

GATEWAY  
HIGH EXPECTATIONS  
**EDUCATION** INTEGRATED ASSESSMENTS  
POTENTIAL **INDEPENDENCE**  
QUALITY **SOCIAL** FINANCIAL FUTURE  
**SECURITY** BASIC COMMUNITY  
& **SSI** INCOME PATHWAY ELIGIBILITY  
SHELTER  
BENEFITS ENFORCED **TRANSPORTATION**  
ACCESSIBLE AVAILABLE EMPLOYMENT  
COMMUNICATION INDEPENDENT FOUNDATION  
LIVING  
BENEFIT **TECHNOLOGY** ENFORCEMENT CIVIL  
CUSTOMIZED TRANSITIONS PRESERVED RIGHTS  
**EQUALITY** ACHIEVEMENT EARLY INTERVENTION  
WELL-TRAINED **OPPORTUNITY**  
DIRECT COMPENSATED  
**SUPPORT** NECESSARY  
**WORKERS**

The Arc, the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Network of Community Options and Resources (ANCOR), the Association of University Centers on Disabilities (AUCD), the National Association of Councils on Developmental Disabilities (NACDD), and United Cerebral Palsy (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. While the United States is one of the wealthiest countries in the world, our nation is far from meeting the diverse needs of our constituents and their families, many of whom find their lives at stake as the federal role in disability policy is being addressed.

  
**The Arc**  
For people with intellectual  
and developmental disabilities

**The Arc**  
1825 K Street, NW, Suite 1200  
Washington, DC 20006  
202-534-3700  
www.thearc.org

  
American Association  
on Intellectual and  
Developmental Disabilities

**American Association  
on Intellectual and  
Developmental Disabilities  
(AAIDD)**  
501 3rd Street, NW, Suite 200  
Washington, DC 20001  
202-387-1968  
www.aaidd.org

  
American Network of  
Community Options  
and Resources

**American Network of  
Community Options and  
Resources (ANCOR)**  
1101 King Street, Suite 380  
Alexandria, VA 22304  
703-535-7850  
www.ancor.org

  
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
RESEARCH, EDUCATION, SERVICE

**Association of University  
Centers on Disabilities  
(AUCD)**  
1010 Wayne Avenue, Suite 920  
Silver Spring, MD 20910  
301-588-8252  
www.aucd.org

  
National Association of  
Councils on Developmental Disabilities

**National Association of  
Councils on Developmental  
Disabilities (NACDD)**  
1825 K Street, NW, Suite 600  
Washington, DC 20006  
202-506-5813  
www.nacdd.org

  
United Cerebral Palsy  
Life without limits for people with disabilities

**United Cerebral Palsy (UCP)**  
1825 K Street, NW, Suite 600  
Washington, DC 20006  
202-776-0406  
www.ucp.org

*An expanded version of this document is available on  
the website of each organization.*

**PUBLIC POLICY  
AGENDA**  
*for the*  
**113<sup>TH</sup> CONGRESS**  
— 2013-2014 —



**AMERICAN ASSOCIATION ON INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES**  
**AMERICAN NETWORK OF COMMUNITY OPTIONS  
AND RESOURCES**  
**ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES**  
**NATIONAL ASSOCIATION OF COUNCILS  
ON DEVELOPMENTAL DISABILITIES**  
**THE ARC**  
**UNITED CEREBRAL PALSY**

ACCOUNTABLE **FREEDOM**  
FUNCTION TRAINING  
**HEALTH CARE** QUALITY  
ACCESSIBLE LONG **LIFELONG**  
HOME AND COMMUNITY TERM  
**MEDICAID** SERVICES  
FUNDING SAFETY NET  
**WELLBEING** **LONG TERM**  
**BUDGET & TAX** REBALANCE **SUPPORTS & SERVICES** MEANINGFUL WORK  
COMMUNITY LIVING INTEGRATED **EMPLOYMENT** SUPPORTED  
JOB DEVELOPMENT **HOUSING** SAFE EMPLOYMENT FUNDED  
AFFORDABLE ACCESSIBLE SUPPORTIVE **CAREGIVERS**  
ESSENTIAL TRAINING **FAMILY SUPPORT**  
REFERRAL **COMMUNITY** RESPECT  
**DIGNITY**

The 113th Congress faces numerous challenges. Continuing federal deficits, cuts in appropriations for discretionary programs, and numerous federal laws requiring expansion and modernization combine to put the system of disability benefits and supports at grave risk. This document presents the major areas needing attention for people with intellectual and developmental disabilities (I/DD) in this Congress.



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

**H**istorically, people with I/DD have been denied fundamental human and civil rights. It is a history of institutionalization, segregation, abuse, and neglect. The last decades of the twentieth century signaled a turning point with the passage of hard-won landmark federal legislation that altered the lives of people with I/DD and their families. Despite the great strides toward expanding rights, there are various policy issues that continue to limit or deny their ability to live fully inclusive lives. These lives, including:

## Budget and Tax Policy

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

## Medicaid

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

## Long Term Services & Supports

Critical for people with I/DD who frequently have lifelong needs for assistance with activities of daily living, such as getting dressed, taking medication, and preparing meals. These services must be widely accessible, consumer controlled, and provided in the community without the requirement that people impoverish themselves.

## Employment

The cornerstone for community living for most adults with I/DD who are able and willing to engage in meaningful work. Integrated employment programs, including supported employment, must be properly funded and administered to provide job development and placement, skills training, job coaching, and other services necessary to help find and maintain employment.

## Housing

Critical for most people with I/DD to live in the community. There must be an adequate supply of safe, accessible, and affordable supportive housing.

## Family Support

Essential for caregivers, especially those who are aging, who provide care in the community. Counseling, support groups, respite, training, cash assistance, and information and referral must be made widely available to family caregivers.

## Education

The gateway to achieving full potential and independence for people with I/DD. The education system must have high expectations, offer integrated instruction by highly qualified teachers, require appropriate assessments, and use only positive behavioral supports to address problem behaviors.

## Social Security & Supplemental Security Income (SSI)

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 budget reduction efforts.

## Transportation

The pathway to employment, health care, recreation, and other aspects of community living for people with I/DD. Accessible transportation programs must be properly funded and administered and anti-discrimination policies in transportation must be enforced.

## Technology

Instrumental in making communication, education, independent living, and employment opportunities available for people with I/DD. Technology must be customized and made widely available to persons who may benefit from it.

## Civil Rights

The foundation for the services and protections that people with I/DD enjoy today. Civil rights must be preserved through vigilant enforcement of laws and regulations as well as strong opposition to efforts to limit the rights of people with I/DD.

## Health Care

Critical for people with I/DD to improve and maintain health and functioning. Health care systems must be accountable for providing timely access to high quality, comprehensive, accessible, affordable, and appropriate services that meet individual needs.

## Direct Support Professionals

Constitute the backbone for community living for people with disabilities. A well-trained, adequately compensated direct support workforce is essential to providing the necessary supports and services to our constituents, where they live and work.

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There are many additional federal policy issues that greatly affect people with I/DD, including quality of services, developmental disabilities programs, research, prevention, and emergency management. See our websites for complete details on our Public Policy Agenda for the 113th Congress.