

Legislative Agenda

for the 111th Congress

2009 - 2010



DISABILITY POLICY COLLABORATION



In Partnership With

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

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Legislative Agenda *for the 111th Congress*

I. INTRODUCTION

WHAT IS THE ROLE OF FEDERAL POLICY IN DISABILITY?

For many decades, the six national disability advocacy organizations that endorse the legislative agenda contained in this document have recognized the vital role the federal government plays in the everyday lives of children and adults with developmental disabilities 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 developmental disabilities. These programs are funded through entitlement programs such as Medicaid and Medicare and discretionary programs such as vocational rehabilitation, HUD housing, and education. Many families and even some 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 such as what 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 nonprofit sectors cannot in any way replace the funding and other roles played by the federal government in dis-



ability policy. It is critical, then, that people with disabilities, their families and advocates, and the disability service system help protect, enhance, and modernize the federal approach to disability policy. The legislative agenda below sets forth critical and priority goals that the U.S. Congress needs to respond to in this Congress.

The Arc and United Cerebral Palsy (UCP) have combined their resources and talents to advance federal disability public policy through a merged government affairs office known as the Disability Policy Collaboration (DPC). Begun in 2003, the collaboration assures cost-effective performance for its parent organizations, while combining for a more powerful voice for people with disabilities. The DPC leads efforts in mobilizing chapters, affiliates, self-advocates, families, and other supporters to become active players in national public policy.

The Arc is a membership organization made up of people with intellectual (such as mental retardation, an old and outdated term seldom used anymore), developmental and other disabilities, their families, friends, interested citizens, and professionals in the disability field. Together they form state and local chapters of The Arc, making up the largest volunteer-based organization in the United States devoted solely to working on behalf of this constituency.

The Arc also advocates for people with other disability labels who, at times, will need similar supports and services in order to be as productive and independent as possible.

For almost 60 years, approximately 800 state and local chapters of The Arc have worked throughout the nation to ensure that their constituents 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.

WHAT IS THE DISABILITY POLICY COLLABORATION?

WHAT IS THE ARC?



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 AAIDD?

The American Association on Intellectual and Developmental Disabilities (AAIDD, formerly AAMR) is the world's oldest and largest interdisciplinary organization of professionals concerned about intellectual and developmental disabilities. Today AAIDD has more than 40,000 members and service recipients, and this year the organization is celebrating more than 133 years of vision and professional leadership. AAIDD's commitment to innovation and progress is as strong today as it was in the Association's earliest days.

AAIDD is the source of credible disability information based on research findings. The Association also provides a unique forum where professionals, parents, advocates, and policy makers can come together to discuss disability research, policy, and service issues.

The AAIDD network strives to provide the best information, resources, supports, and services designed to enhance the quality of life and ensure full societal inclusion of persons with intellectual and developmental disabilities.

WHAT IS ANCOR?

The American Network of Community Options and Resources (ANCOR) is a national, nonprofit membership organization representing private providers of supports and services to people with disabilities. For more than 35 years, ANCOR has distinguished itself in the field by its balance of leading practices, resources, and advocacy for member agencies and the people and families they serve and support. ANCOR's mission is to inform, educate, and network service providers to safeguard, develop, grow, and extend their capacity to support the choices of people with disabilities. Together, ANCOR's nationwide network of 825 providers; 395,000 direct support professionals; and 45 state provider associations daily support more than 385,000 individuals with developmental and other disabilities, promoting an optimal quality of life to advance full participation.

The Association of University Centers on Disabilities (AUCD) is a nonprofit 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 support 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 policy-makers concerned about people living with developmental and other disabilities and their families.

WHAT IS AUCD?

WHAT IS NACDD?

The National Association of Councils on Developmental Disabilities (NACDD) is a national membership organization representing the 55 State and Territorial Councils on Developmental Disabilities. NACDD is a 501(c) 3 organization with the purpose of promoting and enhancing the outcomes of our member councils in developing and sustaining inclusive communities and self-directed services and supports for individuals with developmental disabilities.

WHAT IS A DEVELOPMENTAL DISABILITY?

Developmental Disabilities are physical or mental impairments that begin before age 22, and alter or substantially inhibit a person's capacity to do at least three of the following:

Take care of themselves (dress, bathe, eat, and other daily tasks)

- Speak and be understood clearly
- Learn
- Walk/Move around
- Make decisions
- Live on their own
- Earn and manage an income

Some common types of developmental disabilities are cerebral palsy, intellectual disabilities, autism spectrum disorders, and epilepsy.

WHAT IS AN INTELLECTUAL DISABILITY?

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday 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.” Because the disability community no longer uses that term, 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 the eligibility requirement 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 should remain in use until the official disability classification systems conform to the use of the term “intellectual disability.”

Cerebral Palsy (CP) is a number of disorders of the developing brain affecting body movement, posture and muscle coordination. CP is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; during infancy; or early childhood. It is not a disease, not progressive, nor communicable. The United Cerebral Palsy Research and Educational Foundation estimates between 1.5-2.0 million children and adults have cerebral palsy in the United States

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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 legislative goal applies to everyone represented by our collective organizations.

WHAT IS CEREBRAL PALSY?

