

# AUCD LEGISLATIVE PRIORITIES

for the 113th Session of Congress, 2013



# AUCD

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

AUCD envisions a nation whose high expectations for our citizens with disabilities make possible their active engagement in civic life and full inclusion in society, including the fulfillment of academic potential, health, and productive employment in the community. The Americans with Disabilities Act (1990) and the U.S. Supreme Court in the 1999 *Olmstead* decision affirmed the right of people with disabilities to a life in the community. For decades, Congress has been taking important steps to secure that right and achieve that vision. Now — *even under daunting fiscal constraints* — is not the time to halt that forward movement. This vision is not only just, but in a real sense it is affordable. People with disabilities would rather work and pay taxes than spend their lives in expensive segregated, facility-based settings or day programs. Most people prefer to live in their own homes with the help of personal attendants than in a nursing home or institution. Children with mental health issues would rather stay in school and with their families than end up in the juvenile justice system for want of timely referral to services. We can accomplish these goals.

*AUCD calls upon Congress to work in a bipartisan fashion to address the pressing needs of our citizens with disabilities. Gridlock has serious consequences for these individuals.*

AUCD members are working hard with state and local partners to redirect taxpayer dollars to re-design innovative, efficient systems and policies to achieve the outcomes all Americans want: dignity, meaningful choice, and the opportunity to contribute and to succeed. We want to partner with Congress to achieve these goals.

# **AUCD Legislative Priorities for the 113th Session of Congress, 2013**

Federal Funding and Fiscal Policy  
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Tax Policy



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# Federal Funding and Fiscal Policy

Even in the difficult fiscal environment, the nation's budget must not be balanced at the expense of people with disabilities who—due to the nature of their disabilities—must, at times, rely on government programs for their most basic needs (e.g. education, health, safety, food). AUCD urges Congress to address the significant unmet needs of people with disabilities and their families by increasing and expanding the federal investments in research, education, training, and support and service programs that enable them to live and work as independently as possible in the community. These programs include:

- University Centers for Excellence in Developmental Disabilities (UCEDDs) funded by the Administration on Intellectual and Developmental Disabilities (AIDD)
- Leadership Education in Neurodevelopmental and Related Disabilities programs (LENDs) funded through the Combating Autism Act of 2006
- Intellectual and Developmental Disabilities Research Centers (IDDRCs), funded through the National Institutes of Health (NIH) Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD)
- The National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC), including the State Disability and Health Programs and Act Early Campaign
- Interdisciplinary training, services, and research for individuals with autism spectrum disorders and other developmental disabilities authorized through the Combating Autism Act of 2006
- The Higher Education Opportunity Act, including the Model Comprehensive Transition Programs for Students with Intellectual Disabilities
- Individuals with Disabilities Education Act (IDEA), including the Early Intervention and Early Childhood Programs and Part D national programs that support the Part B state grant programs
- The Assistive Technology Act of 1998, as amended



# Medicaid and Long Term Services and Supports

Medicaid is a lifeline for most people with intellectual and developmental disabilities, who often have significant medical needs and require assistance with activities of daily living throughout their lifetimes. Without the program, most of the 8.8 million Americans with disabilities whose health coverage comes solely through Medicaid would join the ranks of the almost 50 million Americans who are currently uninsured. Private health insurance is generally not an option for Medicaid beneficiaries who often lack access to coverage through their jobs or are unable to obtain private coverage adequate to meet their needs. Medicaid also pays for long-term services and supports that allow people with disabilities to live as independently as possible in their communities, which are typically more cost-effective than institutional services.

Medicaid has an inverse relationship to the economy; its enrollment expands due to rising needs during an economic downturn, when people lose their jobs and their job-based health coverage. This increase in participants and subsequent decrease in state revenues make it difficult for states to balance their budgets, as well as provide adequate coverage to those individuals who most need that coverage. Many states have cut Medicaid spending by scaling back eligibility, reducing critical services, and freezing already inadequate reimbursement rates. These cuts have devastating effects on people with disabilities and on their qualified staff who have lost their jobs. In order to ensure access to vital services and supports through Medicaid, AUCD urges Congress to:

- Develop a coordinated and comprehensive approach to long term supports and services (LTSS) to meet the demands of the 21st Century
- Support implementation of the Commission on Long Term Care authorized by the American Taxpayer Relief Act and promote development of legislation consistent with the goals of inclusive participation, personal choice, personal responsibility, integration, and independence
- Oppose proposals to deconstruct Medicaid or allow states to eliminate basic protections for eligible individuals with disabilities through block grants, entitlement caps, per capita caps, allocations, allotments, or other mechanisms that reduce eligibility, services, or protections
- Allow federal matching rate (FMAP) increases to assist states in times of crisis and avoid adding millions to the ranks of the uninsured

