



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

Disability Policy Recommendations for Presidential Transition and 111th Congress

November 17, 2008

Message

from the Board

Welcome to the Consortium for Citizens with Disabilities (CCD) Recommendations to the Obama Administration and the 111th Congress regarding critical federal policy for people with disabilities and their families.

CCD is a coalition of national organizations working to improve federal Administrative and legislative policy on behalf of people with disabilities.

This transition document conveys the major issues facing the new Administration and Congress for people with disabilities and their families and CCD's recommended solutions. In addition, the document lists those Administration positions subject to Presidential appointment which are critical to people with disabilities and which should be filled with individuals with a disability perspective.

This document is intended as a resource to policy-makers. We encourage you to use it to understand the policy issues facing people with disabilities and their families. We also encourage you to contact the various Task Forces and Co-Chairpersons listed to learn more about these issues. We are eager to work with the Administration and the Congress to develop solutions to these critical issues.

We look forward to working with you.

Sincerely,



Marty Ford
CCD Chairperson - 2008

Presidential Transition Recommendations

2008

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Consortium for Citizens with Disabilities

The Consortium for Citizens with Disabilities (CCD) is a coalition of over 100 national consumer, advocacy, provider, and professional organizations working together to advocate for federal disability policy that ensures the self determination, independence, empowerment, productivity, integration, and inclusion of children and adults with disabilities in all aspects of society.

Since 1973, CCD has advocated on behalf of people of all ages with physical, mental, and sensory disabilities and their families. CCD is headquartered in Washington, D.C.

CCD works to achieve federal legislation and regulatory policy that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

TASK FORCES

CCD's work addresses a broad range of issues that affect people with disabilities and their families. The vast majority of CCD's work is carried out by Task Forces which focus on specific areas of policy touching the lives of people with disabilities. Task Forces are established and reviewed annually at CCD's annual meeting. Throughout the rest of the year, the Task Forces are the locus of work on policy areas. Task Forces are led by volunteer Co-Chairpersons who work with their colleagues across Task Force lines to ensure consistency. In 2008, CCD has 19 Task Forces. Organization for 2009 will occur at CCD's annual meeting in early January 2009.

The policy areas covered in this document roughly track the agendas of the various Task Forces. Each topical page includes contact information for the 2008 Co-Chairs for the Task Force which has taken the lead on that issue. Additional information can be found on CCD's website (www.c-c-d.org) or by contacting the Co-Chairs.

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Vision

The Consortium for Citizens with Disabilities (CCD) envisions an American society in which all individuals, aided by an enabling government, have the freedom and opportunity to exercise individual decisions concerning their own lives, welfare and personal dignity.

CCD envisions a society in which communities are fully accessible to all individuals with disabilities and their families, where they are included and fully participate in all aspects of community life.

In CCD's vision of society, individuals with disabilities exercise their full rights and responsibilities.

Mission

To achieve this vision the CCD engages in advocacy efforts for national public policy that:

- Ensure the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society
- Enhance the civil rights and quality of life of all people with disabilities and their families
- Reflect the values of the Americans with Disabilities Act

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurologically based developmental disorder. There is no known single cause for ASD, nor do children “outgrow” autism. Overall common symptoms include; 1) poor social interaction 2) impaired verbal and nonverbal communication, and 3) repetitive behaviors or interests. Over the past decade the number of reported cases has dramatically increased from one of every 500 children to current reports by the [Centers for Disease Control and Prevention](#) (CDC) of one of every 150 children. Additionally, autism is four times more likely to affect males than females. Assuming the prevalence rate has been constant over the past two decades and based on 4 million children being born in the United States every year, it is estimated that up to 560,000 individuals between the ages of 0 to 21 have an ASD.

The increasing number of children and adults diagnosed with ASD is a growing and urgent concern for families, service providers, and policy-makers, as the nation’s existing health, education, and social service systems struggle to respond to the needs of this population in a comprehensive manner. Spending on ASD and related developmental disabilities research at the [National Institutes of Health](#), the [Centers for Disease Control and Prevention](#), and the [Health Resources and Services Administration](#) should increase. In particular, continued research is needed to document trends in the growth of ASD, as well as research into and development of effective interventions. In addition, greater commitments are needed to expand access to services such as early identification, diagnosis, early intervention, education, family support, and long-term services and supports to better meet the needs of individuals with ASD and related developmental disabilities. This includes providing additional funding for Part B of the Individuals with Disabilities Education Act (IDEA), Part C Infants and Toddler program and Section 619 Preschool Grants. Moreover, many insurers severely limit or entirely deny benefits for applied behavior analysis and other effective, evidence-based interventions that can better the lives of people with ASD. This discrimination must end.

Families need help in providing for the life needs of children with autism and other disabilities. Congress has provided incentives for college savings through qualified tuition programs (section 529 programs) and Coverdell education savings accounts (section 530 programs). Many children with autism, however, do not attend college. Their life needs are not met by current programs that reward savings for higher education. These children need help in financing the services and supports that will enable them to remain productive and independent members of their communities.

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Autism Spectrum Disorder

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Although a number of effective services and funding options for individuals with ASD exist, they tend to be scattered, fragmented, and poorly coordinated. There are no widely accepted or implemented service guidelines for ASD and significant gaps in knowledge among the professionals serving these individuals. Additionally, there is a lack of trained professionals and providers to appropriately serve children and adults with autism with the latest evidence-based information and effective practices. Furthermore, while early detection and treatment are essential, families of children with autism often face numerous obstacles for obtaining high quality services for their children. Similarly, adults with autism face long waiting lists and many barriers in obtaining appropriate community-based supports and services to enable them to participate fully in society.

Individuals with ASD and their families need access to accurate information about scientifically based interventions. The training of a wide range of interdisciplinary professionals also needs to be a top priority so that the findings coming out of our research institutions can be translated and made available to parents and providers across the country as quickly as possible.

To meet these challenges, the Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Provide full funding for all parts of the Combating Autism Act and significantly increase funding to the NIH, CDC, and HRSA autism research budget over the next four years.
- Provide additional funding for Part C Infants and Toddlers Program and Part B of IDEA to meet the growing needs of children with ASD as early as possible.
- Amend the Employee Retirement Income Security Act of 1974 and the Public Health Service Act to require insurance coverage for ASD interventions.
- Support legislation that will enable people with disabilities and their families to save for life needs on a tax-advantaged basis and without fear of losing existing federal benefits.
- Champion legislation to increase the availability of evidence-based services and interventions for individuals with autism across the lifespan by funding direct service, information dissemination, and interdisciplinary professional training activities.
- Provide funding for a National Autism Family Information and Resource Center to assist families of people with autism find services that are appropriate to their family member.

Asset Development, Tax Policy, and Financial Literacy

The passage of the Americans with Disabilities Act in 1990 established an environment that focused on removing barriers to participation in the workforce and improving access in education, health care, and community experience. However, very little attention has concentrated on public policy barriers to economic freedom. For example, if recipients of Supplemental Security Income (SSI) are encouraged to enter or return to work but are not allowed to maintain control of assets above \$2,000, our nation's public policy is sending conflicting messages. If access to critical health care benefits requires individuals with disabilities to have extremely limited assets, then individuals with disabilities face major public policy barriers to lifting themselves out of poverty.

The challenges to creating financial security for Americans with disabilities are daunting. In 2000, 8.7 million people with disabilities were poor, with 17.6 percent age 5 and older, compared to 10.6 percent for people without disabilities. Nearly 19 percent of people with disabilities between the ages of 16 and 64 live in poverty –nearly double the rate for people without disabilities (9.6 percent)(NCD Report 2008). Thirty-nine percent of people with disabilities say that the lack of financial resources is the most serious problem they face (NOD/Harris Survey 2000). Meanwhile, only 37 percent of adults with significant disabilities are participating in the nation's workforce (National Health Interview Survey, 2000). Even when employed, people with disabilities earn substantially less than their non-disabled peers- roughly 72 percent to the dollar (NCD 1996 Report). Public assistance represents 59 percent of the total income of people with significant disabilities and only 8 percent of the total income of people who have no disability (Harris Survey 2000).

True freedom and full community participation for Americans with disabilities will not be achieved until people with disabilities are able to leverage the power of assets and wealth creation to become financially secure.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Individuals with disabilities and families, regardless of economic status, or type of disability, should have a range of asset choices that benefit their economic fitness.
- Tax- advantaged savings options for people with disabilities (similar to Individual Retirement Accounts or 529 Accounts) must be designed to consider the policy barriers and opportunities of accruing assets for persons participating in means-tested programs.
- New savings and asset vehicles for people with disabilities should be made open to private funding and provide incentives for private donations. More than one option should be part of a comprehensive proposal to benefit a target audience of working-age adults with disabilities as well as families with a member with a disability.

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Asset Development, Tax Policy, and Financial Literacy

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- Eligibility for public benefits like Social Security disability and Supplemental Security Income programs, Food Stamps, Temporary Assistance for Needy Families (TANF), Medicaid, etc, must be unaffected by assets held in and distributions from proposed tax-advantaged savings vehicles for people with disabilities. The purpose of tax-advantaged savings options should be to complement, not supplant, other public benefits.
- New proposals for savings options for people with disabilities should be subject to payback regulations for means-tested government benefits. Currently, a person with a disability may qualify for Medicaid even though that person is the beneficiary of certain kinds of trusts. For purposes of determining whether the person is eligible for Medicaid and sometimes other means-tested government benefits the assets of the trust are disregarded. However, when that person dies, the remaining assets of the trust must be used to repay the government for the cost of Medicaid health care provided to the beneficiary of the trust. The same pay-back policy should apply to new proposals for savings options for people with disabilities.
- There should be an evidence-based rationale to justify the need for any proposed tax-advantaged vehicle for people with disabilities based on studies that document the extra costs incurred by people with disabilities for daily living, health care, transportation, assistive technology, and personal assistance services.
- Education and information about beneficial tax provisions and credits and financial education should be made available and known to people with disabilities and should be easy to use and streamlined for ease of understanding to accommodate persons of all abilities.

