

December 22, 2008

Dear President-elect Obama,

Congratulations on capturing the hearts, minds, and hopes of our nation! As grassroots, community-based, consumer-controlled disability organizations, which collectively represent over 50 million Americans with the full spectrum of disabilities, we look forward to working with you and your administration to make cost-effective policy changes to enhance the lives of and restore the civil liberties Americans with disabilities.

Attached you will find nine summaries of the top policy issues facing Americans with disabilities. Taking action on your commitment and these policy measures will not only benefit citizens with disabilities, our nation's wounded warriors, and the ever-growing aging population, it will benefit all Americans and save our government millions of dollars as individuals with disabilities become full participants in society.

They include:

- **Employment:** Reversing the persistently high percentages of people with disabilities who are not working but are ready, willing and able to work;
- **Education:** Increasing access and opportunities for physical activity, and improving quality;
- **Health Care:** Improving access and decreasing disparities and inequities;
- **Home and Community-based Services (HCBS):** Promoting effective community-based services as alternatives to costly nursing homes and other institutions and increase the FMAP to states;
- **Disability Research:** Promoting a quality of life and participation-based research agenda;
- **Civil Rights:** Reinvigorating civil rights enforcement, extending access requirements to new technologies, and continuing to restore protections stripped away by hostile courts;
- **Human Rights:** Protecting human rights of individuals with disabilities at home and abroad;
- **Emergency Preparedness, Response and Recovery Needs:** Planning, coordinating, and providing resources to support people with disabilities before, during, and after a crisis; and
- **Genetic Science and Technology:** Promoting ethical use of new technologies.

Like you, we stand and sit on the shoulders of so many who have come before us. As our nation approaches the 20th anniversary of the Americans with Disabilities Act in 2010, we embrace the disability rights principle, "Nothing About Us, Without Us." For

too long others claimed the need to speak for us, but no other group - professionals or relatives - speak for *us*.

Additionally, we urge you to embrace the fundamental principles for sustainable change, which are essential elements to building healthy, resilient, empowered communities. As you move forward with deliberate speed and consideration, we urge your administration to:

- Provide oversight of federal agency public policy, regulatory, and enforcement actions, and collaborate with consumer and community-based disability organizations as partners to better serve the ever-expanding population of more than 50 million Americans with disabilities;
- Hire qualified professionals with disabilities, who have expertise in policy areas, throughout the administration, including a Special Assistant to the President on Disability Policy;
- Include individuals with disabilities in policy formation in all areas addressed by the administration, and integrate representatives of our community on all advisory boards of all major agencies;
- Provide services that serve people with disabilities across the life span, from cradle to grave, and all those with increased needs for health care, health promotion, and long-term services and community-based supports;
- Incorporate consumer-directed services and include consumers in policy development;
- Embrace the disability experience as part of culturally competent policy and diversity at all levels of planning, policy formulation, implementation, and evaluation; and
- Focus on “universal design” as a cost-effective innovative way to enhance the quality of life and level of participation of all Americans in community life and incorporate it into infrastructure changes in the economic stimulus package so we upgrade the infrastructure for all to use;

Thank you for your support of the need for the federal government to be “diligent about making sure the states enforce the rights affirmed by the Olmstead decision.” Enabling people with disabilities to live independently in their own homes and communities, rather than being forced into costly Medicaid-funded nursing homes and other institutions will ensure civil liberties, enhance the quality of life and full participation of all Americans by creating stronger, sustainable communities of inclusion and acceptance to honor the 10th Anniversary of the Olmstead decision.

As a community of individuals with disabilities, we ask for nothing more than what other Americans expect and already have. We seek inclusion. We seek a voice for the disability rights message in the change you create. As you create more jobs for

Americans, include jobs for Americans with disabilities. As you improve education for America's students, include students with disabilities. As you improve the healthcare system, include the healthcare needs of individuals with disabilities. As you restore civil rights to Americans, include the civil rights of individuals with disabilities. To paraphrase your now immortal words, - We are not a nation of disabled and non-disabled Americans. We are the United States of America.

