**Administration on Intellectual and Developmental Disabilities (AIDD)**

**History of the DD Act**

Adapted From: http://www.acl.gov/Programs/AIDD/DD\_History/index.aspx

The purpose of the [Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)](http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/Index.aspx), as described in the current law, is to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life …”

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**Background and Expanding Eligibility**

Federal “developmental disabilities” legislation developed from the “mental retardation” laws of the early 1960s. In October 1961 President John F. Kennedy convened the President’s Panel on Mental Retardation, which developed “A Proposed Program for National Action to Combat Mental Retardation.” The panel’s work took place within the larger context that people with developmental disabilities in the United States faced exclusion from schools, community activities, and many spheres of public and private life. Large, state-run and often grossly underfunded and under-resourced institutional facilities were pervasive, and systemic abuse and neglect was a problem.

Following the panel’s findings, President Kennedy sent a message to Congress in February 1963, which included a proposed legislative package with objectives regarding intellectual disabilities. Congress enacted some of these recommendations as the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. In 1967 Congress expanded the services related to intellectual disability and increased program funding.

Congress amended the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 in the Developmental Disabilities Services and Facilities Construction Amendments of 1970, a law that introduced the term “developmental disability” and expanded the population covered under the law beyond individuals with mental retardation to include individuals with cerebral palsy, epilepsy, and certain other neurological conditions that originate before the age of 18.

In 1975 the Developmentally Disabled Assistance and Bill of Rights Act defined developmental disability to include specific conditions (e.g., mental retardation and other conditions closely related to mental retardation, cerebral palsy, epilepsy, autism, and dyslexia) that originate prior to age 18, are expected to continue indefinitely, and that constitute a substantial handicap.

In 1978 Congress raised the age of onset to 22, and switched from a list of specific conditions to a more generalized approach focused on a functional definition of a developmental disability as a “severe, chronic disability…attributable to a physical or mental impairment…likely to continue indefinitely” and resulting in substantial functional limitations in three or more areas of major life activity.

The current definition under the DD Act (adopted in 2000) defines “developmental disability” as a severe, chronic disability of an individual that:

* “(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
* (ii) is manifested before the individual attains age 22;
* (iii) is likely to continue indefinitely;
* (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
  + (I) Self-care.
  + (II) Receptive and expressive language.
  + (III) Learning.
  + (IV) Mobility.
  + (V) Self-direction.
  + (VI) Capacity for independent living.
  + (VII) Economic self-sufficiency; and
* (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”

The 2000 law also further clarified the application of the “developmental disability” definition for children from birth through age 9. A child may still be considered to have a developmental disability without meeting 3 or more of the above criteria (items (i) through (v)) if the individual, without services and supports, has a high probability of meeting these criteria later in life.

**Evolution of the Law**

The 1975 amendments articulated findings that people with developmental disabilities have a right to appropriate treatment, services, and habilitation in the least restrictive setting that maximizes developmental potential, and specified that public funds should not be provided to any residential program for people with developmental disabilities that conflicts with, and does not meet, the minimum standards for nutritious diet, medical and dental services, prohibition of physical restraints, visiting rights for relatives, and compliance with fire and safety. In 1978 four priority service areas were established: case management services, child developmental services, alternative community living arrangement services, and nonvocational social-developmental services.

The 1984 amendments articulated the goals for services for people with developmental disabilities “to achieve their maximum potential through increased independence, productivity, and integration into the community …” The statute further defined those terms as follows:

* **Independence:** The extent to which people exert control and choice over their own lives.
* **Productivity:**Engagement in income-producing work.
* **Integration:** Using common community resources, participating in community activities with persons who do not have disabilities, and residing in homes or homelike settings in the community.

The law also authorized prevention-related activities and modified the requirements for State Planning Council membership (referred to here as Councils). People First language was used throughout the Act beginning in 1984.

The 1987 amendments required the Councils to complete two reports by 1990. One report was to provide a review and analysis of eligibility standards based on a developmental disability perspective (rather than strictly a mental retardation perspective). The other report was to provide review and analysis of consumer satisfaction with state agencies providing developmental disabilities services, using independence, productivity, and integration as the benchmarks. Congress here recognized the central role that the family and members of the community, including friends and neighbors, can play in enhancing the lives of people with developmental disabilities.

The 1990 amendments moved from goals of independence, integration, and productivity toward interdependence, inclusion, and recognition of contributions (beyond productivity). The legislation also expanded the purpose of the law to include providing interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities; and to advocate for public policy change and community acceptance.

Findings in the 1994 law included an emphasis on individual dignity, personal preferences, and cultural differences in the provision of services, supports, and other assistance, and recognition that individuals with developmental disabilities and their families are the primary decision-makers regarding services, supports, and other assistance they receive.

The 2000 amendments added the “provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subject individuals with developmental disabilities to no greater risk of harm than others in the general population,” to the Bill of Rights, increased the accountability of programs funded under the Act, and aimed to increase coordination and collaboration within and across those programs.

