

# PUBLIC POLICY AGENDA *for the* 116th CONGRESS 2019–2020

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



## TABLE OF CONTENTS

<b>I. INTRODUCTION.....</b>	<b>2</b>
What are developmental disabilities? .....	3
What is intellectual disability? .....	3
Use of Terms.....	4
Shaping Public Policy .....	5
Implementation of Laws .....	5
<b>II. FEDERAL FISCAL POLICY AGENDA .....</b>	<b>6</b>
Introduction.....	6
Budget, Entitlements, and Appropriations.....	7
Revenue and Tax Policy .....	8
<b>III. PROGRAMMATIC AGENDA .....</b>	<b>9</b>
<b>A. PRIORITY AGENDA .....</b>	<b>9</b>
Civil Rights .....	10
Community-Based Long Term Supports and Services.....	12
Developmental Disabilities .....	14
Direct Support Professionals .....	15
Education .....	17
Employment, Training, and Wages .....	22
Health Care .....	25
Medicaid.....	29
Social Security/Income Maintenance .....	37

<b>B. OTHER CRITICAL GOALS .....</b>	<b>42</b>
Causes and Effects of I/DD.....	43
Child Welfare, Foster Care, and Adoption .....	44
Criminal Justice.....	46
Emergency Management.....	49
Family Support .....	50
Housing .....	53
Immigration and Naturalization .....	55
Liability Insurance Protections.....	56
Non-Profit Organizations .....	56
Quality of Services .....	57
Research and Data Collection.....	59
Tax Provisions.....	61
Technology.....	63
Temporary Assistance for Needy Families (TANF) and Social Services .....	64
Transportation.....	65
<b>IV. PARTNERSHIPS.....</b>	<b>67</b>
The Arc .....	67
AAIDD .....	68
ANCOR .....	68
ASA .....	69
NACDD .....	69
UCP .....	70

## I. INTRODUCTION

The Arc, the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Network of Community Options and Resources (ANCOR), Autism Society of America (ASA), the National Association of Councils on Developmental Disabilities (NACDD), and United Cerebral Palsy (UCP) base our public policy views on the understanding that our constituents are full participants in our democratic society. We work to shape a federal/state partnership that protects their civil rights and provides benefits, supports, and services for our shared constituency.

We envision a nation whose high expectations for all people with disabilities make possible the fulfillment of academic potential, competitive employment in the community, active engagement in civic life, and full inclusion in society.

For decades, Congress has been taking important steps to affirm and secure the right of people with disabilities to a life in the community and to achieve that vision. Now is not the time to halt that forward movement. The vision is based on social justice and civil rights and is also affordable. All branches of the federal government play critical roles in ensuring that the civil rights of persons with disabilities are realized, and the goals below should be considered broadly on how they can be achieved through legislative, regulatory, and other administrative action. It is critical that the White House have a position devoted to disability outreach, engagement, and policy. People with disabilities want to live, learn, work, pay taxes, and be productive and fully included in their communities. People would rather live in the community than in nursing homes or institutions.

It is critical that, in all of their actions, Congress and the Administration, as well as state and local governments, adhere to the principles established by landmark legislation for people with disabilities – the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). Both of these laws embody the fundamental values eloquently expressed in the Developmental Disabilities and Bill of Rights Act:

*“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental*

*disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”*

## **WHAT ARE DEVELOPMENTAL DISABILITIES?**

The federal statutory definition of developmental disabilities within the Developmental Disabilities Act (PL 106-402) includes 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.

## **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. Furthermore, every individual who is or was eligible for a diagnosis of “mental retardation” is eligible for a diagnosis of intellectual disability.

Some federal laws that serve people with disabilities through established eligibility categories still use the term “mental retardation.” In 2010, the President signed Rosa’s Law, which substituted the term “intellectual disability” in federal education, health, and labor laws; however, the term remains in other federal laws. In 2013, the Social Security Administration replaced “mental retardation” with “intellectual disability” in its listing of impairments and other sections of its regulations. In addition, the Centers for Medicare and Medicaid Services issued regulations to change the terms for long term supports and services in the Medicaid program. The Congress should complete this transition by substituting the term “intellectual disability” for the term “mental retardation” whenever a law that uses that term is subject to reauthorization or amendment. This change should not in any way alter eligibility requirements or service availability since the change in terms is not intended to do so. In its 2014 decision in *Hall v. Florida*, the U.S. Supreme Court announced that it will use the term intellectual disability. It is expected that other courts will follow suit.

**USE OF TERMS**

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP support and advocate with and for individuals with intellectual, developmental, and other disabilities, as well as the families and others who support them. In this document, we often refer to these groups as “constituents” or “our constituency” if a public policy goal applies to everyone represented by our collective organizations. Additionally, throughout this document, we will refer to people who have intellectual and/or developmental disabilities using the acronym I/DD.

Where the word “state” appears, it will mean the following: states, territories, the District of Columbia, and Indian reservations, where appropriate.

## SHAPING PUBLIC POLICY

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP base their public policy views on the understanding that our constituents are full participants in our democratic society. We work to shape a federal/state partnership that provides benefits, supports, and services for our shared constituency. All people with disabilities have the right to advocate for themselves at all levels of government.

While all six organizations support these policy goals, each organization may choose to emphasize and prioritize work on goals specifically related to the nature of the individual organization and its respective constituents.

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP will continue to advocate in a bipartisan manner for public policies that address their needs.

The foundation for this public policy agenda for the 116th Congress is built on mission statements, principles, core values, position statements, and current policies of The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP and on input from volunteers, members, and professionals from across the country. These documents can be found on the organization's websites.

For the 116th Congress, we present two tiers of priorities for our programmatic policy agenda. The tiers are "priority agenda" and "other critical goals." We will address any and all of these goals as issues relating to them arise.

## IMPLEMENTATION OF LAWS

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP closely follow how laws, regulations, and policies are crafted and carried out so that our constituency is able to live independent, self-determined lives in the community and be economically self-sufficient. This includes influencing any changes in regulations through the public comment process as well as monitoring how the federal government implements, monitors, and enforces relevant federal activities. Congress also plays a key role in this implementation process in several ways, including through its

oversight function. We will continue to remain involved in the implementation of federal laws that affect people with I/DD whether through the administrative and regulatory process or through the ongoing Congressional oversight role or consideration of improvements or amendments to existing programs.

## II. FEDERAL FISCAL POLICY AGENDA

### INTRODUCTION

Federal fiscal policy is a primary tool used by Congress and the Administration to address critical societal issues through both entitlement and discretionary programs. In the past few years, fiscal policy has been focused on addressing annual federal deficits and long term debt. Federal fiscal policy can and should be used to decisively address the crises facing people with disabilities and their families. The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP support federal funding for the program supports and services that are needed to enable people with disabilities and their families to be fully included in society.

Structural changes or reductions in federal entitlement spending threaten our constituents. Medicaid, Medicare, Social Security, and Supplemental Security Income (SSI) remain major targets to secure deficit reduction. Medicaid finances lifesaving health care and long term supports and services and the lives of the people receiving those supports are inextricably linked to any shift in Medicaid policy – at either the federal or state level. The very lives of our constituents are at stake in these policy deliberations. Some of the changes that have been proposed to the Social Security system, such as reduced benefits and increased retirement ages, could have a devastating impact on beneficiaries.

Like most people, we support the need for a strong American economy. However, a truly strong and secure nation can only be achieved if:

- » Federal funding decisions and tax policy do not result in a federal budget that is crafted at the expense of people with disabilities;
- » Supports, services, and benefits critical to the well-being



of people with disabilities and their families are protected, improved, and expanded while preserving the principles of independence, economic opportunity, and self-determination; and

- » When needed, the federal government leads or assists states and territories in being fair and efficient in carrying out their responsibilities to people with disabilities and their families.

## **BUDGET, ENTITLEMENTS, AND APPROPRIATIONS**

Congress has traditionally set fiscal policy through three major fiscal actions. These actions largely determine the actual funding for all disability benefits, programs, and services for the year:

- » Adopting a budget resolution that sets annual revenue and spending limits. The budget resolution is the blueprint for discretionary and entitlement spending;
- » Adopting annual appropriations bills which set spending levels for the many discretionary programs; and
- » Enacting a reconciliation bill requiring relevant committees to revise tax policy and entitlement spending (such as Medicaid, Medicare, Supplemental Security Income, and the Supplemental Nutrition Assistance Program (SNAP, also known as food stamps)) to comply with the budget resolution.

However, in recent years Congress has not adhered to all of these steps because of disagreements over the role and size of the federal government and how to address federal deficits and the long term debt.

During the 116th Congress, our public policy goals are to:

- » Strengthen, not weaken, vital entitlement programs such as Social Security, Medicaid, Medicare, SSI, Temporary Assistance for Needy Families (TANF), and SNAP (food stamps);
- » Promote cost-effectiveness when such efforts do no harm to our constituents and allow them to live as independently as possible in the community;

- » Eliminate spending caps that impact discretionary programs that support people with disabilities and replace them with a budget that includes revenue increases and no further cuts to programs that support people with disabilities and their families;
- » Address the significant unmet needs, disparities, and inequities faced by people with disabilities and their families by expanding the federal government's investment in people with disabilities to enable them to live and work as independently as possible in the community with appropriate and flexible long term individual and family supports;
- » Ensure that eligibility for services and benefits is not restricted and that the level of services and benefits for entitlement programs (such as Medicaid, Medicare, and Social Security) is not reduced or limited to achieve budget cuts;
- » Remove the Social Security Administration's administrative budget from any budget cap requirements for the Departments of Labor, Health and Human Services, and Education; and
- » Oppose a Constitutional balanced budget amendment.

## REVENUE AND TAX POLICY

During the 116th Congress, our public policy goals are to:

- » Reform tax policy in a manner that raises sufficient revenues to finance the federal government's role in providing essential supports, services, and benefits for people with disabilities and their families over the lifespan;
- » Support the expiration, roll back, or repeal of tax cuts and adjustments of other tax policies, such as those that allow high income individuals and large corporations to minimize their U.S. tax obligations, that put people with disabilities at risk due to lower contributions to federal revenues;
- » Reject tax policies that primarily help the highest income individuals, recognizing that such policies may be made at the expense of those with middle to lower incomes;

- » Address the unmet needs of people with disabilities and their families before extending or making further tax cuts or reforming tax policy in a way that negatively impacts low wage earners and other vulnerable people;
- » Raise revenues in a progressive manner without increasing poverty or income inequality;
- » Protect and enhance, not erode, services and benefits for people with disabilities;
- » Protect the Social Security trust funds for use by current and future beneficiaries;
- » Avoid creating impediments to the states' ability to raise sufficient revenue to meet human needs; and
- » Assure the continuing ability of non-governmental entities to support people with disabilities and their families.

### III. PROGRAMMATIC AGENDA

Priority Agenda areas are those believed to be most likely to come before the 116th Congress; however, all of the issues in the agenda are critical to address for people with I/DD.

