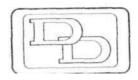


DIEVIELOPMIENTAL
DISABILITIES
PROGRAM
The 1975 amendments



U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE Office of Human Development Developmental Disabilities Office Washington, D.C. 20201



The Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103), which became law in October 1975, broadens the definition of developmental disabilities and the strategies for strengthening services and safeguarding individual rights. The Act amends PL 88-164 to which major amendments were made by PL 91-517 in October 1970 (the Developmental Disability Services and Facilities Construction Act).

A developmental disability is defined as a disability attributable to mental retardation, cerebral palsy, epilepsy, autism (or dyslexia resulting from these), or any other conditions closely related to mental retardation in terms of intellectual and adaptive problems. The handicap must originate before age 18, can be expected to continue indefinitely, and constitutes a substantial handicap.

Program

The Act authorizes grants for the purposes of:

- developing and implementing a compprehensive and continuing plan for a system of services;
- providing services to developmentally disabled persons;
- · construction to house services
- training specialized personnel for services and research;

- developing or demonstrating new or improved techniques of services;
- demonstration and training grants; and
- renovating and modernizing universityaffiliated facilities for the interdisciplinary training of professional personnel.

In addition, the Act provides for a mechanism to establish and protect the rights of persons with developmental disabilities and to assure that they obtain quality services needed for maximum development physically, psychologically, and socially.

FORMULA GRANT PROGRAM

Formula grants are authorized to States for planning, administration, services, and construction of facilities for developmentally disabled persons.

Prime concepts

States are responsible for strategies in the development and implementation of the program.

 Federal support is provided for a wide range of diversified services in terms of lifetime human needs of persons with developmental disabilities. The Act provides for the comingling of funds under this program with those of other programs. This facilitates the development of comprehensive services for the developmental disabled through the combination and integration of the efforts in both specialized and generic services of several State agencies representing diverse areas such as health, welfare, education, and rehabilitation, without imposing a set pattern of services on any one State.

- Comprehensive planning of services and facilities provides for more effective use of existing resources.
- Programs are developed to fill gaps in existing service systems and to expand the reach of existing services to new groups of individuals.
- Services and resources are integrated in all States and local agencies which might effect the developmentally disabled.

Use of Federal funds must not result in a decrease in the level of effort by States and localities in providing services to persons with developmental disabilities. This program should stimulate an increase in effort.

Authorization level:

Fiscal year 1976 \$40 million Fiscal year 1977 \$50 million Fiscal year 1978 \$60 million the amount actually appropriated

(The amount actually appropriated by Congress in any fiscal year may be less than the authorized level.)

Allotments

- 1. Formula for making State allotments: The formula includes the types of factors widely used in determining allocations: population, per capita income, and need (for services and facilities).
- 2. Minimum allotment: Minimum allotment to all States, District of Columbia, and Puerto Rico is \$150,000 in each fiscal year, and not less than \$50,000 for the Virgin Islands, American Somoa, Guam, and the Trust Territories of the Pacific Islands.
- 3. Reallotment of funds: Funds allotted to a State not required for the program in that year may be reallotted to other States.
- 4. Maximum allotment for construction: At the option of the State, alloted funds may be used for construction. The ceiling on the portion of funds a State may use for allocation to construction projects may not exceed 10 percent of the State's allotment.
- 5. Federal share: Up to 75 percent of the eligible cost (90 percent in poverty areas) for planning, administration, provision of services, and construction.

USE OF FUNDS

Formula grants to States may be used for planning, administration, delivery of services, and construction.

Planning

A major thrust in the formula grant program is the development of a plan for a coordinated and integrated service-delivery system. Planning also is to be a continuing process reaching from the State level to local levels and providing technical assistance to poverty areas and involving agencies and consumers at all levels. States may cooperate with other States to provide services more effectively.

Administration

Federal funds may be used to provide for adequate administration of the program. Federal approval is not required for construction projects.

Delivery of services

The services supported by Federal funds are designed to fill gaps in the existing service structure in the State and for expanding services to groups of developmentally disabled persons not now receiving services. The program is not designed to relieve States for support of existing 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 habilitation or rehabilitation of a disabled person.

In most instances, clusters or combinations of services are provided rather than individual discrete services. Services supported under the formula grant program include:

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

Construction

Federal funds may be used to help in constructing facilities to house services for developmentally disabled persons. Under this legislation, "construction" means (1) construction of new buildings; (2) acquiring, expanding, remodeling, or altering existing buildings; (3) initial equipment for buildings; (4) architects' fees. Cost of land is not included.

MECHANISMS FOR ADMINISTERING PROGRAM

The formula grant program operates through two main mechanisms: a State Planning Council and designated State agency.

State Planning Council

The Council sets the direction and the pace of growth of the program through its work in planning and evaluation. It must evaluate the State plan at least once a year and submit revisions to the HEW Secretary. Council membership includes representatives of each of the principal State

agencies and of local agencies and nongovernmental organizations which provide DD services; at least one-third of the Council must be made up of consumers or their representatives.

