

**THE DEVELOPMENTAL DISABILITIES ASSISTANCE  
AND BILL OF RIGHTS ACT**

LEGISLATIVE HISTORY OF THE ACT

**THE 1970 AMENDMENTS**

The Developmental Disabilities Services and Facilities Construction Amendments of 1970, P.L. 91-517. constituted the first congressional effort to address the needs of a group of persons with handicaps designated as developmentally disabled. P.L. 91-517 amended the Mental Retardation Facilities and Community Health Centers Construction Act of 1963. The 1970 amendments defined developmental disability to include persons with mental retardation, cerebral palsy, epilepsy, and other neurological conditions closely related to mental retardation which originate prior to age 18 and constitute a substantial handicap.

The 1970 amendments authorized State allotments for planning, services, and construction of facilities for persons with developmental disabilities. A state plan was required which was to designate a State planning and advisory council. One-third of the Council was to be comprised of consumers of service. The State plan was to describe the quality and extent of services and to show how funds were to be used to augment, rather than duplicate, services already available.

In Connecticut. Governor Meskill appointed the first DD Council on March 2. 1971 and "administratively located" the DD program in what was the Office of Mental Retardation within the Connecticut Department of Health.

Grants to help support interdisciplinary training in institutions of higher education were authorized to help meet shortages of personnel to provide services to persons with developmental disabilities. This has become known as the university affiliated facilities program.

A National Advisory Council on Services and Facilities for the Developmentally Disabled was also authorized.

**THE 1975 AMENDMENTS**

The Developmentally Disabled Assistance and Bill of Rights Act. P.L. 94-103. required that protection and advocacy programs be established in each State as a condition to receive a State grant. The protection and advocacy systems are designed to protect and advocate for the rights of persons with developmental disabilities and to pursue legal, administrative, and other remedies to ensure the protection of rights for such persons.

In Connecticut, the Office of Protection and Advocacy was created under state law in 1977. Connecticut's law expanded the federal mandate to include persons with all types of disabilities.

The 1975 amendments added the "Rights of the Developmentally Disabled", which included congressional findings such as the right to appropriate treatment and services designed to maximize individual potential.

The Federal discretionary grant authority was added by the 1975 amendments. Grants were authorized for demonstration service projects, public information and for other activities designed to improve services for persons with developmental disabilities.

The definition of developmental disability was expanded to include autism and dyslexia, if such dyslexia resulted from one of the other disabilities included in the definition.

The 1975 Amendments defined university affiliated facility to mean a part of a college or university that has a demonstration service program and provides education and training, including interdisciplinary training, to persons needed to render service to persons with developmental disabilities. Satellite centers were authorized to extend training and services to unserved areas.

The Amendments added a requirement that all persons served under authorized programs have in effect a written habilitation plan which states long-term habilitation goals, intermediate objectives, and a plan for service delivery.

#### THE 1978 AMENDMENTS

Title V of P.L. 95-602 amended the Act by authorizing a revised definition for the term developmental disability. Prior to the 1978 amendments, the term was defined to include mental retardation, cerebral palsy, epilepsy, autism, and certain other neurological conditions. A major provision of the 1978 Amendments modified this definition by deleting all references to specific handicapping conditions and establishing a definition based on functional limitations.

The 1978 Amendments established four priority service areas and required that States choose not more than two priority service areas for expenditure of not less than \$100,000 or 65 percent of the State grant funds, whichever was greater. The four priority service areas were: case management services, child development services, alternative community living arrangement services, and nonvocational social-developmental services.

The Amendments repealed authorization for the National Advisory Council on Services and Facilities for the Developmentally Disabled.

## **OMNIBUS BUDGET RECONCILIATION ACT OF 1981**

P.L. 97-35, the Omnibus Budget Reconciliation Act of 1981, provided authorization for the developmental disabilities programs for FY 1983 and FY 1984 and repealed a requirement for individual evaluations of persons served under this Act.

### **THE 1984 AMENDMENTS**

The Developmental Disabilities Act of 1984, P.L. 98-527, added a statement of purpose to the Act which specifies that programs authorized are to help assure that persons with developmental disabilities achieve their maximum potential through increased independence, productivity, and integration into the community.

