

Legislative Goals

for the 110th Congress

2007 - 2008

DISABILITY POLICY COLLABORATION



In Partnership With

aaidd



American Network of Community Options and Resources



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Legislative Goals *for the 110th Congress*

WHO IS THE ARC?

The Arc is a membership organization made up of people with intellectual (such as mental retardation, a term seldom used anymore), developmental and related 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 more than 55 years, approximately 900 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.

WHO IS UCP?

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

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 131 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.

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 empower providers and people with disabilities to celebrate diversity and effect change that ensures full participation. 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.

WHO IS AAIDD?

WHO IS ANCOR?



WHO IS AUCD?

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

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 MENTAL RETARDATION?

Mental retardation is defined as a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. There are approximately 7.2 million Americans living with this condition.

FIVE ASSUMPTIONS ESSENTIAL TO THE APPLICATION OF THE DEFINITION

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.



5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

The term mental retardation is gradually being replaced in common usage by terms such as intellectual disability. The term mental retardation is most commonly used as an eligibility requirement in many federal laws. People with intellectual disabilities have endured generations of social stigma despite efforts to address their inclusion as full participants in communities and society. Many of our federal programs require the use of out-moded and disrespectful terminology, specifically the term “mental retardation”. States are beginning to replace this term in legislation with the term “intellectual disability”, wherever possible, and federal legislation should follow suit, without abandoning eligibility criteria and protections.

Cerebral palsy (CP) describes a group of developmental disorders of movement and posture in children and adults, causing activity restriction or disability attributed to disturbances that occurred in the fetal or infant brain. Cerebral palsy may be accompanied by a seizure disorder and/or by impairment of sensation, cognition, communication, and/or behavior.

It is estimated that some 764,000 children and adults in the United States manifest one or more of the symptoms of cerebral palsy. Currently, about 8,000 babies and infants are diagnosed with the condition each year. In addition, some 1,200 – 1,500 preschool-age children are recognized each year to have cerebral palsy. Due to the nature of this disability, a significant number of people with cerebral palsy have mental retardation.

The Arc, UCP, AAIDD, ANCOR, and AUCD support and advocate with and for individuals with intellectual, developmental and related disabilities and their families. 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 NATIONAL POLICY GOALS

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 a formal Disability Policy Collaboration. Working together, we strive to be more effective in convincing policymakers of the vast unmet needs of our constituents and in mobilizing our constituents, their families, and our chapters and affiliates as active players in national public policy.

The Arc, UCP, AAIDD, ANCOR, and AUCD 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 five 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, and AUCD also participate in non-disability coalitions. These coalitions help further our policy goals.

The Arc, United Cerebral Palsy, AAIDD, ANCOR, and AUCD 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 5 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.

There remains 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 one of the wealthiest countries in the world, there are unmet needs for too many of our constituents and their families. Our organizations understand that strengthening national defense and homeland security is vital. Funding to achieve a safer nation, however, should not come at the expense of any one segment of society, especially those who are the most vulnerable, many of whom are almost totally dependent on both the federal government and state programs with federal roots for their very survival.

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 provide services or maintain waiting lists, or have given up seeking assistance. The Arc, United Cerebral Palsy, AAIDD, ANCOR, and AUCD will continue to advocate for needed changes and additions to public policy that will address their needs.

The foundation for the legislative agenda for the 110th Congress is built on mission statements, principles, core values, position statements and current policies of The Arc, UCP, AAIDD, ANCOR, and AUCD 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

DEVELOPMENT OF LEGISLATIVE GOALS



MONITORING
LAWS AND
POLICIES

I. FEDERAL
FISCAL POLICY
GOALS

INTRODUCTION

the 110th Congress. We will also deal with unexpected issues as they arise.

For the 110th Congress, we maintain three tiers of priorities for our programmatic legislative goals. The tiers include critical goals, priority goals, and additional important goals. 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 goals as issues relating to them arise.

The Arc, UCP, AAIDD, ANCOR, and AUCD closely follow how laws and policies are carried out so that our constituency is appropriately served. This includes influencing any changes in regulations as well as how the federal government implements, monitors, and enforces relevant federal programs.

The 110th Congress is expected to consider tax reform proposals and decide whether a number of tax cuts will become permanent or be rolled back. Certain tax policies can significantly limit the nation's ability to address the unmet needs of our constituency.

