



Developmental Disabilities Assistance and Bill of Rights Act (DD Act) History

UCEDD New Directors Orientation



The DD Act – Some Historical Milestones

- **1961:** President John F. Kennedy’s Panel on Mental Retardation published “A Proposed Program for National Action to Combat Mental Retardation”
- **1963** law established University Affiliated Facilities, which later became the University Centers for Excellence in Developmental Disabilities (UCEDDs)
- **1970** law required states to establish State Planning and Advisory Councils, known today as DD Councils
- **1975** law established State Protection and Advocacy Systems (P&As)
- **1994** law added the Projects of National Significance (PNS) initiative
- **2000:** **Developmental Disabilities and Bill of Rights Act** reauthorized through 2007 (DD Act of 2000)

Please see <http://transition.acf.hhs.gov/programs/aidd/resource/history-of-the-dd-act-1> for more information.



Mental Retardation Facilities and Construction Act (P.L. 88-164)

- Enacted in 1963 to plan activities and construct facilities to provide services to persons with 'mental retardation'




Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517)

- First Congressional effort to help people with developmental disabilities
- Definition of developmental disabilities included individuals with ‘mental retardation’, cerebral palsy, epilepsy and other conditions related to ‘mental retardation’, prior to age 18, and a severe disability



Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517)...

- State Planning Councils started to look at services for persons with developmental disabilities
- Grant money started for construction of University Affiliated Facilities (UAF)
 - training of people to provide services for persons with developmental disabilities.



1975 Amendments (P.L. 94-103)

- Deleted construction authority
- Study to look into UAFs having small centers of service (satellite centers)
- Protection and Advocacy System (P&As) started
- “Rights of the Developmentally Disabled” in law



1978 Amendments (P.L. 95-602)

- Functional definition of developmental disabilities as having a life-long impact in 3 or more major areas
 - Self-care
 - Communication
 - Learning
 - Mobility
 - Self-choice
 - Independent living
 - Economic self-sufficiency



Developmental Disabilities Act of 1984 (P.L. 98-527)

- Added new emphasis – persons with developmental disabilities receive services to achieve their best through living and working in the community



1987 Amendments (P.L. 100-146)

- Yearly Report to Congress on the Developmental Disabilities program - ADD collects information from the Councils, P&As, UAPs and PNS grantees
- 1990 Report - Councils study amount and quality of services being provided and whether consumer is satisfied
- UAFs became University Affiliated Programs (UAPs)



1990 Amendments (P.L. 101-496)

- Added purpose to say that persons with severe disabilities can live and work and contribute to society
- Amended functional definition to include infants and young children
- Established UAP training projects
- PNS include grants to help people with developmental disabilities gain employment and live better



Developmental Disabilities Act of 1994 (P.L. 103-230)

- Respect for the individual, services should be what the individual wants and consider a person's culture when planning and providing services (unserved and underserved)
- Persons with developmental disabilities and their families should make the decisions for that person



Developmental Disabilities Act of 1994 (P.L. 103-230)....

- State Councils
 - Must promote activities that:
 - change the way things are done for people with developmental disabilities
 - Make it easier to do these activities
 - Tell state officials about these activities and the need for more services and programs
- P&As
 - Protect the confidentiality of client records

Developmental Disabilities Act of 1994 (P.L. 103-230)....

- University Affiliated Programs
 - New program standards
- Secretary of Health and Human Services
 - Required ADD to fund a grant to see if it would be a good idea for the State Council to also be responsible for looking at services for persons with severe disabilities other than developmental

Developmental Disabilities Act & Bill of Rights Act Amendments of 1996 (P.L. 104-183)

- Extended authorization of appropriations of ADD programs for three years through Fiscal Years 1997, 1998 and 1999



Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402)

- Secretary directed to set up a process to monitor grantees
- identify and report on progress achieved through advocacy, capacity building, and systemic change activities using indicators of progress developed for chosen area of emphasis



Developmental Disabilities Assistance and Bill of Rights Act of 2000...

- Grantees must include activities that focus on working together
- State Councils
 - set aside 70% (versus 65%) of Federal money for Council goals
 - include more persons with developmental disabilities and their families (60% versus 50%)



Developmental Disabilities Assistance and Bill of Rights Act of 2000...

- P&A
 - Governing board can only stay on for a limited time and must be selected by the P&A
 - Majority of the board must be a person with a developmental disability and family members
 - Broader access to provider/individual records to investigate potential abuse and neglect



Developmental Disabilities Assistance and Bill of Rights Act of 2000...

- New name - University Centers for Excellence in Developmental Disabilities (UCEDDs)
 - receive a core award
 - When there is enough money to fund each Center \$500,000, then each Center has the opportunity for national training grants, additional funding, or additional centers



Developmental Disabilities Assistance and Bill of Rights Act of 2000...

- PNS program authorized to fund grants with other Federal agencies in support of policies on self-determination, independence, productivity, and inclusion in community life of individuals with developmental disabilities.

Developmental Disabilities Assistance and Bill of Rights Act of 2000...

- Established two additional programs
 - Title II Families of Children with Disabilities Support Act of 2000
 - Title III Program for Direct Support Workers Who Assist Individuals with Developmental Disabilities

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