

# **The Arc & UCP Public Policy Collaboration**

## **2004 Legislative Goals**



**In Cooperation with**  
*AAMR*

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## **Who is The Arc?**

The Arc is a membership organization made up of people with mental retardation and related disabilities, their families, friends, interested citizens, and professionals in the disability field. Together they form state and local chapters of The Arc, the largest volunteer-based organization in the United States devoted solely to working on behalf of its constituency. The Arc also advocates for people without the label of mental retardation but who, at times, will need similar supports and services in order to be as productive and independent as possible.

For more than half a century, 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, and have control of their own lives.

## **Who is United Cerebral Palsy?**

For 50 years, United Cerebral Palsy (UCP) has been committed to change and progress for people with disabilities. The national organization and its nationwide network of affiliates strive to ensure the inclusion of people with disabilities in every facet of society. UCP's mission is to advance the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities through commitment to the principles of independence, inclusion, and self-determination. United Cerebral Palsy affiliates serve more than 30,000 children and adults with disabilities and their families every day.

## **What is Mental Retardation?**

According to the definition adopted by AAMR, an individual is considered to have mental retardation based on the following two criteria: intellectual functioning (IQ that is below 70-75) and adaptive behavior (daily living skills needed to live, learn, work, and play in the community). The condition must be present from childhood (defined as age 18 or younger).

There are an estimated seven million people with mental retardation in the United States. Two million of these children and adults need ongoing services and supports throughout their lives and at least five million people will be identified as having mental retardation and need services and supports at some point(s) in their lives. People with mental retardation make up a significant constituency within the broader disability community.

## **What is cerebral palsy?**

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; or during infancy. Cerebral palsy is not progressive. Secondary conditions, however, such as muscle spasticity, can develop and may get better, worse, or remain the same over time.

It is estimated that some 500,000 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 are also people with mental retardation.

## **Who is AAMR?**

AAMR (the American Association on Mental Retardation) is the world's oldest and largest interdisciplinary organization of professionals concerned with mental retardation and related disabilities. AAMR has over 8,500 members in the United States and in 50 countries throughout the world. This year AAMR is celebrating 128 years of vision and professional leadership. AAMR's commitment to innovation and progress is as strong today as it was in the organization's earliest days.

AAMR offers a forum for professionals from numerous disciplines to discuss issues focusing on mental retardation and related disabilities.

The AAMR network of professionals strives to provide the best research, resources, supports, and services to enhance the quality of life and ensure full inclusion in society for persons with mental retardation.

## **DEVELOPMENT OF NATIONAL POLICY GOALS**

### **The Arc and United Cerebral Palsy in Collaboration**

The Arc and UCP have combined their resources, talents, and strong legacy of grassroots involvement in national public policy into a formal Public 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, and AAMR 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 three organizations are founding members of the Consortium for Citizens with Disabilities (CCD). CCD is a Washington, D.C.-based coalition of approximately 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, and AAMR also participate in non-disability coalitions. These coalitions help further our policy goals.

### **Shaping Public Policy**

The Arc, United Cerebral Palsy, and AAMR base their public policy views on the understanding that our constituents are full citizens and full participants in a democratic society. The Arc, UCP, and AAMR support and 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.

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 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 wealthiest country 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. However, funding to achieve a safer nation should not come at the expense of any one segment of society, especially those who are the most vulnerable and many of whom are almost totally dependent on the federal government for their very survival.

Nationwide, hundreds of thousands of people with disabilities wait, sometimes for 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. The Arc, United Cerebral Palsy, and AAMR will continue to advocate for needed changes and additions to public policy that will address their needs.

### **Use of Terms**

The Arc, UCP, and AAMR support and advocate with and for individuals with mental retardation, cerebral palsy, 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 collectively represented by our organizations.

### **Development of Legislative Goals**

The foundation for the 2004 legislative agenda is built on The Arc's, UCP's, and AAMR's mission statements, principles, core values, position statements, current policies, and input developed by 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 coming year. We also deal with unexpected issues as they arise.

For 2004, The Arc, United Cerebral Palsy and AAMR have created three tiers of priorities for our programmatic legislative goals. The tiers include priority goals, critical goals, and additional critical goals. The rationale for the tiered scheme is contained in the programmatic goals section of this document.