Reductions in entitlement spending threaten our constituents. Adverse administrative Medicaid policy changes 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. Certain changes to our Social Security system could have a devastating impact on beneficiaries and on human services funding.

Federal fiscal policy is critical to The Arc, United Cerebral Palsy, AAIDD, ANCOR, and AUCD, 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 and



agree with the importance of strengthening national security. 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, and AUCD promote cost-effectiveness when such efforts do no harm to our constituents and allow them to live as independently as possible in the community.

Congress sets annual fiscal policy by:

1. Adopting a budget resolution that sets annual revenue and spending limits. The budget resolution is the blueprint for discretionary and entitlement spending;
2. Adopting annual appropriations bills which set spending levels for the many discretionary programs; and
3. Enacting a reconciliation bill requiring relevant committees to revise tax policy and entitlement spending (such as Medicaid, Medicare, Social Security, Supplemental Security Income, and 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 110th 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

BUDGET, ENTITLEMENTS AND APPROPRIATIONS



REVENUE POLICY

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 is not reduced or limited in order to achieve a balanced budget; 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 110th 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 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.

The Arc, United Cerebral Palsy, AAIDD, ANCOR, and AUCD 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 long term supports. Nonetheless, most federal programs that support our constituents and their families are grossly under-funded, leaving hundreds of thousands underserved or continually waiting for services, and these numbers are constantly growing.

There is also an explosive national crisis in the availability of appropriately qualified direct support workers, due to factors such as low pay, inadequate benefits, limited career options, and intense competition among employers for entry-level workers. 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. People with disabilities who receive any level of supports

II. PROGRAMMATIC GOALS

INTRODUCTION



A. CRITICAL GOALS

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, and AUCD recognize that the Congress drives the disability agenda and some of our priority goals may not be dealt with in this Congress, and some of our lesser goals will be coming up in this Congress. The DPC will respond as appropriate to all Congressional activity related to disability policy.

The Arc, UCP, AAIDD, ANCOR, and AUCD 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 Congress and the Administration may address Social Security and the Medicaid program in 2007. 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 goals related to Medicaid, Social Security/Income

Maintenance, Direct Support Workers, Family Support, Education and Housing constitute our highest priorities for the 110th Congress.

With appropriate supports, our constituents can be employed, become taxpayers, develop friendships, and participate in community life. Such successes are very fragile for many, and it is vital that government assures our constituents opportunities similar to those that are enjoyed by everyone. Only through government supports can many people with intellectual, developmental and other disabilities have choices in housemates, employment, transportation, and other essential aspects of community life that most citizens take for granted.

Medicaid is the lifeline for most people with severe 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. Actions on Medicaid by the federal government have 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. In order to accomplish true Medicaid reform, the 110th Congress must:

- Maintain the individual entitlement to a full range of Medicaid health and long term supports and services for

MEDICAID



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;
- Change Medicaid law so that consumers and families can choose to exercise control over resources to better meet their individual needs;
- 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;
- 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;
- 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;
- Amend the Medicaid state plan option for home and community services that was enacted under the Deficit Reduction Act to increase the income limit (to at least that allowed for institutional and waiver services) and allow the full range of services



available under the home and community based services waiver;

- Enact a requirement that states provide community attendant services and supports;
- Prior to action by the Centers for Medicare and Medicaid Services (CMS) on any Medicaid waiver and state plan changes, require states to provide enhanced public notification, opportunity for comment, and reporting mechanisms;
- 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;
- Ensure that states increase, and annually update, reimbursement rates and fees for health practitioners and clinical specialists to reflect the cost of providing services;
- Halt proposed changes that would reduce Medicaid services by limiting states' ability to tax health care providers;
- 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;
- Secure protections for dual (Medicaid and Medicare) eligibles with disabilities to ensure that they have timely and affordable access to all medically necessary medications under the new Medicare prescription drug coverage;
- Create a public Independent Medicaid Task Force, as proposed by the Administration's New Freedom Initiative, that includes our constituents and their representatives and the provider community to examine and analyze the Medicaid program and reform proposals prior to Congressional action;



- 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;
- 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;
- 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 mental retardation living in nursing homes, so that they will have access to home and community 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;

- Require CMS to issue guidance to states that will result in expanded coverage of appropriate assistive technology for Medicaid beneficiaries;
- Provide oversight to assure that CMS does not eliminate case management services through administrative measures that undermine the ability of states to fund these services;
- Ensure Medicaid reimbursement for a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies; and
- Ensure that Medicaid eligibility rules and processes do not place undue burdens on applicants and beneficiaries who do not have access to birth or citizenship documentation.

