PUBLIC POLICY AGENDA *for the* 113TH CONGRESS

2013-2014

American Association on Intellectual and Developmental Disabilities

American Network of Community Options and Resources

Association of University Centers on Disabilities

National Association of Councils on Developmental Disabilities

The Arc

United Cerebral Palsy

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I. INTRODUCTION

The Arc, the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Network of Community Options and Resources (ANCOR), the Association of University Centers on Disabilities (AUCD), the National Association of Councils on Developmental Disabilities (NACDD), and United Cerebral Palsy (UCP) envision a nation whose high expectations for all of our citizens with disabilities make possible the fulfillment of academic potential, productive employment in the community, active engagement in civic life, and full inclusion in society. The Americans with Disabilities Act (1990) and the U.S. Supreme Court in the 1999 *Olmstead* decision affirmed the right of people with disabilities to a life in the community.

For decades, Congress has been taking important steps to secure that right and achieve that vision. Now–even under daunting fiscal constraints–is not the time to halt that forward movement. The vision is not only just, but affordable. People with disabilities want to live, 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.

We can accomplish the goals laid out in this Public Policy Agenda. Our members are working hard with federal, state, and local partners to redirect taxpayer dollars within redesigned systems and policies realigned to achieve the outcomes all Americans want: dignity, meaningful choice, and the opportunity to contribute and to succeed.

We look forward to working with Congress to achieve these goals.

What is The Role of Federal Policy in Disability?

For many decades, the six national disability advocacy organizations that endorse the public policy agenda contained in this document have recognized the vital role the federal government plays in the everyday lives of children and adults with intellectual and developmental disabilities (I/DD) and their families. From civil rights protections to community housing, from special education to Social Security benefits, from job training to basic health care, from transportation to long-term supports and services and more, the federal government spends billions of dollars, both directly and in partnership with state government, on people with I/DD. These programs are funded through entitlement programs such as Medicaid and Medicare and discretionary programs such as vocational rehabilitation, HUD housing, and education. Many individuals, families, and professionals in the field are, however, unaware of the huge impact of this federal funding since most of it flows through state and local governments.

State and local governments, particularly during economic crises like our nation is now experiencing, are increasingly dependent on federal dollars. In addition to providing funding for disability benefits, services, and supports, the federal government also monitors state and local governments to assure quality services and protection against the abuse of various civil rights. It also conducts research and prevention programs, improves preparation and response in major emergencies, and collects vital data on disability.

State and local governments and the private and non-profit sectors cannot replace the funding and other roles played by the federal government in disability policy. Therefore, people with disabilities, their families and advocates, and the disability service system are committed to helping protect, enhance, and modernize the federal approach to disability policy.

It is critical that, in all of their actions, Congress, 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) of 1975 and the Americans with Disabilities Act (ADA) of 1990. Both of these laws embody the fundamental values eloquently expressed in the Developmental Disabilities and Bill of Rights Act of 2000:

> *"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."*

The legislative agenda below sets forth critical and priority goals that the U.S. Congress needs to respond to in this Congress.

What is The Arc?

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The Arc encompasses all ages and all spectrums from autism, Down syndrome, Fragile X, and various other developmental disabilities. With more than 140,000 members, serving people with I/DD and family members through 700 state and local chapters nationwide, The Arc is on the front lines to ensure that people with intellectual and developmental disabilities and their families have the supports and services they need, are accepted in their communities, have a voice in policies that affect them, and have control of their own lives.

The Arc's mission is to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes. This is carried out through our public policy work at the federal, state, and local level, as well in our nation's legal system. With a rich history spanning more than 60 years, The Arc is a powerful force in the disability movement of the past, present, and future.

AAIDD

What is AAIDD?

The American Association on Intellectual and Developmental Disabilities (AAIDD, *formerly AAMR*) is the oldest and largest interdisciplinary organization of professionals concerned about intellectual and developmental disabilities. Founded in 1876 to discuss all questions relating to the causes, conditions, and statistics of intellectual and developmental disabilities and to develop best practices in education and services, today AAIDD represents a wide variety of professionals and others in the United States, Canada, and more than 50 other countries. AAIDD members are united by the ideal that each person with a disability has the right to develop personal potential to the maximum extent possible, to satisfy his or her individual needs and preferences, and to become an independent and useful member of the community.

The major functions of the Association 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

What is ANCOR?

The American Network of Community Options and Resources (ANCOR) is a national trade association representing more than 800 private providers of community living and employment supports and services to more than 400,000 individuals with disabilities. As a nonprofit organization, ANCOR successfully addresses the needs and interests of private providers before Congress and federal agencies, continually advocating for the crucial role private providers play in enhancing and supporting the lives of people with disabilities and their families. Through its National Advocacy Campaign, ANCOR seeks to obtain the resources to recruit, train, and retain a sustainable direct support workforce. ANCOR provides organizational, professional, leadership development, and networking opportunities and services, and is continually working toward partnerships and collaborations that advance our vision, mission, and goals. Our prime goal is to be the indispensable

leader, resource, and advocate for a diverse private disability services network that ensures full citizenship and engaged community participation for people with disabilities of all ages.

What is AUCD?

The Association of University Centers on Disabilities (AUCD) is a non-profit organization that represents the national network of university centers on disabilities, which includes University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs, and Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC).

The mission of AUCD is to advance policy and practice for and with people living with developmental and other disabilities, their families, and communities by supporting its members to engage in research, education, and service that supports independence, productivity, and satisfying quality of life. AUCD members represent every state and most territories in the USA and over 80 universities and medical schools. Through its members, AUCD serves as a resource for local, state, national, and international agencies, organizations, and policymakers concerned about people living with developmental and other disabilities and their families.

What is 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. NACDD supports 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 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.

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. Councils work to create communities where people with developmental disabilities are naturally and fully included. Located in every State and Territory, Councils are made up of volunteers who are appointed by Governors. More than 60% of Council members must be people with developmental disabilities or family members.

What is United Cerebral Palsy?

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 every day.

What is a Developmental Disability?

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

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

Developmental disabilities also result in a need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong duration and individually planned and coordinated.

Some common types of developmental disabilities are cerebral palsy, intellectual disability, autism spectrum disorders, Down syndrome, Fetal Alcohol Spectrum Disorder, Fragile X, and epilepsy.

What is Intellectual Disability?

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers conceptual, social, and practical skills. This disability originates 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 services and supports. Furthermore, every individual who is or was eligible for a diagnosis of "mental retardation" is eligible for a diagnosis of intellectual disability.

Most federal laws that serve people with disabilities through established eligibility categories use the term "mental retardation." In 2010, the President signed Rosa's Law, which directed the substitution of the term "intellectual disability" in federal education, health, and labor laws; however, the term remains in other federal laws. The Congress should substitute the term "intellectual disability" for the term "mental retardation" whenever a law that uses that term is subject to reauthorization. This change should not in any way alter eligibility requirements or service availability since the change in terms is not intended to do so. However, because court decisions and federal law regarding the death penalty use the term "mental retardation," that term will likely remain in use until federal law and state and federal courts adopt the use of the term "intellectual disability."