We stand ready to work with you and look forward to an opportunity to discuss our priorities with you personally in the coming months.

Sincerely,

American Association of People with Disabilities (AAPD)
Access Living
American Disabled for Attendant Programs Today (ADAPT)
Autistic Self Advocacy Network
Boston Center for Independent Living (BCIL)
California Foundation for Independent Living Centers (CFILC)
Disability Rights Education and Defense Fund (DREDF)
Generations Ahead
Little People of America
Metro-West Center for Independent Living (MWCIL)
National Association of the Deaf (NAD)
National Coalition for Disability Rights (NCDR)
National Coalition of Mental Health Consumer Survivor Organizations
National Council on Independent Living (NCIL)
National Empowerment Center
National Federation of the Blind (NFB)
Self Advocates Becoming Empowered (SABE)
Special Olympics
Texas State Independent Living Council (TX SILC)
World Institute on Disability (WID)

Attachment

Employment

Background:

- Numerous studies show that Americans with disabilities want to work. However, the current system fails to provide the education, training, supports, and opportunities to enable people with disabilities to obtain meaningful jobs and careers. Consequently, 70% of people with significant disabilities are unemployed.
- Currently, multiple federal programs have overlapping responsibilities and services for addressing employment of individuals with disabilities and they exist in silos, absent meaningful integration.
- In 2006, the average annual household income for Americans without disabilities was \$65,400, compared with \$36,300 for Americans with disabilities. Work disincentives, Supreme Court rulings, and under-funded job training and career development programs, all interfere with the acquisition of skills necessary to obtain, maintain, and advance in employment opportunities.
- Youth with disabilities are twice as likely to drop out of high school, three times as likely to live in poverty, and four times as likely to be involved in the juvenile justice system.

Long Term Goals:

- Establish a National Commission on People with Disabilities, Employment, and Social Security. This Commission would create and strengthen the connection between SSI and SSDI programs within the Workforce Development and Vocational Rehabilitation System. It would examine and propose solutions to work disincentives, revisit the Ticket to Work Act, and study and fund programs to help young people with disabilities transition to employment.
- Increase the focus on youth with disabilities. The administration must increase the emphasis on employment issues young people with disabilities face across systems and agencies, and include them in employment-based funding projects and proposals such as federally funded internships, job readiness, and career-based mentoring programs to address the needs of “disconnected youth.”
- Improve Vocational Rehabilitation Systems’ ability to assist underserved populations by increasing the ability of state vocational rehabilitation programs to

serve traditionally underserved disability populations through technical assistance, pilot program funding, and other mechanisms designed to identify marginalized populations in service-delivery infrastructures and increase their successful employment outcomes.

Short Term Goals:

- Effectively implement Sections 501 & 503 of the Rehabilitation Act, requiring the federal government, and employers who are federal contractors and subcontractors, to “take affirmative action to employ and advance in employment, qualified individuals with disabilities.”
- Direct the Secretary of Labor to make changes to the Section 503 regulations to include goals and timetables that resemble those of Executive Order No. 11246.
- Issue an Executive Order to require the active recruitment and inclusion of “youth with disabilities” in all federally funded projects targeting at-risk or “disconnected youth.”
- Reinstate Executive Order No. 13173, mandating the hiring of an additional 100,000 qualified federal employees with disabilities and establish a dedicated unit within the Office of Personnel Management, led by a senior Administration official designated to implement it.
- Create a White House Office of Disability Policy, appoint a person with a disability to lead it, and provide the authority needed to promote its effectiveness, and the resources to support it.