#### A. PRIORITY AGENDA

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP acknowledge that many vital federal laws affect our constituency. To further the promise of the Americans with Disabilities Act and the U.S. Supreme Court's Olmstead decision, major programs which provide supports and services must be aligned with principles of encouraging and supporting non-discrimination; full, meaningful inclusion in community life; and economic self-sufficiency. Such programs also must be accessible and available to those who need them and must be dependable, even in difficult economic times. Medicaid and Social Security, including Supplemental Security Income (SSI), provide crucial supports to our constituents; potential changes to either program, therefore, require significant attention to the potential impact on people with disabilities. The relationship between Medicaid and direct support professionals requires very

close policy coordination. A free and appropriate public education for students with disabilities remains the lynchpin to being an independent adult who is economically self-sufficient and a taxpayer. Thus, the agenda related to Civil Rights; Community-Based Long Term Supports and Services; Developmental Disabilities; Direct Support Professionals; Education; Employment, Training, and Wages; Health Care; Medicaid; and Social Security/Income Maintenance constitute our highest priorities for the 116th Congress. For convenience, they are listed alphabetically.

**CIVIL RIGHTS**

**Rights**

During the 116th Congress, our public policy goals are to:

- » Protect against forms of discrimination based on disability, ethnicity, race, sex, pregnancy, gender identity and expression, sexual orientation, religion, familial status, age, language, national origin, genetic information, or any other protected status;
- » 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); 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; Air Carrier Access Act; and Section 1557 of the Patient Protection and Affordable Care Act;
- » Protect the authority of and increase funding for federal government entities that enforce disability rights laws, including the Equal Employment Opportunity Commission (EEOC), and civil rights offices in the Departments of Justice, Health and Human Services, Housing and Urban Development, Labor, Education, Homeland Security, and Transportation;

- » Ensure that federal government programs and services are fully accessible and navigable, with high-quality customer service;
- » Recognize and respect supported decision-making agreements and state legislation fostering and respecting the use of supported decision-making and other protective proceedings as less restrictive alternatives to full guardianship and/or conservatorship;
- » Protect, enhance, and ensure adequate funding for federal protection and advocacy programs for people with disabilities;
- » Preserve and enhance legislation and social programs that protect the rights of children and youth with disabilities, particularly those who are served by foster care systems;
- » Prohibit the use of aversive interventions including chemical and mechanical restraints. Prohibit the use of physical restraint where a person does not pose an immediate danger to themselves or others and completely ban seclusion. Support sanctions for use of restraint outside of those emergent situations or any use of seclusion;
- » Provide protection and oversight for cases of abuse and neglect as well as provide training to prevent abuse and neglect;
- » Ensure that legislation addressing issues such as physician-assisted suicide, stem cell research, end-of-life care, organ transplants, and research on human subjects includes protections against abuse and discrimination on the basis of disability;
- » Promote and protect equal rights of children and adults with disabilities in all parts of the world, by supporting the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD); and
- » Ensure access to service animals including emotional support animals to promote full participation in the community for all individuals with disabilities.

## Voting Rights Reform

People with disabilities, individually and collectively, offer an important and needed voice in our nation. Ensuring voting independence, accuracy, and access continue to be key issues for this constituency. The Help America Vote Act (HAVA) required fully accessible voting machines for people with disabilities by January 1, 2006. This promise has not been fulfilled. Too many polling places and voting technology and practices throughout the country remain inaccessible and continue to disenfranchise voters.

During the 116th Congress, our public policy goals are to:

- » Provide strong enforcement of and adequate funding for HAVA to address the right of people with disabilities to vote privately and independently in any federal election, to rectify continuing failures to meet the provisions of the law, and to make recommendations for improvement;
- » Ensure that any new voting reform legislation provides equal and full access to voting systems and polling places for voters with disabilities and does not disenfranchise voters with disabilities regardless of their guardianship status;
- » Ensure that requirements for voter identification and/or voting technology do not hinder or discourage voting by people with disabilities; and
- » Incentivize automatic voter registration when receiving a driver's license or state ID card, or upon reaching legal voting age.

## **COMMUNITY-BASED LONG TERM SUPPORTS AND SERVICES**

The demand for community-based long term supports and services (LTSS) continues to be a critical issue in the 21st century. However, the nation has lacked a comprehensive, proactive, national public-private system of delivery. The current system is a patchwork of inadequate funding, with the largest source of federal funds provided by the Medicaid program that requires most people to be impoverished to receive services. Furthermore, there is an institutional bias that directs these funds to institutional services and

to community services primarily through waivers. With the first of the baby boomers retiring, the need for qualified support workers and family caregivers will exacerbate severe inequities in the ability of individuals with significant disabilities of all ages to live in integrated settings of their choice.

In order to meet this national challenge, the federal government must take the lead in developing a coordinated, comprehensive approach to LTSS. Since Medicaid has become the core of federally supported LTSS, the philosophy of the Medicaid program must be changed to reflect the preference for individualized community-based services over institutional services. In addition, the need for supports outside of the Medicaid program must be addressed, including possibilities of incorporating an LTSS benefit into Medicare. To meet these challenges, during the 116th Congress our public policy goals are to:

- » Expand, modernize, and, where appropriate, maintain national policies that provide individualized supports. Such supports should encourage individual control of services, self-sufficiency, and personal responsibility among our constituents. Such a system should avoid the need for people to impoverish themselves to qualify for services. Supports and services must be:
  - Person-centered and self-directed;
  - Inclusive of personal assistance services and technology appropriate for each individual;
  - Designed and implemented to meet individual needs;
  - Widely accessible; and
  - Provided in the community in inclusive and integrated settings;
- » Advocate for a quality, well compensated and sustainable workforce to ensure that community LTSS can be fulfilled;
- » Promote development of legislation consistent with the goals of inclusive participation, self-determination, personal responsibility, community integration, and independence including reversing the institutional bias in Medicaid, so that community living is the first and preferred option;

- » Ensure adequate funds for federal monitoring, enforcement, and implementation of the U.S. Supreme Court’s Olmstead decision;
- » Provide incentives to community-based organizations to utilize innovative technologies to enhance delivery of supports and services, such as home monitoring and communications technologies;
- » Amend federal law to allow federal employee pension and survivor benefits to be paid to a trust established for an individual with a disability to allow for the long term support of the individual; and
- » Ensure full implementation of the Disabled Military Child Protection Act of 2014, which allows military pension and survivor benefits to be paid to a trust for an individual with disabilities to allow for the long term support of the individual.

## **DEVELOPMENTAL DISABILITIES**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the law that provides support to states and territories to enhance the lives of people with developmental disabilities and their families. This law promotes the independence, productivity, integration, and inclusion in society of people with I/DD.

During the 116th Congress, our public policy goals are to:

- » Ensure that the work of the three Title I DD Act programs (University Centers for Excellence in Developmental Disabilities, Protection and Advocacy Agencies, and State Councils on Developmental Disabilities) reaches and sustains the goals of self-determination, inclusion, and integration for people with I/DD in community settings;
- » Protect and significantly increase funding for programs authorized under the DD Act, including:
  - 1) State Councils on Developmental Disabilities;
  - 2) Protection and Advocacy agencies;
  - 3) University Centers for Excellence in Developmental Disabilities;



- 4) Family Support; and
- 5) Projects of National Significance;
- » Protect and expand the authority and funding for national membership organizations to provide training and technical assistance to their respective DD Act programs;
- » Protect and expand the authority of the Protection and Advocacy agencies to use all available remedies to monitor and investigate abuse, neglect, and deaths of people with I/DD including all types of litigation, including class action litigation, on behalf of our constituents wherever they live;
- » Protect ongoing national research efforts and provide opportunities for investments in new and innovative research as needed through the Projects of National Significance, including data collection on national and state expenditures on programs for people with I/DD;
- » Fund the Title II Family Support program and provide a formula grant to every state and territory with a separate authorization and appropriations line item;
- » Fund Title III Program for Direct Support Workers to address the direct support workforce shortage and improve the recruitment, training, support, and retention of a qualified direct service professional workforce in each state;
- » Ensure additional federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports; and
- » Support legislation to develop evidence-based supports and services for individuals with I/DD.

## **DIRECT SUPPORT PROFESSIONALS**

A well-trained, fairly compensated direct support professional workforce is essential to providing the necessary supports and services to our constituents where they live and work. Medicaid is the primary source of funding for the programs employing these workers. The current Medicaid reimbursement system, cost cutting actions by state legislatures and Medicaid officials, and recent

strides to raise the minimum wage in several cities and states have exacerbated the workforce crisis already hampered by low wages, a lack of affordable health insurance, high turnover, and a shortage of staff. Demand for these workers from private industry and other human services sectors is also high, leading to competition among industries for workers. These problems have been compounded over three decades, leading to a crisis that presents a grave threat to the lives of our constituents and their families.

During the 116th Congress, our public policy goals are to:

- » Ensure adequate funding so that direct support professionals are paid a living wage, including appropriate benefits;
- » Require that CMS incentivize states to develop and implement a plan to address all relevant components that drive the crisis, including low wages and reimbursement rates, high turnover, and inadequate training;
- » Require state reimbursement rates for services to incorporate any local, state, and federal minimum wage increases or changes in employment standards;
- » Ensure adequate reimbursement rates to cover services including appropriate staffing levels to ensure the provision of person-centered services;
- » Ensure financial support, including payment of wages, to provide pre-service and in-service training and other relevant educational opportunities for direct support professionals to meet the diverse needs of individuals with disabilities; and
- » Implement programs aimed at the direct support labor market to increase the pool of available workers, including individuals with disabilities, and improve recruitment, retention, training, and supervision of direct care professionals to better serve individuals with disabilities, and through use of appropriate waivers or statutory changes to allow immigration of qualified workers.

## EDUCATION

Public education for all is a cornerstone of our democracy and is the mechanism by which this nation prepares all students to pursue the benefits of freedom and to exercise fully their rights and responsibilities. The U.S. Department of Education has played a critical role in ensuring access, equity, and opportunity for all students — including students with disabilities — through their oversight, guidance, monitoring, and technical assistance.

The Individuals with Disabilities Education Act (IDEA) ensures that children with disabilities not only have the right to attend public schools, but receive a free and appropriate public education, have access to the general education curriculum, and receive a meaningful education that prepares them for postsecondary education or a career. Similarly, the Every Student Succeeds Act (ESSA) (formerly known as the Elementary and Secondary Education Act (ESEA)), recognizes that our education system must ensure that all children have access to a high quality, standards-based education and that schools provide services and supports to disadvantaged students who are not making progress in school.

During the 116th Congress, our public policy goals are to:

### Overarching

- » Ensure non-discrimination in special education in order to avoid inappropriate over- or under-identification of disability and the overuse of segregated settings or disciplinary actions in students of diverse backgrounds;
- » Ensure special education course-work and practicum experiences for all general education candidates to receive full teaching licensure and certification so that all educators and staff are prepared to serve and support diverse learners in inclusive settings; and
- » Ensure that teacher preparation programs include introduction to theories of behavior and evidence-based practices.

### Discipline, Restraint, Seclusion, and Aversive Interventions

- » Prohibit harmful disciplinary practices such as unwarranted suspensions, expulsions, and referrals to the

juvenile justice system and require schools to work to de-escalate minor school infractions rather than call for police department assistance;

- » Address the over-representation of students with disabilities in the school to prison pipeline, and support appropriate services and successful reentry to community schools;
- » Prohibit corporal punishment; chemical, mechanical, and physical restraints; seclusion; or other interventions that compromise student health and safety. Ensure that parents are notified of all incidents of discipline, restraint, and/or seclusion on the same day;
- » Provide funding and require school personnel, including school resource officers (SROs), to be trained in positive behavioral supports, elopement, and appropriate behavioral interventions for all students;
- » Prohibit SROs from disciplining students with disabilities; and
- » Ensure that measures intended to protect the safety of students and school personnel do not violate due process, civil liberties, and the right to reasonable accommodations; or result in profiling of students based on disability or other status.

