**PUBLIC POLICY AGENDA *for the* 117th CONGRESS**

**2021-2022**

**American Association on Intellectual and Developmental Disabilities (AAIDD)**

**American Network of Community Options and Resources (ANCOR)**

**Autism Society of America (ASA)**

**Autistic Self Advocacy Network (ASAN)**

**Easterseals**

**National Association of Councils on Developmental Disabilities (NACDD)**

**TASH**

**The Arc**

**United Cerebral Palsy (UCP)**

**The Arc, AAIDD, ANCOR, ASA, ASAN, Easterseals, NACDD, TASH,** 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.

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

**WHAT IS INTELLECTUAL DISABILITY?**

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior manifesting during the developmental period. 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.

**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)
* Understanding and using language or 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.

**KEY FEDERAL POLICY ISSUES FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES (IDD)**

Federal public policy is critical to ensuring that people with IDD can live fully inclusive and productive lives in the community. These policies include:

**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 IDD.

**COMMUNITY-BASED LONG TERM SUPPORTS & SERVICES**

These must be widely accessible, consumer controlled, and provided in the community without the requirement that people with IDD 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 IDD where they work and live.

**EDUCATION**

The education system must help people with IDD 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.

**EMERGENCY MANAGEMENT**

The needs of people with disabilities, their families, and the direct support workforce must be considered as a priority in planning for and responding to natural, public health, and human-made disasters and emergencies.

**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 IDD.

**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 IDD.

**HEALTH CARE**

People with IDD 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 IDD 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 IDD. 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 IDD across the lifespan.

**SOCIAL SECURITY & SUPPLEMENTAL SECURITY INCOME (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.

**TAX REVENUE**

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 IDD rely on for their health, safety, and wellbeing.

**TECHNOLOGY**

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

**TRANSPORTATION**

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

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

**The Arc**

1-800-433-5255 | thearc.org

**American Association on Intellectual and Developmental Disabilities (AAIDD)**

202-387-1968 | aaidd.org

**American Network of Community Options and Resources (ANCOR)**

703-535-7850 | ancor.org

**Autism Society of America (ASA)**

1-800-328-8476 | autism-society.org

**Autistic Self Advocacy Network (ASAN)**

info@autisticadvocacy.org | autisticadvocacy.org

**Easterseals**

1-800-221-6827 | [info@easterseals.com](mailto:info@easterseals.com)

**National Association of Councils on Developmental Disabilities (NACDD)**

202-506-5813 | nacdd.org

**TASH**

202-817-3264 | tash.org

**United Cerebral Palsy (UCP)**

202-776-0406 | ucp.org