Designated State agency

One or more State agencies may be designated for the administration of the State plan. An interdepartmental agency such as a commission may be designated to administer all portions of the plan.

A single State agency must be designated as the sole agency for administering construction grants.

State plan

To receive an allocation, a State's plan must be approved by the HEW Secretary. In addition to the requirements concerning the State Planning Council and the designation of State agencies to administer the plan, the goal-oriented plan must:

(1) Describe how other existing State-Federal programs provide for the developmentally disabled and how new programs will complement and augment, but not duplicate, these programs. At least nine specific programs are to 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

(2) Contain a plan to eliminate inappropriate placements in institutions and to improve the quality of care and the state of surroundings for persons who are in institutions. Support the establishment of community programs designed for the care and habitation of persons with developmental disabilities. Provide for fair and equitable arrangements for employees of institutions which are affected by the removal of large number of persons with developmental disabilities.

- (3) Determine priorities for services. Provide for maintaining standards with respect to the scope, quality, and administration of facilities and services under the State plan. Show how services and facilities will be provided. Provide for a design for implementing the State plan and for periodic evaluation. Provide that the administering State agencies will make reports and keep records.
- (4) Contain assurance for the protection of human rights of all persons with developmental disabilities receiving services under the Act.
- (5) Set forth policies and procedures to insure effective expenditures of funds. Contain assurances that 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), and the State itself bears a reasonable share of the non-Federal cost of implementing the plan.

- (6) Provide financial and technical assistance to urban and rural poverty areas in securing services and facilities.
- (7) Provide for early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children.
- (8) Provide for counseling, program coordination, follow-along services, protection services, and personal advocacy on behalf of developmentally disabled adults.
- (9) Provide for an evaluation system and describe the methods to be used to assess the effectiveness of State programs under the plan.
- (10) Provide for the maximum utilization of available community resources, including volunteers serving under the Domestic Volunteer Services Act of 1973.

REGULATIONS AND STANDARDS

The HEW Secretary is required to issue general regulations to cover:

- the kinds of services which are needed to provide adequate programs, as well as persons to be served
- standards as to the scope and quality of services
- the general manner in which a State shall determine priorities, in addition to the consideration given to poverty areas.
- general standards of construction and equipment

Eligible participants

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

Applications for Federal funds under the formula grants program should be sent to the **State Planning Council** or **State developmental disability agency,** not to HEW.

PROTECTION AND ADVOCACY SYSTEM

Respecting individual rights has become an important aspect of the development disabilities act. A condition to receiving an allotment under the formula grants program, for fiscal year ending October 1977, is that the State provide the HEW Secretary assurances that it will have in effect by then (1) a system to protect and advocate the rights of persons with developmental disabilities, and (2) the system will be backed up by legal and administrative authority and be independent of any State agency providing developmental disabilities services.

The Secretary may not allot money to a State under the formula grants program for a fiscal year beginning after September 30, 1977, unless the State has a protection and advocacy system in effect.

EMPLOYING HANDICAPPED PERSONS

Also required in the Developmental Disabilities Act is that States take affirmative action in employing and advancing qualified handicapped persons.

SPECIAL PROJECTS

Special project grants may be made to public or nonprofit organizations for the following:

- improve the quality of services
- demonstrate established programs which hold promise of improving services
- help eliminate attitudinal and environmental barriers through public awareness and public education

coordinate available community resources

demonstrate services to persons with developmental disabilities who are economically disadvantaged

- provide technical assistance related to services and facilities
- a provide training of specialized personnel
- a demonstrate new or improved techniques in the development of services a gather and disseminate information

Approval of grant

Applications for special projects are received, reviewed, approved, and funded directly by the Federal government. Projects are to be consistent with the State plan.

Authorizations:

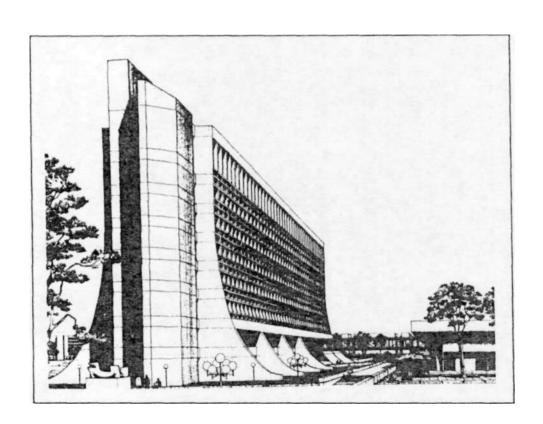
Fiscal year 1976 \$18 million Fiscal year 1977 \$22 million Fiscal year 1978 \$25 million

(The amount appropriated by Congress may be less than the amount authorized.) Federal share: Up to 90 percent of the cost.

(The amount appropriated by Congress may be less than the amount authorized.)

Priorities: Priority consideration is given to projects which have made arrangement for 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.

The Act provides that the HEW Secretary will reserve at least 25 percent of the amount appropriated for the special projects grant program for supporting projects of national significance.