Education

Background:

- Students with disabilities commonly face physical abuse in public and private schools due to policies that allow for restraint, seclusion, and aversives, even though federal laws protect people with disabilities from abuse in institutions and treatment settings through monitoring by the Protection and Advocacy (P&A) system.
- In the Individuals with Disabilities Education Act (IDEA), Congress promised to cover the cost of 40% of the “excess cost” of state special education expenditures, but covers less than half of that.
- The US Supreme Court limited IDEA rights of children with disabilities by placing the burden of proof on parents, and eliminating expert fee reimbursement to prevailing parents.
- No Child Left Behind (NCLB) leaves behind children with disabilities, due to its incentive structure.
- Students with disabilities face significant barriers to transition out of K-12, are less likely to complete or attend higher education, and experience difficulty navigating fragmented adult services.
- Classroom teachers are often unprepared to integrate students with disabilities into mainstream classrooms.
- Children with disabilities are often bullied in school.

Long Term Goals:

- Protect students with disabilities from school abuse. Federal laws that protect people with disabilities from abuse in institutional and treatment settings must apply to *all* schools.
- Fully Fund IDEA to effectively fulfill students’ right to “a free and appropriate public education” in the “least restrictive environment,” increase accountability to ensure effective special education programs based on the latest research, and insure implementation and enforcement of the law.

- Integrate the re-authorization of the Elementary and Secondary Education Act (ESEA) and IDEA so they are accountability-focused, research-driven and advances opportunities for students with disabilities.
- Improve Student Transition: Eliminate barriers that keep students with disabilities from seeking and completing higher education, including barriers to loans and grants, barriers that cause a higher college drop-out rate for students with disabilities, and barriers that prevent students from making a direct transition to work; and widely implement best practices from schools with successful outcomes.

Short Term Goals:

- Issue an Executive Order empowering HHS to implement the DD Bill of Rights Act in *all* schools; ban the use of aversive interventions, non-emergency restraint, and seclusion for punishment; allow HHS to monitor and enforce its provisions through the P&A, and other systems; and assure all federal laws that protect individuals with disabilities in institutions and residential facilities, apply to and are enforced in all schools.
- Work with Congress to:
 - Pass the Stop Child Abuse in Residential Programs for Teens Act of 2008, to safeguard students in residential school programs and end the abuse they now suffer.
 - Pass an IDEA Full Funding Bill, to bring federal funding of special education costs to the promised 40% and require a fiscal and programmatic audit of the use of IDEA funds.
 - Restore IDEA's due process rights, allow reimbursement to prevailing families for expert fees, and place the burden of proof in IDEA challenges on school districts.
- Charge the Secretary of Education to conduct a comprehensive study of students with disabilities and their transition into higher education, the workplace, and adult services infrastructure. Include a focus on underserved populations within the disability community.
- Charge the Secretary of Education to develop model standards for bullying prevention for schools and districts to adopt as part of a DOE-led nation-wide effort to provide technical assistance, fund studies to reduce the prevalence of bullying, harassment, and violence against students with disabilities and other students, and explore the outcomes of zero tolerance programs on students with disabilities

- Work with Congress to
 - Recognize October as National Disability History and Awareness Month, to promote the inclusion of the history of the disability rights movement and the disability experience in education.
 - Ensure the next reauthorization of IDEA highlights transition by requiring experiential learning for students with disabilities to maximize outcomes, and recognizing the significant role state developmental disability service agencies, vocational rehabilitation agencies, and Independent Living Centers and others must play in this process in the transition process.
 - Require NCLB data collection to incorporate transition outcomes for students with disabilities to allow tracking of post-school outcomes for students with disabilities on both a school district and state-by-state basis.
 - Require training and support of all teachers in Universal Design for Learning and other best practices to improve inclusion of students with disabilities into classrooms.
 - Develop and fund leadership programs for youth with disabilities.