Use of Terms

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP support and advocate with and for individuals with intellectual, developmental, and other disabilities, their 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.

DEVELOPMENT OF THE NATIONAL POLICY AGENDA

Partnerships

The Arc, AAIDD, ANCOR, AUCD, 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 convincing 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 Americans, The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP also participate in non-disability coalitions which help further our policy goals.

Shaping Public Policy

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP base their public policy views on the understanding that our constituents are full citizens and full participants in a democratic society. We work to shape a state/federal 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. The vast majority of our constituents have the right to vote.

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

Our system of government was set up to give states substantial responsibility for the health, education, and well-being of our constituents. Historically, state and local governments have been unable to adequately meet the needs of our constituents.

For the past few years, our nation's economic crisis has forced most states to eliminate or scale back services and supports, sometimes returning to outdated and restrictive service models, for children and adults with developmental disabilities.

The ongoing shift of some federal responsibilities and funding to state and local governments is further exacerbating the crisis. The unmet needs of many of our constituents and their families have grown to dangerous levels. Too many people with developmental disabilities remain un-served, are under-served, or have had their supports diminished or eliminated.

Nationwide, hundreds of thousands of people with developmental disabilities wait, often for many years, for funding for services and supports that will enable them to live, thrive, and contribute to their communities. This is unfair to people with disabilities and to American families. Countless others have either not sought services, are in states that do not maintain waiting lists for services, or have given up seeking assistance. The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP will continue to advocate for public policies that address their needs.

A divided Congress, poor economy, escalating Federal deficit, fiscal crises in nearly every state, and other pressures will test the Obama Administration and the Congress. Continued partisanship will make solving these ongoing dilemmas difficult. In many cases, the future of the disability safety net will be placed at risk. The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP will, as always, work in a bipartisan manner to protect vital services and supports for children and adults with developmental disabilities.

Development of Public Policy Agenda

The foundation for the public policy agenda for the 113th Congress is built on mission statements, principles, core values, position statements, and current policies of The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP and on input from volunteers, members, and professionals from across the country. We have taken into consideration expected proposals from the White House and Congress, as well as the laws that need reauthorization in the 113th Congress. We will also deal with unexpected issues as they arise.

For the 113th Congress, we present two tiers of priorities for our programmatic legislative agenda. The tiers are "priority agenda" and "other critical goals." The rationale for the tiered scheme is contained in the programmatic goals section of this document. We will address any and all of these goals as issues relating to them arise.

Monitoring Laws and Policies

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP closely follow how laws and policies are carried out so that our constituency is appropriately served. This includes influencing any changes in regulations as well as how the federal government implements, monitors, and enforces relevant federal programs. The ongoing implementation of the Affordable Care Act (Patient Protection and Affordable Care Act, P.L. 111-148, and Health Care and Education Affordability Reconciliation Act, P.L. 111-152) will continue to be closely scrutinized, particularly any efforts to delay, repeal, or defund its implementation.

II. FEDERAL FISCAL POLICY AGENDA

Introduction

Federal fiscal policy is the primary tool used by Congress and the Administration to address critical societal problems. Fiscal policy has been dominated by efforts to address the 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, AUCD, NACDD, and UCP support federal funding for the program services and supports that are needed to enable people with disabilities and their families to be fully included in society.

Reductions in federal entitlement spending threaten our constituents. Changes at the state level could also jeopardize our constituents. Medicaid, Medicare, and Social Security are major targets to secure deficit reduction. Many proposed reductions or modifications to these vital programs will adversely affect our constituents. Since Medicaid finances lifesaving health care and long term supports for most of our vulnerable constituency who receive supports, their futures 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.

Federal fiscal policy is also critical because state funding is often based on the amount of federal money available. When federal funding for programs is cut, state funding rarely increases to make up the difference, and services to our constituents will be reduced, if not eliminated. The ending of federal stimulus funding has exacerbated the states' difficulty in maintaining their Medicaid programs. The pressure on states to cut back or eliminate Medicaid services is immense.

Like most Americans, we support the need for a strong 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;
- Services, supports, 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, choice, and self-determination; and
- When needed, the federal government leads or assists states in being fair and efficient in carrying out their responsibilities to people with disabilities and their families.

Budget, Entitlements, and Appropriations

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP promote cost-effectiveness when such efforts do no harm to our constituents and allow them to live as independently as possible in the community.

Congress sets annual fiscal policy by:

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

The combination of these three major fiscal actions determines the actual funding for all disability benefits, programs and services for the year.

During the 113th 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);
- Replace the scheduled automatic spending cuts that will impact discretionary programs that support people with disabilities with a balanced deficit reduction package that includes revenue increases and no further cuts;
- Ensure that the recommendations of non-Congressional commissions or bodies are given full consideration by the Congress and not placed on a fast-track to bypass the legislative process;
- Address the significant unmet needs, disparities, and inequities of 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 solely to achieve budget cuts; and

- Remove the Social Security Administration's administrative budget from any budget cap requirements for the Departments of Labor, Health and Human Services, and Education.

Revenue and Tax Policy

During the 113th Congress, our public policy goals are to:

- 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;
- Allow the expiration of, roll back, or repeal tax cuts and adjust other tax policies that put people with disabilities at risk;
- Raise sufficient revenues to reduce the deficit and finance the federal government's role in providing essential supports, services, and benefits for people with disabilities and their families;
- Reject tax policies that help only the most wealthy;
- Assure that tax policies represent a sound investment and will not jeopardize the long term stability of people with disabilities and their families;
- 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

Introduction

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP recognize the vital role that the federal government plays in providing services, supports, and benefits for our constituents and in supporting programs that help prevent the causes and mitigate the effects of mental and physical disabilities. Millions of people with disabilities will continue to depend on the federal government for certain services, supports, and benefits throughout their lives.

Nonetheless, most federal programs that support our constituents and their families are grossly under-funded, leaving hundreds of thousands underserved or continually waiting for services, and these numbers are constantly growing.

There is also an explosive national crisis in the availability of appropriately qualified direct support workers, due to factors such as low pay, inadequate benefits, and limited career options. This situation leads to high turnover among workers and severely limits the ability of providers to maintain or expand their services and supports. Worse, this crisis puts the lives of our constituents at risk. These problems also affect the availability of other professionals in the field.

American society continues to support tremendous mobility of all families within and between states. However, people with disabilities who receive any level of supports from state systems are often unable to move to join family in other states, for example, when their parents move for employment or retirement, or when their parents die and they need to move nearer to adult siblings. Research demonstrates that wage earners in many families decline promotions, transfers, and overtime in order to care for their family member with a disability, thus limiting that entire family's income and future. Research should be conducted to document the hardships of such families, including but not limited to, impacts on the health, income, assets, and divorce rates of caregivers. It is time for the nation to develop family-friendly mechanisms to ensure portability of federally funded supports so that the money can truly follow the person.