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 has created a workforce crisis evidenced by low wages, a lack of health insurance, high turnover, and a shortage of staff. This crisis 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 110th Congress must:

- Ensure that direct support staff are paid a living wage, including appropriate benefits, at the same level of pay and benefits that states provide for staff working in state-operated programs;
- Require that states develop and implement a plan to address all relevant components that drive the crisis, including low wages and reimbursement rates, high turnover, and proper training;
- Require any state and federal minimum wage increases be reflected in state reimbursement rates for services;

DIRECT SUPPORT WORKERS



- 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;
- Establish a program for forgiving tuition loans for direct support workers who work for specified periods providing supports to people with disabilities; and
- Authorize appropriations for the Department of Labor to initiate a study 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.

HOUSING

Across the nation, people with mental and physical disabilities face a crisis in the availability of decent, safe, affordable, and accessible housing. Approximately 730,000 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 110th 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:



- Significantly increasing funding for, and protecting the integrity of U.S. Department of Housing and Urban Development 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;
- Enacting supplemental appropriations to address the emergency need for safe, affordable and accessible housing for individuals with disabilities still affected by the 2005 hurricanes;
- Opposing efforts to limit housing options, including efforts to weaken fair housing protections;
- Removing barriers that prevent people from renting or buying their own homes, through:
 - simplifying programs;
 - ensuring appropriate fair-market rents;
 - eliminating discrimination based on source of income (such as SSI);
 - permitting people to acquire assets;
 - providing funding to educate and train public housing authorities and service providers on the housing needs of people with disabilities;
 - ensuring that non-profit disability organizations can administer tenant-based rental assistance; and
 - ensuring fairness and equity.
- Restructuring and streamlining the Section 811 Supportive Housing for Persons with Disabilities program to ensure funding is used to develop a range of appropriately sized and integrated housing options;

- Enacting legislation requiring newly constructed, federally assisted housing to incorporate visitability standards (elements that afford accessibility to at least a dwelling's first floor);
- Creating a national housing trust fund with deeply targeted eligibility criteria to increase the availability of affordable and accessible housing for people with disabilities;
- Requiring that projects developed through the Low Income Housing Tax Credit apply design standards identical to those in Section 504 of the Rehabilitation Act;
- Providing oversight of the Department of Housing and Urban Development's (HUD) responsibility to meet the housing needs of people with disabilities; and
- Providing oversight of HUD's management of housing programs as they impact our constituents.

FAMILY SUPPORT

Almost 10 million Americans have intellectual and developmental disabilities. The vast majority are able to live independently and survive often with help from family or friends. About one million adults and children receive services that range from very expensive institutional placement to very minimal family supports. Another one million adults and children are not able to survive independently; yet they do not have access to supports of any kind. Their families provide all of their care, often at enormous expense and with terrible consequences for the entire family. The 110th Congress must strengthen the ability of families to maintain typical lifestyles for themselves and their family member(s) with disabilities, and address their unmet needs by:

- Significantly increasing funding and establishing a separate authorization level for the Family Support Program;
- Protecting and expanding services and circumstances covered by the Family and Medical Leave Act to support our constituents and their families;

- 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 special needs and their adoptive or foster families;
- Addressing inequities in access to and funding for direct support caregiver services for all Medicaid-eligible developmental disability populations;
- Authorizing a study of the impact on individuals and families who receive limited direct payments in lieu of comprehensive long term supports and services to meet the needs of a family member with significant disabilities; and
- Creating a registry, consistent with rights to privacy, to facilitate re-unification of individuals with disabilities who were somehow separated from their families.