### **Monitoring Laws and Policies**

The Arc, UCP, and AAMR 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.

## **I. FEDERAL FISCAL POLICY GOALS**

### **Introduction**

The Second Session of the 108<sup>th</sup> Congress is expected to debate additional tax cuts and decide whether some of the recently enacted tax cuts will become permanent or be rolled back. Certain tax policies can limit the nation's ability to address the unmet needs of our constituency.

Reductions in entitlement spending and expected attempts to dismantle Medicaid would create an additional financial burden for state governments, who are already facing their worst budget crisis of the last 50 years. 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. The very lives of our constituents are at stake in these policy deliberations.

Federal fiscal policy is a priority of The Arc, United Cerebral Palsy, and AAMR because state funding is often based on the amount of federal money available. If federal funding for programs is cut, state funding is unlikely to increase and services to our constituents will be reduced. Less money will be available for needed services and supports. Like most Americans, we recognize the need for a strong economy and the importance of strengthening national security. The Arc, UCP, and AAMR will work to ensure that:

- Federal funding decisions 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, and AAMR promote cost-effectiveness when such efforts do no harm to our constituents and allow them to live as independently as possible in the community.

### **Budget, Entitlements, and Appropriations**

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. Passing thirteen 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 Second Session of the 108th 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; and
- Remove the Social Security Administration's administrative budget from any budget cap requirements for the Departments of Labor, Health and Human Services, and Education.

## **Revenue Policy**

The Second Session of the 108th Congress must:

- Address the unmet needs of people with disabilities and their families before making further tax cuts;
- Roll back recently enacted tax cuts that create a deficit or put existing disability programs at risk;
- Assure that tax policies represent a sound investment and will not adversely affect people with disabilities and their families by shifting long term costs to the future;
- 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;
- Avoid creating impediments to the states' ability to raise sufficient revenue to meet human needs;
- 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
- Assure the continuing ability of private sector non-profit organizations to serve and advocate for people with disabilities and their families.

## **II. PROGRAMMATIC GOALS**

### **Introduction**

The Arc, United Cerebral Palsy, and AAMR 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 effects of mental retardation, cerebral palsy, and other disabilities. Our constituents have diverse needs based on their desires, severity of their disability, age, and individual or family circumstance. Because of these factors, many will continue to depend on the federal government for certain services, supports, and benefits.

Federal spending for people with disabilities in the community is an investment that will save taxpayers money by lessening the need for more costly long term supports. Most federal programs that support our constituents and their families are grossly under-funded, leaving hundreds of thousands (and growing) underserved or continually waiting for services.

Currently, there is also an explosive national crisis in the availability of appropriately qualified direct support workers due to factors such as low pay, high turnover, limited career options, and intense competition among employers for entry-level workers. These problems also affect the availability of professionals in the field. This situation severely limits the ability of provider agencies to maintain or expand their services and supports. Worse, this crisis puts the lives of our constituents at risk.

### **A. PRIORITY GOALS**

The Arc, UCP and AAMR acknowledge that many vital federal laws affect our constituency. Some of these laws rise in importance due to the pending Congressional attention being paid to them and the critical role they play in the lives of our constituents. Medicaid and special education statutes are both the most critical and the most vulnerable of these statutes. The relationship between Medicaid, direct support workers, and quality of services requires very close policy coordination. The Individuals with Disabilities Education Act (IDEA) guarantees the fundamental right to a free, appropriate education for students with disabilities. Thus, the goals related to Medicaid, direct support workers, quality of service, and education constitute our highest priorities for 2004.

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

## Medicaid

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. Therefore, states have scaled back eligibility and reduced services, with devastating impact on people with disabilities, their families, and their communities. In order to accomplish true Medicaid reform, the Second Session of the 108th Congress must:

- 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 deconstructing Medicaid, Medicaid block grants, per capita caps, or other mechanisms that cause reductions in eligibility, services, or protections for our constituents;
- 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;
- Address the states' Medicaid budget deficit crises by continuing to increase the federal share of Medicaid costs (Federal Medical Assistance Percentage – FMAP);
- Strengthen the Health Insurance Flexibility and Accountability (HIFA) and the Home and Community-Based Waiver processes by requiring states to establish public notification, opportunity for comment, and reporting mechanisms for applications for proposed waivers and state plan changes;
- 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;
- Create a mandate or option in state Medicaid plans for home and community-based services, and redirect any institutional savings to community-based long term services;
- Create an 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;
- Restore full Medicaid "wrap around" coverage for the new Medicare prescription drug benefit for dual (Medicaid and Medicare) eligibles;
- Improve Medicaid law so that it is consumer-directed to allow consumers and families to exercise control over resources to better meet their individual needs as they define those needs;
- Ensure that Medicaid managed care programs are designed to provide primary and acute care based on individual needs and informed choices 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 children with mental retardation and other disabilities being placed 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-based services and supports and the intermediate care facilities (ICF/MR) program for people with mental retardation and related conditions;
- 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-based services and supports when nursing home care is no longer needed or appropriate;

- Require that the Center on Medicare and Medicaid Services (CMS) recognize consumers and consumer advocacy organizations as their primary "customers"; and
- Require CMS to issue guidance to states that will result in expanded coverage of appropriate assistive technology for Medicaid beneficiaries.

### **Direct Support Workers**

A well-trained, adequately compensated direct support work force is essential to provide the necessary supports and services to our constituents, who constitute a very vulnerable population. The current state and federal reimbursement system has created a workforce crisis evidenced by low wages, high turnover and a shortage of staff. This crisis presents a grave threat to the lives of our constituents and their families. As Medicaid is the primary source of funding for these services, the Second Session of the 108th Congress must:

- Alter any existing Medicaid policy that exacerbates this crisis;
- Require that states address all relevant components that drive the crisis (low wages, high turnover, reimbursement rates, etc.);
- 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;
- Establish a program for forgiving tuition loans for direct support workers who work for specified periods in providing supports to people with disabilities;
- 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;
- 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; and
- Pursue appropriate waivers of immigration law to allow for the active recruitment of immigrants in order to bolster the direct support work force.

### **Quality of Service**

The federal government also 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 to do so, the Second Session of the 108th Congress must:

- Assure high quality services, supports, and access in all programs serving our constituents in which federal funds are used;
- Assure a well trained, well compensated, and stable work force 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;
- Maintain, strengthen, and where appropriate, modernize federal monitoring, oversight, and enforcement roles of state government, which must include assessment of consumer satisfaction to assure appropriate outcomes for beneficiaries;
- Promote enforceable standards that improve inclusion and self-determination for individuals with disabilities and their families;
- Strengthen federal enforcement mechanisms to include criminal, civil and/or financial sanctions for states, communities, and other entities that violate federal requirements;
- Require CMS to develop and publish a comprehensive annual report to Congress on state-level consumer satisfaction and outcome;



- Require CMS to publish annual data on health and safety quality oversight of services, including ICF/MR and waiver programs; and
- Provide training and technical assistance to states in order to implement comprehensive systems of person-centered quality assurance.

## **Education**

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 almost 30-year history. 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. Pending bills before this Congress contain provisions that, if enacted into law, will significantly erode the educational rights of students with disabilities and their parents. The Second Session of the 108th Congress must:

- Provide mandatory full funding of the IDEA;
- Reauthorize the components of IDEA (Part C: Infants and Toddlers with Disabilities and Part D: National Activities to Improve Education of Children with Disabilities) whose authority expires this year. (Part B [IDEA state grant program] is a permanent authority;)
- Create a permanent authority and provide significantly increased funding to expand Part C;
- Expand and improve in-service and pre-service personnel preparation under Part D of IDEA;
- Reject assaults on the IDEA that would reduce the effectiveness of the Individualized Education Program (IEP) and would weaken the due process system by altering or eliminating the "stay put" provision, limiting attorneys' fees for parents who prevail in due process and present to parents a confusing set of options and procedures that will chill their pursuit of due process;
- Expand the transition authority in IDEA for those students age 14 and above to better prepare them for meaningful and productive lives as adults;
- Reject any voucher authority within IDEA that would remove any due process protections or inhibit placements in regular education;
- 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;
- Amend the Higher Education Act to enhance post-secondary educational opportunities for students with disabilities, particularly students with cognitive and/or multiple impairments;
- Ensure that any school reform initiatives (such as charter schools, vouchers and individual education savings accounts) do not adversely affect:
  1. public education;
  2. access of students with disabilities, especially those with mental retardation (who have an abysmally low rate of inclusion), to inclusive educational settings; or
  3. the guarantee of a free, appropriate public education for all students with disabilities; and
- Assess the impact of charter schools and vouchers on students with disabilities.

