

POLICY SEMINAR

THE ARC, AAIDD, AUCD,
UCP AND NACDD

FACT SHEET

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT (D.D. ACT)

Background

The *Developmental Disabilities Assistance and Bill of Rights Act (DD Act)* is up for Reauthorization. Congress last reauthorized the DD Act (Public Law 106-402) in 2000. Over the course of 30 years the DD Act has gained strong bipartisan support. FY 08 Appropriations were: DD Councils: \$72.5 million; P&As: \$39 million; UCEDDS: \$37 million; and PNS: \$14 million.

The Administration on Developmental Disabilities, Administration for Children and Families, in the Department of Health and Human Service is the administering agency for the DD Act programs.

The DD Act focuses on the estimated 4.5 million children and adults in the U.S. who have developmental disabilities. The purpose of the Act is to assure that individuals with developmental disabilities and their families have the opportunity to actively participate in the design of community based programs and have access to community services, individualized supports, and other forms of assistance that promote and create opportunities for independence, productivity, and self determination.

The DD Act consists of four programs that create an intersecting network. Each program, while distinctive in their scope, work with state governments, local communities, and the private sector to reach goals relating to prevention, diagnosis, early intervention, therapy, education, training, employment, health care and community living, and leisure opportunities. Grants fund activities in eight areas of emphasis: quality assurance, education and early intervention, child care, health, employment, housing, transportation and recreation activities. The DD Act Components are:

* **State Councils on Developmental Disabilities (DD Councils)** pursue systems change in some aspect of service or support availability, design or delivery that promote positive and meaningful outcomes for individuals with developmental disabilities and their families. Council grantees are responsible for building capacity necessary for the successful delivery of services and supports for individuals with developmental disabilities; pursuing advocacy activities that support policies and practices that promote self-determination and inclusion in the community, and supporting activities such as initiating and demonstrating innovative approaches, outreach training, public education, and information to policy-makers.

* **Protection and Advocacy (P&A) systems**, one in each state, protect the legal and human rights of individuals with developmental disabilities. P&A strategies include legal, administrative, and other remedies; information and referral; investigation of incidents of abuse and neglect; and education of policy-makers.

* Sixty-seven **University Centers for Excellence in Developmental Disabilities (UCEDDs)** in every state and territory are components of a university system or are public or not-for-profit entities associated with universities. UCEDDs provide interdisciplinary training to students and professionals, engage in cutting-edge research, and provide direct services and supports to people

with disabilities of all ages and their families. UCEDDs are committed to communicating and sharing information and research findings.

* **Projects of National Significance (PNS)** is a discretionary program that focuses on emerging areas of concern. This program supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change

****Family Support Programs***

Title II of the DD Act authorizes the Family Support Program. The intention of this section is to promote and strengthen the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities. However, funding for this program has been woefully underfunded and families continue to struggle with little or no help. Family support services are effective in reducing the costs associated with life-long disability, and in preventing the expense of out-of-home placement.

Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date.

Recommendations

The Second Session of the 110th Congress should reauthorization the Developmental Disabilities Assistance and Bill of Rights Act .

- Fully fund programs authorized under the DD Act, including:
 1. State Grant Programs (Councils on Developmental Disabilities);
 2. Protection and Advocacy Systems;
 3. University Centers for Excellence in Developmental Disabilities, Education, Research, and Service;
 4. Family Support;
 5. Projects of National Significance;
- Increase the meaningful participation of self-advocates and families in the governance of state level Developmental Disabilities Act programs;
- Ensure that any expansion in coverage or activities in the reauthorization of the DD Act be accompanied with increased funding so as not to result in negative fiscal effects or program outcomes for the programs currently authorized under the Act.

Relevant Committees

Senate Health, Education, Labor and Pensions Committee

House Energy and Commerce Committee, House Health Subcommittee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy

Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, AAIDD (202) 387-1968 or the National Association of Councils on Developmental Disabilities (703) 739-4400.