- Continue to work toward elimination of Medicaid’s institutional bias by fully implementing improvements in the program that increase fiscally responsible choices of community- and family-based alternatives, including:
  - The amended Section 1915(i) Medicaid state plan option for home and community-based services that allows states to serve people who do not yet need an institutional level of care
  - The Balancing Incentives Payments Program, spousal impoverishment provisions, and expansion of the Money Follows the Person demonstration program
  - The Community First Choice Option which allows states to provide comprehensive community-based services with a six-percent increase in the federal matching rate for such services
- Ensure that families are supported as Section 1115 and other waivers are being implemented
- Encourage state implementation of the Medicaid expansion to low income individuals and families who are priced out of the insurance market
- Ensure an available and well-trained direct support workforce to provide needed care and support to individuals with disabilities by requiring states to provide livable wages and benefits to these providers
- Ensure protections for people with disabilities who are dually eligible for Medicaid and Medicare to guarantee that they have timely and affordable access to all necessary services, supports, and medication under Medicaid, Medicare, and Medicare prescription drug plans, including Managed Long Term Supports and Services (MLTSS)
- Ensure portability of benefits in Medicaid across states (especially for those military families whose job makes them subject to transient living situations)



# Health Care Reform

The Patient Protection and Affordable Care Act of 2010 will provide access to affordable health insurance for approximately 30 million Americans who are currently uninsured and is vital to the health and well-being of individuals with disabilities. According to the non-partisan Congressional Budget Office, the law will reduce the federal deficit by \$140 billion over the first ten years and \$1.2 trillion over the second ten years. AUCD urges Congress to:

- Ensure that the Affordable Care Act is fully implemented and adequately funded to accomplish the goal of quality, accessible, appropriate, comprehensive, affordable, portable, and non-discriminatory coverage
- Ensure that the Secretary fully implements the essential health benefits requirements that ensures habilitation, behavioral health, dental, and other services for people with disabilities
- Protect the Prevention and Public Health

Fund to pay for transformational prevention programs and ensure that resources and activities paid for by the Fund include and benefit people with disabilities

- Revise the criteria for determination of Medically Underserved Populations to allow the inclusion of people with developmental and other disabilities as required by the Affordable Care Act
- Expand funding for training of all health care providers about the needs of children and adults with disabilities and to help transition youth with disabilities to adult care service systems and providers
- Ensure adequate reimbursement for health and allied health providers to ensure that there are enough providers participating with Medicaid and Medicare to meet the needs of individuals with disabilities



# Combating Autism Act

The U.S. Centers for Disease Control and Prevention and Health Resources and Services Administration report staggering increases in the prevalence of autism spectrum disorders. Since the enactment of the Combating Autism Act in 2006, significant advances have been made in understanding this complex developmental disability, now estimated to affect about two percent of the American children. Additional resources are needed to provide continuing education, interdisciplinary training, and dissemination of new, evidence-based practices to professionals, support workers, family members, and self-advocates in the most effective and efficient manner possible. Individuals with autism also need assistance in the areas of job training, employment, recreation, housing, transportation, and early, primary, secondary, and postsecondary education. Services for transitioning youth and adults with autism are an especially pressing need. With access to and assistance with these types of services and supports, individuals with autism can live rich, full, and productive lives. AUCD urges Congress to:

- Reauthorize the Combating Autism Reauthorization Act of 2011 and provide sufficient resources to expand existing and develop new maternal and child health interdisciplinary Leadership Education in Neurodevelopmental and related Disabilities programs (as exists under section 501(a)(2) of the Social Security Act) in all states, as was originally intended by Congress
- Support legislation that addresses interdisciplinary training, continuing education, and technical assistance needs associated with the increasing number of individuals diagnosed with autism spectrum disorders
- Support legislation to provide direct services to individuals with autism spectrum disorders, including youth and young adults transitioning from school to postsecondary education and/or work



# Developmental Disabilities Act

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental law supporting and enhancing the lives of people with intellectual and developmental disabilities and their families. For more than 30 years, the DD Act has enjoyed strong bipartisan support. It was last authorized in 2000. AUCD urges Congress to:

- Reauthorize the Developmental Disabilities Act to extend the mission of UCEDDs to address the needs of persons with a broad range of lifelong disabilities
- Reauthorize and fully fund Title II, the Family Support program
- Fully fund the Projects of National Significance, including the Data Collection Projects and other efforts focused on emerging critical issues
- Support self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports
- Continue and enhance Title III: Program for Direct Support Workers who Assist Individuals with Developmental Disabilities