### **Early Childhood, Early Intervention, and Preschool Programs**

- » Mandate the availability of early intervention programs under IDEA (Part C);
- » Increase funding for early intervention and preschool programs;
- » Enhance the development, implementation, and execution of Child Find Programs and other related resources to ensure early detection and early access to services;
- » Ensure adequate funds are allocated to conduct research and the development and implementation of evidence-based practices from early intervention through postsecondary education to support learning of students with disabilities;

- » Ensure that young children with disabilities receive early intervention services in their natural environments, including preschool and childcare programs;
- » Ensure coverage of technology needs (including Internet access) in the Individualized Family Service Plan (IFSP), as appropriate; and
- » Ensure access to inclusive opportunities for early childhood education, including funding for the Child Care Block Grant.

### **Elementary and Secondary Education Individuals with Disabilities Education Act (IDEA)**

- » Reauthorize IDEA in a way that enhances the guarantee of a free and appropriate public education in the least restrictive environment;
- » Fully fund all components of IDEA and provide increased funding for Part C, Head Start, and other early intervention programs;
- » Ensure that school choice initiatives including public charter schools, vouchers, and voucher-like programs (education savings accounts, tax credit scholarship, and individual tax credits or deductions) comply with IDEA as well as the accountability provisions under ESSA and do not adversely affect public education;
- » Align the age of transition services to be consistent with the pre-vocational provisions in the Workforce Innovation and Opportunity Act of 2014;
- » Ensure appropriate assessments for all students with disabilities by developing universally designed assessments that accurately measure the progress of students with disabilities;
- » Ensure appropriate early intervention services and culturally competent assessments to prevent inappropriate classifications;
- » Promote universal design for learning guidelines in curriculum and in educational practices so that instructional goals, methods, materials, and assessments

- incorporate flexible approaches that can be customized and adjusted for individual needs;
- » Expand the design and use of assistive technology as appropriate for all students, including ensuring coverage of technology needs (including internet access) in the IEP, as appropriate;
  - » Amend IDEA's due process provision to place the burden of proof on school systems rather than parents;
  - » Amend IDEA to allow courts to reimburse parents' or guardians' expert witness fees incurred as part of the due process proceedings;
  - » Amend IDEA to provide more emphasis on teaching self-advocacy skills and encourage greater student involvement in the IEP process;
  - » Ensure monitoring and enforcement of the major components of IDEA, including least restrictive environment (LRE), due process, transition, cultural competence, and individualized IEPs, are properly and fully implemented, and ensure authorized penalties for non-compliance are enforced;
  - » Ensure that children who display elopement behaviors have their needs assessed and appropriately addressed in the IEP;
  - » Amend IDEA's IEP provision (614(d)) to ensure that, in the case of a child who does not yet have a symbolic mode of communication (oral language, augmentative communication system, and/or manual signs), a funded plan for developing a communication system for that child becomes a part of the IEP to include multiple use technologies, consistent with the Americans with Disabilities Act (ADA) Title II and Section 504; and
  - » Amend IDEA to provide better portability of federally guaranteed services and promote stability in the implementation of IEPs.

### Every Student Succeeds Act (ESSA)

- » Ensure full implementation of Every Student Succeeds Act (ESSA) through appropriate funding, enforcement, and monitoring of all provisions, including:
  - Full participation of students with disabilities in assessment, accountability systems, and reporting systems, including transparency about school performance for students with disabilities in state and local education agencies (LEAs) report cards;
  - Required assessments that are aligned with the challenging state academic standards for the grade in which the student is enrolled;
  - Appropriate justification for State Education Agencies (SEAs) to exceed the 1% cap on the number of students with the most significant cognitive disabilities who take an alternate assessment aligned with alternate academic achievement standards; and
  - Funding and full implementation of the early childhood provisions.

### Postsecondary Education

- » Fully fund disability provisions in Title VII of the Higher Education Opportunity Act (HEOA), including the Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities and Coordinating Center, National Technical Assistance Centers, and Programs to Provide Students with Disabilities with a Quality Higher Education;
- » Ensure students with disabilities, including those with intellectual and developmental disabilities, have access to all forms of federal financial aid;
- » Ensure that all students with disabilities have access to academic courses and the full range of campus programs and activities, including integrated housing;
- » Require colleges to accept a student's relevant formal documentation of disability from high school when seeking

accommodations so students are not required to undergo new costly evaluation to re-prove existence of a disability;

- » Ensure that information is made publicly available on the types of support services offered to help students and their families in selecting a school; and
- » Ensure proper implementation of provisions of the Strengthening Career and Technical Education for the 21st Century Act on career and technical education regarding greater inclusion and access for students with disabilities.

**Personnel**

- » Expand and improve in-service and pre-service personnel preparation under Part D of IDEA, ESSA, and the HEOA so that all special and general education teachers are highly effective;
- » Ensure that teacher preparation programs build a competent workforce of teachers equipped to instruct diverse learners;
- » Develop programs to expand the pool of undergraduates majoring in education who are prepared to educate all students in their classroom including students with disabilities; and
- » Include the recruitment and retention of teachers with disabilities as part of any federal diversity initiatives.

**Apprenticeships**

- » Ensure greater accessibility and availability of apprenticeship programs for people with disabilities, provided they are time-limited and comply with the federal definition of competitive integrated employment.

**EMPLOYMENT, TRAINING, AND WAGES**

The vast majority of our constituents who are of working age remain unemployed or under-employed. In fact, people with disabilities constitute the segment of our society that is least employed. People with I/DD often face a daunting task in securing employment. They can be employed in the community and should earn competitive wages. They should be supported to make

EMPLOYMENT, TRAINING, AND WAGES



informed choices about their work and careers and have access to the resources to seek, obtain, and be successful in competitive integrated employment.

Thus, during the 116th Congress, to assist our constituents to reach their full potential and become as independent as possible through integrated employment, our public policy goals are to:

### **Competitive Integrated Employment**

- » Support implementation of the Workforce Innovation and Opportunity Act (WIOA), toward maximizing employment outcomes, and improving transition outcomes, for people with I/DD;
- » Support “Employment First” policies as a strategy to increase opportunities for competitive integrated employment of individuals with I/DD as the preferred outcome;
- » Build infrastructure and create incentives for private sector employers or other solutions that will expand work opportunities for individuals with significant disabilities in competitive integrated employment;
- » Create incentives for states and territories to expand work opportunities for individuals with significant disabilities in competitive integrated employment, including necessary individualized transportation options so that individuals can maintain employment;
- » Expand training and technical assistance to community rehabilitation providers to transition from the use of subminimum wages and nonintegrated environments, including career counseling and information about training opportunities required by WIOA;
- » Build infrastructure and supports needed to phase out the issuance of sub-minimum wage certificates, including putting in place transition services and safeguards to protect the interests of any people with I/DD affected by this shift;
- » Conduct oversight on and strengthening of the Department of Labor’s monitoring of compliance under the Fair

Labor Standards Act and other federal non-discrimination requirements; and

- » Increase and index the federal minimum wage to increase economic security for people with disabilities and their families.

### **Vocational Rehabilitation**

- » Increase funding for state vocational rehabilitation programs significantly above the required Consumer Price Index (CPI) level to ensure investment in transition to postsecondary opportunities, supported employment, customized employment, and workforce development programs that help our constituents find and keep jobs and have more career options; and build infrastructure and create incentives for employers that will expand work opportunities.

### **Procurement and Contracting**

- » Modernize the Javits-Wagner-O'Day (JWOD) Act to expand competitive integrated employment opportunities and ensure that people with significant disabilities remain a priority for participation in the program;
- » Ensure that federal funds are directed toward funding competitive integrated employment;
- » Expand employment opportunities by establishing federal procurement preferences for all employers who employ people with disabilities; and
- » Assure that federal agencies with oversight require federal government contractors to prioritize the hiring of employees with disabilities, including individuals with I/DD, and continue to focus efforts on increasing requirements for hiring those with the most significant disabilities, including access to such annual hiring and retention data.

### **Employment Standards and Benefits**

- » Support policies that expand workplace flexibility;
- » Assure that part-time, supported, or periodic employees are

included in any proposal that expands or extends fringe benefit coverage; and

- » Expand access to family and medical leave and support paid leave policies, including by mandating employers to provide a reasonable amount of paid sick leave and requiring payers to recognize these costs in their reimbursement rates.

### Other

- » Assure that people with I/DD can access all relevant work programs, including business development opportunities;
- » Provide training and technical assistance to service providers for the purpose of expanding and improving their capacity to provide supported employment, customized employment, and other supports and services that will enhance opportunities for integrated employment consistent with best, promising, and emerging practices;
- » Require the Department of Labor’s Employment and Training Administration to link youth transition services to support competitive integrated employment using youth resources, including internships and apprenticeships;
- » Increase the number of people with disabilities employed by the federal government and federal contractors through streamlining hiring processes, strengthening affirmative action requirements, and improving education and recruitment efforts; and
- » Fully implement the Medicaid Home and Community-Based Services (HCBS) waiver program and State Medicaid plan Section 1915(i) option to promote competitive integrated employment.

### HEALTH CARE

Our organizations are committed to maintaining the comprehensive health care reforms achieved in the passage of the Affordable Care Act (ACA) (Patient Protection and Affordable Care Act, P.L. 111-148, and Health Care and Education Affordability Reconciliation Act, P.L. 111-152). With the enactment of the ACA, we made

significant progress towards accomplishing our nation's goal of universal access to high-quality affordable health care for all people with disabilities. The ACA includes historic coverage expansions; nondiscrimination and health insurance reforms; strengthened prevention provisions; numerous enhancements to Medicare and Medicaid; and other provisions that significantly benefit people with disabilities. It is critical that the essential benefits package designed for the health care exchanges meet the needs of people with disabilities. Protecting the significant achievements of the ACA will continue to be our highest health care priority. In addition, our organizations will work to advance the policy agenda that was not addressed by the ACA or only partially addressed.

Only a small percentage of physicians, nurses, and other health care professionals obtain information about serving people with I/DD as part of their academic coursework and to an even lesser degree are exposed to this population during their internships, practicums, and residencies. A competent health care professional workforce is essential to reducing health disparities and improving quality of life for people with I/DD. Knowledgeable, culturally competent, sensitive, and respectful health care providers have the ability to not only provide quality services but also, by providing holistic and preventive services, decrease health care spending by reducing hospitalization.