Child Abuse Prevention

The U.S. Department of Health and Human Services (HHS) received 3.3 million reports of suspected child abuse and neglect in 2006. The estimated number of substantiated cases of child abuse and neglect investigated by child protective service (CPS) agencies was 905,000. States report that nearly half of the child victims or their families in confirmed cases of child abuse and neglect receive no treatment or any other services following investigation of the report.

Addressing the issue of child abuse and neglect is integral to promoting the well-being of individuals with disabilities and their families, as well as preventing disabilities that occur as a result of abuse and neglect. Indeed, cause and effect are intertwined when it comes to child maltreatment and disabilities. Children with disabilities are particularly vulnerable to child abuse, and child abuse may result in the acquisition or development of disabilities. A 1993 national study found that children with disabilities were 1.7 times more likely to be maltreated than children without disabilities. The studies authors' acknowledge that this finding may underestimate the incidence of abuse among children with disabilities (Crosse, S. B., Kaye, E., & Ratnofsky, A. C., nd) A more recent study, published in 2000, was conducted in Nebraska only, but included more than two times as many children than in the 1993 national study. The study investigators estimated that children with disabilities are 3.76 times more likely to be victims of neglect, 3.79 times more likely to be physically abused, and 3.88 times more likely to experience emotional abuse than children without disabilities (Sullivan & Knutson, 2000).

More recent findings regarding the development of children involved with child welfare who are not in foster care have become available. Using data obtained from the National Survey of Child and Adolescent Well-Being (NSCAW), Stahmer and others (2005) found high rates of developmental and behavioral problems among young children who had been investigated for maltreatment. Also using NSCAW, Rosenberg, Smith, and Levinson (2007) found 47 percent of children who had been substantiated for maltreatment and were younger than 3 years of age had developmental delays that made them likely to be eligible for Part C early intervention.

In 2006, HHS reports that child victims who were identified as having a disability were 52 percent more likely to experience recurrence than children without a disability (Nearly 8 percent of victims -- 7.7 percent -- had a reported disability).

Identification and treatment of the medical, developmental and mental health problems of children have been shown to decrease the amount of time a child spends in out of home placement and increase chances for a stable living situation. Unfortunately, because of inadequate funding, less than half of the children who are abused or neglected receive any services at all; and current public policies focus on treating children after they have been abused, instead of preventing the abuse from ever happening in the first place.

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Additional Resources:

[Child Maltreatment 2006](#)

[CCD Preliminary
Recommendations for
CAPTA Reauthorization](#)

Child Abuse Prevention

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The Child Abuse Prevention and Treatment Act (CAPTA) is the only federal program that provides primary prevention for these families, and specifically mandates the involvement and consideration of the special needs of families of children with disabilities and parents with disabilities in preventing child abuse and neglect. It was reauthorized in 2003 as the Keeping Children Safe Act of 2003 (PL 108-36). The amended law contains several improvements for children who are maltreated to be referred for health and developmental screening and early intervention services. However, more improvements are needed to ensure that these children get the services they need to thrive.

Congress plans to reauthorize the Child Abuse Prevention and Treatment Act (CAPTA) in the 111th Congress. The CCD Child Abuse Task Force is working with the National Child Abuse Coalition on recommendations that would put more emphasis on primary prevention of abuse and neglect. Prevention services such as respite and crisis nurseries are especially important to prevent abuse and neglect among children with disabilities, as well as for parents with disabilities.

Federal funding to help states and communities protect children and prevent child abuse and neglect has been woefully inadequate. Current appropriations for child abuse and neglect are only at half the authorized amounts. In fiscal 2008, basic state grants are funded at \$27 million, discretionary grants at \$33.7 million, and community-based grants at \$37 million. These levels of funding demonstrate a complete disregard for prevention, when compared to billions of dollars spent on foster care and institutionalization at the far end of the child welfare services continuum.

In addition, the breadth of the problem requires a more comprehensive and coordinated approach. We support the recommendations of the National Child Abuse Coalition to expand the responsibilities of a broad range of federal agencies, which each have a role in protecting children and preventing child maltreatment. More often than not, the same children appear for services across systems, including child welfare, juvenile justice, mental health, education, public health or developmental disabilities, to cite a few.

According to the National Child Abuse Coalition, “every federal agency should be charged with examining the relationship of its mission to the abuse and neglect of children, identifying the appropriate role each agency should play in this important undertaking, and targeting programs and policies with a role in protecting children and preventing child maltreatment. Agency leaders should examine the current system of care for children and how that relates to the points at which families touch the various systems their agencies support.”

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Support the CCD’s recommendations for the reauthorization of the Child Abuse Prevention and Treatment Act.
- Increase funding for CAPTA programs at least to their authorization levels.
- Significantly increase appropriations for Part C of the Individuals with Disabilities Education Act (IDEA) so that more eligible children can be served under the program.

Developmental Disabilities Act Programs

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental law supporting states to enhance the lives of people with developmental disabilities and their families. Originally authorized in 1963 as the Mental Retardation Construction Act and last reauthorized in 2000 (PL 106-442), the DD Act focuses on the needs of some of our most vulnerable citizens, the approximately 4.5 million people with developmental disabilities. The purpose of the Act is to help individuals with developmental disabilities achieve *independence, productivity, integration and inclusion* into the community. Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22, that result in substantial limitations in three or more areas of major life activities.

For more than 40 years, the programs of the DD Act have helped to build and positively change the services system, train professionals, perform research, and provide essential services that have vastly improved the lives of people with disabilities and their families.

The Act funds five main programs: State Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities, Projects of National Significance, and the Family Support Program.

State Councils on Developmental Disabilities: In 1970, Congress established and authorized funding for State Developmental Disabilities Councils (DD Councils) in each state and territory. A key mission of DD Councils is to conduct comprehensive analyses of services and supports for individuals with developmental disabilities and advise Governors and State agencies on the use of available and potential resources to meet the needs of individuals with developmental disabilities. DD Councils also engage in advocacy, build capacity and work to enhance systems to contribute to a coordinated, consumer-directed and family-centered array of community services, individualized supports, and other forms of assistance. The goals are increased independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities.

Protection and Advocacy Programs (P&A):

Under the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program created by the DD Act of 1975, P&A systems are empowered to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities. Collectively, the P&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. The original goal of PADD was to ensure that children and adults with disabilities, who lived in institutional settings, were free from abuse and neglect. As disability policy moved from institutions to the community, PADD's mandate expanded.

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Additional Resources: [Developmental Disabilities Act](#)

Developmental Disabilities Act Programs

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Most people are living in the community and PADD efforts emphasize supports and services that make community living a long-term reality: access to education, health care, family supports, housing, employment, transportation, and the right of every person to be safe.

University Centers of Excellence in Developmental Disabilities (UCEDD): Authorized in 1963, there are now 67 UCEDDs, with at least one in every state and territory to provide research, education, and services in the area of developmental disabilities. UCEDDs deliver high quality education and interdisciplinary training to university students at all levels, practicing professionals, direct care providers, individuals and families, and policymakers. UCEDDs engage in cutting-edge research, evaluation, and analysis in areas of importance to the field of disabilities. UCEDDs are committed to communicating and sharing information and research findings to the communities they serve. Located in a university setting, these Centers are in a unique position to facilitate the flow of disability-related information between university and community.

Family Support: The family support program provides grants authorized under the DD Act to help states provide practical, low cost supports and services to families supporting members with disabilities. Family support programs have proven to be both cost-effective and family-friendly in providing practical assistance to families. Without this support, many people caring for family members with disabilities must resort to out of the home placements which are often inappropriate and more expensive.

Projects of National Significance (PNS): PNS are projects that are of national significance funded to collect necessary longitudinal data, provide technical assistance to State DD Councils, P&As, and UCEDDs, and support unique promising projects likely to substantially contribute to the independence, productivity, and integration and inclusion of persons with developmental disabilities into the community.

The DD Act is expected to be reauthorized in 2009 (its authorization ended in 2007).

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Work toward timely reauthorization of the DD Act;
- Provide increased funding to allow the DD Network to meet the critical and emerging needs of people with disabilities;
- Reaffirm the commitment to support people with disabilities in the community;
- Support the inclusion of a separate title, authorization level and funding for self-advocate-directed training and information centers; and
- Oppose legislation that would weaken the ability of protection and advocacy systems to protect the rights of individuals with developmental disabilities through class action litigation.

Education

Public education for all is a cornerstone of our democracy. It is the mechanism by which this nation prepares all students to pursue the benefits of freedom and to exercise fully their rights and responsibilities as citizens.

Since 1975, federal law has guaranteed the rights of all children with disabilities to a free, appropriate public education with individualized services that are designed to meet each child's unique needs. The Individuals with Disabilities Education Act (IDEA) was clarified in 1997 to build on the promise of its 1975 base by requiring that children with disabilities not only have the right to attend public schools but they also have the right to be taught the same curriculum as their non-disabled peers and an expectation of higher academic progress. Finally, with the enactment of the 2002 amendments to the Elementary and Secondary Education Act, also known as the No Child Left Behind Act (NCLB), further alignment between the special education and general education laws ensures that students with disabilities now have their academic achievement measured and reported as part of the "all student" group as well as a subgroup of students with disabilities. In addition, the assessment of academic achievement for students with disabilities is aligned with the State content standards for all students.

The nation's six million children with disabilities who currently receive special education services represent roughly 13 percent of the total public elementary and secondary school populations. More than 700,000 preschoolers receive special education services and 300,000 infants and toddlers with disabilities receive IDEA's early intervention services.

Despite the significant gains in public policy, academic outcomes for students with disabilities remain unacceptably low. One out of every three special education students drops out of high school and only 53 percent graduate with a regular high school diploma. Students with disabilities are also less likely to participate in post-secondary educational opportunities than their non-disabled peers. When they do participate, many are unable to get the services, supports and accommodations that they need to succeed. Approximately ten percent of people with disabilities graduate from college.

Funding for all of IDEA programs must be significantly increased.

