



THE ARC, AIDD, AUCD,  
UCP, NACDD, AND SABE

# 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. It was last authorized in 2000.

The DD Act focuses on the estimated 5 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 education, access to healthcare and employment.

### 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.

### 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

Over 75% of people with ID/DD live with families, often with aging parents. However, families and caregivers often struggle to access any level of formal support. 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 expense of out-of-home placement. The Family Support program should be expanded with a state funding formula based on need.

## Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date. The Administration on Developmental Disabilities (ADD) has held nationwide listening sessions to gather input in preparation for the reauthorization. ADD will hold a number of regional summits on self-advocacy this year. The National Council on Disability will soon publish its report on progress made by DD Act programs: *Rising Expectations: The Developmental Disabilities Act Revisited*.

## Recommendations

The 112th Congress should work toward timely reauthorization of the DD Act that:

- *Increases the authorization for appropriations for all programs authorized under the DD Act;*
- *Reauthorizes the Title III Program for Direct Support Workers to address the direct support work force shortage and improve the recruitment, training, support, and retention of a qualified direct service professional workforce in each state;*
- *Reauthorizes and funds the Title II Family Support program and provides a formula grant to every state and territory with a separate authorization and appropriation line item;*
- *Protects and expands the authority of Protection and Advocacy Systems to investigate abuse, neglect, and deaths and to pursue class action litigation on behalf of our constituents wherever they live; and*
- *Support federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports.*

## 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 Self Advocates Becoming Empowered (802) 760-8856.