To achieve these goals, during the 116th Congress, our public policy goals are to:

### **Affordable Care Act (ACA)**

- » Ensure that the ACA is not further diminished through partial or full repeal or regulatory changes. In particular, the provisions that meet the needs of our constituents for quality, accessible, appropriate, comprehensive, affordable, portable, and non-discriminatory coverage and benefits must be protected;
- » Ensure that the ACA is adequately funded to accomplish the significant goals of the Act for our constituents;
- » Ensure that the Department of Health and Human Services fully implements the essential health benefits requirements, in particular habilitation;

- » Fund demonstration programs to implement individual care coordination for individuals with disabilities, particularly those who have complex and chronic health care needs;
- » Expand vision and preventive and restorative dental coverage under the ACA;
- » Support policies that promote universal coverage;
- » Ensure that there is transparency in health plan selection and that plans have an adequate network of providers and access to medical and other specialists;
- » Protect the Prevention and Public Health Fund and increase funding for primary and secondary prevention and wellness programs for individuals with disabilities;
- » Ensure that privately run wellness programs do not discriminate against people with disabilities or health conditions;
- » Reduce health care disparities experienced by people with I/DD;
- » Expand funding for training of all health care providers about the needs of children and adults with disabilities, including best practices to promote health and wellness, cultural competency, practices to prevent secondary conditions, and systems to help transition youth with disabilities to adult care providers;
- » Ensure that people have access to affordable prescription drugs that meet their individual health care needs;
- » Ensure that all demonstration pilot grants address the needs of people with disabilities; and
- » Ensure access to accessible nutrition and exercise resources and programs.

### **Medicaid/Medicare/Children's Health Insurance Program (CHIP)**

- » Protect existing health care entitlements under Medicare and Medicaid, including Medicaid expansion;
- » Ensure that there is seamless transition between Medicare,

Medicaid, and the health insurance exchanges to ensure continuity of care when an individual's income or job situation changes;

- » Expand access to, and ensure that cost-cutting strategies do not compromise access to durable medical equipment, including complex rehabilitation technology and other rehabilitative therapies and services, and that Medicare is responsive to the unique health care needs of our constituents;
- » Eliminate Medicare's 2-year waiting period under which people with disabilities qualify for Medicare coverage 24 months after receipt of Social Security Disability Insurance (SSDI) benefits;
- » Eliminate Medicare's "in the home" restriction for coverage of mobility devices (e.g., wheelchairs and scooters) for those with expected long term needs;
- » Improve the benefits available to Medicare beneficiaries, ensure affordability, add a long term supports and services benefit, and improve the notice and appeal rights in the Medicare program;
- » Protect funding of the Children's Health Insurance Program to ensure continued access to affordable coverage for children; and
- » Require the Centers for Medicare and Medicaid Services (CMS) to authorize payment for commercial, off-the-shelf, multiple-use technology to support people with I/DD.

### **Mental/Behavioral Health**

- » Ensure that the most appropriate mental/behavioral health services are widely available to people with I/DD who need them across the lifespan;
- » Provide training to providers of mental/behavioral health services to enable competency in meeting the needs of people with I/DD;
- » Increase training to mental/behavioral health professionals regarding the screening for and ruling out of psychiatric disabilities in people with I/DD;

- » Ensure that community-based first responders (e.g., police, emergency medical services, emergency room personnel) are equipped with knowledge about working with people who have I/DD and who are experiencing a behavioral and/or mental health crisis;
- » Ensure that the provisions of the Mental Health Parity and Addiction Equity Act along with the mental/behavioral health and substance use services provisions in the ACA are fully funded and implemented; and
- » Ensure sufficient reimbursement rates for mental/behavioral health service providers in order to promote improved access to needed services.

### Other

- » Reauthorize and fully fund the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act; and ensure more research on individuals across the lifespan and in diverse populations;
- » Reduce harmful chemical exposures that are associated with I/DD;
- » Ensure access to medical cannabis for people who can benefit from it;
- » Recognize developmental and other disabilities as medically underserved populations;
- » Ensure that measures intended to curb drug abuse do not place an undue burden on access to properly prescribed medications, including pain management medications;
- » Strengthen consumer protections to protect people with I/DD from unsafe or untested treatments; and
- » Ensure that medical research is patient-centered in design and implementation.

### MEDICAID

Medicaid is an essential program for most people with significant disabilities. Medicaid is overwhelmingly the largest funding source

of long term individual and family supports in the federal/state I/DD service system, and the primary source of health care payment for many of our constituents. For the increasing number of individuals with disabilities living with aging parents, Medicaid will continue to be essential to meet their future need for long term supports and services.

Medicaid is also a powerful driver of economic activity at the state and local levels. When people with disabilities receive needed services, key family members are able to maintain their own employment. When Medicaid-funded service provider agencies are able to retain staff positions, unemployment is reduced and money is put into the hands of individuals who will spend it. In addition, Medicaid reduces health care costs by allowing people with disabilities to utilize home and community-based supports and services rather than costly and unnecessary institutionalization.

Many states and territories continue to have inadequate reimbursement rates and reduced services with devastating impact on people with disabilities, their families, and their communities. Today, many of our constituents cannot get necessary health care and long term services. Further shifting responsibility for Medicaid to the states and allowing states to reduce eligibility and benefits would place many of our constituents, and our nation's health, therapeutic, and long term support systems for vulnerable populations, at enormous risk. Decreased Medicaid budgets also mean that hundreds of thousands of people with I/DD will remain on waiting lists across the country.

Numerous improvements were made to the Medicaid acute and long term supports and services programs through enactment of the Affordable Care Act (ACA). These program improvements must be properly implemented at the federal and state levels in order to work most effectively for people with disabilities. States must be provided with clear guidance on how to effectively use the flexibility and options created by the ACA.

During the 116th Congress, our public policy goals are to:

### **Overall Structure**

- » Maintain the individual entitlement to a full range of Medicaid health and long term supports and services (LTSS) for all eligible children and adults with disabilities;



- » Oppose Medicaid deconstruction or any moves to provide states with flexibility that eliminates basic protections for eligible individuals with developmental disabilities or the imposition of entitlement caps, Medicaid block grants, per capita caps, allocations, allotments, limiting provider taxes, and other proposals that shift costs to states or other mechanisms that cause reductions in eligibility, services, or protections for our constituents;
- » Oppose requirements that Medicaid beneficiaries be employed in order to receive benefits;
- » Oppose policies that would time limit Medicaid benefits;
- » Reject efforts to repeal, weaken, or block implementation of relevant provisions of the ACA;
- » Require the Centers for Medicare and Medicaid Services (CMS) provide thorough, timely, and consistent review of all state plan amendments and waivers to ensure compliance with the ADA and Olmstead; and
- » Require CMS and the states to provide full and timely public access to state Medicaid plans and waivers, including current and proposed amendments and related public comment, in formats accessible to stakeholders.

### **Eligibility**

- » Incentivize state implementation and ensure protection of Medicaid expansion as authorized by the ACA;
- » Incentivize state implementation of the option in state Medicaid plans for families of children with disabilities to buy into Medicaid if private health insurance is not available or does not meet their needs;
- » Incentivize full implementation by states of options to establish Medicaid buy-in programs for people with disabilities who work;
- » Ensure that Medicaid eligibility rules and processes do not place undue burdens on applicants and beneficiaries who do not have access to birth or citizenship documentation;

- » Protect and improve the ability of families and individuals to establish trusts to benefit Medicaid eligible beneficiaries with I/DD and ensure the integrity of pooled trusts which serve such families and individuals; and
- » Increase the spend-down limit under Medicaid.

### **Benefits**

- » Prohibit issuance or implementation of any regulations that limit or eliminate services;
- » Improve and expand access to the Medicaid buy-in program;
- » Ensure that Medicaid-eligible children with disabilities continue to obtain health-related services during the school day and receive any necessary accessible, affordable, accountable, and flexible transportation to those services;
- » Ensure protections for people with disabilities who are dually eligible for Medicaid and Medicare to ensure that they have timely and affordable access to all medically necessary services, supports, and medications under Medicaid, Medicare, and Medicare prescription drug plans;
- » Protect the entitlement to the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and support sanctions against states that fail to properly implement it;
- » Expand access to dental and vision services;
- » Promote policies that ensure adequate networks of providers and access to medical and other specialists as needed;
- » Require the CMS to issue guidance to states that will result in expanded coverage of appropriate assistive technology and technology-enabled supports for Medicaid beneficiaries, including eliminating barriers to multi-use and commercial off-the-shelf technology that could support independent living in the community;
- » Ensure Medicaid reimbursement for a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies;

- » Support the continuation and expansion of habilitation services under the Medicaid rehabilitation option and other appropriate options and ensure that our constituents have supports, services, and training available to teach them to achieve self-determination and increase independence, productivity, and full citizenship through greater mental, physical, and social development; and
- » Ensure the availability of accessible, affordable, accountable, and flexible transportation to facilitate full community participation.

### **Home and Community-Based Services (HCBS)**

- » Ensure full implementation and enforcement of the HCBS settings rule for both residential and non-residential services, including adequate funding, technical assistance, appropriate individualized transportation options to ensure community integration, and other necessary supports to states;
- » Change Medicaid law to mandate HCBS and require a waiver to provide services in institutions;
- » Ensure that states have plans to provide services to individuals with I/DD who live with aging caregivers or who are in other crisis situations, and allow reimbursement for future planning services;
- » Change Medicaid law so that individuals and families can choose to exercise control over resources to better meet their individual needs;
- » Require CMS to establish policy to include HCBS under the equal access rule, which requires rates to be set to ensure equal access to services;
- » Ensure the full implementation of the Community First Choice (CFC) Option which allows states to provide comprehensive community-based services with an incentive of a six-percent increase in the federal matching rate for such services;
- » Ensure full implementation of 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;

- » Ensure full implementation of all other long term services provisions and expansions included in the ACA to meet the needs of people with disabilities, including the state rebalancing provisions, expansion of the Money Follows the Person demonstration program, expansion of the Aging and Disability Resource Centers, and the spousal impoverishment provisions;
- » Revise Medicaid law to require states to serve all federally Medicaid eligible people with developmental disabilities and not allow states to serve only a subset of the population;
- » Enact a requirement that states implement the CFC Option;
- » Fully implement the Medicaid HCBS waiver program and state Medicaid plan Section 1915(i) option to promote competitive integrated employment;
- » Ensure that amount, duration, and scope of HCBS are provided on the basis of individual need identified through a person-centered planning process; and
- » Expand funding for training of all providers about the needs of children and adults with disabilities, including best practices to promote health and wellness, cultural competency, practices to prevent secondary conditions, and systems to help transition youth with disabilities to adult care providers.

### **Removal of Institutional Bias**

- » Address unmet needs in the community by removing the institutional bias for Medicaid long term supports and services by amending the Medicaid formula for cost-sharing with the states to provide a greater fiscal incentive for supporting individuals in the community rather than in institutions; and
- » Decouple eligibility for HCBS waivers from eligibility for institutional services.

## Portability

- » Improve Medicaid so that benefits are portable from state to state, so that beneficiaries and families are not disadvantaged or deprived by moving from one state to another;
- » Support clarification that states have current authority to facilitate portability; and
- » Support a project by CMS to demonstrate interstate portability of benefits with state coordination and cooperation.

## Reimbursement Rates

- » Increase federal funding for HCBS through incentive payments to states of increased federal matching funds for community-based services;
- » Ensure that states set and update reimbursement rates annually so that they reflect the actual cost of providing Medicaid funded supports and services, particularly state and federal mandates, adequate wages and fully funded benefits for direct support professionals, and reimbursement rates and fees for health care practitioners; and
- » Require strong federal oversight of the adequacy of rate setting methodologies to ensure rates are sufficient to comply with federal and state mandates.