The Arc, AAIDD, ANCOR, AUCD, NACDD, and UCP recognize that the Congress drives the disability agenda, and some of our priority policy agenda may not be dealt with in this Congress. We will respond as appropriate to all Congressional activity related to disability policy.

A. PRIORITY AGENDA

The Arc, AAIDD, ANCOR, AUCD, 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 and full inclusion in community life. 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 provide vital supports to our constituents; potential changes to either program, therefore, require significant attention to the possible impact on people with disabilities. The relationship between Medicaid and direct support workers requires very close policy coordination. Availability of affordable, accessible housing remains a major issue for people with disabilities in communities across the country. A free, appropriate education for students with disabilities remains the lynchpin to a productive and independent adulthood. Family support, although severely underfunded, is very cost effective and best reflects the type of care favored by our nation. Thus, the agenda related to Medicaid, Health Care, Long-Term Community Services and Supports, Social Security/Income Maintenance, Education, Direct Support Workers, Employment, Training, and Wages, Family Support, Housing, Civil Rights, and Technology constitute our highest priorities for the 113th Congress.

Medicaid

Medicaid is the lifeline for most people with significant disabilities. The Medicaid program is overwhelmingly the largest funding source of long-term individual and family supports in the federal/state intellectual/developmental disabilities 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 be essential to meet their future need for long term services and supports.

The state of the national economy has already placed undue pressure on the states. Many states have frozen already 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 health care and long-term services. Further shifting responsibility for Medicaid to the states and increasing flexibility that allows states to reduce eligibility and benefits would place many of our constituents and our nation's health, therapeutic, and long-term care systems for vulnerable populations at enormous risk. When people with disabilities do not receive the services

they need, it often jeopardizes the ability of family members to be employed. Medicaid is an important national program that should ensure portability of benefits across states.

Medicaid is a powerful driver of economic activity at the state and local levels. When Medicaid service provider agencies are able to retain staff positions, unemployment is reduced and money gets 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 services and supports rather than costly and unwanted institutionalization.

Due to the severe economic downturn facing an overwhelming majority of states across our nation, most states are cutting Medicaid spending. Such cuts will have a dramatic impact on our constituents who depend on this program for critical health and long term services. Decreased Medicaid budgets also mean that hundreds of thousands of people with developmental disabilities will remain on waiting lists across the country. Equally disconcerting is the loss of many qualified staff when jobs are eliminated due to Medicaid cuts.

Numerous improvements were made to the Medicaid acute and long term services and supports programs through enactment of the Affordable Care Act of 2010 (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.

In order to accomplish true Medicaid reform, during the 113th 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; and
- 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, provider tax changes and other proposals that shift costs to states, allotments, or other mechanisms that cause reductions in eligibility, services, or protections for our constituents.

Eligibility

- Encourage state implementation of the Medicaid expansion as authorized by the Affordable Care Act;

- Encourage 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;
- Encourage full implementation by states of options to establish Medicaid buy-in programs for people with disabilities who work; and
- 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.

Benefits

- Prohibit issuance or implementation of any regulations that limit or eliminate services;
- Ensure that Medicaid-eligible children with disabilities continue to obtain health-related services during the school day and receive any necessary 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;
- Require the Centers for Medicare and Medicaid Services (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; and
- Support the continuation and expansion to all states of states' current ability to provide habilitation services under the Medicaid rehabilitation option 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.

Home and Community-Based Services (HCBS)

- Change Medicaid policy to mandate home-and community-based services and require a waiver to provide services in large institutions;

- Change Medicaid law so that consumers and families can choose to exercise control over resources to better meet their individual needs;
- Ensure the full implementation of the Community First Choice 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 Affordable Care Act 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;
- Reject efforts to repeal, weaken, or block implementation of the Affordable Care Act;
- Revise Medicaid law to require states to serve all federally Medicaid eligible people with developmental disabilities and not a subset of the population under HCBS ;
- Ensure that people who receive Medicaid funded HCBS are able to choose integrated settings of their choice and to choose with whom to live and from whom to receive their services;
- Enact a requirement that states provide community attendant services and supports;
- Reform current Medicaid Home and Community Based Services waiver (HCBS) and State Medicaid plan Section 1915(i) option to promote competitive, integrated employment; and
- Ensure that amount, duration, and scope of home and community-based services are provided on the basis of individual need identified through a person centered planning process.

Removal of Institutional Bias

- Address unmet needs in the community by removing the institutional bias for Medicaid long term 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 the home and community-based waiver from eligibility for institutional services.

Portability

- Improve Medicaid so that benefits are portable from state to state and so that beneficiaries and families are not disadvantaged by moving from one state to another.

Reimbursement Rates

- Establish an increased Federal Medical Assistance Percentage (FMAP) for home and community-based services (HCBS);
- Ensure that states set and update reimbursement rates annually so that they reflect the actual cost of providing Medicaid funded services and supports, particularly adequate wages and benefits for direct support workers; and
- Ensure that states increase, and annually update, reimbursement rates and fees for health practitioners, and mental health and clinical specialists to reflect the cost of providing services.

Managed Care

- Ensure that individuals receiving services in a managed care system have the right to a person-centered plan;
- 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;

- 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;
- Require states to 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, 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. LTSS data needs to be established and tracked over time relying upon LTSS claims (realizing there are limited data) as a baseline and then incorporating costs as determined through person-centered planning;
- Require states to articulate explicit performance outcome measures and metrics in purchasing specifications and contract language with providers under FFS or other entities the state uses such as accountable care organizations (ACOs) or managed care organizations (MCOs). In addition to acute and behavioral health outcomes, non-clinical LTSS performance measures and metrics must also be articulated that incorporate independence, productivity, integration, inclusion, and self-direction into all RFPs and contracts;
- Encourage states to structure assessment and rate setting methodology to include financial incentives to achieve person-centered outcomes consistent with the principles of *Olmstead* and the ADA; and
- Require states to 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.

Other

- Protect and improve the ability of families and individuals to establish trusts to benefit Medicaid eligible beneficiaries and ensure the integrity of pooled trusts which serve such families and individuals; and
- Establish an incentive program of increased FMAP for states that commit to eliminating the wage differential between workers in community services and workers in government-run Medicaid services by increasing the wages and benefits of the community workers.

Health Care

Our organizations are committed to maintaining the comprehensive health care reforms achieved in the passage of the Affordable Care Act (ACA). With the enactment of the ACA, we have made significant progress towards accomplishing our nation's goal of universal access to high quality affordable health care for all Americans. The ACA includes historic coverage expansions, nondiscrimination and health insurance reforms, strengthened prevention provisions, and numerous enhancements to Medicare, Medicaid, and other provisions that will significantly benefit people with disabilities. It is critical that the essential benefit package designed for the new health care exchanges meet the needs of people with disabilities and special health care needs. Protecting the significant achievements of the ACA will be our highest health care priority. In addition, our organizations will work to advance the legislative agenda that was not addressed by the ACA or only partially addressed.