Over the past 15 years, the number of young children receiving early intervention services has grown by 70 percent and funding has not even stayed current with inflation. Nearly 20 percent of these children reach their developmental milestones by age three and thus do not need additional special education services. These data demonstrate that an investment in early intervention could result in a decline in the number of elementary school students who need special education services. In addition, since 1993, the number of preschoolers receiving special education services has increased by 40 percent, with funding not even staying current with inflation.

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Additional Resources:

[CCD Principles for the
reauthorization of No Child
Left Behind](#)

[IDEA User's Guide\(pdf\)](#)

Education

Continued ...

High quality general and special education teachers must have both the skills and knowledge necessary for teaching academic content and the skills and knowledge necessary for teaching diverse learners. A significant portion of students with disabilities are being taught by unqualified teachers and receiving support from unqualified specialized instructional support personnel. Investments in this area could directly increase the number of students with disabilities who graduate with a standard high school diploma and decrease the number of students who drop out of high school.

Research-based instructional strategies must be the basis for educational services. Dissemination of research-based best practices to families and service providers must continue to be a high priority. An ongoing federal commitment to educational research and translation to practice will ensure the most effective and appropriate education for all students. With more children with disabilities, including those with special health care needs and behavioral issues, being served in the general education classrooms, more research and training should be directed toward interdisciplinary efforts involving educators working together with professionals from other disciplines. Consideration should also be given to research and dissemination of findings related to the needs of children with complex needs and severe disabilities.

The promise from Congress to fund 40 percent of the average per-pupil expenditure to defray the costs associated with educating students with disabilities is now entering its 4th decade. With state and local governments suffering through severe economic crisis, the Federal Government is fulfilling less than half of its fiscal promise to schools, students and their families. This funding gap must be closed.

CCD encourages the new Administration to develop education policy on two central principles: all children should be provided a quality public education that promotes academic success AND all students with disabilities are general education students first.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Strengthen our nation's educational infrastructure through the following initiatives.
 - Increase funding for all IDEA programs within IDEA, including early intervention and preschool programs.
 - Increase funding for teacher professional development, including for the preparation and retention of special education teachers, specialized instructional support personnel, and higher education faculty.
 - Index Part D funding at a level that makes Part D ten percent of Part B to ensure that research, training and dissemination resources keep pace with direct service efforts.
 - Increase the investment in higher education for students with disabilities by funding the new programs authorized in the Higher Education Opportunity Act.

Education

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- Expand and enhance the commitment to effective monitoring and enforcement of the Individuals with Disabilities Education Act, the Americans with Disabilities Act, the Elementary and Secondary Education Act, and Section 504 of the Rehabilitation Act through monitoring that focuses on improving child outcomes.
- Promulgate regulations to implement Part C of IDEA.
- Continue to measure and report the academic progress of all students with disabilities.
- Continue to require states to develop a variety of universally-designed assessments to appropriately and accurately measure the progress of students with disabilities.
- Provide guidance to states to assist schools in the implementation of evidence-based best practices, including positive behavior supports.
- Provide guidance to states to enhance the availability of effective transition services for all students with disabilities.
- Provide guidance to states to assist colleges and universities to support students with disabilities and to revise policies at institutions of higher education that currently have the effect of excluding students with disabilities, including those with mental health needs.
- Champion legislation to require expert witness fees to be treated in the same manner as attorneys fees under IDEA.

Emergency Management

People with disabilities constitute the largest minority group in America, 19.3 percent of the 257.2 million people (U.S. Census Bureau), yet they remain disproportionately marginalized and endangered in emergency events and disasters. It has been well documented that many people with disabilities and activity limitations continue to lose their independence -- or their lives --because people with disabilities are not adequately included in emergency planning, response or recovery and the impact of disasters on this population already at risk can be catastrophic. The lessons learned and documented over the last 30 years regarding the inclusion of this population in emergency planning are not yet uniformly applied at all levels of emergency management.

Emergency management initiatives from local to national levels remain uncoordinated, and planners and responders repeatedly fail to adequately consider the preparedness, evacuation, sheltering, response and recovery needs and contributions of people with disabilities. Federally-funded research has shown that people with disabilities have little input into disaster planning (White et al. 2004). Emergency plans must be developed that take into consideration the needs of people with disabilities. "Only 39 percent of people surveyed had an emergency plan in place for evacuating their home in the event of an emergency (National Organization on Disability 2002b)." Even if there have been significant advances since these studies, anecdotal evidence after recent wildfires, floods and hurricanes all indicate that there is much to do.

Inclusion of people with disabilities in each phase of emergency management is vital and this must be mandated at all community levels. Investing in preparation for those who need the most assistance in a catastrophic event will decrease disproportionate service usage among people with disabilities who also have manageable health and functional needs during and after a disaster. In times of disruption of civic infrastructure, individuals with disabilities and their families may experience a loss of the very medical, community living, or other support services on which they rely for daily functioning under the circumstances. Therefore, planning for the contingency and resumption of vital services is one piece in this complex picture.

Most disaster response systems are designed for people who can walk, run, see, drive, read, hear, speak and quickly understand and respond to instructions and alerts. A better way to think about the needs of people with disabilities and activity limitations is to use an orientation that considers major functional needs: communication, medical, maintaining functional independence, supervision, and transportation. Using a framework built on an essential functional based orientation addresses the needs of more people, more efficiently and effectively.

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Emergency Management

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Narrow definitions of disability do not work in disaster planning and response because there are large segments of the population that have functional needs. Separate “special needs population” planning is not effective. Segregating and isolating the needs of significant numbers of the population is inefficient with regard to budgeting, procurement and resource allocation. Planning is not a two stage process comprised of “the critical plan” and then “the special plan.” Separate planning often means the planning is never done. If the value that everyone should be included is not infused into planning, then not everyone will be included.

State and local governments must comply with Title II of the ADA in the emergency- and disaster-related programs, services, and activities they provide. This requirement applies to programs, services, and activities provided directly by state and local governments as well as those provided through third parties, such as the American Red Cross, private nonprofit organizations, and religious entities. Despite clear guidance from the Department of Justice, implementation and enforcement of civil rights laws are still haphazard and inconsistent by state and local jurisdictions. "To date, DHS has not initiated funding terminations to enforce Section 504 against grantees that violate the law. NCD believes that stronger efforts should be devoted to clearly communicating to grantees that their funds can be withheld if they violate Section 504 or ADA."

It is vital too that all levels of action in emergency management understand that disability is a natural state which exists for every demographic and region of the country and that the most vulnerable members of our society—low income families, seniors and people who are homeless—are in double jeopardy in times of emergency due to preexisting conditions or disabilities acquired as a result of a catastrophic event.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Establish an Office on Disability in Federal Emergency Management Agency (FEMA) and provide adequate authority and resources for the role of Disability Coordinator to fulfill the expectations expressed in the Stafford Act to meet needs before, during, and after emergencies and disasters.
- Establish expert teams to address specific disability supports following the current National Disaster Medical System or Medical Reserve model.
- Foster coordination between federal, state and local governments, as well as contractors, in planning for and responding to disasters inclusively for people with disabilities.
- Enforce Federal civil rights laws and terminate federal funding if there is a violation.
- Enforce laws that better enable people who are deaf or hard of hearing to understand emergency information.
- Include disability and independent living experts in disaster case management services.
- Provide the resources needed by community service agencies in both preparing for and during times of emergency so they are not using their already limited resources to prepare for and recover from catastrophe.

Employment and Training

Disability can happen to any one at any time of life. In 2005, an estimated 38 percent of working-age men and women with a disability were employed. Meanwhile, the workforce participation rate of similar populations without disabilities is almost 80 percent.¹ By any definition, this vast disparity [38% vs. 80%] should be recognized as a crisis when this country faces an impending worker shortage and millions of Americans with disabilities are excluded from the labor market.

CCD offers the following recommendations to draw attention to the broad array of steps that should be taken to minimize employment barriers and reduce dependence on federal income support programs for people with disabilities.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- **Support and enforce the Americans with Disabilities Act (ADA)** - Proper compliance and enforcement of the ADA is critical for people with disabilities to gain meaningful employment and career opportunities.
- **Educate, encourage, and assist employers to hire people with disabilities** - Workforce intermediary organizations with expertise in disability, including community-based nonprofits as well as organizations like the US Business Leadership Network and Job Accommodation Network, offer resources valuable to employers who want to hire people with disabilities. Tax incentives, aggressive public awareness campaigns, and a White House Conference on Employment of People with Disabilities can draw employer attention to this underutilized workforce.
- **The federal government should be the "gold standard" in employment of people with disabilities** - Federal agencies should be held accountable for using existing hiring authorities to improve the employment of people with disabilities. In addition, the President should ensure that his Cabinet reflects a commitment to full participation by people with disabilities in the operation of government beyond those "traditional" disability-related offices.
- **Ensure that education and training systems respond to the post-secondary needs of youth with disabilities** - Post-school outcomes for youth with disabilities can be significantly improved when young adults are exposed to a comprehensive array of transition services and planning. Some examples include school-based preparatory classes and activities, career preparation and work-based learning experiences, leadership activities, connections to community resources, college preparation information, and family involvement and supports.