## Family Support

An estimated 75 percent of people with developmental disabilities live with their families, often with aging parents. Families and caregivers consistently struggle to access any level of formal support. Furthermore, given our nation's fiscal challenges, it is likely that greater numbers of individuals with intellectual and developmental disabilities will be living with their families for longer periods. AUCD urges Congress to support federal initiatives that recognize the important role of families and the need for comprehensive family supports, including:

- Reauthorize and fully fund Title II of the DD Act, the Family Support program, and provide a formula grant to every state and territory to promote the ability of families to support their family members with disabilities
- Reauthorize and fully fund the Lifespan Respite Care Act
- Reauthorize and amend the National Family Caregiver Support Program within the Older Americans Act to provide supports to aging parents and siblings caring for their adult family members with developmental disabilities
- Amend the Family and Medical Leave Act to expand the definition of 'covered family member' to include

siblings, grandparents, and domestic partners

- Address the disparate treatment experienced by parents with disabilities by adding specific protections for parents with disabilities in the Adoption and Safe Families Act, e.g. extending the time period for these parents to determine permanency to prevent termination of their parental rights
- Ensure that programs providing personal assistance services include supports and services for parents with disabilities, such as expanding the definition of 'activities of daily living, or ADL' to include parenting activities

## Research and Data Collection

The collection of accurate data on the incidence, prevalence, and wellbeing of individuals with disabilities and families, including parents with disabilities, and other unserved/underserved populations, is essential to informing public policy. AUCD believes the federal government should invest in a broad range of research and evaluation initiatives across federal agencies to improve the lives of individuals with disabilities. AUCD urges Congress to:

- Provide additional funding to the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRCs), which have provided outstanding contributions to understanding child development, discovering ways to prevent developmental disabilities, and discovering treatments and interventions to improve the lives of people with intellectual and developmental disabilities and their families. Additional resources are needed for research infrastructure and expansion of cores so that IDDRCs can conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.
- Support the recommendation from over 40 of the National Children's Study site leaders and investigators for the appointment of an Institute of Medicine expert panel to formally review the sampling and design plan for the main study and incorporate their findings and



recommendations into continued funding for the National Children’s Study. The National Children’s Study is one of the most comprehensive research efforts geared toward studying children’s health and development and will form the basis of child health guidance, interventions, and policy for generations to come.

- Ensure continued support for ongoing nationwide data collection and information on trends in intellectual and developmental disabilities service systems under the Developmental Disabilities Act Projects of National Significance
- Provide funding for national data collection on the incidence of child abuse and neglect, including the nexus between abuse/neglect and disabilities
- Expand funding for research in health disparities, including the current status and strategies for mitigation of disparities in health services and supports to un-served and underserved populations, including people with disabilities
- Authorize federal agencies to gather effective data on parents with disabilities and their interaction with child welfare and dependency court systems

## Education

All students deserve to learn and thrive in school and become college- and career-ready. In order to do so, students with disabilities must have access to the general education curriculum and be fully included in the student achievement system. Students must also be protected from physical or mental abuse, restraint, seclusion, and aversive interventions which are used disproportionately on students with disabilities and frequently result in trauma, injury, and even death.

The Elementary and Secondary Education Act (“No Child Left Behind”) emphasizes equal access to education, establishes high standards and accountability, and requires the inclusion of all students with disabilities in the school accountability system. AUCD urges Congress to:

- Reauthorize the Elementary and Secondary Education Act to ensure full access to the general education curriculum and accountability of all students
- Reauthorize IDEA and reject any legislation that results in the diminution of the guarantee of a free and appropriate public education



- Reauthorize the Higher Education Opportunity Act, including programs to provide opportunities for students with intellectual disabilities, and permanently authorize the current demonstration Transition Programs for Students with Intellectual Disabilities Into Higher Education
- Ensure appropriate assessments for all students with disabilities by developing a variety of universally designed assessments that accurately measure the progress of students with disabilities, including students with significant cognitive disabilities
- Strengthen federal interagency coordination to achieve effective transition planning, including needed services and supports, that is focused on student post-school goals for postsecondary education, national service, and/or integrated competitive employment
- Support training and research initiatives and expand the use of student-centered planning to enhance effective transition services to assist students with disabilities to enter postsecondary education programs or integrated employment
- Expand and improve in-service and pre-service personnel preparation under Part D of IDEA, ESEA, and the Higher Education Opportunities Act so that all special education teachers and related personnel are highly qualified
- Establish federal protections against abuse, aversive interventions, restraint, and seclusion for students in schools
- Amend IDEA's individual education plan (IEP) provision to mandate that, in the case of a child who does not yet have a symbolic mode of communication (oral language, augmentative communication system, written language, Braille, and/or manual signs), a plan for developing a communication system for that child becomes a part of the IEP