Improve Health Care

Background:

- The Institute of Medicine reports persons with disabilities comprise the largest and most important health care consumer group with an estimated 49.7 million members in 2000.
- People with disabilities experience significant health inequities and health disparities.
- People with disabilities experience poorer health and a higher prevalence of secondary conditions. They use more health care and fewer preventive services than others.
- People with disabilities face barriers to care including, but not limited to:
 - provider stereotypes about disabilities and lack of knowledge or appropriate training to treat people with disabilities, including intellectual disabilities;
 - lack of accessible medical facilities and examination equipment;
 - failure to provide necessary accommodations to access care, including qualified sign language inter-preters, assistive communication technology (AAC), and other means to effective communication.
- One in three people with disabilities report delaying care, skipping medication, or going without needed equipment due to cost or coverage that *limits or prevents* their access to the following critical tools and interventions that enable independence and self-determination:
 - prescription drugs, durable medical equipment, such as wheelchairs, grab bars, raised toilet seats, breathing devices, hearing aids, and corrective lenses;
 - necessary specialists; post-acute and rehabilitative services; long-term care; and care coordination.

Long Term Goals:

Ensure comprehensive health care reform provides meaningful access to health care, including mental health care, and adequate coverage to meet the needs of people with disabilities;

Short Term Goals:

- Work with Congress to ensure the upcoming health care reform debate includes all issues of concern to people with disabilities, including access requirements of ADA and Section 504 in health care delivery.
- Issue an Executive Order instructing the Secretary of HHS to include “individuals with disabilities” in all federal programs that address health disparities and health inequities and work with Congress to ensure inclusion in all health disparities and inequities legislation and in Healthy People 2020.
- Work with Congress to advance the Promoting Wellness for Individuals with Disabilities Act, which establishes accessibility standards for medical diagnostic equipment, creates grants for specialized wellness programs, and promotes training of medical and dental personnel in how to treat individuals with disabilities, including intellectual disabilities.
- Ensure the Economic Stimulus Package includes requirements to make school facilities accessible, such as health clinics, gymnasiums, playgrounds, and sports fields, and invite individuals with disabilities and community groups to use them for health, fitness, recreation, and wellness programs.

Promoting Home and Community-Based Services (HCBS)

Background:

- Too many people with disabilities live in nursing homes and other institutions - declared 'discrimination' by *Olmstead* - since Medicaid requires institutional care, but *not* HCBS.
- The Deficit Reduction Act allows money-saving waivers that enable people with disabilities to live in the community, provide supports to work, and enhance quality of life.
- There is not enough accessible, affordable, integrated housing for individuals with disabilities and individuals with disabilities are often isolated because of the lack of adequate transportation
- Professionals and relatives traditionally make decisions "for" individuals with disabilities. Full participation in community life requires self-determination and consumer control.

Long Term Goals:

- Shift Medicaid and Medicare funding to home and community-based services (HCBS) to promote community living. Increasing the FMAP to states, community-based, self-directed, peer-delivered, holistic care, and creating more community-based alternatives to costly Medicaid nursing homes and other institutions, will change the focus to independent living and participation.
- Increase access to affordable, accessible, integrated housing for individuals with disabilities
- Increase access to transportation for individuals with disabilities.

Short Term Goals:

- Direct CMS to convene a summit with consumers, family members, and experts to establish principles, priorities and a timeline to design a Community Living Waiver for national use.
- Work with Congress to:
 - Pass Senator Harkin's Community Choice Act, to require states to offer community-based supports for Medicaid-eligible consumers so they may choose

to live in their own home, as a cost-effective, community-based alternative to institutional care.

- Provide tax incentives for building accessible housing and other buildings and include making infrastructure and public building accessible in all economic stimulus packages.
- Pass the Community Living Attendant Services and Supports Act (CLASS) to promote independence.
- Direct the Secretary of HHS and the Attorney General to make implementation of the Olmstead decision a priority through HHS' OCR and the DOJ.
- Assure the Executive Order on Olmstead implementation is followed and its scope is broadened.
- Ask the National Governors Association and the National Conference of State Legislatures to work with your Administration to fully implement *Olmstead* and the Community Choice Act.
- Direct the Secretary of HUD to develop a plan to end homelessness and provide adequate, safe, affordable housing for people with disabilities, and increase the number of Section 8 vouchers.
- Increase investment in public transportation in rural areas where people with disabilities are often isolated and unable to participate in society or meet their needs of daily living.
- Support States and localities to develop coordinated human services delivery systems, increase funding for United We Ride, and other resources for transportation-coordination, planning tools, and technical assistance.