## **B. CRITICAL GOALS**

The seven legislative goals delineated below reflect major laws and programs that are expected to receive scrutiny in the Second Session of the 108<sup>th</sup> Congress. These laws and programs also play key roles in the lives of our constituents and their families. In particular, they provide the essential cash benefits, health care, housing, employment, transportation, and technology supports to make community living a reality for our constituents. Given their importance, and the expectation that they will be addressed this year, they are critical goals (for convenience, they are listed alphabetically).

## **Assistive Technology**

The Second Session of the 108<sup>th</sup> Congress should reauthorize the Assistive Technology Act and:

- Increase authorization levels for all components of the Act and restore funding lost to states due to the sunset provision;
- Expand the availability of assistive technology to allow people with disabilities who require such devices and supports to become more independent in their homes and communities; and
- Finance the purchase of supports, the creation of systemic approaches to assistive technology, and the training and technical assistance to industry, providers, and individuals and their families.

## **Employment, Training, and Wages**

The Second Session of the 108<sup>th</sup> Congress should recognize that most of our constituents who are of working age remain unemployed or under-employed. Thus, the Congress should help our constituents reach their full potential and become as independent as possible through integrated employment by:

- Reauthorizing the Rehabilitation Act, increasing funding for its many programs, and maintaining the integrity of the Act;
- Protecting and increasing funding for supported employment and projects with industry programs;
- Reauthorizing the Workforce Investment Act (WIA), including strengthening of the linkage between WIA and the Rehabilitation Act;
- Assuring that people with mental retardation, cerebral palsy and other developmental disabilities can access all relevant work programs, including all appropriate workforce development programs and business development opportunities;
- Eliminating barriers to full participation in the workforce development system;
- Eliminating remaining work disincentives for people who depend on the Social Security disability programs (such as increasing the Substantial Gainful Activity (SGA) level to that used for people who are blind);
- Increasing funding for the state vocational rehabilitation program significantly above the required Consumer Price Index (CPI) level and increasing funding for workforce development programs that help our constituents find and keep jobs, have more career choices, and ensure full due process protections;
- Assuring that federal employees with disabilities do not lose their federal employment status due to outsourcing;
- 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 the compliance of the Fair Labor Standards Act and other federal non-discrimination requirements;
- Increasing the federal minimum wage; and
- Assuring that part-time, supported, or periodic employees are included in any proposal that expands or extends fringe benefit coverage.

## **Health Care**

The Second Session of the 108<sup>th</sup> Congress should:

- Pursue a high quality universal health care system that meets the individual needs of our constituents. This system should:
  - Be affordable;
  - Be non-discriminatory;

- Be comprehensive;
- Allow choice of providers;
- Include well-trained and experienced providers;
- Be fair and efficient;
- Be consumer controlled;
- Include strong consumer protections;
- Promote primary and secondary prevention; and
- Protect existing health care entitlements such as Medicaid and Medicare.
- Ensure that appropriate long term services and supports are available for chronic health care needs;
- 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, such as Medical Savings Accounts and proposals that would weaken existing state insurance mandates, such as Association Health Plans and Multiple Employer Welfare Arrangements;
- Ensure that the Medicare program continues to serve people with disabilities and expands access to health care and durable medical equipment for Medicare 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;
- 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 on the same basis as they cover other neurological disorders.

## **Housing**

The Second Session of the 108th Congress should increase the supply of affordable 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 generic and disability-specific housing programs;
- 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;
  - ensuring that non-profit disability organizations can administer tenant-based rental assistance;
  - revising 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; and
  - creating a national housing trust fund with deeply targeted eligibility criteria to increase the availability of affordable and accessible housing for people with disabilities; and

- Enacting legislation requiring newly constructed, federally assisted housing to incorporate visitability standards (elements that afford accessibility to a dwelling's first floor).