Children with disabilities, like their non-disabled peers, have a right to a free, appropriate public education. The Individuals with Disabilities Education Act (IDEA) guarantees this right; yet this vital law has never been fully implemented, enforced, or funded in its 30-year history. Most children with intellectual disabilities and developmental disabilities continue to remain segregated from their age appropriate peers in school. Investing in a successful educational experience under IDEA is the major route for individuals with disabilities to become independent, productive, and contributing members of our community. The No Child Left Behind Act (NCLB) is scheduled for reauthorization in this Congress. NCLB can

EDUCATION



play a vital role in measuring the academic progress of students with disabilities. The 110th Congress must:

- Fully fund all components of IDEA and NCLB;
- 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;
- Amend IDEA to place the burden of proof on school systems 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 LRE, due process, transition, and IEPs are properly and fully implemented;
- Amend the Higher Education Act to enhance post-secondary educational opportunities for students with disabilities, particularly students with intellectual and/or multiple impairments;
- Reauthorize the No Child Left Behind Act with emphasis on assuring that all students with disabilities are appropriately served and assessed under the law;
- Adjust student assessment policies in No Child Left Behind and IDEA to assure appropriate skill advancement and assessment of all students;
- Ensure that initiatives such as charter schools, vouchers, and individual education savings accounts do not adversely affect public education; the access of students with disabilities, especially those categorized as having mental retardation (who have an extremely low rate of inclusion), to inclusive educational settings; or the guarantee of a free, appropriate public education for all students with disabilities;

- Reauthorize Head Start with an emphasis on increasing professional standards for Head Start staff, ensuring access to pre-literacy and school readiness curriculum, maintaining a comprehensive approach to child development, and improving accountabilities for positive outcomes for the children served; and
- Require any federal funds used to construct and renovate schools enable such schools to become fully accessible.

Social Security is not only a retirement program. It is also 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 since the impact of the resulting benefit cuts or additional trillions of dollars in deficits would be devastating for people with disabilities.

The 110th Congress must:

- 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);

SOCIAL SECURITY/
INCOME
MAINTENANCE



- 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;
- 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 severe disabilities;
- Maintain the insurance protections of the Title II programs for people with disabilities;
- Recognize that mental retardation, 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;
- Ensure adequate benefit levels and protect buying power through appropriate cost of living adjustments;
- Increase the Substantial Gainful Activity (SGA) level to the level used for people who are blind;
- 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;
- Eliminate the 24-month waiting period for Medicare for Title II beneficiaries;



- 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;
- 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 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;
- Eliminate marriage penalties in Social Security disability policy;
- 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;
- 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;
- Permanently extend eligibility for SSI to refugees and asylees who are disabled or elderly;

B. PRIORITY GOALS

- 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 without jeopardizing their eligibility for SSI; and
- 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.

The legislative goals delineated below reflect major laws and programs that are expected to receive scrutiny in the 110th 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, emergency preparedness, employment, health care and community supports are addressed by these goals. Given their importance, and the expectation that they will be addressed in this Congress, they are deemed priority goals (for convenience, they are listed alphabetically).

AMERICANS WITH DISABILITIES ACT RESTORATION

In passing the Americans with Disabilities Act (ADA) in 1990, the Congress intended for the law to stop employers from making employment decisions based on disability. In reality, people with disabilities are still being judged unfairly, and the employment rate of people with disabilities has not markedly improved.

Over the years, problematic court decisions have had the effect of denying the ADA's protection to people with disabilities that Congress clearly intended to cover, including individuals with conditions like epilepsy, diabetes and mental illness. Court decisions have created an absurd Catch-22 whereby employers can say a person is "too disabled" to do the job but not "disabled enough" to be protected

by the law. The case is then thrown out of court and the individual is never given the chance to prove he or she can do the job.

The 110th Congress should:

- Restore protections under the Americans with Disabilities Act (ADA) lost or weakened due to Court decisions by clarifying the “definition of disability” as originally intended by Congress; and
- Reject attempts to weaken any of the provisions of the Americans with Disabilities Act such as proposed ADA notification legislation.

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 under the Act.

The 110th Congress, therefore, should 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.
- Research and Development – Provide sufficient appropriations to support a meaningful level of research and development of assistive technology devices and standards.

ASSISTIVE TECHNOLOGY



CIVIL RIGHTS
VOTING RIGHTS
REFORM

- The Congress should also restore and enhance access to assistive technology by funding projects such as the Technology Opportunities Program formerly in the Department of Commerce.