## Managed Care

- » Ensure that individuals receiving services in a managed care system have the right to a person-centered plan which is generated by an assessment and a care coordination model which are relevant to the needs of people with I/DD;
- » Ensure that individuals have the right to have their person-centered plan developed in conjunction with an entity of the individual's choosing independent of the provider and the managed care organization;

- » Recognize the necessity of Health Information Technology (HIT) or Electronic Health Records (EHR) for effective care coordination of acute and long term supports and services for people with disabilities, and provide adequate federal funding assistance;
- » Recognize the paucity of experience and claims data for managed care for LTSS and reject proposals to mandate the states to move people with disabilities who are dually eligible for Medicaid and Medicare into managed care programs until sufficient, reliable claims and outcome data from demonstration projects are collected and analyzed;
- » Maintain the prohibition against the mandatory placement of children with disabilities into Medicaid managed care without an approved waiver;
- » Require CMS to provide strong federal oversight in states where acute, behavioral health care and/or LTSS are provided through Medicaid managed care or other integrated care programs and expand existing managed care consumer protections;
- » Require transparency and meaningful opportunities for stakeholder engagement during all phases of the development and adoption of financing and service delivery changes, including concept development, contract specifications, evaluation, oversight, and CMS review of waiver applications/state plan amendments; and
- » Require CMS to require states to:
  - Structure assessment, care coordination, and rate setting methodology to include financial incentives to achieve person-centered outcomes consistent with the principles of Olmstead and the ADA;
  - Build rate setting methodology by collecting at least 2–3 years of Medicaid (and, as appropriate, Medicare) claims data, including acute, behavioral health, and LTSS claims, and workforce data as available and appropriate. Acute and behavioral health claims data should not be used to determine costs of LTSS as those supports are not medically based; articulate explicit performance

outcome measures and metrics in purchasing specifications and contract language with providers under fee for service or other entities the state uses such as accountable care organizations (ACOs) or managed care entities (MCEs); and

- Commission an independent evaluation of their managed care programs and other integrated care models and include the findings and conclusions from this evaluation in a state's renewal request.

## **SOCIAL SECURITY/INCOME MAINTENANCE**

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. The Social Security Act provides Old Age, Survivors, and Disability Insurance under Title II of the Act, Supplemental Security Income (SSI) under Title XVI of the Act, and related health insurance under Medicare (Title XVIII) and Medicaid (Title XIX). Approximately one-third of all Social Security checks go to non-retirees, including approximately ten 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. Many depend solely on their Social Security or SSI benefits and related health coverage for their basic survival. Discussions about Social Security reform, however, usually focus on retirement benefits and seldom address potential effects on people with disabilities in the retirement, disability, and survivors programs.

We support efforts to ensure the solvency of the Social Security Trust Funds over a 75-year time frame while preserving the program's basic structure and strengthening its insurance functions. We do not support efforts to create private accounts out of the Social Security Trust Funds. The impact of the resulting market risk, benefit cuts, or additional trillions of dollars in deficits would be devastating for people with disabilities.

In recent years, inadequate funding of SSA's operating budget has eroded the agency's services across the board. People with disabilities have experienced long delays and decreased service

in accessing critical Social Security benefits. Processing times for disability claims have grown, especially at the hearing level where delays have reached historic and intolerable levels. Behind the numbers are individuals with disabilities whose lives have unraveled while waiting for decisions – families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many individuals die.

During the 116th Congress, our public policy goals are to:

### **Overall structure**

- » Protect and expand the effectiveness of income support programs and their related health coverage programs in the Social Security Act, including the Old Age, Survivors, and Disability Insurance (Title II) programs, SSI (Title XVI) program, Medicare (Title XVIII), and Medicaid (Title XIX);
- » Reject any proposal to privatize or otherwise diminish Social Security trust funds or revenues dedicated to the trust funds;
- » Support proposals to ensure the long term solvency (over 75 years) of the Social Security trust funds through adjustments that spread the costs and preserve current and future benefits, through options such as expanding the earnings that are subject to the Federal Insurance Contributions Act (FICA), increasing FICA rates, or expanding the base of workers who participate in the Social Security system;
- » Support proposals to put Social Security’s Old-Age and Survivors Trust Fund and Disability Insurance Trust Fund on an even financial path by reallocating FICA taxes or creating a single Social Security Trust Fund;
- » Make adjustments to ensure the solvency of the Social Security programs through changes outside of a deficit reduction context;
- » Reject proposals to increase the retirement age, change the benefit formula, reduce annual cost-of-living adjustments, or otherwise cut benefits;



- » Maintain the insurance protections of the Title II programs for people with disabilities; and
- » Recognize that intellectual and developmental disabilities are life-long conditions. Therefore, maintain SSI and Title II as cash assistance programs that are relevant and viable for children and adults with these conditions.

### **Definition of Disability**

- » Reject any proposal that would further narrow the definition of disability and lead to the loss of benefits, supports, and services;
- » Increase the Substantial Gainful Activity (SGA) level at least to the level used for people who are blind; and
- » Support adherence to a common language of diagnostic terms, including “intellectual disability”, in the Social Security listings to minimize confusion and unintended exclusions from eligibility.

### **Administrative Issues**

- » Fully fund the administrative expenses of the Social Security Administration (SSA) to ensure that the service needs of the public are met, particularly for people applying for disability benefits and those who request a hearing;
- » Monitor changes in the process for determining disability and ensure the protection of claimants’ due process rights to an individualized decision, including the right to a full and fair administrative hearing by an independent decision-maker who provides impartial fact-finding and adjudication;
- » Require SSA to minimize overpayments by establishing an efficiently working, beneficiary-friendly, system for collection of earnings reports and adjustments of benefits payments. Require SSA to waive non-fraudulent overpayments when SSA has failed to notify the beneficiary within a reasonable time period; and

- » Provide oversight to review and improve the representative payee system.

### **Supplemental Security Income**

- » Substantially increase the resource limit for SSI to at least the level it would have been had it been indexed for inflation since inception. Annually index the SSI resource limit for inflation;
- » Increase the SSI earned and unearned income exclusions to at least the level they would be had they been indexed for inflation since inception, and index for inflation annually thereafter;
- » Extend continued Medicaid eligibility for SSI/Medicaid beneficiaries who earn their way into the Title II Disability Insurance program so that they may continue to have the supports necessary to work;
- » Permanently extend eligibility for SSI to refugees, asylees, and other immigrants who are disabled or elderly;
- » Ensure adequacy of SSI benefits and remove barriers to independence, community integration, savings, work, marriage, and assistance or support by families; and
- » Ensure that SSI beneficiaries can participate in appropriate Individual Development Accounts, retirement plans (such as 401(k) accounts), ABLE accounts, and other similar accounts without jeopardizing their eligibility for SSI.

### **Retirement, Survivors, and Disability Insurance**

- » Eliminate the 5-month waiting period for eligibility for Title II disability benefits and eliminate the additional 24-month waiting period for Medicare for Title II beneficiaries with disabilities;
- » Enact an earnings offset work incentive for Title II beneficiaries; and
- » Enact simplification of work incentives, including allowing on-going presumptive re-entitlement to Title II disability benefits and on-going eligibility for Medicare for those who lose benefits due to work but continue to be disabled.

### Disabled Adult Child (DAC) Benefits

- » Improve requirements for DAC benefit eligibility to eliminate work disincentives;
- » Exempt DAC beneficiaries from the Family Maximum when they are not living in the household of the parent/spouse; and
- » To eliminate potential disincentives for adoption, ensure that individuals who adopt children with special needs are not affected by application of the family maximum with respect to those adopted children.

### Employment Issues

- » Provide cash assistance outside of Social Security and SSI to assist working individuals with disabilities in meeting their disability-related costs, regardless of their income or assets;
- » With the aim that everyone should earn at least minimum wage, ensure that people who work in sub-minimum wage or wage-subsidized situations have FICA taxes paid on their behalf and receive appropriate work credits for Title II and Medicare eligibility;
- » Enact technical and substantive changes to the Ticket to Work and Work Incentives Improvement Act to ensure the Act operates as intended for our constituents; and
- » Ensure that beneficiaries have access to information about work incentives and employment services, benefits counseling, and legal advocacy under the Work Incentives Planning and Assistance (WIPA) and Protection and Advocacy for Beneficiaries of Social Security (PABSS) programs.

### Other

- » Ensure adequate benefit levels and protect buying power through appropriate cost of living adjustments;
- » Provide workers who leave the workforce temporarily to care for a family member, including a child or adult with a

disability, with a credit toward their future Social Security benefits (currently these workers receive no credit toward their Social Security benefits during the years they are out of the workforce for caregiving, which can greatly reduce any future Social Security benefits);

- » Eliminate marriage penalties in Social Security disability policy;
- » Permanently authorize SSA's authority to conduct demonstration programs, so long as participation is voluntary and beneficiaries are protected from any disadvantage, such as loss of benefits or eligibility, as a result of participating in demonstration projects;
- » Exclude the AmeriCorps State and National and AmeriCorps National Civilian Community Corps program payments for purposes of determining Title II disability program eligibility and benefit amounts; and
- » Support development of interdisciplinary teams of clinicians with specialized developmental and assessment expertise to provide expertise for adjudicators who determine eligibility for disability benefits.

## B. OTHER CRITICAL GOALS

The legislative goals delineated below reflect major laws and programs that may be addressed in the 116th Congress. These laws and programs also play key roles in the lives of our constituents and their families. In particular, they provide essential health care, employment, family, transportation, and technology supports to make community living a reality for our constituents. Essential investments in the causes and effects of I/DD; child welfare, foster care, and adoption; criminal justice; emergency management; family support; housing; immigration and naturalization; liability insurance protections; non-profit organizations; quality of services; research and data collection; tax provisions; technology; Temporary Assistance for Needy Families and social services; and transportation are addressed by these goals. For convenience, they are listed alphabetically.

## CAUSES AND EFFECTS OF I/DD

The federal government should investigate the causes, avoid those that are preventable, and limit the negative effects of conditions that cause I/DD through prevention programs, policies, and practices. To increase research and services for the prevention of primary and secondary disabilities, during the 116th Congress, our public policy goals are to:

- » Protect the Prevention and Public Health Fund created in the Affordable Care Act designed to increase the national investment in prevention and public health, improve health, and enhance the quality of health care;
- » Support public health and safety interventions for persons with I/DD, including training to help prevent and reduce the harm from wandering (also known as elopement);
- » Increase funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Environmental Protection Agency (EPA) and for other existing federal education and prevention initiatives, in areas including but not limited to:
  - Autism Spectrum Disorder;
  - Cerebral Palsy;
  - Developmental Disabilities;
  - Environmental hazards;
  - Fetal Alcohol Spectrum Disorders;
  - Food additives and harmful drugs;
  - Intellectual Disability;
  - Lead poisoning;
  - Microcephaly, and other disabilities caused by the Zika virus;
  - Product safety;

- Sexual exploitation and abuse;
  - Smoking; and
  - Transportation safety;
- » Reduce harmful chemical exposures that can result in I/DD;
  - » Require public and private insurance payers to pay for evidence-based special diet foods that prevent disabilities such as special phenylalanine-free preparations to control Phenylketonuria (PKU);
  - » Ensure full implementation of the mandated Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program;
  - » Protect and expand the disability-related warnings for alcohol products and venues;
  - » Support efforts to provide data that can be cross-tabulated and disaggregated on the prevalence of I/DD and associated environmental causes; and
  - » Increase resources for the NCBDDD and other similar federal agencies to expand the State Disability and Health program in order to help prevent health disparities and the occurrence of secondary conditions, including obesity-related chronic diseases for individuals with lifelong disabilities.