The 1984 Amendments added employment-related activities as one of the priority service areas. Employment-related activities must be one of a State's priority service activities after FY 1986 if the appropriation for the State grant program equals or exceeds \$50.25 million in that year. The Amendments provide that States may choose up to three priority service areas beginning in FY 1987. The Amendments deleted nonvocational social-developmental services as a priority service area, but retained authorization for these services on a nonpriority basis. Also, services to promote and coordinate activities to prevent developmental disabilities were authorized by the amendments.

The State Planning Council membership was required by the Amendments to include representatives of the State agencies that administer the Rehabilitation Act, the Education of the Handicapped Act, and Title XIX of the Social Security Act (Medicaid), as such title affects persons with developmental disabilities. Protection and advocacy systems, higher education training facilities, and each university affiliated facility or satellite center in the State are to be represented on the Council.

The Amendments required that not more than 25 percent of the State grant funds be allocated to the administering agency for the provision of services by such agency.

Minimum allotments established by the Amendments provided that when appropriations reached \$47 million. States were to receive a minimum allotment of \$300,000 (compared to \$250,000 prior to the amendments), and territories were to receive a minimum of \$160,000 (compared to \$100,000 prior to the amendments).

The Amendments prohibited States from redesignating the agency that administers the protection and advocacy system unless the State determines that good cause exists for the redesignation. States are to give notice to persons with developmental disabilities or their representatives regarding any intention to redesignate. Information and referral services were authorized for protection and advocacy systems.

Protection and advocacy systems were given access to the records of persons with developmental disabilities living in residential facilities if there are complaints regarding the facility and if the individual does not have a legal guardian or the State is the legal guardian.

Minimum allotments established by the 1984 Amendments provided that when appropriations equalled or exceeded \$11 million. States were to receive \$150,000 (compared to \$50,000 prior to the amendments), and territories were to receive a minimum of \$80,000. (There was no statutory minimum for territories prior to the 1984 amendments.)

The 1984 Amendments provided that no new university affiliated facilities were to be funded after FY 1985 unless a feasibility study had been conducted and the need for the facility documented. Applications for university affiliated facilities and satellite centers were required to provide assurances that the human rights of persons receiving services were protected according to section 110 of the Act, Rights of the Developmentally Disabled.

When appropriations reached \$8.5 million, the minimum amount for a grant to a university affiliated facility was to be \$17,000. (The previous grant minimum was \$150,000.) The minimum grant to a satellite center. \$75,000. was not changed by the 1984 amendments.

In Connecticut, Connecticut's University Affiliated Program started in May 1985 as a satellite to the Rose F. Kennedy Center UAP at the Albert Einstein College of Medicine in New York. Administratively the UAP was a unit of the University of Connecticut's Special Education.

The UAP's off-campus location in East Hartford reflects a strong preference of the DD Council for a visible community UAP - one that would take a leadership role in helping move the DD service system in a community direction.

The 1984 Amendments specified that special projects are to expand and improve services to underserved groups of persons with developmental disabilities, including Native Americans and Native Hawaiians.

## **THE 1987 AMENDMENTS**

The 1987 Amendments reaffirmed the thrust of the basic State grant program and included several amendments that clarified and strengthened the program. The findings section of the Act focused on the capabilities, competencies, and preferences as well as the needs of persons with developmental disabilities and emphasized the important role the family and members of the community play in enhancing the lives of persons with developmental disabilities, especially when necessary support services are provided.

The Act also clarified and strengthened the independence of the State Planning Councils to carry out their advocacy role under the Act and refocused the activities the Councils fund to include policy analyses and other activities that are most likely to have

a positive impact on the greatest numbers of persons with developmental disabilities. The Act also amends the State plan to require States to take a hard look at how they are meeting the needs of persons with developmental disabilities attributable to a physical impairment, a mental impairment, or a combination of physical and mental impairments. The bill also increased State flexibility in selecting priority areas in which to focus their efforts.

The Act increased the minimum State allotment under the basic State grant to \$350,000. It authorized to be appropriated \$62,200,000 for FY 1988. \$69,000,000 for FY 1989. and \$77,400,000 for FY 1990.

The Act added several provisions designed to enhance the accountability of the protection and advocacy system by: ensuring particular attention to be paid to the needs of members of racial and ethnic minorities who are developmentally disabled: requiring the establishment of a grievance procedure: and providing, the public with an opportunity to make public comment on the priorities established by the System.