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 2006 elections, polling places and voting technology throughout the country remain inaccessible. Additionally, state laws requiring voter identification and/or voting machines with “paper trails” have created inconsistency in voting technology and confusion among voters with disabilities. 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 110th 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.



The 110th Congress should:

- Pass legislation that will protect individuals from discrimination based on genetic information in health insurance, health care, and employment;
- 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;
- 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;

OTHER
CIVIL RIGHTS



DEVELOPMENTAL DISABILITIES

- 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.

The 110th Congress should:

- Reauthorize the Developmental Disabilities Assistance and Bill of Rights Act (DD Act);
- Fully fund programs authorized under the DD Act, including:
 1. State Grant Programs (Councils on Developmental Disabilities);
 2. Protection and Advocacy Systems;
 3. University Centers for Excellence in Developmental Disabilities, Education, Research, and Service;
 4. Projects of National Significance;
- Ensure increased funding and a separate authorization level for the Family Support Program under the Act;
- 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;
- 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; and



- Increase the meaningful participation of families and people with disability in the governance of state level Developmental Disabilities Act programs.

The hurricanes of 2005, public health and other natural and manmade disasters have demonstrated that both preparedness and relief efforts have been 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 took place in the 109th Congress, much remains to be done. Further, the legislative progress that was achieved must be built upon.

The 110th 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) to document the progress achieved in implementing legislation from the 109th Congress addressing the needs of people with disabilities in emergency preparedness and response efforts, to 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;
 - 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;

EMERGENCY PREPAREDNESS AND RESPONSE



EMPLOYMENT, TRAINING, AND WAGES

- 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; 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; and
- Appropriating and targeting adequate resources throughout the U.S. to coordinate state and local efforts specifically to ensure the effective involvement of people with disabilities and their representatives in disaster and emergency preparedness efforts.

The 110th Congress should recognize that most of our constituents who are of working age remain unemployed or under-employed. Thus, the 110th Congress should help our constituents reach their full potential and become as independent as possible through integrated employment by:

- 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 program, improving transition policy, expand-



ing work experience opportunities, removing barriers to participation by people with disabilities, and ensuring full due process protections;

- Increasing funding for the state vocational rehabilitation program significantly above the required Consumer Price Index (CPI) level and increasing funding for supported employment, projects with industry programs, and workforce development programs that help our constituents find and keep jobs and have more career choices;
- Assuring that people with intellectual disabilities, cerebral palsy, and other disabilities can access all relevant work programs, including business development opportunities;
- Assuring that federal employees with disabilities do not lose their federal employment status due to outsourcing;
- Expanding employment opportunities by establishing federal procurement preferences for employers who employ significant numbers of people with 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;
- Increasing the federal minimum wage;
- Supporting policies that expand work place flexibility;
- Modernizing the Javits-Wagner-O'Day (JWOD) Program to expand employment opportunities and ensure that people with significant disabilities remain a priority for participation in the program;



HEALTH CARE

- Assuring that part-time, supported, or periodic employees are included in any proposal that expands or extends fringe benefit coverage; and
- 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.

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. Community health supports for our constituents must address mental and physical health needs, 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 110th Congress must:

- Protect existing health care entitlements such as Medicare and Medicaid;
- Ensure that our constituents have meaningful choice and control over their health care and enjoy strong consumer protections;
- Fund individual care coordination for individuals with disabilities who have complex and chronic health care needs;
- 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 people with disabilities;
- 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;

- Reject initiatives that would further segment the insurance market or weaken existing state insurance mandates because such initiatives would increase the number of our constituents who are uninsured and undermine the goal of universal access to health care;
- Protect and ensure adequate funding for the State Children's Health Insurance Program (SCHIP) as a dedicated program for insuring currently uninsured children, and reject efforts to co-mingle SCHIP with any initiatives to cap the Medicaid program;
- 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;
- Support efforts to ensure that people in public and private health plans have access to affordable prescription drugs;
- Include preventive and restorative dental coverage under all applicable federal health care programs;



LONG TERM
COMMUNITY
SERVICES AND
SUPPORTS FOR
INDIVIDUALS

- Enact legislation requiring health plans to cover treatment for mental illness on the same terms and conditions as all other medical diagnoses; and
- Enact legislation to require health plans to cover Pervasive Developmental Disorder and Alzheimer's Disease on the same basis as they cover other neurological disorders.