USE OF TERMS

DEVELOPMENT OF THE NATIONAL POLICY AGENDA

THE ARC AND UNITED CEREBRAL PALSY IN COLLABORATION

OTHER PARTNERSHIPS

SHAPING PUBLIC POLICY



The Arc and UCP have combined their resources, talents, and strong legacy of grassroots involvement in national public policy into the formal Disability Policy Collaboration. 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.

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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. All six organizations are leading members of the Consortium for Citizens with Disabilities (CCD). CCD is a Washington, D.C.-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, United Cerebral Palsy, AAIDD, ANCOR, AUCD, and NACDD also participate in non-disability coalitions which help further our policy goals.

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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. These individuals and their families have an interest in learning about and having an influence on the laws that affect them. 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. Since state and local governments often cannot or will not adequately meet the needs of our constituents, an increased federal role in ensuring and providing supports is necessary.

In recent years there has been an ongoing effort to shift some federal responsibilities to state and local governments. In many instances, this shift has weakened or eliminated the very services and supports children and adults with disabilities and their families need to survive. Despite the fact that the United States is the one of the wealthiest countries in the world, there are unmet needs for too many of our constituents and their families.

During their Senate tenures, President Obama and Vice President Biden have consistently demonstrated an appreciation for the needs of persons with disabilities and the imperative to address those needs. Our organizations understand that the Administration is faced with significant challenges – a severe economic downturn, two wars, and an ever growing deficit. The weakened economy contributes to the daunting challenges facing our constituents. The Obama Administration’s pledge of change is expected to offer new opportunities to improve, modernize, and expand supports and benefits for our constituency.

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, UCP, AAIDD, ANCOR, AUCD, and NACDD will continue to advocate for needed changes and additions to public policy that will address their needs.

DEVELOPMENT OF
LEGISLATIVE
AGENDA

The foundation for the legislative agenda for the 111th Congress is built on mission statements, principles, core values, position statements and current policies of The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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 111th Congress. We will also deal with unexpected issues as they arise.

For the 111th Congress, we present two tiers of priorities for our programmatic legislative agenda. The tiers are critical agenda and priority agenda. The rationale for the tiered scheme is contained in the programmatic goals section of this document. The DPC will address any and all of these issues as they arise.

MONITORING
LAWS AND
POLICIES

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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.

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 and is being wielded with force in an effort to address the current economic crisis in the financial services and other industries. So too, federal fiscal policy can and should be used to decisively address the crises facing people with disabilities and their families. The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD support full and adequate 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 entitlement spending threaten our constituents. Adverse administrative Medicaid policy changes set in motion by the previous Administration as well as changes at the state level could 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 at 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 changes in the benefit payment formula resulting in reduced benefits, could have a devastating impact on beneficiaries and on human services funding.

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. 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; 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.

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD 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

BUDGET,
ENTITLEMENTS,
AND
APPROPRIATIONS



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 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.

The 111th Congress must:

- Address the significant unmet needs of people with disabilities and their families by increasing existing federal funding and 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 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 in order to achieve budget cuts;
- Ensure that the current economic crisis does not severely impact our constituents by enacting a significant temporary increase to the federal share of Medicaid spending; 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.

The 111th Congress must:

- Address the unmet needs of people with disabilities and their families before making further tax cuts or reforming tax policy so that it negatively impacts low wage earners and other vulnerable people;
- Protect low income tax payers from paying higher taxes;
- Enable people with disabilities to be independent and productive;
- Protect and enhance, not erode, services and benefits for people with disabilities;
- Assure that tax policies represent a sound investment and will not jeopardize the long term stability of people with disabilities and their families;
- Protect the Social Security trust funds for use by current and future beneficiaries;
- Raise sufficient revenues to balance the annual budget and finance the federal government's role in providing essential supports, services, and benefits for people with disabilities and their families;
- Roll back or repeal tax cuts and adjust other tax policies that create a deficit or put existing disability programs at risk;
- 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, UCP, AAIDD, ANCOR, AUCD, and NACDD 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. Our constituents have highly diverse needs based on their personal preferences and desires, the severity of their disabilities, their ages, and their individual or family circumstances. Many people with disabilities will continue to depend on the federal government for certain services, supports, and benefits throughout their lives.

Federal spending for people with disabilities living in the community, most of whom live with their families, is an investment that is proven to save taxpayer money by lessening the need for more costly out of home long term supports. Nonetheless, most federal programs that support our constituents and their families are grossly underfunded, 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 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. It is time for the nation to develop mechanisms to ensure portability of federally funded supports so that the money can truly follow the person.

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

The Arc, UCP, AAIDD, ANCOR, AUCD, and NACDD acknowledge that many vital federal laws affect our constituency. Some of these laws rise in importance due to pending Congressional attention and the critical role they play in the lives of our constituents. 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, Long Term Community Services and Supports for Individuals, Direct Support Workers, Health Care, Employment Training and Wages, Housing, Family Support, Education, Social Security/Income Maintenance, and Transportation constitute our highest priorities for the 111th Congress.

With appropriate supports, our constituents can be employed, become taxpayers, develop friendships, and participate in community life. Such successes

A. CRITICAL AGENDA

MEDICAID

are very fragile for many, and it is vital that government assures our constituents opportunities similar to those that are enjoyed by most other Americans. Only through receiving supports and services can many people with intellectual, developmental and other disabilities have choices in housemates, employment, transportation, and other essential aspects of community life that most Americans take for granted.