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Additional Resources:

[CCD Employment and Training Task Force: Statement of Principles on Employment of People with Disabilities](#)

¹ <http://www.ilr.cornell.edu/edi/disabilitystatistics/issues.cfm#Unemployment>

Employment and Training

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- **Reauthorize and strengthen the Workforce Investment Act and Rehabilitation Act to ensure the workforce development and vocational rehabilitation systems work for people with disabilities** - Ensuring physical and programmatic access to all Workforce Investment Act (WIA) One Stop Career Centers is essential along with development of performance standards that recognize the differences in various populations served. Technical assistance for customized, supported employment must be provided in order to promote employment opportunities for people with the most severe disabilities. Employment of people with disabilities should become the top priority for the Department of Labor's Employment and Training Administration and better coordination of and support for federal agencies and programs responsible for disability employment are desperately needed. To ensure adequate resources for all those seeking Title I services, double the state vocational rehabilitation program budget over five years and amend the Rehabilitation Act to replace the generic Consumer Price Index with a "Vocational Rehabilitation CPI" that reflects the true costs of providing VR services."
- **Promote opportunities in self-employment and entrepreneurship for people with disabilities** - A comprehensive data gathering strategy is needed to document the extent to which entrepreneurs with disabilities already operate in the national economy and the challenges they face. Existing program definitions to promote small business should be broadened to include entrepreneurs with disabilities. Improvements can be made in state vocational rehabilitation programs to support self-employment. Public-private partnerships can assist people with disabilities in developing business plans and locating capital and other resources.
- **Improve access to health care that supports employment of people with disabilities** - Comprehensive health system reform that takes into account the needs of people with disabilities would alleviate many of the problems with today's health policy affecting people with disabilities. In the absence of comprehensive reform, certain steps could be taken to address specific issues such as elimination of the Medicare "homebound" rule that restricts many people who use wheelchairs to their homes; enhanced opportunities for working people with disabilities to obtain health care through Medicaid buy-ins; tax incentives to assist people with disabilities in purchasing health coverage; and reform of long term health care policies that adversely affect workers with disabilities.
- **Remove systemic barriers to employment for people with disabilities who rely on Social Security disability benefits** - CCD has written extensively on the multi-faceted approaches needed to modernize Social Security disability and Supplemental Security Income programs so that beneficiaries have greater opportunities to return to work. For details, see CCD's paper - Statement of Principles: Social Security Disability Program Work Incentives and Related Issues at http://www.c-c-d.org/task_forces/social_sec/CCD-Principles-and-Recom-29-08.pdf.
- **Remove systemic barriers to employment for veterans with disabilities** - Improvements need to be made in the VA Vocational Rehabilitation and Education program that serves veterans with service-connected disabilities. Collaboration between the VA and state vocational rehabilitation programs that serve all veterans with significant disabilities must be supported and encouraged. Non-VA federal programs that serve veterans with disabilities must have adequate funding to support them without having to deny services to other individuals with disabilities. Existing federal programs designed to assist veteran entrepreneurs with disabilities need to be monitored and enforced. The VA pension "cash cliff" should be eliminated by phasing out pension benefits as earned income rises.

Fiscal Policy

Federal fiscal policy is critical to ensure adequate resources to support programs that promote the independence and productivity of children and adults with disabilities in the United States. Unfortunately, federal resources for these critical programs have been eroding over the past eight years. In Fiscal Year 2009, the appropriations bill that provides funding for most programs that impact people with disabilities, the Labor, Health and Human Services and Education appropriations bill, has not yet been enacted, preventing any increases to existing programs or funding for new programs. The result of this lack of investment is that more, not fewer, children are deprived of all of the best in a free, appropriate public education. More, not fewer, people with disabilities find it hard to get and keep gainful employment. More, not fewer, families are financially devastated by the lack of assistance with excessive health care expenses for their family member with a disability. And more, not fewer communities are diminished by the lack of inclusion of and participation from some of their most valuable citizens, those with disabilities.

CCD supports working toward a strong economy. This can be accomplished 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.

Reductions in entitlement spending threaten the health care and quality of life for people with disabilities. 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. Certain changes to our Social Security system also could have a devastating impact on beneficiaries and on human services funding.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Address the significant unmet needs of people with disabilities and their families by increasing existing federal funding and expanding the federal government's investment in people with disabilities to enable them to live and work as independently as possible in the community with appropriate flexible long term individual and family supports;
- Ensure that eligibility for services and benefits is not restricted and that the level of services and benefits for entitlement programs is not reduced or limited in order to achieve a balanced budget;

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Fiscal Policy

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- Remove the Social Security Administration's administrative budget from any budget cap requirements for the Departments of Labor, Health and Human Services, and Education;
- 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;
- 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; and
- Assure the continuing ability of non-governmental entities to support people with disabilities and their families.

Health

Americans with disabilities and chronic health conditions have diverse, complex health care needs that make access to appropriate, adequate, and affordable health care imperative to their ability to lead productive lives.

Because individuals with disabilities represent some of the most vulnerable populations and intricate medical conditions, they can provide a “litmus” test for health care reform; that is, if a new health care system provides for the needs of the population CCD represents, then certainly the changed system will also encompass the needs of individuals without complex health conditions.

Medicaid, Medicare, and SCHIP can all be improved to better serve individuals with disabilities. In the Medicaid program, waivers and certain state plan amendments often make significant programmatic changes in state Medicaid programs, which have serious consequences for Medicaid beneficiaries, especially people with disabilities. Often these programmatic changes are made without transparency, oversight or public involvement or input.

The Centers for Medicare and Medicaid Services’ (CMS) inaugural report, issued in October 2008, calls for lawmakers to take steps to slow Medicaid’s growth. However, since Medicaid is the primary program that serves individuals with disabilities and complex health conditions, regulatory and legislative cuts to the program disproportionately hurt these populations. In addition, Medicaid beneficiaries’ ability to access needed health care is further jeopardized by the current economic downturn.

The State Children’s Health Insurance Program (SCHIP) was funded from 1998 to 2007. Since then, the program has been reauthorized by Congress, with a current expiration date of March 31, 2009. If the SCHIP program is allowed to expire, millions of low income children, including low income children with disabilities, will become uninsured. Currently, many eligible children are not enrolled in the program because SCHIP allows states to deny coverage to fully eligible children and places caps on each state’s federal funding based on statutory formulas and administrative policies.

Fifteen percent of Medicare beneficiaries are non-elderly people with disabilities. Although Medicare contains many attractive elements (e.g. the ability of the beneficiary to choose their own doctor), the program has many limitations, including the two-year waiting period for eligibility, the restrictive “in-the-home” rule, and lack of coverage for technologies such as hearing aids and other devices that would increase safety and independence.

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Health

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The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Require CMS make the federal and state waiver approval processes transparent and accessible to the public. These new procedures should apply to waivers authorized under both section 1115 and section 1915(c) and to state plan amendments authorized under sections 1937 and 1915(i). In addition, the new administration should ensure that section 1115 waivers, which are intended to be demonstration projects, are properly evaluated;
- Rescind the outpatient regulation along with the other six with moratoria that expire in April and oppose legislative and/or regulatory changes to Medicaid that result in cuts to the program;
- Enact a temporary increase to the federal share of Medicaid spending to counteract states' fiscal crises;
- Extend and expand the State Children's Health Insurance Program (SCHIP) beyond the current authorization ending March 31, 2009 to guarantee coverage for all eligible children;
- Ensure access to appropriate health care for at-risk and low-income children by expanding SCHIP to include dental and mental health benefits, ensuring better long term health;
- Eliminate the two year waiting period for Medicare eligibility for SSDI beneficiaries;
- Eliminate unnecessarily burdensome restrictions on care such as the "in the home" restriction on mobility devices;
- Implement portable electronic health records with appropriate patient privacy provisions; and
- Create a permanent solution to the Medicare Outpatient Therapy Caps Rule.

Housing

Everyone wants to be part of their community life. This goal is shared by people with disabilities, their families and advocates. A home of one's own – either rented or owned – is the cornerstone of independence for most individuals, including people with disabilities. However, across the nation, people with disabilities historically have faced a severe crisis in the availability of decent, safe, affordable, and accessible housing. Today many still live in large congregate facilities or other inappropriate places like institutions or nursing homes. 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.

The ever-worsening fiscal crisis that our nation currently is facing -- due to lack of oversight in the housing market -- is having an impact on millions of Americans, who now face the loss of housing. The impact of this situation on people with disabilities, who have faced a historical affordability gap, is even more frightening.

According to *Priced Out* in 2006, the four million Americans with disabilities who rely on monthly Supplemental Security Income (SSI) of \$632 for all their basic needs would be required to pay up to 113% of their entire monthly income if they wanted to rent a modest one-bedroom unit – an obviously impossible situation. When the CCD Housing Task Force developed its “transition recommendations” in 2000, it took 98% of an SSI payment to rent a modest one-bedroom apartment. It is obvious that over the past eight years, an already impossible situation has worsened considerably.

It is not only affordability that keeps people with disabilities from finding housing in the community. Other major problems include the ongoing construction of housing that does not comply with the accessibility requirements of the Fair Housing Amendments Act or other critical civil rights laws. Another issue related to ineffective implementation of fair housing laws is the continuing unavailability of reasonable accommodations. An additional overarching problem has been the loss of public and federally-assisted housing due to elderly-only designation – a policy which was implemented based on one more problem consistently faced by people with disabilities – stigma and discrimination.

All of these issues come together as a perfect storm to stymie the efforts of people with disabilities to live as independently as possible in the community and also thwart nationwide efforts to close down totally inappropriate institutions and allow people to live where they want to -- and where they should live – in their home communities.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Support effective HUD and DOJ implementation and vigorous enforcement of all fair housing and civil rights laws. This includes the Fair Housing Amendments Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act. Issues of importance include basic non-discrimination, accessibility, and reasonable accommodations, and well as at intervening/filing amicus briefs when necessary to ensure fair housing rights. The current administration's failure to intervene in important cases hindered the intent and enforcement of these laws.