## **CHILD WELFARE, FOSTER CARE, AND ADOPTION**

Many children and youth in foster care systems have disabilities, yet the very systems intended to protect them were not designed to identify, assess, and manage the needs of children with disabilities and their foster families. Once in the foster care system, children with disabilities may face a full range of systemic problems that prevent positive life experiences and often experience abuse and neglect. All too often, caseworkers lack the tools to identify and assess disabilities, foster parents lack even basic information about the unique needs of children placed in their homes, and there are systemic and attitudinal barriers to adoption for children with disabilities.

During the 116th Congress, our public policy goals are to:

- » Fully fund all programs under the Social Security Act and other federal policies designed to support and assist children and youth in foster care systems, including:
  - Title IV-E Foster Care Program;
  - Title IV-E Adoption Assistance Program;
  - Title IV-B Child Welfare Services Program;
  - Title XX Social Services Block Grant Program;
  - Child Care and Development Block Grant;
  - Child Abuse Prevention and Treatment Act (CAPTA);
  - Head Start; and
  - Medicaid services for foster children;
- » Require the Departments of Health and Human Services and Education to:
  - Develop and establish a uniform national data system to identify children and youth in foster care systems who have disabilities and to assess the quality of their lives, their integration, and self-determination as a result of the government-provided supports and services they receive;
  - Establish a coordinated approach to information, support, and training for foster families, child welfare workers, and educators that will serve to enhance the supports provided and the quality of life for all involved;
  - Establish planning protocols and services for youth with disabilities who are transitioning out of foster care due to their age; and
  - Strengthen efforts to identify and support adoptive families for children and youth with disabilities in foster care systems;
- » Ensure DOJ enforcement of the Olmstead mandate of integration in the provision of foster care services; and

- » Establish protections for parents with disabilities under the Adoption and Safe Families Act to ensure that parents with disabilities do not lose custody of their children and/or are not prohibited from adopting children solely because of their disability.

## CRIMINAL JUSTICE

People with disabilities enter criminal justice systems as victims, witnesses, and suspects/offenders. Interactions between law enforcement and criminal justice systems with people with disabilities are occurring more frequently, highlighting the need for better protections for people with disabilities throughout criminal justice systems. The systems must provide better protections of the interests of people with disabilities; better support, access, understanding, and diversion at every level of the system for individuals with disabilities is needed. Statistics clearly indicate that more individuals with disabilities are entering juvenile justice facilities, jails, and prisons. Many are placed in such settings due to failures throughout the criminal justice systems. They are also entering the criminal justice system due to failures in the educational and the social service systems when early and accurate identifications of I/DD are not made and essential services and supports are not provided, which can result in criminal justice involvement later in life. This issue has become more public as the press has documented numerous disturbing but typical incidents.

During the 116th Congress, our public policy goals are to:

### Training

- » Require training for teachers, other school professionals, and community providers so that they have an understanding of the criminal justice system;
- » Mandate ongoing evidence-based training of all personnel in criminal justice systems (e.g., law enforcement, judges, public defenders, prosecuting attorneys, and victim advocates) about issues unique to people with I/DD, including identification of a disability, communication, and de-escalation strategies (including in education settings) to avoid unnecessary involvement in criminal justice systems;



- » Provide training to all personnel in the criminal justice system about due process protections and include reliable, culturally competent assessments for determining existence of ID and legal competency; and
- » Provide training to individuals with I/DD, especially youth, about personal safety, crime prevention, reporting, and what to do if they are involved in a crime as a witness, suspect, or victim.

### **Research and Identification**

- » Support the creation of a system that collects valid, reliable, national data on the number of people with I/DD currently within the criminal justice systems; and
- » Collect valid, reliable, national data relating to crimes involving individuals with I/DD as witnesses, suspects, or victims, including data on the alleged perpetrators in new and within existing data sets and reporting systems.

### **Interventions**

- » Promote and expand best practices for successful law enforcement interaction with people with disabilities, including training on behaviors such as wandering, different communication styles, and stressful reactions to physical prompts and restraints or environmental stimulation;
- » Provide appropriate crime victim, witness, and suspect assistance and accommodations to people with I/DD;
- » Ensure reasonable accommodation in all stages of criminal proceedings to assist individuals with I/DD in understanding their rights, understanding the charge(s), and appropriately participating in the proceedings and their defense;
- » Ensure that competency standards and findings reflect contemporary clinical practices and do not have the impact of indefinitely detaining individuals with disabilities with no resolution;
- » Prevent discrimination on the basis of disability by the

criminal justice systems against victims, witnesses, and those accused of crimes;

- » Promote best practice alternatives to incarceration, including diversion, for people with I/DD;
- » Ensure appropriate special educational services for incarcerated youth with disabilities;
- » Ensure that health care and other interventions are available to individuals with disabilities who are in the criminal justice systems;
- » Ensure “re-entry” programs include accommodations for successful transition from criminal justice systems to the community such as training and reference materials related to conditions of probation and parole; and
- » Incentivize court systems to assess and address functions, procedures, and rules that more harshly impact people with I/DD, which inhibit exercise of their civil or constitutional rights, or which unnecessarily delay return to society.

### **Protections**

- » Ensure enforcement of the ADA and Section 504 of the Rehabilitation Act when it comes to arrests and detention for individuals with disabilities;
- » Ensure that the DOJ enforces due process rights throughout the criminal justice systems, including when individuals are placed in alternative treatment programs;
- » Ensure inexpensive and timely access by families, providers, and states to federal criminal background checks for anyone employed in the disability service system;
- » Prosecute individuals who commit, and entities that are party to, physical, psychological, or sexual abuse, mistreatment, or neglect of children or adults with disabilities;
- » Ensure that the rights of people with I/DD are protected during all interactions with law enforcement; and

- » Support full implementation of the Prison Rape Elimination Act (PREA) standards and ensure that these practices apply to inmates with I/DD, who are especially vulnerable to abuse within correctional settings.

## EMERGENCY MANAGEMENT

Recent natural, public health, and man-made disasters demonstrate that preparedness and mitigation, as well as response and recovery efforts, remain critically inadequate with regard to people with disabilities. People with disabilities still disproportionately represent those who remain uprooted and at risk in communities around the country following any type of disaster or emergency. During the 116th Congress, our public policy goals are to:

- » Assure that all federal agencies, entities receiving federal funds, service providers, and other relevant organizations are held accountable for developing and participating in coordinated approaches to disaster and emergency preparedness that are efficient, non-duplicative, and address the needs of people with disabilities;
- » Fund and target adequate resources throughout the U.S. to coordinate state and local efforts, specifically to ensure the effective involvement of people with disabilities and their representatives in disaster and emergency preparedness efforts;
- » Conduct oversight (e.g., hearings, reports) of existing laws to document progress to date; address the needs of people with disabilities in emergency mitigation, preparedness, response, and recovery efforts; and address continuing failures and challenges and make recommendations for improvement;
- » Pass additional legislation, with adequate funding that will:
  - Require disaster plans in all settings that receive federal funds;
  - Require fully accessible temporary and long term relief housing for at least 10% of available or developed housing resources;

- Ensure that general shelters are accessible to people with disabilities and that medical shelters are used only in cases of extreme need;
- Exclude institutionalization as a solution to housing needs for people with disabilities, except in a dire emergency and for an extremely short period of time;
- Provide specific disability-related service coordination (case management) for longer periods of time;
- Provide mental health and substance abuse services specifically related to disasters and emergencies;
- Provide for legal services offered by legal experts with specialized training in disability rights and other disability law;
- Increase support for regional disability coordinators;
- Develop resources and training for first responders and other personnel on the functional needs of people with disabilities and their families;
- Ensure that direct support professionals are considered “essential personnel” in emergency preparedness plans and response;
- Ensure that private health insurance, Medicaid, and Medicare Part D cover and provide a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies; and
- Require the Administrator of the Federal Emergency Management Agency to maintain the Office of Disability Integration and Coordination, with a Disability Coordinator and adequate staff, to ensure that the needs of people with disabilities are addressed in emergency preparedness and execution.

**FAMILY SUPPORT**

.....  
Across the nation, the vast majority of people with I/DD live at home with their families. Families are broadly understood to include relationships of blood, marriage, or choice. These families

often receive few services and lose jobs and income as they try to meet their family members' needs. In addition, families of children and adults face the lack of necessary supports for their family member to meaningfully participate in appropriate programs and employment. Life-long caregiving for individuals with disabilities, without support or assistance, has long term negative economic, health, and social impacts on the well-being and quality of life of families. As people with disabilities are living longer, siblings and other family members are playing increasingly important roles across the lifespan and frequently assume primary caregiving responsibilities when aging parents are no longer able. The rapidly growing population of aging care-givers is in great need of supports and services. Given our nation's fiscal challenges, it is likely that greater numbers of individuals with I/DD will be living with their families for longer periods.

To strengthen the ability of families and other caregivers to support their relatives or others with disabilities whom they support, during the 116th Congress, our public policy goals are to:

- » Support federal initiatives that recognize the important role of families and the need for comprehensive family supports and ensure that any such initiatives explicitly recognize that they cannot be a substitute for creating a national solution to provide appropriate long term supports and services for persons with disabilities;
- » Ensure the timely implementation of legislation to develop a strategy for family caregivers;
- » Significantly increase funding and establish a separate authorization level for the Family Support Program under Title II of the DD Act;
- » Maintain full funding for a state capacity development program on family support;
- » Ensure the Family and Medical Leave Act (FMLA) covers more workers by reaching smaller employers and part-time workers and ensure the definition of covered family member includes, for example, siblings, grandparents, and domestic partners;

- » Provide paid family and medical leave that is inclusive, covering workers broadly and using an inclusive definition of family; comprehensive, providing leave for workers to care for their own or a family member's serious illness or to welcome a new baby or new child; adequate, replacing a sufficient percentage of wages to provide economic security; secure, providing job protections such as under the FMLA; and affordable, for both workers and employers, such as when funded through a social insurance model;
- » Support initiatives that remove barriers to employment, such as flex time, job sharing, and telecommuting, in order to prevent the descent into poverty of caregiving families;
- » Provide incentives for businesses to offer employer-provided individual and family supports for employees who have a family member with I/DD as part of employee-assistance programs;
- » Fully fund the Lifespan Respite Care Act to help ensure the availability of respite care for families, regardless of age or disability;
- » Fully implement and increase funding for the National Family Caregiver Support program;
- » Reauthorize and increase funding for the Child Care and Development Block Grant (CCDBG) to expand child care services and provide technical assistance to child care providers so that they are better able to meet the needs of children with disabilities;
- » Improve and expand adoption assistance and foster care programs to better address the multiple challenges facing children with disabilities and their adoptive or foster families;
- » Amend the Adoption and Safe Families Act to extend the timelines for permanency for parents with disabilities as well as the "reasonable efforts" provision to keep children with their parents;
- » Authorize Title IV-E of the Social Security Act waivers to

encourage the use of in-home services to prevent the use of out of home placements;

- » Address inequities in access to and funding for direct support caregiver services for all Medicaid-eligible developmental disability populations;
- » Provide a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses;
- » Ensure that programs providing personal assistance services include supports and services for parents with disabilities; and
- » Continue funding of the Social Security Act Title V Maternal and Child Health Program.