Promote a Disability Research Agenda

Background:

- Federally funded disability research focuses disproportionately on basic scientific research to discover the cause of “disabling conditions,” while ignoring the impact of disabilities on quality of life and participation for individuals affected by the particular condition or disability.
- A quality of life and participation-based research agenda will provide evidence on the most effective and methods of delivering services in housing, transportation, education, prevention, wellness, healthcare, recreation, and other community services that empower individuals with disabilities, and enhance and promote transition and independent living.
- At present, the minimal research related to quality of life and participation of individuals with disabilities is split between many federal agencies, and lacks coordination, and noticeable outcomes.
- Under several federal programs, researchers who work on basic scientific research are eligible for student loan forgiveness, while researchers who investigate quality of life and participation of individuals with disabilities do not, thereby disincentivizing disability research.
- A robust coordinated disability agenda that includes input from the disability community will ensure that federal disability research programs compliment other aspects of disability policy, such as de-institutionalization (*Olmstead*), IDEA’s requirement for evidence-based methodologies for students with disabilities, and increasing the number of individuals with disabilities in the workforce.

Long Term Goals:

- Establish parity between basic science and quality of life and participation-based research in the federal disability research agenda and within each disability specific research agenda.

Short Term Goals:

- Issue an Executive Order requiring that all federal agencies, including, but not limited to NIH, HRSA, NIDRR, CDC, DOL, SSA, and HHS, provide at least equal

funding for services-related, quality of life, and participation-based research, as basic science research, both within general disability research agendas and within each disability specific research agenda, and where feasible, use methodologies that include individuals with disabilities as equal partners.

- Issue an Executive Order appointing representatives of the disability community to the Interagency Committee on Disability Research to provide consumer input and ensure this order applies to all disability specific inter-agency research committees, such as the Inter-Agency Autism Coordinating Committee.
- Issue an Executive Order including student loan forgiveness for services-related or quality of life and participation-based researchers on parity with researchers who work on basic scientific research.

Protecting Civil Rights

Background:

- Over the last decade, US Supreme Court decisions, amendments to certain disability rights legislation, and changes in federal regulations have undermined the right to equal protection under the law for Americans with disabilities.
- The ADA Amendments Act of 2008 rejected the Supreme Court's narrow interpretation of "disability" under the ADA to make it easier to obtain protection against disability-based discrimination. However, the law still fails to consider certain impairments "disabilities," subjecting some individuals with disabilities to continued discrimination.
- In June 2008, the Federal Register published over 800 pages of DOJ's proposed rules to revise Title II and III regulations, including revisions to the ADA Accessibility Guidelines (ADAAG). The 60-day comment period was woefully inadequate to analyze and respond to the massive NPRM.
- President Bush signed the ADA Amendments Act into law on September 25, 2008. Effective January 1, 2009, the law requires EEOC revise portions of its regulations that define "disability."
- Many Americans are unfamiliar with their civil rights and responsibilities under Title III of the ADA.
- In January 2008, Senator Kennedy and Congressman Lewis introduced the Civil Rights Act of 2008 to restore civil rights protections that courts have limited.

Long Term Goals:

- Continue the restoration of the Americans with Disabilities Act. Legislation should afford protection to individuals with impairments not covered by the current law and should:
 - Mandate that virtual or online businesses using the Internet are "places of public accommodations."
 - Eliminate the catalyst theory of attorney fees (*Buckhannon*).
 - Revise upwards the current \$300,000 limit for damages under Title I of the ADA.
 - Allow damages under Title III of the ADA and modify standing requirement for injunctive relief.