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Additional Resources:

[Opening Doors Housing
Initiative for the Disability
Community](#)

[Priced Out in 2006](#)

Housing

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- Promote effective and accurate gathering and dissemination of data on the housing needs of individuals with disabilities. This includes requiring states, communities, public housing agencies (PHAs), and tax-credit developers to document the needs of individuals with disabilities in the filing of applications for federal housing funds and in their reports to HUD.
 - Support immediate release of the \$30 million for incremental Section 8 vouchers for non-elderly people with disabilities that Congress appropriated for FY 2008 and for which HUD has yet to issue a Notice of Funding Availability.
 - Ensure full and effective implementation of the Affordable Housing Trust Fund as authorized in the Housing and Economic Recovery Act of 2008 (P.L. 110-289). The new Administration must ensure that the conservator overseeing Fannie Mae and Freddie Mac certifies that contributions from government sponsored enterprises (GSEs) to the new Trust Fund move forward in 2010 and beyond.
 - Support continuation of the HUD Disability Task Force. The current Task Force, which has been chaired by the Assistant Secretary for Fair Housing and Equal Opportunity, has brought together key HUD staff and disability advocates and has been effective.
 - Support immediate enactment of the Frank Melville Supportive Housing Investment Act. This bill passed the House in September 2008 and is critical to the reform of the Section 811 Supportive Housing for Persons with Disabilities program.
 - Support immediate enactment of the McKinney-Vento Homeless Assistance Act with a continued emphasis on the development of permanent housing for individuals with disabilities experiencing chronic homelessness.
 - Oppose expansion of the McKinney-Vento definition of homelessness to the Department of Education's definition.
 - Support increased funding for Section 8 Vouchers targeted to non-elderly individuals, and increased funding for the Section 811 and McKinney-Vento programs.
 - Support development of affordable housing for those with the lowest incomes through the Affordable Housing Trust Fund. This program cannot be allowed to flounder due to the current housing crisis.
 - Support inclusion of people with disabilities in all housing assistance programs related to the current housing and fiscal crisis.
 - Monitor and insist on accountability for HUD and DOJ actions related to the implementation of fair housing requirements; the effectiveness of housing programs administered through HUD, the Department of Agriculture, and the Department of Veterans Affairs, in addressing the needs of individuals with disabilities; and HUD's management of housing voucher programs designed to address the needs of people with disabilities. A specific focus should be on HUD's misallocation of disability-specific vouchers to individuals without disabilities contrary to Congressional intent.

International

Through adoption of the Americans with Disabilities Act (ADA), the United States is a recognized leader in establishing the rights of individuals with disabilities in domestic law. U.S. policy concerning individuals with disabilities beyond U.S. borders, however, has failed to match our domestic record.

U.S. foreign policy does not reflect leadership involving the new International Convention on the Rights of Persons with Disabilities (CRPD). In December 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations General Assembly. The Convention entered into legal force in May 2008. As of October 6, 2008, 41 nations have ratified, and 137 nations have signed this newest human rights treaty. The U.S. has not signed the Convention, and is not at the table with current parties to the CRPD who have begun establishing a Committee on the Rights of Persons with Disabilities.

Though the Bush administration provided technical assistance in the drafting of the CRPD, it announced that such assistance was offered “not with the expectation that [the United States] will become party to any resulting legal instrument.” The administration further indicated that any international convention would not necessarily be helpful to other countries, asserting that the rights of people with disabilities were a “largely domestic mission.”

In May 2008, the U.S. National Council on Disability (NCD) issued a report comparing the CRPD requirements with current U.S. law, concluding that “as a general matter, the aims of the CRPD are consistent with U.S. disability law.” The report went on to find that “for the majority of articles, U.S. law can be viewed as either being of a level with the mandates of the Convention or capable of reaching those levels either through more rigorous implementation and/or additional actions by Congress.”

Further, the United States does not assure proper implementation of disability policies in U.S. foreign assistance programs, and does not maintain a Foreign Service work environment for Americans with disabilities free from discrimination. In 1996, NCD issued a report critical of U.S. foreign policy in regards to disability which stated that:

Those responsible for creating and implementing U.S. overseas policies and programs generally lack awareness of disability issues, cannot articulate our national policies with respect to people with disabilities, do not incorporate the interests of people with disabilities into U.S. foreign policy objectives, and do not see the importance of U.S. disability advances and achievements for people with disabilities in other countries.

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*National Council on
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Analysis of Disability Laws in
the United States to the
Convention on the Rights of
Persons with Disabilities](#)*

*National Council on
Disabilities, [Foreign Policy
and Disability](#)*

[U.N. Enable](#)

International

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In June 2004, an Advisory Committee on Persons with Disabilities was established to advise “the Secretary of State and the Administrator of the Agency for International Development [USAID]. . . with respect to the consideration of the interests of persons with disabilities in the formulation and implementation of U.S. foreign policy and foreign assistance.” The State Department now includes a section on disability rights in the annual *Country Reports on Human Rights Practices*, and in 2004 and 2005, USAID created policy directives which mandate the use of accessibility standards in all USAID-financed construction or reconstruction efforts, and requires contracting and agreement officers to include a provision supporting USAID’s disability policy in all solicitations for, and awards of contracts, grants, and cooperative agreements.

Despite these efforts, however, there has been little real progress on integrating disability issues into U.S. foreign policy.

- The implementation of USAID policy directives have been primarily based on individuals’ interest rather than enforced by an institutional commitment.
- Older U.S. Embassies are not accessible to individuals with disabilities.
- The Foreign Service Act of 1981 allows the State Department to exclude or limit participation of Foreign Service applicants who may have certain medical conditions resulting in discrimination for individuals with disabilities who are qualified for these positions.
- Limited funding is available to support disability organizations and other non-government organizations in other nations to report on and protect the rights of individuals with disabilities.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Sign the International Convention on the Rights of Persons with Disabilities (CRPD) with the eventual expectation of submitting to the Senate for ratification. Ensure that all US foreign assistance adheres to accepted accessibility standards and does not discriminate against persons with disabilities. Such a change could be accomplished through an Executive Order.
- Revise and strengthen internal USAID and State Department policies, contracting and procurement including personnel policies to ensure they comply with Sections 501, 503, 504, and 508 of the Rehabilitation Act of 1973, as amended.
- Propose an amendment to the Foreign Service Act of 1981 that ends discrimination against job applicants with disabilities consistent with the requirements of Section 501 the Rehabilitation Act of 1973, as amended.

Long Term Services & Supports

Long-term services and supports encompass a broad range of assistance with everyday activities, such as assistance and supervision with dressing, bathing, using the bathroom, preparing meals, taking medication, managing a home, and managing money. An estimated 10 million Americans currently have needs for long-term services. As the U.S. population ages and expands, the number of individuals needing long-term services is projected to increase to 26 million by 2050. However, the nation lacks a comprehensive, proactive national public-private system for delivering long-term services and supports.

Over 85% of all long-term services are delivered informally. However, programs that provide respite and other key supports for families and other unpaid caregivers are underfunded. Only 3% of adults have long-term care insurance. Private insurance plans are unaffordable for many Americans and unavailable to most individuals with disabilities due to underwriting practices. Nearly half of all funding for long-term services is provided through Medicaid, which requires individuals to be impoverished to receive supports. There is an institutional bias in Medicaid where approximately two-thirds of all spending for long-term services is directed towards nursing homes and other institutions instead of community-based services. Hundreds of thousands of individuals with disabilities and their families are on waiting lists for Medicaid Home and Community Based Services (HCBS). Moreover, the direct support professional workforce needs to be strengthened to enhance its performance. There is a crisis in the availability of professionals to provide these direct supports, which often contributes to continuous turnover and jeopardizes the health, safety, and ability of individuals with disabilities to be active members of society.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- 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 people with disabilities and avoid the need for people to impoverish themselves to qualify for services. 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.

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Long Term Services & Supports

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- Amend Medicaid to mandate state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals.
 - 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.
 - Support legislation to amend the Medicaid program to provide funds to states to enable them to increase the wages paid to targeted direct support professionals providing services and supports to individuals with disabilities.
 - Support legislation to make the following improvements to the Medicaid 1915(i) Home and Community Based state plan option:
 - Remove the authority for states to cap services, limit services to certain sections of the state, and maintain waiting lists;
 - Allow states to provide the full range of services that can currently be provided under the HCBS waiver (including other services approved by the Secretary); and
 - Remove the limit on coverage of people with incomes up to 150 percent of poverty and allow the full range of income eligibility allowed for people in facility-based settings.
 - Fully fund programs that provide community-based supports to caregivers and families of individuals with disabilities, such as the Lifespan Respite Care Act, National Family Caregiver Support Program, and the Family Support Program (Title II of the Developmental Disabilities Act).

Prevention

There are over 50 million people in America with disabilities. Approximately two thirds of individuals with disabilities acquired a disability after the age of 20 years. The acquisition of many disabilities can be prevented. In the formative years of development, disability can be prevented by state of the art pre- and post-natal procedures and through effective education, child development practices, and rehabilitation. In adult life, health diminishes and can result in a host of chronic conditions that may result in disability. By the age of 75, over 50 percent of elderly persons have a disability. Diminished health over the life span that may lead to disability through physical and mental impairments can result in significant functional limitations that impede full participation in society.

The primary function of public health is to promote and protect health so it does not diminish and result in disability. Thus, effective public health policy is a powerful force to prevent the acquisition of disability.

Public health policies should focus on promoting health. This includes addressing:

- *Chronic Conditions:* Chronic conditions include cardiovascular and respiratory diseases and musculoskeletal disorders such as arthritis, and other orthopedic conditions. They are the precursors to disabilities and account for 70 percent of acute health care costs.
- *Physical Activity:* Sedentary lifestyles are, in large part, responsible for the chronic health conditions that lead to disability. This public health issue can be addressed through both public school health and physical education and informal recreational activity.
- *Nutrition:* There is evidence of widespread non-participation of eligible persons in federal nutrition programs. There should be adequate nutrition for people in America.
- *Unintentional Injuries:* Traffic accidents are the 3rd greatest cause of disability. There is need to address traffic safety issues through the Transportation Department.
- *Substance Abuse and Mental Health:* Substance abuse contributes to chronic health conditions and disability. Initiatives are needed through SAMHSA and CMS to prevent and facilitate recovery for people at risk of mental health and substance abuse disabilities.
- *Toxic Chemical Exposure:* An estimated 12 million children (17 percent) have one or more learning, developmental, or behavioral disability and these numbers appear to be increasing. Exposures to environmental toxins such as lead, mercury, PCBs, alcohol, toluene and tobacco have been proven to cause developmental disabilities.