## HOUSING

Across the nation, people with disabilities face a crisis in the availability of decent, safe, affordable, and accessible housing. For people who use wheelchairs or other mobility devices, finding housing with even basic accessibility features (e.g., an entrance with no steps) ranges from daunting to impossible. While there are unique issues in urban, suburban, and rural areas, this difficulty is magnified in rural areas where there is a scarcity of any rental housing and new units are rarely developed. For people with disabilities whose resources are limited to Supplemental Security Income (SSI) benefits, the affordability crisis is even worse.

Therefore, during the 116th Congress, our public policy goals are to increase the supply of affordable and accessible housing options that are integrated in the community, including home ownership and rental housing, to meet the growing unmet needs of people with disabilities and their families by doing the following:

- » Significantly increase funding for, and protect the integrity of U.S. Department of Housing and Urban Development (HUD) programs such as the Section 8 Housing Choice Voucher program, the Section 811 Supportive Housing for Persons with Disabilities program, the HOME Investment Partnerships program, and the Community Development Block Grant program and increase funding for U.S.

Department of Agriculture housing programs as well as all other federal housing programs providing funding for people with disabilities;

- » Provide funding to address the need for safe, affordable, and accessible housing for individuals with disabilities due to housing foreclosures, other financial crises, and weather-related and other emergencies;
- » Ensure adequate funding and full implementation of the National Housing Trust Fund, with deeply targeted eligibility criteria to increase the availability of affordable and accessible housing for people with disabilities;
- » Provide funding for and ensure proper implementation of the Frank Melville Supportive Housing Investment Act of 2010, which reformed the Section 811 Supportive Housing for Persons with Disabilities program to use proven “best practice” models to increase the number of units created, improve leveraging of other affordable housing funding streams, and develop a range of appropriately sized and integrated permanent housing opportunities;
- » Oppose efforts to weaken fair housing protections or limit implementation and enforcement of fair housing rules;
- » Remove barriers that prevent people from renting or buying their own homes, through:
  - Simplifying programs;
  - Ensuring appropriate fair-market rents;
  - Eliminating discrimination based on source of income (such as SSI);
  - Permitting people to acquire assets;
  - Providing funding to educate and train public housing authorities and service providers on the housing needs of people with disabilities;
  - Ensuring that non-profit disability organizations can administer tenant-based rental assistance; and
  - Ensuring fairness and equity;



- » Enact legislation requiring newly constructed, federally assisted housing to incorporate universal design and visitability standards (elements that afford accessibility to at least the first floor of a dwelling);
- » Remove barriers and promote access to affordable, accessible housing for people with disabilities who have been involved in the criminal or juvenile justice systems;
- » Require that projects developed through the Low-Income Housing Tax Credit apply design standards identical to those in Section 504 of the Rehabilitation Act; and
- » Provide oversight of HUD's management of housing programs to ensure that they meet the housing needs of people with disabilities.

## IMMIGRATION AND NATURALIZATION

People with I/DD who wish to enter the United States to visit on a variety of visas, to immigrate to live on their own or with their families, or to seek refuge or asylum should have the same opportunities as any other non-citizens. However, there are numerous roadblocks in their way despite the enthusiastic and successful efforts in the 1990's to ensure accommodations in the process for interviewing and testing for naturalization and for accommodations in administering the oath of allegiance. The rules prohibiting entry for people deemed to be at risk of becoming a "public charge" by using certain public benefits fall particularly harshly on people who need supports in their daily lives despite their contributions to their families and communities. Immigration and naturalization policies and rules must recognize the humanity of all persons who wish to enter the U.S. and provide for humane and fair opportunities.

During the 116th Congress, our public policy goals are to:

- » Ensure that non-citizens with any type of disability have a fair opportunity to enter and reside legally in the United States and to become citizens, without unnecessary or discriminatory restrictions based on their disability, including those needing protection as refugees, asylees, and victims of human trafficking;

- » Ensure that our constituents who are legal residents have access to essential supports and services, such as Supplemental Security Income (SSI), Supplemental Nutrition Assistance Program (SNAP), and Medicaid, without impact on their current or future rights to travel, visas, residency, or citizenship;
- » Ensure that individuals with disabilities who are facing deportation or other legal action are provided with legal representation, due process protections, and reasonable accommodations and that they are not unnecessarily detained and segregated in immigration facilities;
- » Ensure that children and adults with disabilities are not arbitrarily separated from their families before, during, or after proceedings to determine their or their family members’ immigration status and that all efforts are made to keep family members together; and
- » Pursue appropriate waivers of, or changes in, immigration law to allow for the active recruitment of qualified immigrants in order to bolster the direct support and other professional workforce.

**LIABILITY INSURANCE PROTECTIONS**

During the 116th Congress, our public policy goals are to:

- » Ensure fair compensation to our constituents for the negligence of another person or a corporate entity, including health insurance and managed care plans and non-profit organizations; and
- » Ensure that no entity can be absolved of liability because the individual affected has a disability.

**NON-PROFIT ORGANIZATIONS**

The voluntary and faith-based non-profit sector has provided the overwhelming majority of supports and services for our constituents. In addition, the non-profit sector must be allowed to maintain its important traditional role of advocacy.

LIABILITY INSURANCE PROTECTIONS

NON-PROFIT ORGANIZATIONS

During the 116th Congress, our public policy goals are to:

- » Protect the charitable deduction for federal income taxes and reject any provisions that would likely serve as disincentives to charitable donations;
- » Assure the continuing ability of private sector non-profit organizations to serve and advocate for people with disabilities and their families;
- » Assure fair eligibility for non-profit groups under any new charitable tax credit or deduction;
- » Assure that federal procurement rules do not discriminate against non-profits and that non-profits are afforded the same privileges and benefits as small and minority businesses;
- » Support oversight activities that assure accountability by non-profits, while making certain that this does not place undue burdens on non-profits, does not duplicate existing requirements, and is coordinated with state oversight efforts;
- » Increase the ability of non-profit organizations to engage in civic participation such as voter registration and outreach activities through the clarification of rules on allowable political activity; and
- » Protect the provisions of federal tax law that keep charitable non-profits, houses of worship, and foundations from engaging in partisan political campaigns.

## **QUALITY OF SERVICES**

The federal government has an important role in ensuring quality services. This includes ensuring that services are based upon principles of maximizing independence, self-direction, and person-centered community-supported life, while providing for health and safety. The federal government should be fulfilling its role in monitoring and enforcement of the quality of services to our constituents.

During the 116th Congress, our public policy goals are to:

- » Assure high quality, and where possible, evidence-based, services, supports, and access to all programs serving our constituents in which federal funds are used;
- » Assure that new service delivery models, such as long term supports and services (LTSS) in managed care, meet or exceed appropriate and comprehensive national quality standards and include outcomes based on an individual's person-centered plan;
- » Require federal agencies to include people with disabilities, their families, service providers, advocates, and Developmental Disabilities Act programs in all aspects of development of quality measures and assessment of quality;
- » Require the provision of training and technical assistance to states and territories in order to implement comprehensive systems of person-centered quality assurance;
- » Assure that people with disabilities, through enforceable standards, have the option to hire or fire their own staff, manage their own service budgets, and have a voice in how the service system operates;
- » Maintain, strengthen, and, where appropriate, modernize federal monitoring, oversight, and enforcement roles, including upgrading and enhancing data collection and management information systems. The federal role must assure assessment of consumer outcomes and satisfaction to assure appropriate outcomes for beneficiaries;
- » Strengthen federal enforcement mechanisms to include criminal, civil, and/or financial sanctions for states and territories, communities, and other entities that violate federal requirements;
- » Assure a qualified, well-trained, well-compensated, and stable workforce to support people with disabilities and their families;

- » Fund high quality pre-service and in-service training to meet the diverse needs of individuals with disabilities;
- » Require that the Centers for Medicare and Medicaid Services develop and publish a comprehensive annual report to Congress on state-level consumer satisfaction and outcomes; and
- » Require CMS to publish annual data on health and safety and quality of services, including Intermediate Care Facilities for people with ID and related conditions (ICFs/ID) and home and community-based services (HCBS) programs.

## RESEARCH AND DATA COLLECTION

A variety of federal agencies are responsible for undertaking vital research and data collection activities regarding the impact of disability and to improve the quality of life for children and adults with I/DD. Some of these research efforts directly target our constituents, while others are more broadly based. The collection of accurate data on the incidence, prevalence, and well-being of individuals with I/DD is essential to informing public policy. Significant gaps in data collection exist. Many national surveys still do not include questions that identify disability in a consistent manner. Different definitions of disability and measures of disability across various surveys make it difficult to assess the status of people with disabilities and identify trends. Consequently, there is no comprehensive data on individuals with developmental disabilities and their families.

During the 116th Congress, our public policy goals are to:

- » Significantly expand federal funding of basic and applied research at the Centers for Disease Control and Prevention (CDC), the Administration on Community Living (ACL), the Administration on Intellectual and Developmental Disabilities (AIDD), the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the National Council on Disability (NCD), and the Environmental Protection Agency (EPA) designed to both improve the quality of life for our constituents and to prevent the causes and effects of I/DD;

- » Support and expand research efforts of University Centers for Excellence in Developmental Disabilities (UCEDDs), Leadership Education in Neurodevelopmental and related Disabilities (LEND) Programs, and Intellectual and Developmental Disabilities Research Centers (IDDRCs) to discover and understand the causes of I/DD, as well as effective treatments and supports for persons with I/DD and their families;
- » Provide funding for all relevant agencies to translate and disseminate to practitioners, families, and policymakers new knowledge about effective practices in culturally appropriate ways;
- » Reauthorize and fully fund the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act; and ensure more research on individuals across the lifespan and in diverse populations;
- » Assess the financial, social, and human impact of unmet needs of our constituents;
- » Support training of existing and emerging scholars to conduct relevant research;
- » Promote the prompt publication and dissemination of appropriate findings, written in commonly understood language;
- » Support research that examines the effects of multiple chemical exposures on the developing nervous system and ensure that chemical exposure research and surveillance includes individuals with I/DD in any biomonitoring dataset;
- » Promote research on emerging treatments and interventions within properly regulated clinical trials and assure that people with I/DD are not excluded from benefitting from effective treatments;
- » Increase the participation of people with I/DD in research studies by ensuring that those who can give informed consent are not categorically excluded;
- » Support research on impacts of disability on individuals

and caregivers, including but not limited to, impacts on health, income, assets, and divorce rates;

- » Require the NIDILRR to prioritize and fund field-initiated and other research in the areas of physical, intellectual, and developmental disabilities that represents a mixture of methodological approaches, including qualitative and quantitative research and policy analysis;
- » Promote translation of research findings to practice;
- » Support research on disability and aging;
- » Support research on pain management strategies for individuals with disabilities;
- » Incorporate disability status in federally funded research;
- » Expand funding to determine the current status and what can be done to alleviate the disparities in health supports and services to un-served and underserved populations;
- » Require research and reporting on long term employment outcomes for people with I/DD, including those who are not successful in attaining or maintaining competitive integrated employment;
- » Protect the use of the common set of questions about disability in national surveys including the American Community Survey and the Current Population Survey and promote additional use in other national surveys;
- » Develop initiatives to collect comprehensive national interagency data on the needs of parents with I/DD and their families; and
- » Provide funding to improve and expand the collection and publication of population-based and other data regarding our constituents, and as appropriate, other disabilities.