To achieve these goals, during the 113th Congress, our public policy goals are to:

Affordable Care Act (ACA)

- Ensure that the ACA is not partially or fully repealed. In particular, the provisions that meet the needs of our constituents for quality, accessible, appropriate, comprehensive, affordable, portable, and non-discriminatory coverage must be protected;
- Ensure that the ACA is adequately funded to accomplish the significant goals of the Act for our constituents;
- Ensure that HHS 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 preventive and restorative dental coverage under the ACA;
- 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;
- Expand funding for training of all health care providers about the needs of children and adults with disabilities, including practices to prevent secondary conditions and to help transition youth with disabilities to adult care providers;

- Ensure that people have access to affordable prescription drugs; and
- Ensure that all demonstration pilot grants address the needs of people with disabilities.

Medicaid/Medicare

- Protect existing health care entitlements under Medicare and Medicaid;
- 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;
- Ensure that cost cutting mechanisms in Medicare 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;
- Phase out 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; and
- Eliminate Medicare's "in the home" restriction for coverage of mobility devices (e.g., wheelchairs and scooters) for those with expected long-term needs.

Other

- Ensure that behavioral health services that are specifically designed for people with I/DD, including applied behavior analysis and positive behavioral supports and interventions, are widely available to people with I/DD who need them;
- Enact legislation to reduce harmful chemical exposures that are associated with intellectual and developmental disabilities; and
- Reauthorize the Combating Autism Reauthorization Act of 2011.

Long Term Community Services and Supports

The demand for long term services is a critical issue in the 21st century. However, the nation has lacked a comprehensive, proactive national public-private system for delivering long term services. 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. 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 own choice.

In order to meet this national challenge, the federal government must take the lead in developing a coordinated, comprehensive approach to long term supports and services (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 community-based services over institutional services. Significant progress was made with the enactment of the Community Living Assistance Services and Supports (CLASS) Act, as part of the Affordable Care Act, to establish a national long-term supports insurance program. This insurance plan was designed to assist people in meeting their needs and allow many to avoid impoverishing themselves to become eligible for the Medicaid program. However, its promise has yet to be realized – Congress repealed the CLASS Act as part of the American Taxpayer Relief Act and established a Commission on Long Term Care to make recommendations on long term supports and services.

To meet these challenges, during the 113th Congress, our public policy goals are to:

- Expand, modernize, and, where appropriate, maintain national policies that provide individual 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. Services and supports must be:
    - consumer controlled;
    - 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.
- Support implementation of the Commission on Long Term Care and promote development of legislation consistent with the goals of inclusive participation, personal choice, personal responsibility, integration, and independence;
- 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 services and supports, such as home monitoring and communications technologies; and
- Amend federal law to allow military and other federal employee pension and survivor benefits to be paid to a trust established for an individual with disabilities, to allow for the long-term support of the individual.

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. More than one-third of all Social Security checks go to non-retirees, including over 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 Supplemental Security Income 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.

People with severe disabilities experienced increasingly long delays and decreased service in accessing critical Social Security benefits for many years. Processing times grew, especially at the hearing level where delays reached intolerable levels. In some hearing offices, claimants waited more than two years to receive a hearing and decision. After years of advocacy efforts, Congress and the Administration began to devote substantial resources to reducing the backlog and the waiting times began to come down. However, with the recent economic crisis and the aging of the population, the Social Security Administration is receiving hundreds of thousands more applications than usual and the backlogs are growing and pressures in the claims and hearings offices are growing again despite the increased resources. 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 113th 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, Supplemental Security Income (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;
- Make adjustments to ensure the solvency of the Social Security programs through changes made 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 disability, cerebral palsy, and most other developmental disabilities are lifelong 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 critical supports and services for children and adults with significant disabilities; and
- Increase the Substantial Gainful Activity (SGA) level at least to the level used for people who are blind.

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 the Social Security Administration (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 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 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;
- Enact a program to allow SSI beneficiaries to maintain resources dedicated for housing purposes; and
- Ensure that SSI beneficiaries can participate in appropriate Individual Development Accounts, retirement plans (such as 401(k) 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 that parallels work incentives for SSI; and
- Enact simplification of work incentives, including allowing on-going presumptive re-entitlement to Title II disability benefits for those who lose benefits due to work but continue to be disabled.

Disabled Adult Child (DAC) Benefits

- Improve requirements for "disabled adult child" eligibility to eliminate work disincentives;
- Exempt Disabled Adult Child 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

- 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 care giving, which can greatly reduce any future Social Security benefits);
- Eliminate marriage penalties in Social Security disability policy;
- Permanently authorize the Social Security Administration's authority to conduct demonstration programs, so long as beneficiaries are protected from any disadvantage 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.

Education

Public education for all is a cornerstone of our democracy. It is the mechanism by which this nation prepares all students to pursue the benefits of freedom and to exercise fully their rights and responsibilities as citizens. The Individuals with Disabilities Education Act (IDEA) ensures that children with disabilities not only have the right to attend public schools but have access to the general education curriculum and meaningful educational experiences. Similarly, the Elementary and Secondary Education Act (ESEA), also known

as the No Child Left Behind Act (NCLB), recognizes that our educational system must ensure that all children have access to a high quality education. Accordingly, leaders must continue to align special education and general education laws.

To ensure that the goals of the IDEA and ESEA are met, students with disabilities must be held to the same high expectations as their non-disabled peers, and their academic progress must be accurately measured and reported. In addition, student assessments and educational services must be culturally competent. Moreover, all facets of the educational system must share responsibility for the academic and social outcomes of all children.

Students with disabilities face multiple attitudinal, environmental, financial, and support barriers in accessing postsecondary education. During a student's education there will be several major transitions, such as moving from early intervention to preschool, from elementary to secondary education, and ultimately, from the school system to adult living, including employment and/or higher education. The Higher Education Opportunity Act (HEOA) offers an opportunity for students with intellectual disability to overcome some of those barriers and have access to a postsecondary education that was until recently unavailable.

During the 113th Congress, our public policy goals are to:

IDEA

- Reauthorize IDEA and reject any legislation that results in the diminution of the guarantee of a free, appropriate, public education;
- Fully fund all components of IDEA and provide a significant infusion of funds into Part C, Head Start, and other early intervention programs;
- 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;
- Ensure monitoring and enforcement of the major components of IDEA, such as least restrictive environment (LRE), due process, transition, cultural competence and individualized education programs (IEPs), are properly and fully implemented;
- 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 plan for developing a communication system for that child becomes a part of the IEP;

- Ensure enforcement of IDEA provisions regarding disciplinary practices to prevent unwarranted suspensions, expulsions, and referrals to the juvenile justice system;
- Ensure enforcement of IDEA provisions to address the overrepresentation of students with disabilities in the juvenile justice system, and support appropriate services and successful reentry to community schools; and
- Develop and require implementation of policies that support portability and continuity of student IEPs across jurisdictions.