**Programs**

The program areas established by the DD Act have evolved over time to their current structures. Sometimes referred to as the DD Network, the State Councils on Developmental Disabilities (Councils); University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs); and Protection & Advocacy Systems (P&As) operate in every state and territory. They often participate in related, complementary work and collaboration even though they have different mandates.

The DD Act also funds national initiatives, such as the Projects of National Significance, as well as the newer Family Support and Direct Support Workforce programs. The Administration on Intellectual and Developmental Disabilities (AIDD), a federal agency presently located in the U.S. Department of Health and Human Services, Administration for Community Living, allocates the funds for these organizations and projects.

**State Councils on Developmental Disabilities (Councils)**

Councils were established to coordinate and integrate the provision of services for individuals with developmental disabilities in the least restrictive environment, largely in response to advocates arguing that government funding should apply to a broad range of services (rather than primarily toward building and modifying institutions), and that the DD community, including parents and advocates, should participate in decisions on how the DD money is used. In the 1975 law, the scope of the Councils was revised to include advocacy and a requirement to prepare plans on deinstitutionalization in each Council’s respective state. The Councils later changed focus from service provision or demonstration to policy change.

Council membership requirements have changed under the law: the 2000 DD Act raised the requirement to a composition of at least 60 percent people with developmental disabilities and their families, including a requirement that one-third of members must be individuals with developmental disabilities; one-third must be parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with developmental disabilities who cannot advocate for themselves; and one-third must be a combination of the above categories. At least one member must represent someone who resides or resided in an institution or is an adult who resides or resided in an institution.

According to the 2000 DD Act, the purpose of the Councils is to undertake advocacy, capacity building, and systemic change activities that contribute to a coordinated consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

**University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)**

UCEDD programs evolved out of the University Affiliated Facilities (UAFs), which were established in 1963, but were not funded until the 1970 law, authorizing grants to help support interdisciplinary training in institutions of higher education to help meet shortages of personnel to provide services to people with developmental disabilities. The original grants included funding to build medical/training facilities and emphasized clinical services, diagnosis and treatment programs, and interdisciplinary training of personnel. The grants later eliminated the funding for facilities, and UAFs became University Affiliated Programs (UAPs) in 1987.

Since the late 1980s, the programs have expanded their focus from medical and allied health care to include education, consumer empowerment, productivity, independence, and inclusion. Recent DD Act reauthorizations have increased the importance of community-based programming, technical assistance, and dissemination. The 2000 reauthorization added research as a core function and renamed the University Affiliated Programs UCEDDs. The focus of the centers has evolved as the values identified in the DD Act have moved from institution-based services to community-based services to community integration and self-determination.

The core functions of the UCEDDS, as described in the current DD Act, include providing interdisciplinary pre-service education of students and fellows, providing community services (including training or technical assistance), conducting research, and disseminating information.

**Protection & Advocacy System (P&As)**

P&As were created in the DD Act to protect the legal and human rights of individuals with developmental disabilities through legal action and advocacy in every state and territory, as well as within a Native American program. Initiated in 1975 to protect individuals with developmental disabilities living in large institutions from abuse and neglect, and prompted in part by investigations of the dreadful conditions at Willowbrook State School and Hospital (a state residential institution for people with developmental disabilities in Staten Island, NY), the P&As are designed to protect and advocate for the rights of people with developmental disabilities and to pursue legal, administrative, and other remedies to accomplish these ends.

The 1984 DD Act gave P&As access to the records of people 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.

P&As have played a key part in the deinstitutionalization process, and their mission has grown to include helping students and their parents advocate for appropriate education under the Individuals with Disabilities Education Act (IDEA), implementing and enforcing the Americans with Disabilities Act (ADA), and enforcing the rights of people with mental health challenges and other disabilities.

**Projects of National Significance (PNS)**

The 1975 DD Act established and authorized funding for this discretionary grant program to address national needs and respond to emerging or urgent areas of concern more quickly. In 2000, the purpose of PNS was defined as a program to “create opportunities for individuals with developmental disabilities to directly and fully contribute to, and participate in, all facets of community life; and support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities, the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals.”

PNS programs support innovation, provision of practical information, data collection with respect to people with developmental disabilities, and training and technical assistance.

**Family Support Programs**

In 2000 Congress added Title II, Families of Children with Disabilities Support Act, to promote and strengthen implementation of comprehensive state systems of support services for family members providing care. Congress first allocated funds directly to the program beginning in 2008, although PNS funds had been used for Family Support initiatives in prior years.

In 2003 a multiyear Family Support 360 program was initiated, supporting one-stop centers serving at least 50 families per year.

**Direct Support Workforce**

The 2000 DD Act added Title III, Program for Direct Support Workers Who Assist Individuals with Developmental Disabilities, to increase the workforce serving people with developmental disabilities. Congress has not provided direct funding for this program, although PNS funds have been used for an online training course for direct support workers, the College of Direct Supports, which is used as a resource by agencies and states.