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 mental retardation/developmental disabilities system, and the primary source of health care payment for most of our constituents. For the increasing number of individuals with disabilities living with aging parents, Medicaid will be the solution to meet their needs. The state of the national economy has already placed undue pressure on the states. Many states have scaled back eligibility, 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 and long term care services. Further shifting responsibility for Medicaid to the states and increasing flexibility that allows states to reduce eligibility and benefits is placing many of our constituents and our nation's health, therapeutic and long term care systems for vulnerable populations at enormous risk. Medicaid should evolve instead into a national program.

Medicaid is a powerful driver of economic activity at the state and local levels. Research has shown temporary increases in the federal medical assistance percentages (FMAP) to be an effective tool for economic stimulus because Medicaid generates jobs. 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 not utilize 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.

In order to accomplish true Medicaid reform, the 111th Congress must:

Overall Structure

- Maintain the individual entitlement to a full range of Medicaid health and long term supports and services for all eligible children and adults with disabilities;
- Oppose Medicaid deconstruction or any moves to provide states with flexibility that eliminates basic protections for eligible individuals with developmental disabilities or the imposition of entitlement caps, Medicaid block grants, per capita caps, allocations, allotments, or other mechanisms that cause reductions in eligibility, services, or protections for our constituents;
- Extend moratoria on the rehabilitative services, targeted case management, and school based administrative services/transpiration regulations if they are not withdrawn;

Responding to State Budget Crises

- Provide a significant temporary increase in the federal share of Medicaid spending (FMAP) to address the economic crises facing states across the country and ensure that states maintain their level of effort;

Eligibility

- 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;
- 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 under the student's Individualized Education Program and receive any necessary transportation to those services;
- Secure protections for people who are dual (Medicaid and Medicare) eligibles with disabilities to ensure that they have timely and affordable access to all medically necessary medications under 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 for Medicaid beneficiaries;
- Ensure Medicaid reimbursement for a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies;
- Support the continuation and expansion 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 while requiring a waiver to provide new 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;
- 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;
- Amend the Medicaid state plan option for home and community-based services that was enacted under the Deficit Reduction Act to increase the income limit (to at least that allowed for institutional and waiver services); allow the full range of services available under the home and community based services waiver; and otherwise improve it for supporting people with disabilities;

- Ensure that people with disabilities using HCBS waiver or option services live in settings of their choice;
- Enact a requirement that states provide community attendant services and supports;

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;
- Decouple eligibility for the home and community based waiver from eligibility for institutional services;

Portability

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

Reimbursement Rates

- Establish an increased 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;
- Ensure that states increase, and annually update, reimbursement rates and fees for health practitioners and clinical specialists to reflect the cost of providing services;

Other

- Protect 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;

- Establish an incentive program of increased Federal Medical Assistance Percentage (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;
- Prior to action by CMS on any Medicaid waiver and state plan changes, require states to provide enhanced public notification and outreach, opportunity for comment, and reporting mechanisms;
- Require that Medicaid managed care programs provide primary and acute care based on individual needs and informed choices as determined by the individuals and their doctors and include appropriate consumer protections and enforceable quality standards;
- Reject the placement of Medicaid long term services and supports within a managed care system;
- Maintain the prohibition against the mandatory placement of children with disabilities into Medicaid managed care without an approved waiver;
- Ensure effective quality assurance mechanisms, oversight, and enforcement of state governments' implementation of federally supported community services and supports and the intermediate care facilities program for people with "mental retardation and related conditions" (ICF/MR), including the involvement of people with developmental disabilities and their families in statewide quality assurance systems;
- Restore the annual resident review and maintain the preadmission screening protections under the Preadmission Screening and Annual Resident Review (PASARR) program for people with intellectual disabilities living in nursing homes, so that they will have access to home and com-

LONG TERM
COMMUNITY
SERVICES AND
SUPPORTS FOR
INDIVIDUALS

munity services and supports when nursing home care is unnecessary or inappropriate;

- Require that CMS recognize consumers and consumer advocacy organizations as their primary “customers” and that CMS develop appropriate training and information materials that allow its customers to understand their rights and responsibilities under Medicaid.

The demand for long term supports is a critical issue in the 21st century. Yet, the nation lacks a comprehensive, proactive national public-private system for delivering long term supports. 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 supports. With the first of the “baby boomers” now 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 homes 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. Since Medicaid has become the core of federally-supported long term services and supports, the philosophy of the Medicaid program must be changed to reflect the preference for community based services over institutional services.

To meet this challenge, the 111th Congress must:

- 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 services and supports must be:
 - consumer controlled;
 - inclusive of personal assistance services;

- designed and implemented to meet individual needs;
- widely accessible; and
- provided in the community.

Such a system should avoid the need for people to impoverish themselves to qualify for services.

- Support legislation to create a national, long term supports insurance program that is premium-based and non-means-tested, that will cover most workers, and that will provide cash benefits to assist beneficiaries in avoiding the need to impoverish themselves to qualify for Medicaid;
- Ensure adequate funds for federal monitoring and implementation of the U.S. Supreme Court’s Olmstead decision;
- Establish pilot projects to encourage home health agencies to utilize home monitoring and communications technologies; and
- Amend federal law to allow military survivor benefits to be paid to a trust established for an individual with disabilities, to allow for the long-term support of the individual.