## TAX PROVISIONS

In addition to the overall Revenue and Tax Policy discussed in Section II, there are some specific tax policies that are important to people with disabilities and their families. Therefore, in enacting tax policy, during the 116th Congress, our public policy goals are to:

- » Support tax policy that promotes the employment of people with disabilities, including enactment of a tax credit for individuals with disabilities who work, improving the impairment-related work expense deduction and the usefulness of the architectural and barrier removal deduction and disabled access credit;
- » Ensure full implementation of the Achieving a Better Life Experience (ABLE) Act and enact expansion of eligibility to those who have onset of disability after age 25;
- » Ensure that improvements to and implementation of the ABLE program foster equity and fairness among beneficiaries of means-tested programs to the extent possible and support, rather than undermine, the purposes of those programs;
- » Ensure that federal retirees can designate trusts for family members with disabilities as beneficiaries for their pension benefits;
- » Ensure full implementation of the Disabled Military Child Protection Act of 2014 which allows military pension and survivor benefits to be paid to a trust for an individual with disabilities to allow for the long term support of the individual;
- » Amend tax provisions necessary to restore the viability of designating charitable entities as remainder beneficiaries of individual retirement accounts;
- » Provide incentives for the private sector to provide cost-effective supports for individuals with disabilities and their families;
- » Allow income tax deductions for charitable donations by non-itemizers;
- » Protect the charitable deduction and reject any provisions that would likely serve as disincentives to charitable donations;
- » Permanently extend the Work Opportunity Tax Credit (WOTC), and allow its application to non-profit organizations to be used for people with disabilities, so



long as the Social Security Trust Funds are made whole by general revenues for lost payroll taxes; and

- » Allow a tax credit for individuals or their families who incur out-of-pocket expenses in meeting long term support and other disability-related needs.

## TECHNOLOGY

Many people with disabilities benefit from accessible technology and technology-enabled supports to maximize independence. Advances in technologies will continue to affect the lives of people in dramatic ways. These technologies, including commercial off-the-shelf products, can be readily available from a variety of program funding sources, and could help to make services more cost-effective. The 116th Congress should facilitate access to new technology from all sources to support the independence, inclusion, and community participation of people with disabilities.

In particular, the Assistive Technology Act (ATA) of 2004 called for new approaches on the part of programs authorized under the Act to assure that people with disabilities and their families are able to access the assistive technology they need. Funding of the ATA is key to making progress.

During the 116th Congress, our public policy goals are to:

- » Ensure that people with disabilities have information about and access to affordable, appropriate, useable, and accessible technology throughout their lifetimes to fully participate in society;
- » Protect, enhance, and fully fund all of the provisions of the ATA:
  - State Assistive Technology Act (AT) Programs – Bring every state and territorial program to at least the “minimum allotment” level as defined in the 2004 reauthorization, and, for affected state programs, restore funding that has been lost in recent years. In addition, fully fund the State AT programs to allow states and territories to better support any of the four state-level activities that include device demonstration, device

loans, reutilization, and state financing activities, that are in high-demand in their state;

- Protection and Advocacy for Assistive Technology;
  - National Technical Assistance – to ensure quality technical assistance to each state and territorial program; and
  - Research and Development – to support a meaningful level of research and development of assistive technology devices and standards;
- » Expand the adoption of commercial, off-the-shelf, multiple-use technology to support people with I/DD; and
  - » Require the Centers for Medicare and Medicaid Services (CMS) to authorize payment for and issue guidance to states and territories that will result in expanded coverage of appropriate assistive technology and technology-enabled supports, including smart home technologies, for Medicaid beneficiaries, including eliminating barriers to multi-use and commercial off-the-shelf technology that could support independent living in the community.

**TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF) AND SOCIAL SERVICES**

During the 116th Congress, our public policy goals are to improve the TANF program and take appropriate steps to address the growing poverty rates in our country. The unique needs of TANF recipients with disabilities and their families must be addressed. In addition, Title XX of the Social Security Act, the Social Services Block Grant (SSBG), provides states with funding to provide many community-based services to people with disabilities and other targeted low income populations. Desired provisions include the following:

- » Improve screening and assessment for disability;
- » Secure appropriate supports and services, including employment and training services;
- » Allow a more expansive understanding of the care of

a child or other family member with a disability to be counted as a work activity;

- » Increase state flexibility by giving states credit for their effort to provide rehabilitative and other supports and services over a longer period of time in order to assist more individuals with disabilities to return to work;
- » Provide pre-sanction reviews to ensure that TANF recipients with disabilities are not improperly sanctioned for an inability to comply with TANF rules;
- » Ensure affordable and accessible transportation and other supports necessary to obtain and retain employment; and
- » Protect and adequately fund the Title XX SSBG.

## TRANSPORTATION

Millions of people with disabilities have difficulties obtaining transportation. People often have trouble traveling from place to place because transit systems are unavailable, inaccessible, or not coordinated. Transportation provides a vital means for people with disabilities to access employment, education, health care, and community life. Principles of universal design must be integrated in the development of new transportation devices and projects to ensure greater mobility for people with disabilities.

During the 116th Congress, our public policy goals are to:

- » Increase funding for the Federal Transit Administration programs, including mass transit programs (including paratransit), Section 5310 program for the enhanced mobility of seniors and people with disabilities, and other critical programs;
- » Effectively implement the Fixing America’s Surface Transportation (FAST) Act provisions impacting people with disabilities;
- » Create funding opportunities and support technological solutions for coordinated services across jurisdictional lines;
- » Expand mobility management and travel training services

- for individuals with disabilities in order to create more public and private coordinated transportation systems;
- » Simplify the coordinated planning process for the programs that serve people with disabilities and create transparency and accountability at the Department of Transportation;
  - » Ensure that state and local transportation systems are accessible;
  - » Promote tax policy that increases access to transportation for people with disabilities;
  - » Ensure accessibility in and around transit locations;
  - » Promote policies that expand the availability of accessible taxis, ride-sharing vehicles, buses, and other transportation vehicles and systems, particularly for travel in rural and underserved communities and across jurisdictional lines;
  - » Ensure that autonomous vehicles are accessible to people with disabilities;
  - » Provide funding to Amtrak to ensure station accessibility and hold Amtrak and other responsible entities accountable for a plan to achieve accessibility;
  - » Significantly improve air travel accessibility to meet and exceed the ADA standards and provide incentives to the airline industry to comply rapidly;
  - » Ensure that the Transportation Security Administration (TSA) works with disability advocacy groups to improve TSA's policies, procedures, and the provision of reasonable accommodations, regarding airport screening that respect the rights and dignity of people with disabilities and expand training of all airport security personnel to follow those policies and procedures;
  - » Require new federally supported transportation technologies to meet universal design standards; and
  - » Work toward interstate reciprocity among state para-transit systems so that people with disabilities can travel nationwide.

## IV. PARTNERSHIPS

### DEVELOPMENT OF THE NATIONAL POLICY AGENDA

The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP each have a rich history of building and participating in coalitions and collaborating with each other and with other organizations in pursuit of national public policy goals. Working together, we lead efforts in informing policymakers of the vast unmet needs of our constituents and in mobilizing people with disabilities, their families, and our chapters and affiliates as active players in national public policy. All six organizations are leading members of the Consortium for Citizens with Disabilities (CCD). CCD is a Washington, DC-based coalition of more than 100 national organizations representing consumers, family members, providers, professionals, and other advocates. Because our constituents share the same needs and interests as other people, The Arc, AAIDD, ANCOR, ASA, NACDD, and UCP also participate in non-disability coalitions which help further our policy goals.

#### The Arc



The Arc is the largest national community-based organization advocating with and serving people with intellectual and developmental disabilities (I/DD) and their families. The Arc has a network of nearly 650 chapters across the country promoting and protecting the human rights of people with I/DD, including Down syndrome, autism, fetal alcohol spectrum disorders, cerebral palsy, and other diagnoses, and actively supporting their full inclusion and participation in the community throughout their lifetimes and without regard to diagnosis. With a rich history spanning nearly 70 years, The Arc is a powerful force in the disability movement of the past, present, and future.

## AAIDD



The American Association on Intellectual and Developmental Disabilities (AAIDD) is the oldest and largest interdisciplinary organization of professionals concerned about intellectual and developmental disabilities. AAIDD was founded in 1876 to address questions relating to the causes, conditions, and understanding of intellectual and developmental disabilities and to develop best practices in education and services. The major functions of the AAIDD are to (a) support its members' leadership in activities that impact people with intellectual and developmental disabilities; (b) publish cutting edge research and materials that inform policy and practice; (c) develop and implement educational opportunities for professionals, policy makers, and others; and (d) engage in activities that promote progressive public policy.

## ANCOR



For nearly 50 years, the American Network of Community Options and Resources ([anchor.org](http://anchor.org)) has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities (I/DD). As a national nonprofit trade association, ANCOR represents more than 1,600 organizations employing more than a half-million professionals who together serve more than a million individuals with I/DD. ANCOR also represents 55 state provider associations. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

## ASA



The Autism Society of America has been improving the lives of all affected by autism for over 50 years and envisions a world where individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued. We provide advocacy, education, information and referral, support, and community at national, state, and local levels through our strong nationwide network of approximately 80 Affiliates.

## NACDD



The National Association of Councils on Developmental Disabilities (NACDD) serves as the national voice of the 56 State and Territorial Councils on Developmental Disabilities (DD Councils). NACDD supports DD Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and promoting the interests and rights of people with developmental disabilities and their families. The DD Act charges DD Councils to identify the most pressing needs of people with developmental disabilities in their state or territory and to engage in advocacy, systems change, and capacity building activities to help states meet the identified needs.

DD Councils work to promote the independence, integration, and productivity of people with developmental disabilities and promote systems change that will eliminate inequities in areas such as employment, education, housing, and access to health care. The

ASA

NACDD

goal of their work is to create communities where people with developmental disabilities are fully included. Located in every State and Territory, DD Councils are made up of volunteers who are appointed by the Governor. At least 60% of DD Council members must be people with developmental disabilities or family members.

## UCP



United Cerebral Palsy (UCP) is one of the nation's leading organizations serving and advocating for the more than 54 million Americans with disabilities. Its mission is to advance the independence, productivity, and full citizenship of people with disabilities through an affiliate network. Over half of UCP consumers are people with disabilities other than cerebral palsy. Through its nationwide affiliate network, UCP offers to individuals, families, and communities such services as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals, and advocacy. UCP affiliates directly serve more than 170,000 children and adults with disabilities and their families on an annual basis.





**The Arc**  
Phone: 202-783-2229 | Web: [thearc.org](http://thearc.org)



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



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



**Autism Society of America**  
Phone: 1-800-328-8476 | Web: [autism-society.org](http://autism-society.org)



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



**United Cerebral Palsy**  
Phone: 202-776-0406 | Web: [ucp.org](http://ucp.org)