Elementary and Secondary Education Act (as amended by No Child Left Behind)

- Reauthorize ESEA and continue to align it with IDEA to ensure a meaningful education through access to the general education curriculum, related services, and programs such as health and physical education;
- 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;
- Adopt and use a consistent method to calculate and report graduation rates that accurately accounts for the academic achievement of all students, with data broken down by types of disabilities;
- Adopt new policies to significantly reduce the unacceptably high dropout rate of students with disabilities;
- Support training and research initiatives and programs to enhance effective transition services from secondary education to postsecondary education and employment;
- Enhance adult education, vocational training, post-secondary education, and lifelong learning opportunities for students with disabilities, particularly students with intellectual and/or multiple impairments;
- Ensure that initiatives such as charter schools, vouchers, and individual education savings accounts do not adversely affect public education; the access of students with disabilities, especially those categorized as having intellectual disability (who historically have extremely low rates of inclusion in these initiatives), to inclusive educational settings; or the guarantee of a free, appropriate public education for all students with disabilities;
- Require that any federal funds used to construct and renovate schools enable such schools to become fully accessible;

- 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;
- Enact protections, including sanctions, against abuse, aversive interventions, and the inappropriate non-emergency use of physical, mechanical, and chemical restraints and seclusion for all students in schools;
- Provide funding and require school personnel to be trained in positive behavioral supports and appropriate behavioral interventions for all students; and
- Amend IDEA to provide better portability of federally guaranteed services and promote stability in the implementation of Individualized Education Programs (IEPs).

Early Intervention and Preschool Programs

- 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 of evidence-based practices from early intervention through postsecondary education to support learning of students with disabilities; and
- Support efforts to ensure that young children with disabilities receive early intervention services in their natural environments.

Higher Education

- Fully fund current and new disability provisions in Title VII of the Higher Education Opportunity Act, including the Model Comprehensive Transition and Postsecondary Programs and Coordinating Center, National Technical Assistance Centers, and Programs to Provide Students with Disabilities with a Quality Higher Education;
- Ensure students with intellectual disability enrolled in Comprehensive Transition and Postsecondary Programs have access to work study program and Pell grants; and
- Establish a Unified Education Curriculum and standards incorporating 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.

Personnel

- Expand and improve in-service and pre-service personnel preparation under Part D of IDEA, NCLB, and the Higher Education Act so that all special education teachers are highly qualified and develop programs to expand the pool of undergraduates majoring in special education; and
- Reject attempts to lower the ESEA standards for "highly qualified" teachers.

Direct Support Workers

A well-trained, adequately compensated direct support workforce is essential to providing the necessary supports and services to our constituents, where they live and work. The current Medicaid reimbursement system, and cost cutting actions by state legislatures and Medicaid officials, has exacerbated the workforce crisis hampered by low wages, a lack of health insurance, high turnover, and a shortage of staff. 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. Medicaid is the primary source of funding for the programs employing these workers.

During the 113th Congress, our public policy goals are to:

- Ensure adequate funding so that direct support workers are paid a living wage, including appropriate benefits, at the same level of pay and benefits that states provide for staff working in state-operated programs.
- Require that states 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 any state and federal minimum wage increases or changes in employment standards be reflected in state reimbursement rates for services;
- Support authorizing legislation and continuing financial support to provide pre-service and in-service training and other relevant educational opportunities for direct support workers 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 and improve recruitment, retention, training, and supervision of direct care workers to better serve individuals with disabilities.

Employment, Training, and Wages

People with I/DD can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

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. Given the overall high unemployment in the private sector, people with I/DD face a daunting task in securing employment. People with disabilities want to work, pay taxes, and be contributing members of society.

Thus, during the 113th Congress, our public policy goals should help our constituents reach their full potential and become as independent as possible through integrated employment by:

Wages and Integrated Work Environments

- Supporting "Employment First" policies as a strategy to increase opportunities for competitive, integrated employment of individuals with I/DD;
- Building infrastructure and creating incentives for employers or other solutions that will expand work opportunities for individuals with significant disabilities in integrated employment at competitive wages;
- Expanding training and technical assistance to community rehabilitation providers to transition from the use of subminimum wages and nonintegrated environments;
- Building infrastructure and supports needed to phase out the issuance of subminimum wage certificates including putting in place transition services and safeguards to protect the interests of any people with I/DD affected by this shift; and
- Conducting oversight on and strengthening the Department of Labor's monitoring of compliance under the Fair Labor Standards Act and other federal non-discrimination requirements.

Vocational Rehabilitation

- Reauthorizing the Rehabilitation Act and the Workforce Investment Act (WIA) to maximize employment outcomes for people with I/DD, including strengthening the linkage between WIA and the Rehabilitation Act, preserving the integrity of the Rehabilitation Act, increasing the emphasis on employment by strengthening and expanding the supported employment and customized employment programs, improving transition policy, expanding work opportunities, removing barriers to participation

by people with disabilities, creating demonstration programs and incentives to replicate best practices, and ensuring full due process protections; and

- Increasing funding for state vocational rehabilitation programs significantly above the required Consumer Price Index (CPI) level, transitions to postsecondary opportunities, supported employment, and workforce development programs that help our constituents find and keep jobs and have more career options.

Procurement and Contracting

- Modernizing the Javits-Wagner-O'Day (JWOD) Act to expand integrated employment opportunities and ensure that people with significant disabilities remain a priority for participation in the program;
- Expanding employment opportunities by establishing federal procurement preferences for all employers who employ people with disabilities; and
- Assuring that federal employees with disabilities do not lose their federal employment status due to outsourcing.

Employment Standards and Benefits

- Supporting policies that expand workplace flexibility;
- Assuring that part-time, supported, or periodic employees are included in any proposal that expands or extends fringe benefit coverage; and
- Expanding access to family and medical leave and supporting paid leave policies, including by mandating employers to provide a reasonable amount of paid sick leave and requiring payors to recognize these costs in their reimbursement.

Other

- Assuring that people with intellectual disability, cerebral palsy, and other disabilities can access all relevant work programs, including business development opportunities;
- Providing technical assistance to service providers for the purpose of expanding and improving their capacity to provide supported employment, customized employment, and other services and supports that will enhance opportunities for integrated employment consistent with best, promising, and emerging practices;
- Restoring the funding and requiring the Department of Labor's Office of Disability Employment Policy to fulfill its role regarding policy, programs, and research to advance the employment of people with significant disabilities;

- Requiring 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;
- Increasing 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;
- Permanently extending the Work Opportunity Tax Credit (WOTC) and having it apply to non-profit organizations; and
- Reforming current Medicaid Home and Community-Based Services waiver (HCBS) and State Medicaid plan Section 1915(i) option to promote competitive, integrated employment.

