funded from numerous sources with no fixed pattern.

The Act expanded the forms of the UAF program to involve new programs for other developmental disabilities as well as mental retardation.

About one half of the UAFs are represented on State Planning and Advisory Councils. In several instances, the UAF representative is chairman or vice-chairman. Of particular note has been the success in affiliating a number of junior colleges with the UAF centers.

Each university-affiliated center has responded to the guidelines in unique ways and to the differing needs of the communities served, consequently there is no format on which we might summarize the many activities.

FURTHER INFORMATION

The programs provided for in this Act are administered by the Rehabilitation Services Administration (RSA), Social and Rehabilitation Service, Department of Health, Education, and Welfare. The RSA staff in the Regional

Offices listed below are available for consultation regarding provisions in past and current legislation:

Boston:	Rehabilitation Services Administration Department of Health, Education, and Welfare Joint F. Kennedy Federal Building Government Center Boston, Massachusetts 02203	Region 1
New York:	Rehabilitation Services Administration Department of Health, Education, and Welfare Federal Building, 26 Federal Plaza New York, New York 10007	Region II
Philadelphia:	Rehabilitation and Self-Support Services Department of Health, Education, and Welfare Post Office Box 12900 Philadelphia, Pennsylvania 19108	Region III
Atlanta:	Rehabilitation Services Administration Department of Health, Education, and Welfare 50 - 7th Street, N.F., Room 404 Atlanta, Georgia 30323	Region IV
Chicago:	Rehabilitation Services Administration Department of Health, Education, and Welfare 300 South Wacker Drive, 30th Floor Chicago, Illinois 60007	Region V
Dallas:	Rehabilitation Services Administration Department of Health, Education, and Welfare 111 Commerce Street, 9th Floor Dallas, Texas 75202	Region VI
Kansas City:	Rehabilitation Services Administration Department of Health, Education, and Welfare 601 East 12th Street Kansas City, Missouri 64106	Region VII
Denver:	Rehabilitation Services Administration Department of Health, Education, and Welfare 19th and Stout Streets Federal Office Building, Room 9017 Denver, Colorado 80202	Region VIII

San Francisco: Rehabilitation Services Administration
Department of Health, Education, and Welfare Region IX
Federal Office Building
50 Fulton Street
San Francisco, California 94102

Seattle: Rehabilitation Services Administration
Department of Health, Education, and Welfare Region X
Arcade Building
1321 Second Avenue (MS 505)
Seattle, Washington 98101