The demand for long term supports is a critical issue in the 21st century. However, 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.

To meet this challenge, the 110th 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 homes 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; 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.

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 110th 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;

QUALITY OF SERVICES



Tax Policy

- Strengthen federal enforcement mechanisms to include criminal, civil, and/or financial sanctions for states, communities, and other entities that violate federal requirements;
- Assure a well trained, well compensated, and stable workforce to support people with disabilities and their families by enacting legislation and increasing financial support to provide pre-service and in-service training of professionals and other workers to meet the diverse needs of individuals with disabilities;
- Require 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.

In enacting tax policy, the 110th Congress must:

- Reject repeal of or reform of the Estate Tax and other tax reform that helps only the most wealthy;
- Protect low-income taxpayers from paying higher taxes;
- Enable families of people with disabilities to stay intact, independent, and self-sufficient, and allow for tax-favored savings for long term support needs similar to Section 529 educational savings plans;
- Incentivize the private sector to provide cost-effective supports for individuals with disabilities and their families;
- Permanently extend the Work Opportunity Tax Credit;
- Allow income tax deductions for charitable donations by non-itemizers;
- Reject any provisions that would likely serve as disincentives to charitable donations; and



- Allow a tax credit for individuals or their families who incur expense in meeting long term support needs.

The 110th Congress should expand transportation opportunities for people with disabilities by:

- Ensuring that programs funded by the Federal Transit Administration such as mass transit programs (including para-transit), Section 5310 program for the elderly and people with disabilities, Section 5317 the New Freedom program, the United We Ride interagency initiative, and other critical programs receive the maximum funding authorized in the law; and
- Promoting policies that expand the availability of accessible taxis.

The following goals, listed alphabetically, represent vital policy elements of importance to the disability community. Some of these goals may be addressed in the 110th Congress.

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 110th 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 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;
 - Developing data and conducting research, including on victims of crime;

TRANSPORTATION

C. ADDITIONAL IMPORTANT GOALS

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

DATA COLLECTION

The 110th Congress should:

- 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;
- Information on the incidence and prevalence of cerebral palsy and mental retardation;
- Abuse, neglect, hate crimes, capital punishment, and other forms of victimization against people with mental retardation, cerebral palsy and, as appropriate, other disabilities; and
- Effective health promotion and primary, secondary, and tertiary disability prevention strategies.

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. 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 110th 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

FOSTER CARE AND ADOPTION



- 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;
 - Establish a coordinated approach to information 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.

HABILITATION

The 110th Congress should 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.

IMMIGRATION AND NATURALIZATION

The 110th 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 110th 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.

The voluntary and religious non-profit 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 110th Congress must:

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

LIABILITY
INSURANCE
PROTECTIONS

NON-PROFIT
ORGANIZATIONS



Legislative Goals
for the 110th Congress

PREVENTION

The 110th 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;
 - Cerebral palsy;
 - Developmental disabilities;
 - Environmental hazards;
 - Fetal Alcohol Syndrome and Effects;
 - Food and drugs;
 - Lead poisoning prevention through detection and abatement;
 - Mental retardation;
 - Product safety;
 - Secondary disabilities;
 - Sexual exploitation and abuse; and
 - Transportation safety.
- Requiring public and private insurance payers 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; and
- Supporting legislation that will provide nationwide tracking for the prevalence of developmental disabilities and associated environmental causes.

The 110th Congress should:

RESEARCH

- 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 mental retardation, cerebral palsy, and related disabilities;
- 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 disabilities and mental retardation that represents a mixture of methodological approaches, including qualitative research, policy analysis, survey research and experimental design; and
- Promote the implementation of accurate and independent research findings that assist people with developmental and other disabilities to lead quality lives in the community.



SOCIAL SERVICES

TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF)

The 110th Congress should recognize that social services programs are underfunded and that a wide variety of needs remain unmet. Title XX of the Social Security Act, the Social Services Block Grant, provides states with 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 the fully authorized level of \$2.8 billion in FY 2008; and
- Ensure that people with disabilities who are served by Title XX social service programs are not harmed by new performance standards that do not address the unique needs of people with disabilities.

The 110th Congress should improve the TANF program by addressing the unique needs of the nearly 50% of TANF recipients who have disabilities and their families. 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 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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