The Act clarified that access to the records of a person with developmental disabilities applied to a person who resides or was abused or neglected while residing in a facility for persons with developmental disabilities. The Act also clarified the authority of the protection and advocacy system to investigate incidences of abuse and neglect reported to the system if there is probable cause to believe that the incidents occurred. These changes were consistent with comparable authority set out in the Protection and Advocacy for Mentally ill Individuals Act of 1986. P.L. 99-319.

The Act increased the minimum State allotment for protection and advocacy systems to \$200,000. The bill authorized to be appropriated \$20,000,000 for FY 1988: \$22,000,000 for FY 1989: and \$24,200,000 for FY 1990.

The Act retained the current focus of the part of the legislation establishing university affiliated programs (UAPs). which are designed to assist in the provision of interdisciplinary training, the demonstration of exemplary services and technical assistance and the dissemination of information which will increase and support the independence, productivity, and integration into the community of persons with developmental disabilities.

The Act permitted universities to apply for funds to study the feasibility of establishing new UAPs and satellite centers and directed the Secretary of Health and Human Services to consider expanding the number of UAPs and centers into unserved States. In addition, the Act increased the amount of core funding for existing UAPs. The Act required in the application that the UAP demonstrate coordination between its activities and the activities conducted by the State under the State plan.

Separate line-items were established for core funding and for the funding of grants. The Act authorized to be appropriated for core funding \$9,400,000 for FY 1988. \$10,200,000 for FY 1989, and \$11,000,000 for FY 1990. For grants

to university affiliated programs, the Act authorized to be appropriated \$4,600,000 in FY 1988, \$5,000,000 in FY 1989. and \$5,500,000 in FY 1990.

Finally, the Act renamed the special projects part of the Act to read "projects of national significance". The Secretary who authorized to make grants to, or enter into contracts with, agencies and nonprofit entitles for projects of national significance relating to persons with developmental disabilities to educate policymakers develop an ongoing data collection system, determine the feasibility and desirability of developing a nationwide information and referral system, pursuing interagency initiatives and other projects of sufficient size and scope which hold promise of expanding opportunities for persons with developmental disabilities. The Act authorized to be appropriated \$3,650,000 for each of the fiscal years 1988-1990.

## **THE 1990 AMENDMENTS**

The 1990 Amendments expanded the purpose of the Act to include providing interdisciplinary training and technical assistance to professionals, paraprofessionals. family members and individuals with developmental disabilities; advocacy for public policy change and community acceptance; promoting inclusion in community life; promoting interdependence; and recognizing individual contributions at home, school, work and in recreation and leisure time.

The definition of developmental disability was clarified to apply to infants and young children from birth to age 5. inclusive, whose disabilities have a high probability of resulting in developmental disabilities if services are not provided.

The 1990 Amendments replace and expand the State plan priority area of "case management" to "System Coordination and Community Education" with a focus on eliminating barriers to access, enhancing systems design and individual, family and citizen involvement.

Integration is defined as the use of the same community resources as people without disabilities for living, learning, working and enjoying life, and the development of friendships with persons without disabilities.

The 1990 Amendments require the State Developmental Disabilities Planning Councils to build upon their 1990 reports of unserved and underserved people in relation to services and supports in future State plans and priorities.

The 1990 Amendments strengthen the authority of the DD Council to hire, supervise and evaluate a Director and the authority of the Director to hire and supervise staff for the Council.

The responsibilities of the designated State agency are expressly limited to ensuring that expenditures are made in a manner consistent with State law regarding grants and contracts, proper accounting and bookkeeping and other fiscal controls, the

provision of assurances, and the provision of administrative support services. The State agency should consult with the Council on all final matters.

**OTHER 1990 AMENDMENTS INCLUDE THE FOLLOWING:**

- o Mandates an annual statement of objectives by the Protection and Advocacy System in each State.
- o Expands the ability of the Protection & Advocacy System to access records in selected situations of potential harm.
- o Requires the establishment of a community advisory committee at every University Affiliated Program.
- o Expands the University Affiliated Program Training initiatives to include assistive technology and positive behavior management.
- o Establishes criteria for training at University Affiliated Program's including value-based and competency-based components.

**COUNCIL ON DEVELOPMENTAL DISABILITIES**