Family Support

An estimated 75% of people with I/DD live at home with family and most families receive few or no services and face long waiting lists for needed supports. Families of children with disabilities continue to face obstacles to finding and keeping high quality, inclusive child-care. As a result, families often lose jobs, lose income, and face financial challenges, in addition to not receiving necessary supports for their children to meaningfully participate in appropriate programs. Children with disabilities remain less ready to learn in school because they cannot access the same early care and education programs as their peers. Beyond childhood, 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. Families with relatives who have developmental disabilities are more likely to live in poverty than other families. Women, providing the bulk of informal caregiving, often juggle caregiving and employment. As people with disabilities are living longer, siblings are playing increasingly important roles across the lifespan and frequently assume primary caregiving responsibilities when aging parents are no longer able. Currently, there are over 730,000 people with I/DD living with aging caregivers (over 60 years of age), a population rapidly growing and in great need of services and supports. 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.

During the 113th Congress, our public policy goals are to strengthen the ability of families to support their relatives with disabilities by:

- Supporting federal initiatives that recognize the important role of families and the need for comprehensive family supports;

- Significantly increasing funding and establishing a separate authorization level for the Family Support Program under Title II of the DD Act;
- Maintaining full funding for a state capacity development program on family support;
- Expanding the Family Medical Leave Act to cover more workers by reaching smaller employers and part-time workers; providing paid leave; and expanding the definition of covered family member to include, for example, siblings, grandparents, and domestic partners;
- Fully funding the Lifespan Respite Care Act to help ensure the availability of respite care for families, regardless of age or disability;
- Expanding and increasing funding for the National Family Caregiver Support program to fully include caregivers of children and adults with disabilities; and
- Reauthorizing and increasing 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;
- Improving and expanding adoption assistance and foster care programs to better address the multiple challenges facing children with disabilities and their adoptive or foster families;
- Amending 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;
- Authorizing Title IV-E waivers to encourage the use of in-home services to prevent the use of out of home placements;
- Addressing inequities in access to and funding for direct support caregiver services for all Medicaid-eligible developmental disability populations;
- Providing incentives for businesses to offer employer-provided individual and family supports for employees that have a family member with I/DD as part of employee-assistance programs;
- Creating a registry, consistent with rights to privacy, to facilitate re-unification of individuals with disabilities who were separated from their families during emergencies;
- Providing a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses; and
- Ensuring that programs providing personal assistance services include supports and services for parents with disabilities.

Housing

Across the nation, people with intellectual, developmental, and physical disabilities face a crisis in the availability of decent, safe, affordable, and accessible housing. Over 730,000 people with I/DD live with aging parents (at least one of whom is over age 60). 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 benefits, the affordability crisis is even worse.

Therefore, during the 113th 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:

- Significantly increasing funding for, and protecting 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, the Community Development Block Grant program and increasing funding for U.S. Department of Agriculture housing programs as well as all other federal housing programs providing funding for people with disabilities;
- Providing 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;
- Funding the National Affordable Housing Trust Fund with deeply targeted eligibility criteria to increase the availability of affordable and accessible housing for people with disabilities;
- Providing funding for and ensuring 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;
- Opposing efforts to limit housing options, including efforts to weaken fair housing protections;

- Removing 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.
- Enacting 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);
- Requiring that projects developed through the Low Income Housing Tax Credit apply design standards identical to those in Section 504 of the Rehabilitation Act; and
- Providing oversight of HUD's management of housing programs to ensure that they meet the housing needs of people with disabilities.

Civil Rights

Voting Rights Reform

Individuals with disabilities, individually and collectively, offer an important and needed voice within the voting public. Ensuring voting independence, accuracy, and access continue to be key issues for this constituency. The Help America Vote Act (HAVA) of 2002 required fully accessible voting machines for people with disabilities by January 1, 2006. This promise has not been fulfilled. According to a September 2009 Government Accountability Office (GAO) report, too many polling places and voting technology throughout the country remain inaccessible. Additionally, state laws requiring voter identification and/or voting machines with "paper trails" have created inconsistency in voting technology and confusion among voters with disabilities.

During the 113th Congress, our public policy goals are to:

- Provide strong enforcement of the Help America Vote Act (HAVA) of 2002 addressing 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;
- Ensure that requirements for voter identification and/or voting technology do not hinder or discourage voting by people with disabilities; and
- Ensure adequate funding for the Protection and Advocacy for Voter Access programs.

Other Civil Rights

During the 113th Congress, our public policy goals are to:

- Promote and protect equal rights of children and adults with disabilities in all parts of the world, by ratifying the UN Convention on the Rights of Persons with Disabilities (CRPD);
- Protect and promote stronger enforcement of existing civil rights laws for people with disabilities, particularly the Americans with Disabilities Act; Individuals with Disabilities Education Act (IDEA); Fair Housing Act; Civil Rights of Institutionalized Persons Act (CRIPA); Sections 503, 504, and 508 of the Rehabilitation Act; Help America Vote Act (HAVA); National Voter Registration Act ("motor voter"); Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act; Genetic Information Nondiscrimination Act; and Air Carrier Access Act;
- 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;
- Preserve and enhance all 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;
- Enact protections, including sanctions, against abuse, neglect, and inappropriate non-emergency use of physical, mechanical, and chemical restraints and seclusion in all settings;
- 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; and
- Create and fund a research and training effort focusing on international cooperation on disability.

Technology

Many people with disabilities could benefit from accessible technology and technology enabled supports to maintain independent lives and maximize health options. 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 113th 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 113th Congress, our public policy goals are to:

- Ensure that people with disabilities have information about and access to affordable, useable technology to support and enhance their lives;
- Reauthorize and fully fund all of the provisions of the Assistive Technology Act of 2004:
  - State Grant Programs – Provide sufficient appropriations to 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;
  - Alternative Financing Program – Increase funding for the programs to enable individuals with disabilities to purchase Assistive Technology devices and services through financial loans;
  - Protection and Advocacy – Provide sufficient appropriations to ensure viable Protection and Advocacy for Assistive Technology services in each state and territory;
  - National Technical Assistance – Provide sufficient funding to ensure quality technical assistance to each state and territorial program; and
  - Research and Development – Provide sufficient appropriations to support a meaningful level of research and development of assistive technology devices and standards.
- Promote 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 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.

B. OTHER CRITICAL GOALS

The legislative goals delineated below reflect major laws and programs that may receive scrutiny in the 113th Congress. These laws and programs also play key roles in the lives of our constituents and their families. In particular, they provide the essential health care, employment, family, transportation, and technology supports to make community living a reality for our constituents. Essential criminal justice; data collection; Developmental Disabilities; emergency management; child welfare, foster care, and adoption; immigration and naturalization; liability insurance protection; non-profit organizations; prevention; quality of services; research; social services; tax policy; Temporary Assistance for Needy Families; and transportation are addressed by these goals. For convenience, they are listed alphabetically.