Public health policies should also protect health. This encompasses policies in the area of:

- *Food and Drug Administration:* The FDA, through regulation, assures safety, efficacy and security of human biological products, medical devices, and food supply.
- *Environmental Health:* The Environmental Protection Agency protects health through regulation of toxic air, water, land, waste, and radiation. It bases environmental health protection through the best available science.
- *Occupational Health:* There are approximately 400,000 workers who acquire a disability each year. The Department of Labor should take initiatives to provide greater worker safety.
- *Infectious Disease:* There is variability of standards to control infectious disease in the U.S. Also, insufficient supplies of vaccines have been cited. There should be improved control of infectious diseases that can diminish health of Americans.
- *Violence and Abusive Behavior:* Initiatives should be taken to promote the health and well being of families and communities by preventing violence through the Departments of Justice and Health and Human Services.

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Prevention

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Public health policies should also promote access to health care. This encompasses:

- *Health Services:* There are 47 to 85 million people in the U.S. without health care. Failure to access timely health care can diminish health. Health care reform should provide adequate, affordable health care for all, all of the time.
- *Maternal and Infant Child Health:* A child in Cuba has a 60 percent greater chance of reaching his or her 5th birthday than a child born in the U.S. Issues of maternal, infant and child health should be a priority of health care reform.

Public health policies should address health disparities.

- Vulnerable populations are disproportionately impoverished and rely on public health entitlement programs such Food Stamps, Women, Infants, and Children program, TANF, SCHIP, Medicaid and SSI and SSDI. There are many eligible non-participants that need to be reached for these disability prevention programs.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Initiate and/or support legislation, regulations and oversight with adequate funding for substance abuse and mental health programs.
- Initiate and/or support legislation, regulations and oversight with adequate funding for pre- and post-natal health care to reduce infant mortality and birth defects.
- Initiate and/or support legislation, regulation and oversight with adequate funding for public health entitlement programs to promote access to health care and nutrition.
- Initiate and/or support interagency legislation, regulations and oversight and adequate funding for school health programs that include effective health education, counseling services, and environmental safety, prevention of obesity and school wellness policies of the Child Nutrition Act.
- Initiate and/or support legislation, regulations and oversight and adequate funding of the Food and Drug Administration and Consumer Product Safety Commission to protect consumer health.
- Initiate and/or support legislation, regulations and oversight and adequate funding for prevention of violence and social justice issues of incarcerated persons with disabilities through the Department of Justice.
- Initiate and/or support legislation regulations, oversight and funding for clean air and water, controls of nuclear waste and toxic substances through EPA and Departments of Defense and Interior.
- Initiate and/or support legislation, regulations, oversight and adequate funding of protection of worker safety through the Department of Labor.
- Initiate and/or support legislation, regulations and adequate funding for timely medical services that include clinical preventive services, and immunizations that prevent diminished health that lead to chronic health condition and disability.
- Provide full funding for the National Children's Study to continue research examining the effects of environment on children's health and development.

Rights

The CCD Rights Task Force focuses on promoting the civil rights and protections for people with disabilities, and the enforcement of rights provisions by federal agencies. This includes all issues within the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the protections secured through the Individuals with Disabilities Education Act (IDEA). Ensuring self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities also requires legislative or regulatory action and enforcement in the areas of law enforcement, education, voting, employment, and hate crimes. Ensuring people with disabilities have access to legal representation to protect their rights is also critical. The federally mandated Protection and Advocacy (P&A) System and the Client Assistance Program (CAP) network is the largest provider of legally based advocacy services to people with disabilities in the United States. There is a P&A /Cap system in every state, the District of Columbia, Puerto Rico, and four U.S. territories. In addition, there is a federally-mandated Native American P&A serving the 4 corners of Colorado, New Mexico, Arizona, and Utah.

While the first P&A program was enacted to protect individuals with developmental disabilities living in institutions from abuse and neglect, over time the P&A /CAP network has expanded to provide legal advocacy for individuals with all types of disabilities and in all types of circumstances. The legally based advocacy provided by the P&A /CAP network empowers individuals to obtain supports and services to succeed in school, to reach their employment goals, to be afforded the basic right of making meaningful choices in their daily lives, and to be free from abuse and neglect in both institutional and community settings.

The CCD urges the Administration and Congress to:

- Enforce and fully implement the Americans with Disabilities Act (ADA) and fully fund the agencies that provide enforcement;
- Issue regulations to implement the ADA Amendments Act and restore Congress' intent that the ADA protect a broad group of people with disabilities;
- Continue to pursue involvement in key *Olmstead* cases by implementing policies that maximize the potential for community integration of people with disabilities.
- Ensure that people with disabilities receive fair pay in the workforce by:
 - Passing and signing into law legislation to amend Title VII of the Civil Rights Act of 1964, the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and other laws to clarify that illegal pay discrimination takes place every time compensation is paid pursuant to a discriminatory compensation decision.
- Ensure individuals with disabilities have access to attorneys and legal services to protect their civil rights by:
 - Passing and signing into law a civil rights act that provides attorney's fees and expert fees in major civil rights and labor cases and makes other changes needed to restore civil rights protections eliminated by the courts.

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Rights

Continued...

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- Enhancing the authority of the Protection and Advocacy (P&A) program in federal facilities including VA hospitals, schools, and the facilities where people with disabilities reside.
 - Funding the P&A program to an adequate level to ensure the protection of all people with disabilities.
 - Promote full participation and representation of people with disabilities by enacting and enforcing legislation to increase voting access and protection by:
 - Enforcing the National Voter Registration Act (NVRA)'s requirement that social service and disability agencies routinely offer voter registration to their consumers;
 - Amending the NVRA so that Medicaid, Social Security, and Medicare are mandated voter registration agencies;
 - Protecting the voting accessibility features of the Help America Vote Act;
 - Supporting legislation that mandates that voters be able to verify their votes from the actual voting media and that the media must be accessible;
 - Preventing the inappropriate disenfranchisement of people with mental disabilities based on state laws and practices; and
 - Insisting that the U.S. Census document voting behaviors of voters with disabilities the same way as it does the voting behaviors of other minorities.
 - Ensure the protection of the rights of people with disabilities in all education systems by:
 - Enforcing and fully implementing the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act and Section 504 of the Rehabilitation Act;
 - Improving access to all educational programs and opportunities within both public and private schools for students with disabilities; and
 - Eliminating usage of seclusion and restraint on students with disabilities in schools, treatment programs, and residential facilities and improve the quality of investigations of such abusive practices.
 - Ensure the protection of the rights of people with disabilities to fair and appropriate treatment by first responders, by law enforcement, and by the federal and state judicial systems by:
 - Educating and training law enforcement officers regarding people with disabilities to prevent the abuse and mistreatment of people with disabilities during all law enforcement-civilian interactions and legal processes;
 - Ensuring that the local law enforcement officers used by U.S. Immigration and Customs Enforcement (ICE) receive adequate education and training regarding people with disabilities to prevent the abuse and mistreatment of people with disabilities during immigration investigations, raids, and legal process;
 - Ensure that ICE agents and detention facilities provide appropriate access, accommodations, and services for individuals with disabilities, particularly those with developmental disabilities, mental health conditions, and HIV;
 - Protect people with disabilities from crimes of hate based upon their disability; and
 - Enact hate crimes legislation that includes bias crimes against people on the basis of real or perceived disability within the purview of federal jurisdiction.

Social Security Disability and Supplemental Security Income Benefits

Social Security disability and Supplemental Security Income cash benefits, along with the related Medicaid and Medicare benefits, are the means of survival for millions of individuals with severe disabilities. These are programs of last resort with extremely strict eligibility rules, but they allow people with the most significant work impairments to live an independent life with a measure of economic security. They rely on the Social Security Administration (SSA) to promptly and fairly adjudicate their applications for disability benefits. They also rely on the agency to handle many other actions critical to their well-being including: timely payment of the monthly benefits to which they are entitled; accurate withholding of Medicare Parts B and D premiums; and timely determinations on post-entitlement issues that may arise, e.g., overpayments, income issues, and prompt recording of earnings.

Why are Social Security and SSI benefits so important to individuals with disabilities?

- **Millions of families face disability.** About 3 in 10 men and 1 in 4 women become disabled before reaching normal retirement age.
- **Adults with serious disabilities have a very low employment rate.** Surveys indicate that less than half of individuals with disabilities reported working full or part time, compared to those who do not have disabilities.
- **Workers and families of workers who become disabled need a guaranteed income.** Benefits are paid not only to the wage-earner, but also to dependents. The current value of Social Security is equal to a disability insurance policy worth \$353,000 for a young worker who has a spouse and two young children. Social Security benefits also have played an important role in reducing poverty among individuals with disabilities.

The most significant problem facing the Social Security Administration is the persistent under-funding of SSA's administrative budget. Recent media reports and Congressional hearings have documented the hardships suffered by people with disabilities as the backlog in decisions on disability claims continues to grow and access to other key services is diminished. Behind the numbers are individuals with disabilities whose lives have unraveled while waiting for decisions – families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many individuals die. Access to other key services, such as replacing a lost check or promptly recording earnings, also has diminished. Despite dramatically increased workloads, staffing levels throughout the agency are at the lowest level since 1972. Without adequate appropriations, the situation will deteriorate even more.

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Additional Resources:

[Statement of Principles](#)

Social Security Disability and Supplemental

Security Income Benefits

Continued ...