- Assure input into ADA Amendments Act Regulations. Since the regulations implementing the ADAA have substantial impact on individuals with disabilities and their relationships with employers and courts, the process must allow substantial input from the disability community. “Nothing about us without us.”
- Appoint Supreme Court Justices who demonstrate commitment to disability rights as civil rights law.
- Enhance enforcement of Title III of the ADA. to create accessible communities of inclusion for all individuals with disabilities.

Short Term Goals:

- Work with Congress to identify an appropriate legislative vehicle to ensure that all people with disabilities are protected against employment discrimination.
- Direct EEOC and other agencies to use Advanced Notice of Proposed Rulemaking or Negotiated Rulemaking to develop draft ADA Amendment Act regulations with input from the disability community.
- Direct the DOJ to reopen the comment period on its Notice of Proposed Rulemaking to ADA Titles II and III, including the ADAAG, allow a reasonable period to review the more than 800 pages, and revise portions of its regulations based on public comments.
- Direct DOJ to improve enforcement of Title III of the ADA and support its efforts to:
 - Create a working group to bring together DOJ staff to coordinate their efforts and train them in the most up-to-date information about individuals living with the spectrum of disabilities, incorporating individuals with disabilities as trainers;
 - Increase DOJ’s budget for technical assistance so it can encourage compliance and facilitate the removal of physical and attitudinal barriers, as part of the economic stimulus package that will fix the nation’s infrastructure;
 - Direct more technical assistance efforts to those for whom information is not readily available and to those individuals in the disability community who have not typically filed complaints with DOJ; and
 - Identify opportunities to educate the public about their rights and responsibilities under Title III of the ADA and the work of the Civil Rights Division of DOJ.
- Work with Congress to pass the Civil Rights Act of 2008 to restore legislative intent, and strengthen accountability when discrimination occurs, including disability-based discrimination.

Promote Human Rights

Background:

- The United Nations adopted The United Nations Convention on the Rights of Peoples with Disabilities (CRPD) on December 13, 2006. Forty-two nations ratified the CRPD and a total of 136 nations have signed it, indicating their intent to ratify.
- During the campaign, President-elect Obama indicated that the administration would support US ratification.
- The CRPD will promote, protect, and ensure the full and equal enjoyment of all human rights by persons with disabilities.
- It addresses the rights of people with disabilities to self-determination, physical and programmatic access, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, and equality and non-discrimination.
- When the US ratifies the CRPD, it will underline its recognition of and commitment to enforce human rights and equality for people with disabilities.
- Americans with disabilities still face barriers to these rights, including the right to community living outside of institutions, guaranteed by the United States Supreme Court in *Olmstead*.
- Enabling people with disabilities to live independently in their homes and communities, rather than in costly Medicaid-funded nursing homes and mental institutions will not only save millions of dollars, but also will enhance the quality of life for millions of Americans.
- Young people need more supports to promote the transition from school to independent living and work to enhance quality of life and decrease the alarming number of unemployed individuals with disabilities.
- Individuals with disabilities are subjected to hate crimes, but specific data is limited.

Long Term Goals:

- Promote and protect human rights of individuals with disabilities at home and abroad.
- Promote policies that emphasize the transition from school to independent living and work.

Short Term Goals:

- Sign the UN Convention on the Rights of Peoples with Disabilities and work with Congress to ratify it.
- Work with the States to make sure they enforce the right to community living outside of institutions, as mandated by the United States Supreme Court in *Olmstead*, and with Congress to provide the States with the tools they need to enforce it.
- Require law enforcement agencies currently required to keep surveillance data on hate crimes to collect specific data on the disabilities of hate crime victims and provide technical assistance to the public and law enforcement agencies to encourage reporting.

