



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 the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. For over 30 years, the DD Act has enjoyed strong bipartisan support.

The DD Act focuses on the estimated 5.4 million children and adults in the United States and territories who have developmental disabilities. The Act provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self-determination.

The DD Act consists of four programs that create an intersecting network. Grant funds support initiatives in civil rights protections, education and early intervention, child care, health, employment, housing, transportation, recreation, family support, and other services. The DD Act components are:

State Councils on Developmental Disabilities (DD Councils)

Councils on Developmental Disabilities are located in every State and Territory and include volunteers who are appointed by Governors. More than 60% of these volunteers must be people with developmental disabilities or family members. Councils are charged by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost effective ways to address those needs in a manner that upholds the dignity and value of people with developmental disabilities. Councils work to promote the independence and productivity of people with developmental disabilities and promote systems change that will eliminate obvious inequities in areas such as employment, education, and access to healthcare.

Protection and Advocacy (P&A) systems

Under the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, P&As are required to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities. Collectively, the P&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. The federally mandated P&As serve individuals with a wide range of disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems

On March 3, Rep. Barney Frank (D-MA) reintroduced a bill (H.R. 1255) that would limit the ability of Protection and Advocacy Systems to protect individuals with developmental disabilities in institutions. The bill was introduced with 11 other bipartisan co-sponsors and referred to the House Judiciary Committee. The Voice of the Retarded (VOR), a parent group, is making a strong push to get cosponsors for this legislation. Members of Congress need to be educated about the true nature of this bill and urged to NOT co-sponsor or in any way support H.R. 1255.

University Centers for Excellence in Developmental Disabilities (UCEDDs)

The DD Act authorizes core funds to 67 UCEDDs, at least one in every state and territory, that 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, provide technical assistance, and direct services and supports to people with disabilities of all ages and their families. UCEDDs share information and research findings.

Projects of National Significance (PNS)

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 to promote and strengthen the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities. Family support services are effective in reducing the costs associated with life-long disability, and in preventing the expensive of out-of-home placement. However, this Title needs its own line item funding (\$15M.)

Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date. The Omnibus Appropriations Act (passed in February 2009) included modest increases in funding for DD Act programs for FY 2009.

Recommendations

1. Congress should provide a significant increase in appropriations over FY 2009 Levels for DD Act programs so that these programs can continue to respond to the needs of people with disabilities. With state budget cuts and inflation, these programs struggle to meet the demands of the growing population of people with developmental disabilities who experience multiple barriers to get and keep jobs, an education, and appropriate community based supports and services. Specifically, disability advocates seek a \$6 million increase for **each** of the three main components of the Act: UCEDDs, DD Councils, and P&As, a \$3 million increase for Programs of National Significance (PNS) and a \$2 million increase for Protection and Advocacy System for Voting Access (PAVA) program. In addition, we urge Congress to provide \$15 million towards family support activities as authorized in Title II of the DD Act.

2. Congress should work toward timely reauthorization of the DD Act that:

- Increases the funding authorization levels for the programs under the Act to expand the capacity of the DD Network and Family Support
- Supports a separate title and funding authorization level (above and beyond funding for existing DD Act Programs) for self-advocate-directed Training and Information Centers.
- Reauthorizing Title III – Preparation of Direct Support Professional Workforce to provide grants to states for personal preparation, model demonstrations and systems change projects to improve the recruitment, training, support and retention of a qualified direct service professional workforce in each state.

Relevant Committees

House and Senate Appropriations Committees
House Energy and Commerce Committee
House Education and Labor Committee
Senate Health, Education, Labor and Pensions Committee

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, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

TALKING POINTS FOR ADVOCATES

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

- The DD Act is the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. It promotes full inclusion and participation of individuals with developmental disabilities in all facets of community life and has enjoyed strong bipartisan support for nearly 40 years.
- The DD Act was last reauthorized in 2000 and is up for reauthorization this year.
- People with disabilities have the right to live independently, have control over their lives and participate fully in their communities -- including school, work and making choices about where and with whom they live.
- The DD Act covers: State and Territorial Councils on Developmental Disabilities (DD Councils); University Centers for Excellence in Developmental Disabilities (UCEDDS); Protection and Advocacy Systems (P&As); Projects of National Significance (PNS) and Family Support.

Congress should:

- **Provide an increase in funding for FY 2010** so that DD Act program can continue to respond to the needs of people with developmental disabilities. Specifically, we seek a \$6 million crease for each of the three main components of the Act: UCEDDs, DD Councils, and P&As, and a \$2 million increase for P&A System for Voting Access (PAVA) program and \$3 million increase in PNS.
- **Reauthorize the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in the 111th Congress and:**
 - Fully fund all programs authorized under the DD Act;
 - Increase funding for the Family Support Program and provide adequate funding for every state to support its families;
 - Reauthorize and support the Title III Preparation of Direct Workforce Professionals; and
 - Support a separate title and funding authorization level (above and beyond funding for existing DD Act Programs) for self-advocate-directed Training and Information Centers.