### **Social Security/Income Maintenance**

The Second Session of the 108th Congress should:

- 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) of the Social Security Act;
- Reject any proposal to privatize or otherwise threaten Social Security trust fund investments;
- Maintain the important insurance protections of the Title II programs for people with disabilities;
- Recognize that mental retardation and cerebral palsy 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, including the SGA used for the Trial Work Period in Title II;
- 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;
- Support improvements 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;
- Improve protections for beneficiaries whose benefits are paid to representative payees;
- 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 where SSA has failed to notify the beneficiary within a reasonable time period;
- Improve requirements for "disabled adult child" eligibility to eliminate work disincentives;
- 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 laws to provide benefits and services to those individuals who have inappropriately lost them when Temporary Assistance for Needy Families (TANF) was enacted, particularly children affected by SSI eligibility changes;
- Eliminate any marriage penalties that exist in current 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;
- Enact a program allowing SSI beneficiaries to maintain resources dedicated for housing purposes; and
- Ensure that SSI beneficiaries can participate in appropriate Individual Development Accounts without jeopardizing their eligibility for SSI.

## **Temporary Assistance for Needy Families (TANF)**

The Second Session of the 108th Congress should support those changes to TANF that address the unique needs of the many TANF recipients with disabilities and their families who live in poverty. Desired amendments include:

- Appropriate screening and assessment for disability;
- Access to appropriate supports and services;
- Reasonable accommodations as necessary;
- Access to care for families with a child or adult family member with a disability who receive TANF benefits;
- Pre-sanction reviews; and
- Access to transportation and other supports necessary to obtain and retain employment.

## **Transportation**

The Second Session of the 108<sup>th</sup> Congress should:

- Reauthorize the Transportation Equity Act for the 21<sup>st</sup> Century (TEA-21) to address the needs of our constituents, including the consideration of a nationwide database to effect a system of reciprocity among communities so people with disabilities can utilize accessible transportation wherever they may be;
- Increase funding for mass transit (including paratransit) to expand affordable, accessible, and available transportation for people with disabilities; and
- Increase funding for transportation programs to assist people with disabilities to get to work and to fully participate in their communities, such as those programs developed under the New Freedom Initiative.

## **C. ADDITIONAL CRITICAL GOALS**

The following goals, listed alphabetically, represent vital policy elements of importance to the disability community. Some of these goals may be addressed in the Second Session of the 108<sup>th</sup> Congress.

### **Constitutional and Civil Rights**

The Second Session of the 108th Congress should:

- Protect and promote stronger enforcement of existing civil rights laws for people with disabilities, particularly the Americans with Disabilities Act, IDEA, Fair Housing Act, Civil Rights of Institutionalized Persons Act, Title V of the Rehabilitation Act, affirmative action, the National Voter Registration Act ("motor voter"), and the Air Carrier Access Act;
- Restore protections provided by the Americans with Disabilities Act lost due to recent Supreme Court decisions;
- Improve, enforce, and fund federal laws to afford individuals with disabilities the opportunity to vote in any election, including full implementation of the Help America Vote Act;
- Increase the funding for federal government entities that enforce disability rights laws, including the Equal Employment Opportunity Commission and the Departments of Justice, Health and Human Services, Housing and Urban Development, Labor, Education, and Transportation;
- Preserve and enhance all federal programs that support protection and advocacy services for people with disabilities;
- Enact protections, including sanctions against abuse, neglect, and inappropriate use of physical and chemical restraints and seclusion in all settings;
- Assure that legislation dealing with issues such as hate crimes, physician-assisted suicide, and human subjects in research includes protections against abuse and discrimination on the basis of disability; and

- Prevent genetic discrimination on the basis of disability.

## **Criminal Justice**

The Second Session of the 108th Congress should:

- Expand the authority and the funding for the Department of Justice to carry out activities related to criminal justice that affect individuals with disabilities, including those unique to individuals with mental retardation and/or cerebral palsy in the following areas:
  - Training of all personnel in the criminal justice system about issues unique to our constituents, including assessment of disability;
  - Developing data and conducting research, including on victims of crime;
  - Developing and disseminating models of best practices;
  - Enforcing applicable requirements to accommodate people with mental retardation and/or cerebral palsy;
  - Providing appropriate 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 cerebral palsy and/or mental retardation; and
  - Prosecuting individuals and entities that physically, psychologically, or sexually abuse, mistreat, or neglect children and adults with disabilities; and
- Pass hate crimes legislation that includes people with disabilities as a protected class under the definition of hate crimes and provides prosecution assistance to states.