Emergency Preparedness, Response and Recovery Needs

Background:

- Up to 1/3 of individuals affected by emergencies or disasters, have functional needs related to disability and/or chronic conditions that affect their safety, health and independence.
- Policies, practices and programs of local, state and federal agencies charged with emergency management fail to adequately address the needs of individuals with disabilities.
- During emergencies and disasters, human and civil rights violations are rampant, despite simple and readily achievable solutions to protect lives and maximize limited resources.
- Agencies charged with emergency management often underutilize experts in emergency management needs of people with disabilities, and often exclude them from planning and response at all levels.
- The Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) fails to adequately address proper disaster management needs and results in misuse of limited resources.
- Studies show every dollar spent in preparedness saves nine dollars in response and recovery for the general population and significantly more for preparedness needs of individuals with disabilities.

Long Term Goals:

- Establish a mandate for the interagency coordinating council to incorporate expertise available outside the federal government into its decision.
- Appoint a coordinator with expertise in the needs of people with disabilities to all federal agencies with specific emergency preparedness responsibilities, and the authority and resources to act on them.
- Provide adequate resources and authority to FEMA, the National Council on Disability, the HHS Office on Disability, and the Domestic Policy Council to design, implement, and coordinate policy and practice initiatives across agencies to improve outcomes for individuals with disabilities.

- Mandate that emergency management agencies at every level engage disability community experts to help address the needs of people with disabilities before, during and after disasters.

Short Term Goals:

- Ensure the National Security review team assesses FEMA's progress in fulfilling the directives in the 2006 Stafford Act amendment as outlined by the ten statutory charges for the Disability Coordinator.
- Establish an Office on Disability in FEMA with adequate authority and resources for the Disability Coordinator to fulfill the expectations of this position.
- Include expertise in emergency preparedness, response and recovery of people with disabilities on the Domestic Policy Council team and all other areas throughout the administration charged with emergency preparedness.
- Change the composition and authority of the Interagency Coordinating Council formed under Executive Order 13347 to include private sector experts at the table.
- Ensure that people with disabilities have equal access to necessary services and supports to maintain health and independence during, and after emergencies, disasters, and/or crises.

Genetic Science and Technology

Background:

- Society is rapidly increasing its use of genetic technologies, including prenatal genetic testing and screening, trait selection, stem cell therapy, and personalized medicine. Individuals increasingly face complex decisions about how to use genetic technologies.
- The general public's understanding of what it means to have a disability or raise a child with a disability is limited. Physicians, genetic counselors, personalized genomics companies, friends, family, and the media may offer limited information which often provides a medical prognosis without the context of life experiences of people with disabilities.
- Income, geography, and language often limit access to genetic technologies, leading to disparities in the use of genetic testing, therapies, and other treatments.
- Genetic technology policy discussions often assume the need to prevent or cure disability without contextualizing the issue in a broader discussion of funding priorities for supports and services.

Long Term Goals:

- Convene a national summit to develop a consensus protocol for assessing the impact of genetic technology policy on people with disabilities, considering the impact - not simply the intent - of policy, practice, and regulation and include leaders of the disability community.
- Assure all administration policies affirm the rights and values of people with disabilities, support the autonomy of women and families, and promote an ongoing dialogue.

Short Term Goals:

- Hire and appoint people with disabilities who have worked with prominent consumer-controlled disability organizations and have expertise in genetic and related ethical issues, to the Office of Science and Technology Policy and the President's Council on Bioethics.
- Ensure active participation of people with disabilities as leaders in the debates surrounding genetic technologies, challenging assumptions about the need to prevent, cure, or eliminate disability by appointing them to decision-making agency and interagency bodies.

- Seek appropriate funding to implement the Prenatally and Postnatally Diagnosed Conditions Awareness Act, with leadership from national consumer-controlled disability organizations to gather information about living with intellectual, developmental, physical, visual, auditory, sensory, and mental health disabilities, and distribute in accessible formats and multiple languages.
- Implement the Genetic Information Nondiscrimination Act (GINA) with leadership from consumer-controlled disability organizations that have expertise in living with genetic conditions.
- Ensure that all genetic research goes forward with a proper understanding of the ethical issues involved and sufficient support to positively affect the quality of life of people with disabilities.
- Fund research to explore the social and demographic consequences of genetic testing and selective abortion/implantation on disability populations and the general population.