

## WHAT ARE DEVELOPMENTAL DISABILITIES?

Developmental disabilities are physical or mental impairments that begin before age 22, are likely to continue indefinitely, and result in substantial functional limitations in at least three of the following:

- Self-care (dressing, bathing, eating, and other daily tasks)
- Speaking and being understood clearly
- Learning
- Walking/mobility
- Self-direction
- Independent living
- Economic self-sufficiency

Developmental disabilities may also result in a need for a combination and sequence of specialized, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are lifelong and require individual planning and coordination.

Some disabilities which often meet the developmental disabilities description above are cerebral palsy, intellectual disability, autism spectrum disorder, Down syndrome, fetal alcohol spectrum disorder, fragile X syndrome, Williams syndrome, tuberous sclerosis, and epilepsy.



**The Arc**  
Phone: 202-783-2229 | Web: thearc.org



**American Association on Intellectual and Developmental Disabilities (AAIDD)**  
Phone: 202-387-1968 | Web: aaidd.org



**American Network of Community Options and Resources (ANCOR)**  
Phone: 703-535-7850 | Web: ancor.org



**Autism Society of America**  
Phone: 1-800-328-8476 | Web: autism-society.org



**National Association of Councils on Developmental Disabilities (NACDD)**  
Phone: 202-506-5813 | Web: nacdd.org



**United Cerebral Palsy**  
Phone: 202-776-0406 | Web: ucp.org



## PUBLIC POLICY AGENDA for the 116th CONGRESS

— 2019–2020 —  
SUPPORTING THE LIFESPAN

American Association on Intellectual and Developmental Disabilities  
American Network of Community Options and Resources  
Autism Society of America  
National Association of Councils on Developmental Disabilities  
The Arc  
United Cerebral Palsy



## WHAT IS INTELLECTUAL DISABILITY?

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior originating before the age of 18. The term intellectual disability covers the same population of individuals who were diagnosed previously with “mental retardation” in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized supports and services. The old term has fallen out of favor and has been replaced in a number of federal and state statutes, regulations, and court decisions.

This brochure highlights many federal policy issues which greatly affect people with intellectual and/or developmental disabilities (I/DD). See the full policy agenda on the websites of the partnering organizations.

**The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP** are national organizations that serve and advocate for people with intellectual, developmental, and other disabilities. We work together to shape, expand, and protect a strong federal role that provides vital benefits, services and supports and assures civil rights for our constituency.

# KEY FEDERAL POLICY ISSUES FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES (I/DD)

Federal public policy is critical to ensuring that children and adults with I/DD can live fully inclusive and productive lives in the community.

These policies include:



## BUDGET AND TAX

Sufficient tax revenue must be raised in order to appropriately fund social insurance (Social Security, Medicare), safety net (Medicaid, Supplemental Security Income (SSI)), and discretionary programs (such as housing, education, employment, and transportation) that people with I/DD rely on for their health, safety, and wellbeing.



## CIVIL RIGHTS

Civil rights must be preserved through vigilant enforcement of laws and regulations as well as strong opposition to efforts that limit the rights of people with I/DD.



## COMMUNITY-BASED LONG TERM SUPPORTS & SERVICES

These must be widely accessible, consumer controlled, and provided in the community without the requirement that people with I/DD impoverish themselves in order to obtain assistance with activities of daily living, such as getting dressed, taking medication, and preparing meals.



## DIRECT SUPPORT PROFESSIONALS

These professionals must be well trained and fairly and adequately compensated to provide the necessary supports and services for people with I/DD where they work and live.



## EDUCATION

The education system must help people with I/DD to achieve their full potential and independence by having high expectations, integrated instruction by certified and effective teachers, inclusive classrooms, appropriate assessments, and only using positive behavioral supports.



## EMPLOYMENT

Employment programs must be expanded to provide more job development, placement, and coaching, skills training, and other services necessary to help find and maintain competitive, integrated employment for people with I/DD.



## FAMILY SUPPORT

Counseling, support groups, respite, training, cash assistance, and information and referral must be made widely available to family caregivers, especially those who are aging, and who provide supports in the community. This will help avoid costly and unwanted institutional placements of individuals with I/DD.



## HEALTH CARE

People with I/DD must have timely access to high quality, comprehensive, accessible, affordable, and individualized health care services to improve and maintain health and functioning.



## HOUSING

An adequate supply of safe, accessible, integrated, and affordable supportive housing in the community for people with I/DD must be available.



## MEDICAID

This program is the single largest funding source of both acute health care and long term supports and services for people with I/DD. It must be preserved and rebalanced to make home and community based services the norm and institutional services the exception.



## RESEARCH AND TRAINING

There is a need for more comprehensive federal research, surveillance, analysis, education, and training concerning people with I/DD across the lifespan.



## SOCIAL SECURITY & SSI

This system provides the primary income sources for many people with significant disabilities to meet their basic needs for food, shelter, and clothing. Benefits and eligibility must be maintained and the long-term financial future of these programs must be considered outside of deficit reduction efforts.



## TECHNOLOGY

Technology must be accessible and made widely available to make communication, education, independent living, and employment opportunities available for people with I/DD.



## TRANSPORTATION

Accessible transportation programs must be expanded and anti-discrimination policies must be enforced to help people with I/DD access employment, health care, recreational activities, and other aspects of community living.

This document is also available on the websites of the participating organizations.