## **Data Collection**

The Second Session of the 108th Congress should:

- Provide funding to improve and expand the collection and publication of population-based and other data regarding people with cerebral palsy and mental retardation, 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 and/or cerebral palsy; and
  - Effective health promotion and primary, secondary, and tertiary disability prevention strategies.

## **Developmental Disabilities**

The Second Session of the 108th Congress should:

- Fully fund the four components of Title I of the Developmental Disabilities Act:
  1. State Grant Program
  2. Protection and Advocacy Systems
  3. University Centers for Excellence in Developmental Disabilities, Education, Research, and Service
  4. Projects of National Significance; and
- 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.

## **Family Support**

The Second Session of the 108th Congress should strengthen the ability of families to maintain typical lifestyles for themselves and their family member(s) with mental retardation, cerebral palsy, and related disabilities and address their unmet needs by:

- Significantly increasing funding and establishing a separate appropriations line item for the Family Support Program authorized under Title II of the Developmental Disabilities Act;
- Protecting and expanding services and circumstances covered by the Family and Medical Leave Act to support children and adults with mental retardation, cerebral palsy, and related disabilities and their families;
- Ensuring that people with mental retardation, cerebral palsy, and related disabilities and their families are part of any family caregiver support programs, including respite care;
- Authorizing competitive grants to states and other entities to make respite care services available and accessible to family caregivers, regardless of age or disability;
- Reauthorizing and increasing funding for the Child Care and Development Block Grant (CCDBG) to provide technical assistance to child care providers so that they are better able to meet the child care needs of children with disabilities; and
- 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.

### **Habilitation**

The Second Session of the 108th 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 Second Session of the 108th Congress should:

- Ensure that non-citizens with mental retardation, cerebral palsy, or related disabilities have a fair opportunity to enter and reside legally in the United States and to become citizens without unnecessary or discriminatory restrictions; and
- Ensure that our constituents who are legal residents have access to essential supports and services, such as SSI, food stamps, and Medicaid.

### **Liability Insurance Protections**

The Second Session of the 108th Congress should:

- Ensure fair compensation to our constituents for the negligence of another person or of 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.

### **Long Term Community Services and Supports for Individuals**

The Second Session of the 108th Congress should explore avenues in addition to the Medicaid program to expand, modernize, and, where appropriate, maintain national policies that provide individual supports that encourage self-determination, self-sufficiency, and personal responsibility among our constituents. Such services and supports must be available to people who need them, including those waiting for services, regardless of age, disability, impairment, and income level. Services should:

- Be consumer-controlled;
- Be of high quality;
- Include personal assistance services;
- Be designed and implemented to meet individual needs;
- Be widely accessible; and

- Be home- and community-based.

## **Prevention**

The Second Session of the 108th Congress should endeavor to increase the prevention of causes of disabilities by:

- Increasing funding for the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention and for other existing federal education and prevention initiatives, including but not limited to:
  - Fetal Alcohol Syndrome;
  - Cerebral palsy;
  - Mental retardation;
  - Autism;
  - Developmental disabilities;
  - Food and drugs;
  - Product safety;
  - Lead poisoning prevention through detection and abatement;
  - Environmental hazards;
  - Transportation safety; and
  - Sexual exploitation and abuse.
- 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; and
- Enacting legislation to limit the advertising of alcohol products to at-risk populations.

## **Research**

The Second Session of the 108th Congress should:

- Significantly expand federal funding of basic and applied research at the Centers for Disease Control and Prevention, National Institutes of Health, and the National Institute of Disability and Rehabilitation Research designed to both improve the quality of life for our constituents and to prevent the causes and effects of mental retardation and cerebral palsy;
- 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; and
- Promote the implementation of accurate research findings that assist people with mental retardation, cerebral palsy, and other developmental disabilities to lead quality lives in the community.

## **Tax Policy**

The Second Session of the 108th Congress should enact tax policies that:

- Protect and enhance services and benefits for people with disabilities;
- Enable people with disabilities to be independent and productive;
- Enable families of people with disabilities to stay intact, independent, and self-sufficient;
- Enable the private sector to provide cost-effective supports for individuals with disabilities and their families;
- Permanently extend the work opportunity tax credit;



- Assure fair eligibility for non-profit groups under any new charitable tax credit or deduction;
- Allow charitable deductions for non-itemizers; and
- Allow a tax credit for individuals (or their families) with long term support needs.

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