A well-trained, adequately compensated direct support workforce is essential to providing the necessary supports and services to our constituents, who constitute a very vulnerable population. The current Medicaid reimbursement system, and cost cutting actions by state legislatures and Medicaid officials, has allowed states to create a workforce crisis evidenced 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. The 111th Congress must:

- Ensure adequate funding so that direct support workers are paid a living wage, including appropriate benefits, at the same level of pay and benefits

DIRECT SUPPORT WORKERS



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 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.

HEALTH CARE

Health care reform is a top priority for the 111th Congress. Our organizations are firmly committed to universal access to high quality, affordable health care for all Americans. We recognize the importance of comprehensive primary and specialty care for our constituents. People with disabilities are among the most medically underserved populations in our country. Community health supports for our constituents must address mental and physical health needs (including dental care), as well as issues unique to aging with a disability. These supports must be accessible, non-discriminatory, comprehensive, coordinated, and affordable and be delivered by well trained, experienced, and culturally competent providers.

To achieve these goals, the 111th Congress must:

Medicaid/Medicare

- Protect existing health care entitlements such as Medicare and Medicaid;
- Ensure that Medicare continues to serve people with disabilities, is responsive to the unique health care needs of our constituents, and expands access to health care and durable medical equipment for Medicare beneficiaries with disabilities.
- Enact legislation to phase-out Medicare's two-year waiting period under which people with disabilities qualify for Medicare coverage 24 months after receipt of Social Security Disability Insurance (SSDI) benefits;
- Enact legislation to eliminate Medicare's "in the home" restriction for coverage of mobility devices (e.g., wheelchairs and scooters) for those with expected long-term needs;
- Ensure that cost-cutting measures allowed under Medicare and Medicaid do not harm beneficiaries with disabilities;
- Provide a subsidy to purchase health care coverage for individuals with disabilities who lose their Medicare or Medicaid eligibility by taking a job and cannot afford coverage;

Health Care Reform

- Enact health care reform legislation that meets the needs of our constituents for quality, accessible, appropriate, comprehensive, affordable, portable, and non-discriminatory coverage;
- Ensure that our constituents have meaningful choice and control over their health care and enjoy strong consumer protections;
- Reject initiatives that would further segment the insurance market or weaken existing state insurance man-

dates because such initiatives would increase the number of our constituents who are uninsured and undermine the goal of universal access to health care;

State Children's Health Insurance Program (SCHIP)

- Protect and expand the State Children's Health Insurance Program (SCHIP) as a dedicated program for insuring currently uninsured children and include dental and mental health benefits;

Benefits

- Fund individual care coordination for individuals with disabilities, particularly those who have complex and chronic health care needs;
- Prevent insurance companies from using arbitrary and discriminatory classifications to limit coverage for particular diseases or conditions;
- Include preventive and restorative dental coverage under all applicable federal health care programs;
- Provide funding for primary and secondary prevention and wellness programs for individuals with disabilities;
- 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;
- Support efforts to ensure that people in public and private health plans have access to affordable prescription drugs;

Other

- Support a full range of managed care reforms that meet the needs of children and adults with disabilities, including a broad definition of medical necessity, enforceable federal standards, and legal remedies; and

- Revise relevant law to declare people with disabilities an underserved population.

The 111th Congress should recognize that the vast majority of our constituents who are of working age remain unemployed or underemployed. In 2005, an estimated 38 percent of people with a disability were employed. Meanwhile the workforce participation rate of similar populations without disabilities is almost 80 percent. This trend is not improving. By any definition this vast disparity should be recognized as a crisis. People with disabilities want to work and pay taxes.

Thus, the 111th Congress should help our constituents reach their full potential and become as independent as possible through integrated employment by:

Vocational Rehabilitation

- Reauthorizing the Rehabilitation Act and the Workforce Investment Act (WIA), 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 programs, improving transition policy, expanding work experience opportunities, removing barriers to participation by people with disabilities, creating demonstration programs and incentives to replicate best practices and ensuring full due process protections;
- Increasing funding for the state vocational rehabilitation program significantly above the required Consumer Price Index (CPI) level, transitions to postsecondary opportunities, supported employment, projects with industry programs, and workforce development programs that help our constituents find and keep jobs and have more career options;

Economic Stimulus

- Assuring that people with disabilities benefit through increased integrated employment opportunities from any employment related provisions of the economic stimulus efforts;

Procurement and Contracting

- Modernizing the Javits-Wagner-O'Day (JWOD) Program 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 employers who employ significant numbers of people with disabilities;
- Assuring that federal employees with disabilities do not lose their federal employment status due to outsourcing;

Subminimum Wage and Sheltered Work

- Creating incentives for employers or other solutions that will allow a phase out of the issuance of subminimum wage certificates without harming the employment opportunities of people with significant disabilities;
- Assuring that people currently earning sub-minimum wages in supported or sheltered employment have their federal and other benefits and supports protected if any wage and hour policy shift would result in the loss of employment, benefits, or supports;
- Conducting oversight on the Department of Labor's monitoring of compliance under the Fair Labor Standards Act and other federal non-discrimination requirements;

Employment Standards and Benefits

- Supporting policies that expand work place flexibility;
- Assuring that part-time, supported, or periodic employees are included in any proposal that expands or extends fringe benefit coverage;

- Expanding access to family and medical leave and supporting paid leave policies, including mandating employers to provide a reasonable amount of paid sick leave, and requiring payors to recognize these costs in their reimbursement;

Other

- Assuring people with intellectual disabilities, cerebral palsy, and other disabilities can access all relevant work programs, including business development opportunities;
- 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; and
- Permanently extend the Work Opportunity Tax Credit (WOTC) and have it apply to nonprofit organizations.