Criminal Justice

Statistics clearly indicate that more and more individuals with disabilities are ending up in penal institutions and juvenile justice facilities. Many end up in such placements due to the lack of alternative treatment programs. These individuals frequently are victims of abuse and neglect. Too little is being done to protect these individuals and prevent systemic mistreatment.

During the 113th Congress, our public policy goals are to:

- Expand the authority and the funding for the Department of Justice (DOJ) to carry out criminal justice initiatives and activities that affect individuals with I/DD in the following areas:
  - Training of all personnel in the criminal justice system about issues unique to our constituents, including identification of a disability;
  - Training of all personnel in the criminal justice system about due process protections that include reliable, culturally competent assessments for determining existence of ID and legal competency;
  - Providing for research to assist the Attorney General in collecting valid, reliable national data relating to crimes against individuals with I/DD for the National Crime Victims Survey conducted by DOJ;
  - Providing appropriate crime victim assistance and accommodations to people with I/DD;
  - Preventing discrimination by the criminal justice system against victims, witnesses, and those accused of crimes on the basis of disability;
  - Ensuring appropriate treatment of prisoners with I/DD, including appropriate special educational services for incarcerated youth with

disabilities, and ensuring that penal and juvenile justice facilities are not used as "dumping grounds" for such individuals;

- Ensuring that appropriate medical interventions, including pharmaceuticals, are available to individuals with disabilities, to ensure that they are not inappropriately relegated to the criminal justice system;
- Prosecuting individuals that commit, and entities that are party to, physical, psychological, or sexual abuse, mistreatment, or neglect of children or adults with disabilities;
- Ensuring inexpensive and timely access by families, providers, and states to federal criminal background checks of anyone employed in the disability service system;
- Ensuring reasonable accommodation in all stages of criminal proceedings to assist individuals with I/DD in understanding and participating in the proceedings and their defense; and
- Exploring alternatives to incarceration for people with I/DD who are not competent to stand trial that represent best practices and include community options.

Data Collection

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 I/DD and their families.

During the 113th Congress, our public policy goals are to:

- Establish an Office of Disability Statistics; charge this office with consulting with federal and state agencies, disabilities advocates, and other stakeholders to develop common definitions of terms, so that data collected from various sources can be meaningfully reported, compared, and interpreted. This office should be empowered to work with other appropriate agencies and use the common set of questions about disability in national surveys, as included in the American Community Survey and the Current Population Survey;
- 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.

Developmental Disabilities

The Developmental Disabilities and Bill of Rights Act (DD Act) is the fundamental law supporting states 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 113th Congress, our public policy goals are to:

- Make the reauthorization of the DD Act a priority;
- Increase funding for programs authorized under the DD Act, including:
    1. Councils on Developmental Disabilities;
    2. Protection and Advocacy Systems;
    3. University Centers for Excellence in Developmental Disabilities, Education, Research, and Service;
    4. Family Support; and
    5. Projects of National Significance.
- Reauthorize and 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;
- Reauthorize the 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;
- Protect and expand the authority of Protection and Advocacy Systems to investigate abuse, neglect, and deaths of people with I/DD and to pursue class action litigation on behalf of our constituents wherever they live;
- Ensure federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports;
- Reauthorize the Combating Autism Reauthorization Act of 2011; and
- Support legislation to develop evidence-based services and supports for individuals on the autism spectrum and increase training for professionals who work with individuals with Autism Spectrum Disorders and other developmental disabilities.

Emergency Management

Recent natural, public health, and man-made disasters demonstrate that preparedness and relief 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. While significant legislative action to address the situation of people with disabilities in emergency preparedness and relief efforts has taken place, much remains to be done. Furthermore, the legislative progress that was achieved must be built upon.

During the 113th Congress, our public policy goals are to build on the progress made in addressing the needs of the disability community in emergency preparedness and response efforts by:

- Conducting oversight (e.g., hearings, reports) of existing laws to document progress to date, address the needs of people with disabilities in emergency preparedness, response, and mitigation efforts, and address continuing failures and challenges and make recommendations for improvement;
- Passing additional legislation that will:
  - Require disaster plans in all childcare and educational settings;
  - Require fully accessible temporary and long-term relief housing of 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 specifically for mental health and substance abuse services related to disasters and emergencies;
  - Provide for legal services offered by legal experts with special training in disability rights and other disability law;
  - Increase support for regional disability coordinators;
  - Develop resources and training for first responders and other personnel in the functional needs of people with disabilities and their families;
  - Provide 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
- Amend the Homeland Security Act to require the Administrator of the Federal Emergency Management Agency to establish the Office of Disability Integration and Coordination as a statutory entity, with a Disability Coordinator and adequate staff, to ensure that the needs of people with disabilities are addressed in emergency preparedness and execution.

- Assuring that all federal agencies, federally contracted entities, and other relevant organizations are accountable for developing and participating in coordinated approaches to disaster and emergency preparedness that are efficient and non-duplicative and address the needs of people with disabilities; and
- Appropriating and targeting 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.

Child Welfare, Foster Care, and Adoption

At least one-third of the more than 400,000 children and youth in American foster care systems today have disabilities. The very systems intended to protect children 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. 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 foster children with disabilities are often considered "unadoptable."

During the 113th Congress, our public policy goals are to:

- Fully fund all programs 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 tracking system, consistent throughout the states 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 services and supports 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.

Immigration and Naturalization

During the 113th 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;
- Ensure that our constituents who are legal residents have access to essential supports and services, such as SSI, Supplemental Nutrition Assistance Program (SNAP, also known as food stamps), and Medicaid;
- Ensure that individuals with disabilities who are facing deportation are provided with legal representation and due process protections and that they are not unnecessarily detained and segregated in immigration facilities; and
- Pursue appropriate waivers of immigration law to allow for the active recruitment of qualified immigrants in order to bolster the direct support and professional workforce.

Liability Insurance Protections

During the 113th 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, 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, and must continue to provide, the overwhelming majority of services and supports for our constituents. Disability related non-profits are assuming greater roles as state funding is reduced. The non-profit sector must also be allowed to maintain its traditional role of advocacy.

During the 113th Congress, our public policy goals are to:

- 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 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; and
- Oppose any provision that would limit the ability of non-profit organizations to engage in voter registration and outreach activities.