In addition, while much has been done to improve policy to encourage work, there remain many areas in Social Security's programs where change is needed to remove barriers to work and to support people with disabilities who work or attempt work. Beneficiaries should receive every support and encouragement to work. Instead, in the current system, they often face the loss of benefits for their efforts, long before they have demonstrated ability for long term survival without them.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Ensure that SSA is given sufficient funding to make disability decisions in a timely manner and to carry out other critical workloads. SSA must be provided with adequate funds for its administrative expenses to make significant strides in reducing the disability claims backlog, improve other services to the public, and conduct its program integrity activities. Congress also should consider separation of SSA's administrative budget authority from the Section 302(a) and (b) allocations for discretionary spending in other important programs. The budget would still be subject to the annual appropriations process and Congressional oversight.
- Develop proposals to promote employment among beneficiaries and potential beneficiaries and improve work incentives. However, any proposals should not make changes that would damage the existing Social Security and SSI disability programs. CCD has developed a [set of principles](#) to guide the development of proposals. The principles include: no changes to the Social Security definition of disability; no work requirements or time limits in the Social Security and SSI disability programs; and no cutbacks to eligibility criteria for these programs. The Statement also includes a comprehensive discussion of improvements to the disability programs and work incentives that CCD has supported over the years.
- Ensure that proposed changes to the disability claims process protect the rights and interests of people with disabilities and do not elevate speed of adjudication above accuracy of decision-making. This is problematic and not appropriate for a non-adversarial process. CCD has numerous suggestions for improving the disability claims process for people with disabilities and many have already been initiated by SSA. We believe that these recommendations and agency initiatives, which overall are not controversial and which we support, can go a long way towards reducing and eventually eliminating the disability claims backlog. The CCD recommendations, which include improved development of evidence at the beginning of the process and technological improvements, are summarized in testimony presented before the [House Ways and Means Committee](#) on April 23, 2008.
- Guarantee, if the debate on the solvency of the Social Security Trust Funds is revived, that the impact on people with disabilities is considered and that their interests are protected. CCD has urged that consideration of any proposal be required to include a beneficiary impact statement.
- Improve, simplify, and update the SSI program through legislative, regulatory, and operational changes.

Technology and Telecommunications

Many people with disabilities and seniors rely extensively on assistive technologies and accessible and usable technology infrastructures, such as telephony and television systems, to maintain lives of independence and to maximize health choices. Their technology-related needs are critical, for instance, to seek and maintain employment; to view and hear any electronic pictures, sound or information; to participate in civic responsibilities; and during emergency situations. Numerous statutes that include technology provisions for people with disabilities have not been fully appropriated or implemented or need revision and updating in light of new technologies or medical coding practices. Policies that act as barriers to accessible, usable, and affordable technology for people with disabilities must be removed.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Find ways to include the transport of assistive technology (AT) in emergency planning and response protocols.
- Create means of reimbursement for lost or damaged AT as part of emergency relief packages.
- Include successful transport of AT as an outcome measure when conducting evaluations of post-emergency response efforts.
- Incorporate the technology needs of people with disabilities in training for federally-funded agencies and first responders.
- Find ways to include individuals with disabilities who use AT in non-medical shelters along with their community peers.
- Enact comprehensive telecommunications and video programming policies that would meet the unique needs of the 30 million people with hearing disabilities, 20 million people with vision loss, and almost 100,000 people who are deaf-blind.
- Propose and publish new implementing regulations for the Americans with Disabilities Act (ADA) unambiguously reinforcing recent statutory clarifications that guarantee, among other things, that employees who use assistive technology are nevertheless protected from discrimination regardless of the ameliorative effects of the use of such technology on their disabilities.

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Technology and Telecommunications

Continued...

- Ensure Department of Justice regulations account for effective communication needs, accessibility of both fixed and free-standing equipment by covered entities, and the accessibility and usability of Internet-only public accommodations (i.e., banks, retailers and other commercial concerns operating exclusively on-line) in the implementing regulations for the ADA.
- Reauthorize the Assistive Technology Act and support this ongoing federal commitment with expanded funding to enable the AT Programs to offer quality services in the states and territories.
- Ensure that the AT provisions in enacted legislation are fully implemented to reach the expanding aging and disability populations the Act was meant to serve.
- Appropriate funds to develop secure voting systems that are accessible to and usable by people with disabilities, as required by the Help America Vote Act (HAVA) to ensure full civic participation by people with disabilities.
- Develop a new benefit category for complex rehabilitation technology that recognizes and reimburses for the skilled professional services provided by the rehabilitation technology supplier.
- Support additional federal investment in assistive technology and universally designed research and development activities.
- Address barriers to accessing therapy services for required seating and mobility evaluations caused by home health consolidated billing and by lack of coverage codes for clinicians providing services.
- Conduct re-evaluation of complex rehabilitation codes and reimbursements for wheelchair accessories to ensure better product and service delivery.
- Streamline the documentation required by small businesses that use the Small Business and the Work Opportunity Tax credits and promote the availability of such credits.

Transportation

Access to transportation provides a vital lifeline for people with disabilities to access employment, education, healthcare, and community life. Yet too often, people with disabilities lack accessible, affordable, reliable transportation options. A national study by the United States Bureau of Transportation Statistics in 2002 found that 6 million people with disabilities have difficulties obtaining transportation. The 2000 Harris Poll, funded by the National Organization on Disability, established that nearly one-third of people with disabilities report having inadequate access to transportation.

The federal programs that are specifically aimed at increasing the mobility of people with disabilities are small yet effective, and the creation of the New Freedom Program (Section 5317) in the last transportation reauthorization is a positive step. As the nation ages and more demand is put on these specialized systems, it is imperative that the Administration and Congress increase the accessibility of our nation's transportation network and the mobility of all Americans.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Increase investment in public transportation options for all Americans. Because people with disabilities are disproportionately dependent on public transportation, expanding the public transportation system will lessen demand for specialized services. This is particularly true in rural areas where public transportation options are not available, leaving many people with disabilities isolated and unable to participate in work and social activities.
- Expand the Program for the Elderly and People with Disabilities (Section 5310), the Job Access Reverse Commute Program, and the New Freedom Program to better meet transportation demands.
- Work with human service and transportation providers to make regulatory and legislative changes that will make federal transportation programs easier to access. This includes allowing for Section 5310 dollars to be used for operating expenses.
- Support increased access to mobility management and travel training services that work directly with people with disabilities and transportation providers to maximize the success of both riders with disabilities and the transportation systems that serve them.

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Transportation

Continued ...

- Hold Amtrak accountable for meeting the legislatively mandated deadline of 2010 for full station accessibility under the Americans with Disabilities Act (ADA) and provide funding for accessibility initiatives.
- Adopt livable community principles that ensure that the mobility of people with disabilities is included in community planning including transportation and pedestrian environments
- Improve enforcement of the civil rights laws that promote access to transportation (the ADA, Air Carrier Access Act) and fully fund the agencies that are charged with the enforcement of these important laws.
- Support legislation that expands volunteer driver programs by increasing the allowable mileage reimbursement and deduction rates to be more consistent with the business rate.
- Promote tax policy that encourages greater mobility for people with disabilities.
- Promote the expansion of accessible taxis and other public and private transportation vehicles.

TANF and Family Income Supports

Individuals with disabilities are disproportionately represented among those living in poverty. As a result, social programs targeted to low income individuals and families – including food stamps, Temporary Assistance to Needy Families (TANF), housing and energy assistance programs – also serve individuals with disabilities. Social programs must appropriately serve and accommodate individuals with disabilities represented in their target population.

TANF is one example of a social service program that fails to appropriately serve families that include family members with a disability. The replacement of Aid to Families with Dependent Children (AFDC) with the TANF program represented a radical shift in how cash assistance and work supports are provided to low income families with children. Under the TANF program, work effort among single parent families increased.

While many low income households have transitioned successfully from cash assistance to greater economic independence, families that include a person with a disability are disproportionately represented among those who remain on cash assistance. The Government Accountability Office (GAO) has determined that approximately 44 percent of TANF recipients still left on the rolls have a disability or have a child or adult relative with a disability. Worse, families that include a person with a disability are disproportionately represented among those who have lost access to the cash assistance and supports that the TANF program provides through sanctions. TANF recipients with disabilities may have significant barriers to employment and many struggle to obtain employment before their TANF benefits end.

While the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) explicitly requires states to adhere to the Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973 when administering TANF, states are still expected to meet target work participation rates or face financial penalties. The reauthorization of the TANF program in the Deficit Reduction Act of 2006 failed to incorporate provisions supported by a bipartisan group of Senators to provide states with greater flexibility to appropriately serve families that include a person with a disability. Instead, the amended law and corresponding regulations issued by HHS significantly curtailed the ability of states to appropriately serve families that include a person with a disability and avoid financial penalties incurred when states fail to meet the requirements of the block grant. The narrow interpretation adopted by HHS currently places families that include a person with a disability at higher risk for continuing to live in poverty and for slipping into deeper poverty and hardship when they lose TANF benefits due to sanctions and time limits.

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TANF and Family Income Supports

Continued ...

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Support an aggressive effort to reduce poverty in half in ten years.
- Ensure that programs targeting low income families appropriately serve and accommodate individuals with disabilities. In the TANF program, this can be accomplished by adopting provisions that provide states the flexibility to tailor the work participation hours and activities for families that include a person with a disability.
- Provide incentives to states to provide access to supports such as rehabilitative services, mental health, substance abuse treatment or vocational education that would allow families that include a person with a disability to truly transition into greater self-sufficiency.

Veterans

The honorable men and women who become disabled in the service of our country deserve our support in every way. To this end, the CCD Veterans Task Force seeks to advance the following policy principles:

- All veterans with disabilities should receive the highest quality services from the Department of Veterans Affairs (VA) or any other service provider.
- Veteran-specific service systems should have adequate resources to respond to the needs of veterans with disabilities.
- Veterans with disabilities should have easy access to the host of programs and benefits designed for the broader population of Americans with disabilities.
- The VA should augment its capacity to meet the needs of veterans with disabilities by working proactively to utilize/partner with the components of the broader disability system, including federal, state and local public agencies and non-profit/community-based organizations.
- Veterans with disabilities should have a smooth transition from Department of Defense (DoD) to VA and to the community, including information about accessing available benefits, services and supports.

The public mental health system and community service providers already provide a large array of services to veterans. Strengthening these services and other systems of care is critical to ensuring services to non-VA using veterans with disabilities.

At the end of 2006, 2.7 million – or 11 percent of the 23.5 million veterans living in the U.S. and Puerto Rico were receiving benefits for service-connected disabilities. Meanwhile, in 2006, approximately 154,000 veterans under age 65 with non-service-connected disabilities already appeared on Social Security's rolls.¹ While veterans with disabilities receive many services and supports from the VA, they also rely on a host of programs and benefits designed for the broader population of Americans with disabilities. It is critical, therefore, to consider the impact of public policies on this segment of the disability community.