Across the nation, people with intellectual, developmental, and physical disabilities face a crisis in the availability of decent, safe, affordable, and accessible housing. Over 700,000 people with developmental disabilities live with aging parents (at least one of whom is over age 65). 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, the 111th Congress must 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:

HOUSING

- 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 increase 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 weather related emergencies and the housing foreclosure and finance crisis;
- Providing increased funding for the National Affordable Housing Trust Fund with deeply targeted eligibility criteria to increase the availability of affordable and accessible housing for people with disabilities;
- Reforming and restructuring the Section 811 Supportive Housing for Persons with Disabilities program using 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 nonprofit 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 a dwelling’s first floor);
 - 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.

There are approximately 7 million individuals with intellectual and developmental disabilities in the United States. While over 75% live at home with family, most families receive little or no services and face long waiting lists for needed supports. 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 711,000 aging caregivers (over 60 years of

FAMILY SUPPORT



age) of adults with developmental disabilities, a population rapidly growing and in great need of services and supports.

The 111th Congress must strengthen the ability of families to support their relatives with disabilities by:

- Significantly increasing funding and establishing a separate authorization level for the Family Support Program;
- Maintaining full funding and ensure oversight for a national clearinghouse and technical assistance center 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 members 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 with members of all ages with disabilities;
- Restoring funding to 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;
- Improving and expanding adoption assistance and foster care to promote and support parents with disabilities who wish to adopt or be foster parents;
- Addressing inequities in access to and funding for direct support caregiver services for all Medicaid-eligible developmental disability populations;

- Creating a registry, consistent with rights to privacy, to facilitate re-unification of individuals with disabilities who were somehow separated from their families;
- Expanding and increasing funding for the National Family Caregiver Support program to fully include older caregivers of adults with disabilities; and
- Providing a caregiver tax credit to financially assist families with out-of-pocket costs for disability-related expenses.

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 all children with disabilities not only have the right to attend public schools but have access to the general education curriculum and meaningful educational experiences. The Elementary and Secondary Education Act, also known as the No Child Left Behind Act (NCLB), must ensure that all children have access to a high quality education and continue to align special education and general education laws. Students with disabilities must be held to the same high expectations as their non disabled peers and their academic progress accurately measured and reported. Students with disabilities face multiple attitudinal, environmental, financial, and support barriers in accessing postsecondary education. The Higher Education Opportunity Act (HEOA) offers an opportunity for students with intellectual disabilities to overcome some of those barriers and have access to a post-secondary education that was until recently unavailable.

The 111th Congress must:

IDEA

- Fully fund all components of IDEA and provide a significant infusion of funds into Part C, Head Start, and other early intervention programs;

EDUCATION



- Amend IDEA to place the burden of proof on school systems rather than parents under the due process provision;
- Amend IDEA to allow courts to award fees to expert witnesses who are not attorneys;
- Provide oversight to ensure that the major components of IDEA, such as least restrictive environment (LRE), due process, transition, and individualized education programs (IEPs) are properly and fully implemented;

*Elementary and Secondary Education Act
(as amended by NCLB)*

- Reauthorize ESEA and continue to align IDEA to ensure access to the general education curriculum and a meaningful education;
- Ensure appropriate assessments for all students with disabilities by developing a variety of universally-designed assessments that accurately measure the progress of students with disabilities;
- Adopt and utilize a consistent calculation and reporting of a graduation rate that accurately accounts for the academic achievement of all students;
- Adopt new policies to significantly reduce the unacceptably high drop out rate of students with disabilities;
- Support training and research initiatives to enhance effective transition services from secondary education to postsecondary 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 hav-

ing intellectual disabilities (who historically have extremely low rates of inclusion in these initiatives), to inclusive educational settings; and the guarantee of a free, appropriate public education for all students with disabilities;

- Require any federal funds used to construct and renovate schools to enable such schools to become fully accessible;

Early Intervention and Preschool Programs

- Increase funding for early intervention and preschool programs;
- Ensure adequate funds are allocated to conduct research and the development of evidence-based practices from early intervention through post-secondary education to support learning of students with disabilities;

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 disabilities enrolled in Comprehensive Transition and Postsecondary Programs have access to work study program and Pell grants; and

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 can meet the new “highly qualified” standard and to develop programs to expand the pool of undergraduates majoring in special education.

Social Security is not only a retirement program. It is an insurance program to protect against poverty in retirement or as a result of disability or death of a family wage earner. More than one-third of all Social Security checks go to non-retirees, including nearly seven 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 have experienced increasingly long delays and decreased service in accessing critical Social Security benefits. Processing times have grown, especially at the hearing level where delays have reached intolerable levels. In some hearing offices, claimant representatives report that claimants wait more than two years to receive a hearing and decision. People with severe disabilities have been bearing the brunt of the backlog crisis. 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. Local SSA field offices have been threatened with closing or having their hours open to the public reduced. Despite dra-

matically increased workloads, staffing levels throughout the agency are at record lows.