# Employment

Working-age people with intellectual and developmental disabilities are among the most unemployed and underemployed segments of our society. Far too many of these individuals are in non-work settings or are in segregated settings and earn subminimum wages. Even given the current economic downturn, with the declining birth rate as well as the aging of the current workforce, there will be a shortage of workers to meet employer demands in the coming decade. We must ensure that all people who want to work have the training and support they need to be employed and remain employed. AUCD urges Congress to:

- Reauthorize and reform the Workforce Investment Act to better support people with disabilities in integrated employment and their families
- Increase resources for supported employment, workforce development programs, transition programs, and model program development
- Support Employment First strategies, policies, and practices that target integrated employment at minimum or prevailing wages or above for all individuals with developmental and other significant disabilities
- Support the utilization of national and community service opportunities in transition and vocational planning for individuals with disabilities as a gateway to integrated employment and exempt the AmeriCorps State and National Civilian Community Corps program payments for purposes of determining SSDI eligibility and benefits
- Increase resources for research and training to better serve un-served/underserved populations



# Rights

People with disabilities want the same opportunities to live, work, and recreate in the community and to be free of abuse and neglect. To achieve these goals of equality, AUCD urges the Federal government to protect and promote stronger enforcement



of existing civil rights laws for people with disabilities, particularly the Americans with Disabilities Act; Individuals with Disabilities Education Act (IDEA); Fair Housing Act; Civil Rights of Institutionalized Persons Act (CRIPA); Sections 503, 504 and 508 of the Rehabilitation Act; Help America Vote Act (HAVA); National Voter Registration Act (“motor voter”); Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act; Genetic Information Nondiscrimination Act; and Air Carrier Access Act. AUCD also urges Congress to promote and protect equal rights of children and adults with disabilities in all parts of the world, through international measures, including ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

# Transportation

Accessible and reliable transportation is critical to the full participation of people with intellectual and developmental disabilities in the community. People often have trouble finding affordable, accessible, and reliable transportation to get to and from jobs, school, medical appointments, and other community activities. AUCD urges Congress to:

- Enforce existing civil rights laws that provide for accessible transportation and support federal initiatives to help states increase accessible and reliable transportation for people with disabilities
- Work toward interstate reciprocity among state paratransit systems so that people with disabilities can travel barrier-free nationwide

# Social Security

Social Security is not only a retirement program. It is an insurance program to protect against poverty in retirement or as a result of disability or death of a family wage earner. More than one-third of all Social Security checks go to non-retirees, including nearly nine million people with disabilities. These beneficiaries include workers with disabilities and people with disabilities who are dependents and survivors of disabled workers, retirees, and deceased workers. Any changes in Social Security will affect everyone who receives benefits. AUCD urges Congress to:

- Protect and expand income support programs and their related health coverage programs in the Social Security Act
- Support development of interdisciplinary teams of clinicians to assist adjudicators with eligibility determinations for disability benefits
- Preserve Social Security through long-term, gradual changes outside the context of deficit reduction to meet the needs of people who are eligible now and in the future
- Eliminate marriage penalties in Social Security disability policy

# Tax Policy

- Ensure that deficit reduction proposals are fair and balanced to include revenues, not just spending cuts as deficit reduction only through spending cuts unfairly lays the majority of the financial burden on societal groups least able to bear it, particularly individuals with disabilities and their families
- Allow individuals with disabilities and their families to fund tax-favored savings plans for long term support needs which will not negatively impact eligibility for, or benefits from, government programs.
- Support tax policy that promotes employment for people with disabilities by improving and expanding deductions and credits aimed at promoting employment, such as Impairment-Related Work Expense Deduction, Architectural and Transportation Barrier Removal Deduction, and the Disabled Access Credit

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AUCD advocates for legislation that is critical to individuals with disabilities and their families. Legislative priorities are developed for each Congress by the AUCD Legislative Affairs Committee and the Board of Directors based on the Association's vision and mission, as well as input from the entire AUCD network, including individuals with disabilities and their families.

In addition to developing its own priorities, AUCD partnered with The Arc, UCP, AAIDD, ANCOR, and NACDD to develop joint legislative goals for the 113th Congress.