Prevention

During the 113th Congress, our public policy goals are to endeavor to increase research into the prevention of disabilities and secondary disabilities by:

- Protecting 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;

- Increasing 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), Environmental Protection Agency (EPA), and for other existing federal education and prevention initiatives, in areas including but not limited to:
  - Autism spectrum disorders;
  - Cerebral palsy;
  - Developmental disabilities;
  - Environmental hazards;
  - Fetal alcohol spectrum disorders;
  - Food additives and harmful drugs;
  - Intellectual disability;
  - Lead poisoning prevention through detection and abatement;
  - Product safety;
  - Sexual exploitation and abuse;
  - Smoking; and
  - Transportation safety.
- Enacting legislation to reduce harmful chemical exposures that can result in intellectual and developmental disabilities;
- Requiring 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);
- Ensuring full implementation of the mandated Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program;
- Protecting and expanding the existing disability-related warnings on alcohol products;
- Supporting legislation that will provide nationwide tracking for the prevalence of developmental disabilities and associated environmental causes;
- Increasing resources for the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and other similar federal agencies to expand the State Disability and Health Program in order to prevent the occurrence of secondary conditions for individuals with lifelong disabilities;

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 a 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 113th Congress, our public policy goals are to:

- Assure high quality - and where possible, evidence-based - services, supports, and access in all programs serving our constituents in which federal funds are used;
- Assure that new service delivery models, such as managed care in LTSS, include appropriate and comprehensive national quality standards that include outcomes based on an individual's person-centered plan;
- Require federal agencies to include families, people with disabilities, service providers, and DD Act programs in all aspects of development of quality measures and assessment of quality;
- Require training and technical assistance to states 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, communities, and other entities that violate federal requirements;
- Assure a well-trained, well-compensated, and stable workforce to support people with disabilities and their families by enacting legislation and increasing financial support to provide pre-service and in-service training of professionals and other workers to meet the diverse needs of individuals with disabilities;
- Require that CMS 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, safety, and quality of services, including ICF/ID and home and community-based services programs.

Research

A variety of federal agencies are responsible for undertaking vital research activities to prevent and ameliorate 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 broad based.

During the 113th Congress, our public policy goals are to:

- Significantly expand federal funding of basic and applied research at the Centers for Disease Control and Prevention, the Administration on Intellectual and Developmental Disabilities, the National Institutes of Health, the National Institute on Disability and Rehabilitation Research, and the Environmental Protection Agency designed to both improve the quality of life for our constituents and to prevent the causes and effects of I/DD;
- Support and expand the research efforts of the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers to discover the causes of, as well as effective treatments and supports for, persons with developmental and related disabilities;
- Provide funding for all relevant agencies to translate and disseminate to practitioners, families, and policymakers new knowledge about effective practices;
- 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;
- Require the National Institute on Disability and Rehabilitation Research (NIDRR) 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 research, policy analysis, survey research, and experimental design;

- Promote the implementation of accurate and independent research findings that assist people with I/DD to lead quality lives in the community;
- Support research on disability and aging;
- Fully fund the National Children's Study to continue research examining the effects of the environment on children's health and development;
- Incorporate disability status in federally funded research; and
- Expand funding to determine the current status and what can be done to alleviate the disparities in health services and supports to un-served and underserved populations.

Social Services

During the 113th Congress, our public policy goals are to recognize that social services programs are underfunded and that a wide variety of needs remain unmet. Title XX of the Social Security Act, the Social Services Block Grant, provides states with funding to provide many community-based services to people with disabilities and other targeted low income populations. The Congress should protect and, at a minimum, restore funding for Title XX to $2.8 billion or bring it to the level it would have been had it been adjusted annually for inflation.

Tax Policy

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 113th Congress, our public policy goals are to:

- Allow a tax credit for individuals or their families who incur expenses in meeting long term support needs;
- Assist families of people with disabilities to stay intact, independent, and self-sufficient by allowing families to fund tax-favored savings plans for long-term support needs which will not negatively impact eligibility for or benefits in government programs;
- Provide incentives for the private sector to provide cost-effective supports for individuals with disabilities and their families;
- Provide a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses;
- 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; and
- Support tax policy that promotes the employment of people with disabilities, including improving the impairment-related work expense deduction and the usefulness of the architectural and barrier removal deduction and disabled access credit.

Temporary Assistance for Needy Families (TANF)

During the 113th 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. Desired provisions include:

- Improving screening and assessment for disability;
- Securing appropriate supports and services, including employment and training services;
- Allowing a more expansive understanding of the care of a child or other family member with a disability to be counted as a work activity;
- Increasing state flexibility by giving states credit for their effort to provide rehabilitative and other services and supports over a longer period of time in order to assist more individuals with disabilities to return to work;
- Providing pre-sanction reviews to ensure that TANF recipients with disabilities are not improperly sanctioned for an inability to comply with TANF rules; and
- Ensuring affordable and accessible transportation and other supports necessary to obtain and retain employment.

Transportation

Millions of Americans 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 lifeline for people with disabilities to access employment, education, health care, and community life. With the two year extension of the Moving Ahead for Progress in the 21st Century (MAP-21) accomplished, Congress must begin addressing the longer term need for reauthorization of the surface transportation legislation. A significant expansion of public transportation will achieve many important societal goals such as more jobs, a cleaner environment, and better mobility options for seniors and people with disabilities. Principles of universal design should be integrated in the

development of new transportation devices and projects to ensure greater mobility for people with disabilities.

During the 113th Congress, our public policy goals are to expand transportation opportunities for people with disabilities by:

- Increasing funding for the Federal Transit Administration programs, including mass transit programs (including paratransit), Section 5310 Program for the Elderly and People with Disabilities, the United We Ride interagency initiative, and other critical programs;
- Creating funding opportunities for coordinated services across jurisdictional lines;
- Expanding mobility management and travel training services for individuals with disabilities in order to create more public and private coordinated transportation systems;
- Simplifying the coordinated planning process for the programs that serve people with disabilities and creating transparency and accountability at the Department of Transportation;
- Ensuring that state and local transportation systems address accessibility;
- Promoting tax policy that encourages greater mobility for people with disabilities;
- Improving accessibility in and around transit locations;
- Promoting policies that expand the availability of accessible taxis, buses, and other transportation vehicles and systems, particularly for travel in rural and underserved communities and across jurisdictional lines;
- Providing funding to Amtrak to improve station accessibility and holding Amtrak and other responsible entities accountable for a plan to achieve full accessibility;
- Improving airline and airport accessibility;
- Ensuring that the Transportation Security Administration (TSA) both (i) works with disability advocacy groups to ensure that TSA's policies and procedures regarding airport screening respect the rights and dignity of people with disabilities, and (ii) trains all airport security personnel to follow those policies and procedures;
- Requiring new federally supported transportation technologies to meet universal design standards; and
- Work toward interstate reciprocity among state paratransit systems so that people with disabilities can travel nationwide.

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Association of University Centers on Disabilities (AUCD)
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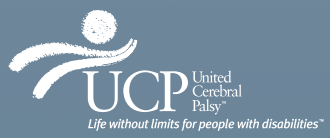

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This document is also available on the websites of the participating organizations.