The 111th Congress must:

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 are as minimal as possible;
- Maintain the insurance protections of the Title II programs for people with disabilities;
- Recognize that intellectual disabilities, 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;
- Increase the Substantial Gainful Activity (SGA) level 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, including the right to a full and fair administrative hearing by an independent decision-maker who provides impartial fact-finding and adjudication;
- Permanently extend the attorneys' fees payment system to people in the SSI program.
- 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;
- 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;
- 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;
- Allow 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;
- Ensure that individuals who adopt special needs children are not affected by application of the family maximum with respect to those adopted children;

Employment Issues

- Ensure that people who work in sheltered or other subsidized settings 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;

Other

- Ensure adequate benefit levels and protect buying power through appropriate cost of living adjustments;
- 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 the development of interdisciplinary teams of clinicians with specialized developmental and assessment expertise to provide expertise for adjudicators who determine eligibility for disability benefits.

TRANSPORTATION

Millions of Americans with disabilities have difficulties obtaining transportation. Transportation provides a vital lifeline for people with disabilities to access employment, education, healthcare and community life. With the upcoming reauthorization of the Safe, Accountable, Flexible, Efficient Transportation Equity Act – a Legacy for Users (SAFETEA-LU) and the urgent need for economic stimulus, significant expansion of public transportation is possible. These investments 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. The

111th Congress should expand transportation opportunities for people with disabilities by:

- Increasing funding for the Federal Transit Administration programs including mass transit programs (including paratransit), the Section 5310 program for the elderly and people with disabilities, the Section 5317 of the New Freedom program, the United We Ride interagency initiative, and other critical programs;
- Streamlining the 5310 program so that it is readily available for nonprofit organizations for the purpose for which they are established;
- 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;
- 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 rural and underserved communities;
- Providing funding to Amtrak to improve station accessibility;
- Improving airline accessibility; and
- Requiring new federally supported transportation technologies to meet universal design standards.

B. PRIORITY AGENDA

The legislative agenda delineated below reflect major laws and programs that are expected to receive scrutiny in the 111th 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 civil rights protections, criminal justice, data collection, the Developmental Disabilities Act, emergency preparedness, foster care and adoption, immigration and naturalization, liability insurance protection, non-profit organizations, prevention and quality of services are addressed by this agenda. Given their importance, and the expectation that they will be addressed in this Congress, they are deemed our priority agenda (for convenience, they are listed alphabetically).

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 1992 required fully accessible polling places for people with disabilities by January 1, 2006. This promise has not been fulfilled. According to voters who reported their experiences in the 2008 elections, too many polling places and voting technologies 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. Deceptive, misleading and intimidating practices on the part of some election officials and others have made it more difficult for many individuals with disabilities to become properly registered and/or to vote.

The 111th Congress should:

- Conduct oversight (e.g. hearings,

reports) to document the progress achieved in implementing the Help America Vote Act (HAVA) of 1992 addressing the right of people with disabilities to vote privately and independently in any election, to rectify continuing failures to meet the provisions of the law and to make recommendations for improvement;

- Pass legislation that will protect people with disabilities from deceptive, misleading and intimidating practices on the part of election officials and others; and
- Ensure that any new voting reform legislation provides equal and full access to voting systems and polling places for voters with disabilities;

Other Civil Rights

The 111th Congress should:

- Pass legislation that will include disability in the federal definition of “hate crime” and provide resources to states for the prosecution of hate crimes based on disability;
- 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”), and Air Carrier Access Act;
- Increase funding for federal government entities that enforce disability rights laws, including the Equal Employment Opportunity Commission (EEOC), the Election Assistance Commission (EAC) and civil rights offices in the Departments of Justice, Health and Human Services, Housing and Urban Development, Labor, Education, Homeland Security, and Transportation;

- Pass new legislation to protect individuals from discrimination in areas such as victimization or criminalization based on disability.
- Preserve and enhance all federal programs that support protection and advocacy services 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 use of physical and chemical restraints and seclusion in all settings;
- Ensure that legislation dealing with issues such as physician-assisted suicide, stem cell research and research utilizing human subjects includes protections against abuse and discrimination on the basis of disability;
- Take action to ensure that the United States is an active leader in promoting the human and civil rights of children and adults with disabilities in all parts of the world, specifically by ratifying the UN Convention on the Rights of Persons with Disabilities; and
- Create and fund a research and training effort focusing on international cooperation on disability.

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 other alternate treatment programs. Such individuals are frequently the victims of abuse and neglect. Too little is being done to protect these individuals and prevent systemic mistreatment.

The 111th Congress should:

- Expand the authority and the funding for the Department of Justice to carry out criminal justice initiatives and activities that affect individuals with

CRIMINAL JUSTICE

disabilities, including those unique to individuals with intellectual disabilities, cerebral palsy, and other related disabilities in the following areas:

- Training of all personnel in the criminal justice system about issues unique to our constituents, including identification of a disability;
- Providing for research to assist the Attorney General in collecting valid, reliable national data relating to crimes against individuals with developmental and related disabilities for the National Crime Victims Survey conducted by the Department of Justice;
- Developing and disseminating models of best practices;
- Providing appropriate crime victim assistance to people with disabilities;
- 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 intellectual disabilities or psychiatric diagnoses, 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, particularly those with behavioral 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; and

DATA COLLECTION

- Ensuring inexpensive and timely access by families, providers and states to Federal criminal background checks for anyone employed in the disability service system.