The Consortium for Citizens with Disabilities urges the Administration and Congress to consider the following priorities:

- Adequate funding for the VA health care system must be provided in a timely and predictable manner with attention to protection of specialized services important to veterans with significant disabilities.

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¹ Social Security Administration, 2006 Annual Statistical Supplement, Table 9.F1

Veterans

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- Increased attention must be given to mental health issues, including quick and effective responses to the growing need for mental health services among the general population of veterans, not just those returning from Iraq and Afghanistan.
 - DoD and VA should enhance efforts to de-stigmatize mental illness through increased awareness and education about symptoms of mental illness, recovery and access to available services and supports, including home- and community-based services.
 - Expanded resources must be provided for meeting the needs of veterans with disabilities through collaborative partnerships between the VA and both state and federal agencies as well as non-profit community based organizations. Resources must meet the needs of reservists, national guardsmen, female veterans and veterans in rural areas.
 - While DoD and VA have taken steps to smooth the processes between their disability determination systems, veterans with severe disabilities must still undergo a second disability determination to apply for Social Security disability insurance. Legislation is needed to automatically qualify for SSDI those veterans given a disability rating of 100% by the VA.
 - Systemic barriers to employment of veterans with disabilities should be removed. Steps include improving the way VA contracts with VR providers through changes in the VA's national acquisition strategy in order to offer more vocational options to veterans with disabilities. In addition, the VA Vocational Rehabilitation and Education program that serves veterans with service-connected disabilities must be modernized. Collaboration between the VA and state vocational rehabilitation programs that serve all veterans with significant disabilities must be supported and encouraged. Existing federal programs designed to assist veteran entrepreneurs with disabilities need to be monitored and enforced. Finally, the VA pension "cash cliff" should be eliminated by phasing out pension benefits as earned income rises.
 - It is time to lift the cap on the VA's Independent Living program to ensure that all qualified veterans receive these vital services.
 - Families and caregivers are often the most critical supports for veterans with disabilities but seldom receive any assistance from the VA. Even when veterans and their families are entitled to benefits, as with the VA pension program, they are often unaware of their eligibility. As recommended in a report to the VA Office of Policy, Planning and Preparedness, VA should improve its outreach efforts so that veterans and spouses who are entitled to benefits are able to access them.² Additionally, VA mental health services to eligible veterans should include family-centered supports and services.

² Evaluation of VA Pension and Parents' DIC Programs - VA Pension Program Final Report, ORC Macro, Economic Systems Inc., Hay Group, Dec. 22, 2004, www1.va.gov/op3/docs/pension.pdf

Presidential Appointment Recommendations: Ensuring Representation of a Disability Perspective in Federal Government

Individuals with disabilities should be actively recruited and considered for leadership positions across all sectors of government including appointments to Cabinet, Secretarial, and judicial positions.

Individuals selected for leadership positions in the Administration should embrace a disability perspective. Such an individual should embrace principles that demonstrate a commitment to the full inclusion, independence, empowerment, and integration of children and adults with disabilities into every sector of our society as a guiding principle in the development of national policy. Attention to these principles means a better society for all.

All Administration officials should:

- Demonstrate a commitment to aggressive adherence and enforcement of civil rights laws such as the Americans with Disabilities Act (ADA), the Civil Rights Act of 1991, the Fair Housing Act Amendments of 1988, and to Section 503 and 504 of the Rehabilitation Act of 1973 (as amended) and other statutes;
- Have a record of inclusion, empowerment, and integration of people with disabilities in the agencies and organizations they have led;
- Commit to the full inclusion, empowerment, and integration of people with disabilities in the agencies they will lead; and
- Commit to following the principles of full inclusion, independence, empowerment, and integration of people with disabilities in the execution of his or her duties.

Attention to the inclusion and integration of people with disabilities is appropriate across all government sectors, however, administration officials who will have specific responsibility to lead or implement policies that significantly impact people with disabilities must also demonstrate knowledge of, and experience in, affecting disability policy. Individuals with responsibility for implementing policies that impact people with disabilities should also demonstrate:

- public commitment to non-discrimination, school and community inclusion, family supports, full employment, independence, integration, and community accessibility for full participation by people with disabilities;
- understanding of and support for the disability rights movement, especially the principles of independence, inclusion, productivity, empowerment, and integration;
- understanding of the need for consumer driven service delivery systems, especially with regards to Medicaid, housing, and health care programs;
- commitment to community-based supports that facilitate the integration and inclusion of people with disabilities within our communities;

Presidential Appointment Recommendations: Ensuring Representation of a Disability Perspective in Federal Government

Continued...

- understanding of the critical role social programs such as Social Security, rehabilitation programs, and Medicaid (among many others) have on the ability of millions of individuals with disabilities to achieve greater independence, empowerment, inclusion, and integration within our communities; and
- understanding of the critical need for well-trained staff in social programs serving people with disabilities.

Individuals assuming leadership positions in programs impacting people with disabilities should have appropriate program and policy management expertise. Leaders should demonstrate a commitment to implementing and refining policy through open communication and consensus building with the disability advocacy community.

The President will be expected to appoint individuals for many leadership positions in his Administration. We believe it is critical that the individuals selected for the following positions have careers that exemplify their commitment to a disability perspective. The positions include:

Office of Management and Budget

OMB is the primary gatekeeper for much of what does and does not get done within the federal government. As the agency responsible for the President's budget, OMB is the most important administrative entity for decisions about anything that costs the federal government money.

In addition, OMB exercises power over proposed and final federal regulations, agency testimony, proposed legislation, agency reports, and many other aspects of policies and programs. Thus, OMB's power is transcendent – encompassing both financial and policy matters of all federal entities.

Appointees to senior OMB positions should make both fiscal and policy decisions that respect and implement the policy recommendations addressed throughout this transition document. OMB appointees should understand that activating these recommendations will not only benefit people with disabilities and support maximum independence and participation in all aspects of American society; they will also enrich us all by removing barriers to the contributions that people with disabilities can and will make to our society.

Key OMB positions include:

- Director (Presidential Appointment with Senate Confirmation)
- Senior Advisor to the Director (Noncareer Appointment)
- Deputy Director (Presidential Appointment with Senate Confirmation)
- Deputy Director for Management (Presidential Appointment with Senate Confirmation)
- General Counsel (Noncareer Appointment)

Presidential Appointment Recommendations: Ensuring Representation of a Disability Perspective in Federal Government

Continued...

White House Domestic Policy Council

Because disabilities issues transcend nearly all categories and silos, there should be a new senior full-time person on the Domestic Policy Council staff who is responsible for making sure that disabilities issues and perspectives are considered and incorporated into decision-making about domestic policy and funding.

- Senior disabilities advisor – White House Domestic Policy Council

Department of Education

- Secretary of Education
- Assistant Secretary, Office of Planning, Evaluation and Policy Development
- Assistant Secretary, Office of Special Education and Rehabilitative Services
- Assistant Secretary, Office of Vocational and Adult Education
- Commissioner of Rehabilitation Services Administration
- Director of National Institute on Disability and Rehabilitation Research
- Director of Office of Special Education Programs
- Director, Institute for Education Sciences

Department of Health and Human Services

- Secretary of Health and Human Services
- Assistant Secretary for Health and Human Services
- Assistant Secretary for Planning and Evaluation
- Assistant Secretary for Aging
- Director, Office on Disability
- Commissioner, Administration on Developmental Disabilities
- HRSA Administrator
- Centers for Disease Control and Prevention Director
- U.S. Surgeon General

Centers for Medicare and Medicaid Services

- Administrator, Centers for Medicare and Medicaid Services
- Director, Center for Medicare Management
- Director, Center for Beneficiary Choices
- Deputy Administrator, Center for Medicare and Medicaid Services
- Director, Center for Medicaid, and State Operations

Department of Housing and Urban Development

- Assistant Secretary, Housing
- Federal Housing Commissioner
- Assistant Secretary, Community Planning and Development
- Assistant Secretary, Public and Indian Housing
- Assistant Secretary, Policy Development and Research
- Assistant Secretary, Fair Housing and Equal Opportunity

Presidential Appointment Recommendations: Ensuring Representation of a Disability Perspective in Federal Government

Continued...

Department of Labor

- Assistant Secretary, Veteran's Employment & Training Services (VETS)
- Deputy Assistant Secretary, Office of the Assistant Secretary for Policy
- Associate Deputy Secretary, Office of the Assistant Secretary for Policy
- Deputy Secretary, Office of the Assistant Secretary for Policy
- Associate Deputy Secretary, Office of the Assistant Secretary for Policy
- Assistant Secretary, Employment & Training Administration
- Deputy Assistant Secretary, Employment & Training Administration
- Assistant Secretary, Office of Disability Employment Policy
- Deputy Assistant Secretary, Office of Disability Employment Policy

Department of Veterans' Affairs

- Secretary
- Deputy Secretary of Veterans Affairs
- Undersecretary for Benefits
- Undersecretary for Health

Social Security Administration

- Commissioner of Social Security (incumbent Michael Astrue's term expires Jan 2013)
- Deputy Commissioner of Social Security (unconfirmed acting incumbent; appointee's term will expire Jan 2013)
- Chief of Staff
- Deputy Commissioner for Retirement and Disability Policy
- Deputy Commissioner for Disability and Adjudication Review
- Deputy Commissioner for Legislation & Congressional Affairs
- General Counsel
- Deputy Commissioner for Communications
- Associate Commissioner for Retirement Policy
- Chief Information Officer
- Senior Advisor to the Deputy Commissioner of Social Security
- Associate Commissioner for External Affairs
- Special Assistant to the Commissioner
- Senior Advisor to the Deputy Commissioner, Office of Legislation & Congressional Affairs

Social Security Advisory Board

- Chair
 - Note: The current Chair's tenure *as Chair* ends when he is replaced by the new President. He will remain a *Member* of the Board as a Republican appointee until the end of his term in September 2009. The new President may appoint as Chair either an existing Member or a new appointee.
- One current vacancy

Social Security Board of Trustees

- One Trustee subject to Presidential appointment