UNIVERSITY AFFILIATED FACILITIES

Federal support under this Act is given to university-affiliated facilities (UAFs) to assist them in meeting the cost of operating demonstration facilities for the provision of services for persons with developmental disabilities and for interdisciplinary training of specialized personnel.

Satellite centers

Included in the program are "satellite centers" for spreading the work of UAFs to areas not presently served. Satellites function as community or regional extensions in offering training and services over an extended area.

Training programs

Grants may be made for administering and operating demonstration facilities and interdisciplinary training programs for persons who render specialized services to persons with developmental disabilities.

Authorizations:

Fiscal	year	1976	\$15	million
Fiscal	year	1977	\$18	million
Fiscal	vear	1978	\$21	million

Construction program

Grants are made to help in meeting the costs of renovating or modernizing UAF buildings or to pay part of the costs of establishing satellite centers, provided studies have proved their feasibility.

Authorization:

Fiscal	year	1976	\$3	million
Fiscal	year	1977	\$3	million
Fiscal	year	1978	\$3	million

(The amount appropriated by Congress may be less than the amount authorized.)

Federal share: Up to 75 percent of the eligible costs of the construction project (90 percent in poverty areas).

NATIONAL ADVISORY COUNCIL

The Developmentally Disabled Assistance Act provides for the establishment of a National Advisory Council on Services and Facilities for the Developmentally Disabled.

The purpose of the Council is to advise the HEW Secretary on regulations; study and evaluate the effectiveness of programs provided under the Act to help persons with developmental disabilities; review grants; approve projects of national significance and develop policies for special projects. The Secretary is to consult the Council on special studies. The Council may receive technical assistance, and the Secretary is required to make available the assistance and data the Council needs in carrying out its functions.

The Advisory Council has 25 members, 9 representing Federal agencies, 16 from the field, including State and local governments, institutions of higher education, and organizations representing consumers of services. At least five members represent State or local public or private agencies, and at least five must be developmentally disabled or the parents or guardians of developmentally disabled persons.

ESTABLISHING AND PROTECTING RIGHTS

The Act makes these findings respecting the rights of persons with developmental disabilities:

- Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation.
- The services should be designed to maximize the developmental potential and be provided in a setting that is least restrictive of the persons's personal liberty. a The Federal government and the States have an obligation to assure that public funds are not provided to any institutional or other residential program when treatment is not appropriate and when minimum standards are not met in diet, medical care, safety, visiting hours, and personal treatment, including use of physical or chemical restraints.
- All programs for persons with developmental disabilities should meet standards which assure the most favorable possible outcome for those served.



Habilitation plan

States receiving Federal support must assure the HEW Secretary that every program has a habilitation plan for each developmentally disabled persons receiving services under the Act and that they provide for annual review of each plan. The Act stipulates that habilitation plans shall:

- · be in writing;
- be developed jointly by representatives of the service-delivery organization, the disabled person, and, where appropriate, the disabled person's parents or other representative.
- provide for evaluation of program
- be reviewed at least annually
- contain a statement of specific services to be provided, identifying personnel and agencies involved and duration of services
- specify the role and objectives of the persons implementing the plan

Studies

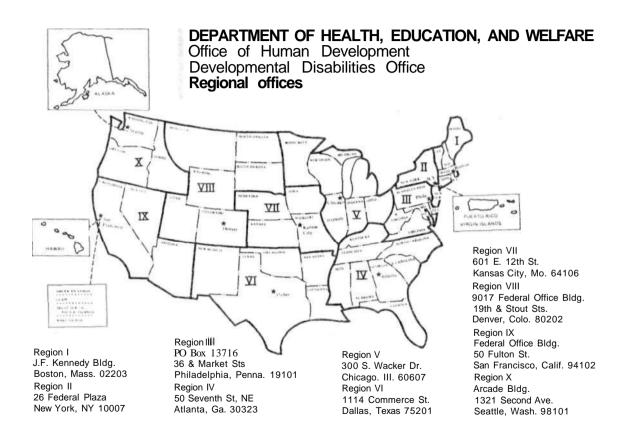
The Act requires the HEW Secretary to conduct three studies: (1) develop a system for evaluating services provided to persons with developmental disabilities

through government programs funded under this Act (within two years); (2) review and evaluate the standards and qualify assurance mechanisms applicable to facilities and community agencies under various authorities in HEW (within 18 months); and (3) determine the conditions of persons which should be included as developmental disabilities (within months), and an independent study to determine the appropriateness of the basis of the definition of developmental disability; and the nature and adequacy of other Federal programs for persons with disabilities not included.

Information

Programs provided for in this Act are administered by the Developmental Disabilities Office in HEW's Office of Human Development. Following is a list of the 10 regional offices, and regional staff members are available to explain the provisions of this legislation.

Photos courtesy of the President's Committee on Mental Retardation.





U.S. Department of Health, Education and Welfare Washington, D.C.

Official Business



Postage and Fees Paid by U.S. Department of Health, Education and Welfare

HEW-391