The collection of accurate data on the incidence, prevalence and wellbeing of individuals with developmental disabilities 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 measures of disability across various surveys make it difficult to assess the status of people with disabilities and identify trends. Consequently, there is no comprehensive data on individuals with developmental disabilities and their families.

The 111th Congress should:

- Establish an Office of Disability Statistics;
- Insert a common set of questions about disability in national surveys, such as those included in the American Community Survey and the Current Population Survey;
- Provide funding to improve and expand the collection and publication of population-based and other data regarding our constituents, and as appropriate, other disabilities, including:
 - Federal health, income maintenance, educational, employment, housing, transportation, social, economic, and criminal justice demographics and statistics;
 - Information on unmet needs of individuals with disabilities who are unserved or underserved, including specific data on state waiting lists;
 - Information on the incidence and prevalence of cerebral palsy, intellectual and developmental disabilities;

- Health status in national initiatives such as Healthy People 2010 and Healthy People 2020;
- Projected demographic trends among individuals with developmental and other disabilities;
- Projected demand for direct support workers, including statistics related to recruitment, training and retention innovations;
- Abuse, neglect, hate crimes, capital punishment, and other forms of victimization against people with intellectual disabilities (formerly referred to as mental retardation) cerebral palsy and, as appropriate, other disabilities;
- Effective health promotion and primary, secondary, and tertiary disability prevention strategies; and
- Identify individuals who are Medicaid eligible but not able to access services, and ascertain impact on families.

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 helps the approximately 4.5 million people with developmental disabilities achieve independence, productivity, integration and inclusion in society.

The 111th Congress should:

- Reauthorize the Developmental Disabilities Assistance and Bill of Rights Act (DD Act);
- Increase funding for programs authorized under the DD Act, including:
 - 1.State Grant Programs (Councils on Developmental Disabilities);
 - 2.Protection and Advocacy Systems;

DEVELOPMENTAL DISABILITIES ACT



3. University Centers for Excellence in Developmental Disabilities, Education, Research, and Service;
 4. Projects of National Significance;
- 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;
 - Provide a formula grant to every state and territory for the Family Support Program under the Act with a separate appropriations line item;
 - Give states the option to provide traditional family support systems change activities and/or service integration activities;
 - Protect and expand the authority of Protection and Advocacy Systems to investigate abuse, neglect, and deaths, and to pursue class action litigation on behalf of our constituents wherever they live;
 - Increase the meaningful participation of people with disabilities and families in the advisory and/or governing bodies of state DD Act programs;
 - Support federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports;
 - Initiate a leadership development program for public and private human service organizational leadership;
 - Ensure that any expansion in coverage or activities in the reauthorization of the DD Act be accompanied with increased funding so as not to result in negative fiscal effects or program outcomes for the programs currently authorized under the Act; and

- Expand the areas of emphasis that are addressed by the UCEDDs and State Councils to include post secondary education

Recent natural, public health and man made disasters continue to demonstrate that both preparedness and relief 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, as well as on the Gulf Coast. 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.

The 111th Congress should 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 and response efforts, and address continuing failures and challenges and to make recommendations for improvement;
- Passing additional legislation that will:
 - Require fully accessible temporary and long-term relief housing of at least 10% of available or developed housing resources;
 - Provide housing for individuals with disabilities in general shelters using ‘medical shelters’ only as specifically needed;
 - 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 specifically for disability-related service coordination;

- 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;
 - Provide for a well coordinated network of regional disability coordinators to work with the disability coordinators at the federal level;
 - Develop resources and training of first responders and other personnel in the specialized needs of people with disabilities and families; and
 - Provide that direct support professionals are considered “essential personnel” in emergency preparedness plans and response;
- 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, non-duplicative and address the needs of people with disabilities;
 - 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; and
 - Establishing an Office on Disability in Federal Emergency Management Agency (FEMA) and provide adequate authority and resources for the role of Disability Coordinator to fulfill the expectations expressed in the Stafford Act.

At least one third of the more than 500,000 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 special needs of children placed in their homes, and foster children with disabilities are often considered “unadoptable.”

The 111th Congress should:

- 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
 - Medicaid services for foster children
- Pass legislation requiring the Departments of Health and Human Services and Education to collaborate to:
 - Develop and establish a uniform national data tracking system, consistent throughout the states that identifies children and youth in foster care systems who have disabilities and to assess the quality of their lives as a result of the government provided services and supports they receive;

IMMIGRATION
AND
NATURALIZATION

- 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.

The 111th Congress should:

- 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, food stamps, and Medicaid; 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 work force.

The 111th Congress should:

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

LIABILITY
INSURANCE
PROTECTIONS

The voluntary and religious nonprofit sector has provided, and must continue to provide, the overwhelming majority of services and supports for our constituents. The nonprofit sector must also be allowed to maintain its traditional role of advocacy.

The 111th Congress must:

- Assure the continuing ability of private sector nonprofit organizations to serve and advocate for people with disabilities and their families;
- Assure fair eligibility for nonprofit groups under any new charitable tax credit or deduction;
- Assure that federal procurement rules not discriminate against nonprofits and that nonprofits are afforded the same privileges and benefits as small and minority businesses;
- Support oversight activities that assure accountability by nonprofits, while making certain that this does not place undue burdens on nonprofits, does not duplicate existing requirements and is coordinated with state oversight efforts; and
- Oppose any provision that would limit the ability of nonprofit organizations to engage in voter registration and outreach activities.

The 111th Congress should endeavor to increase the prevention of causes of disabilities by:

- Increasing funding for the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, the National Institutes of Health, the Environmental Protection Agency, and for other existing federal education and prevention initiatives, including but not limited to:
 - Autism spectrum disorders;
 - Cerebral palsy;
 - Developmental disabilities;
 - Environmental hazards;

PREVENTION

- Fetal alcohol spectrum disorders;
 - Food and drugs;
 - Intellectual disabilities;
 - Lead poisoning prevention through detection and abatement;
 - Product safety;
 - Secondary disabilities;
 - Sexual exploitation and abuse;
 - Smoking; and
 - Transportation safety.
- Requiring public and private insurance payors to pay for medical foods that prevent disabilities such as 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;
 - Enacting legislation to limit the advertising of alcohol products to at-risk populations;
 - Supporting legislation that will provide nationwide tracking for the prevalence of developmental disabilities and associated environmental causes;
 - Enhancing efforts to prevent the occurrence of secondary conditions for individuals with life long disabilities through increasing resources to the National Center on Birth Defects and Developmental Disabilities and by expanding the State Disability and Health program.

The federal government has an important role in quality assurance, particularly regarding health and safety issues. Rather than divest more of this responsibility to states, the federal government should be fulfilling its role in monitoring and enforcement of the quality of services to our constituents.

In order for this to happen, the 111th Congress must:

- Assure high quality services, supports, and access in all programs serving our constituents in which federal funds are used;
- Require federal agencies to include families, people with disabilities, service providers, and Developmental Disabilities Act programs in all aspects of development 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 and have a voice in how the service system operates;
- Maintain, strengthen, and, where appropriate, modernize federal monitoring, oversight, and enforcement roles. This must include assessment of consumer outcomes and satisfaction to assure appropriate outcomes for beneficiaries, as well as upgrading and enhancing data collection and management information systems;
- 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

RESEARCH

to meet the diverse needs of individuals with disabilities;

- Require CMS to develop and publish a comprehensive annual report to Congress on state level consumer satisfaction and outcomes; and
- Require CMS to publish annual data on health and safety quality oversight of services, including ICF/MR and home and community based services programs.

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 developmental disabilities. Some of these research efforts directly target our constituents while others are more broad based.

The 111th Congress should:

- Significantly expand federal funding of basic and applied research at the Centers for Disease Control and Prevention, 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 intellectual disabilities, cerebral palsy, and related disabilities;
- Support and expand the research efforts of the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers to discover the causes, 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 into effective practices;
- Assess the financial and social impact of the failure of government to address the 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;
- Require the National Institute on Disability and Rehabilitation Research 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 developmental and other disabilities 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; and
- Incorporate disability status in any health related research

The 111th Congress should recognize that social services programs are under funded and that a wide variety of needs remain unmet. Title XX of the Social Security Act, the Social Services Block Grant, provides states with flexible funding to provide many community based services to people with disabilities and others targeted low income populations. The Congress should:

- Increase funding for Title XX to \$2.8 billion.

SOCIAL SERVICES



TAX POLICY

In enacting tax policy, the 111th Congress must:

- Reject repeal or reform of the estate tax and other tax reform that helps only the most wealthy;
- Protect low income taxpayers with disabilities from paying higher taxes;
- Enable families of people with disabilities to stay intact, independent, and self-sufficient, and allow families to fund tax-favored savings plans for long term support needs which will not negatively impact eligibility for or benefits in government programs;
- Incentivize the private sector to provide cost effective supports for individuals with disabilities and their families;
- Permanently extend the Work Opportunity Tax Credit and have it apply to non-profit organizations;
- Allow income tax deductions for charitable donations by non-itemizers;
- Reject any provisions that would likely serve as disincentives to charitable donations;
- Support tax policy that promotes the employment of people with disabilities; and
- Allow a tax credit for individuals or their families who incur expense in meeting long term support needs.

TECHNOLOGY

Many people with disabilities rely on accessible technology, assistive and otherwise, to maintain independent lives and maximize health options. The Assistive Technology Act 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 is key to making progress.

The 111th Congress, therefore, should

- Ensure that people with disabilities have access to affordable, useable technology to support and enhance their lives;

- 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. Protect and preserve the effectiveness of the alternate financing programs;
 - 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.

The 111th Congress should improve the TANF program and take appropriate steps to address the growing poverty rates in our country. The unique needs of the nearly 50% of TANF recipients who have disabilities and their families must be addressed. Desired provisions include:

- Improving screening and assessment for disability;
- Securing appropriate supports and services, including vocational rehabilitation;
- 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

TEMPORARY
ASSISTANCE FOR
NEEDY FAMILIES
(TANF)



supports over a longer period of time in order to assist more individuals with disabilities to return to work;

- Pre-sanction reviews to ensure that TANF recipients with disabilities are not improperly sanctioned for an inability to comply with TANF rules; and
- Affordable and accessible transportation and other supports necessary to obtain and retain employment.

Disability Policy Collaboration

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This document is also available on the Web sites of the participating organizations.