



Legislative & Advocacy

Priorities Guide

Summer 2014



A Message from the Executive Director

Dear Advocates and Allies,

I am pleased to announce the release of the summer edition of the National Council on Independent Living's 2014 Policy Priorities. This publication will introduce you to a sample of the many legislative issues NCIL is currently pursuing in order to secure full inclusion and equality for people with disabilities in our great nation.

I would like to draw particular attention to issues surrounding Independent Living funding and the creation of an Independent Living Administration. After decades of work by NCIL leaders and advocates across the nation, the *Workforce Innovation & Opportunities Act* is on its way to the President's desk. *WIOA* includes the Reauthorization of the *Rehabilitation Act*, which authorizes funding for America's Independent Living Program.

On this momentous occasion for the Independent living Movement, NCIL extends our most heartfelt appreciation to the members of Congress who supported this historic legislation and our sincerest gratitude to the Independent Living advocates who made this a reality.

CILs and their statewide counterparts are the only organizations directly working to address the issues outlined in this publication. They use shoe-string budgets to successfully advocate for individuals with disabilities facing discrimination while fighting to win an even playing field and ensure the civil and human rights of all Americans.

I am very proud of our community's hard work to bring these issues to Congress. Together we will see the passage of our legislative priorities, the restoration of our civil rights, and a world in which people with disabilities are truly valued equally and participate fully.

Sincerely,



Kelly Buckland
Executive Director
National Council on Independent Living

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What is Independent Living? ←

Independent Living (IL) is the most widely accepted perspective on disability rights in America. The National Council on Independent Living is a national organization responsible for advocating this philosophy, which emphasizes that people with disabilities are the best experts on their own needs, that they have crucial and valuable perspective to contribute to society, and deserve equal opportunity to decide how to live, work, and take part in their communities.

Independent Living is a nonpartisan priority in both Democratic and Republican Administrations. Congress established the Independent Living Program within the Department of Education and continues to provide funding for Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs), which are Congressionally-mandated organizations that plan or deliver services and support people with disabilities to live independently.

CILs are consumer-controlled, community-based, cross-disability, nonresidential, private, nonprofit agencies that are designed and operated within local communities by individuals with disabilities.

There are over 400 federally funded CILs and 56 SILCs representing every state and Congressional district. Elected members of Congress must know about their local Centers if they plan on actively supporting their constituents with disabilities.



Independent Living & Reauthorization of the Rehabilitation Act

Workforce Innovation and Opportunities Act

The *Workforce Innovation and Opportunity Act (WIOA)* passed the full Senate (June 25) and the full House (July 9). It is now awaiting the signature of President Obama.

WIOA represents a compromise between the *SKILLS Act (H.R. 803)*, which passed the House of Representatives in March 2013 with bipartisan support, and the *Workforce Investment Act of 2013 (S. 1356)*, which passed through the Senate Health, Education, Labor, and Pensions (HELP) Committee with a bipartisan vote of 18-3 in July of 2013.

The *Workforce Innovation and Opportunities Act* includes the Reauthorization of the *Rehabilitation Act*, which authorizes funding for America's Independent Living Program.

On behalf of the NCIL Board, staff, and our members nationwide, we thank the Senators and House members who voted in favor of this historic bi-cameral, bi-partisan bill.



Employment and Economic Equity ←

“I believe that we need to modernize our largest federal programs so that they do not require people to prove they cannot work.”

- Senator Tom Harkin, *Unfinished Business* report, July 2012

NCIL’s Response: The CareerACCESS Public Policy Initiative

2014 Update

NCIL youth presented on the CareerACCESS policy initiative at NCIL’s 2013 Annual Conference on Independent Living. The NCIL Board of Directors has adopted a strong statement of support of the initiative. Legislative discussions with key Congressional staff will continue at this year’s Annual Conference.

NCIL is working with the World Institute on Disability and PolicyWorks to secure support and funding for CareerACCESS pilot projects in up to five states. The California State Council on Developmental Disabilities has written both Houses of Congress requesting these pilot projects be funded and carried out.

For additional information on CareerACCESS, please use the QR Code below on your smart phone, visit www.ourcareeraccess.org, or email Aya Aghabi at aya.aghabi@wid.org.



NCIL Asks Congress: Reform SSI for Career Building Youth!

QR Code: www.ourcareeraccess.org

The CareerACCESS initiative will revolutionize how youth who are eligible for Social Security's SSI program (Supplemental Security Income) find and use employment support services, while maintaining disability cash benefits and encouraging asset building.

CareerACCESS shifts the objective for career building youth with disabilities from living to maintain SSI benefits to employing benefits and supports to build careers and achieve independence.

The current SSI program requires individuals exploring work to balance their needs for financial assistance, health care, personal attendant care and accommodations, while overcoming low cultural expectations, lack of employment experience and a challenging job market.

Since 1956, youth with disabilities must prove their inability to work to be eligible for Social Security disability programs. Current SSI rules leave recipients little ability to build assets, relegating



individuals with disabilities to lives of poverty to remain eligible for cash benefits and health care.

The goal of the 12 year CareerACCESS pilot initiative is to build on existing, innovative practices to increase employment rates for youth with disabilities and provide an effective alternative to the current SSI benefits program.

CareerACCESS confronts the inherent challenges of disability determination and benefits eligibility, transforming SSI's supplemental security income from a safety net to a springboard of opportunity for youth building careers.

Pilot Project Design

Piloted in up to 5 states, CareerACCESS will serve youth who are eligible for SSI while eliminating the requirement for applicants to prove an inability to work.

It will blend and braid services and supports from across federal agencies to provide ACCESS (Adult Coaching, Counseling, and Employment Support Services) for youth up to age 30.

CareerACCESS features seek to change:

- **Eligibility** - Establish new eligibility rules eliminating tests for work incapacity. Applicants with a disability under the age of 28, who meet the current SSI income and resource rules, are auto-enrolled in an alternate benefit program. Eligible applicants must meet or equal the current Social Security Listing of Impairments, excluding the test for work incapacity.
- **Supports** - Design a mix of new and existing supports, with blended and braided funding from the Department of Education, Health and Human Services, Department of Labor, and Social Security, to serve youth with disabilities who are in compliance with an Individualized Career Plan (ICP) that meets federal rules and standards.

The ICP will be reviewed and updated annually by all affected parties. This allows youth to develop their career through an alternative to the current SSI benefits program. If a participant becomes non-compliant for any reason, they may exit to the traditional SSI program.
- **Cash and Counseling** - Implement a “cash and counseling” approach, similar to successful Medicaid models, to provide life coaching services to enrollees and their families. Services include: counseling and guidance on navigating systems, benefits planning, asset development, health care access, as well as career planning and coaching.
- **Simplification** - Test simplification of SSI earning / work rules to include allowing CareerACCESS project participants to keep their federal SSI stipend (\$721 for an individual, \$1082 for a couple) until gross earnings exceed preset limits in the current 1619(a) and (b) rules (use Connecticut or highest state earnings threshold), to offset career expenses and the high costs of managing disability.

WHITE HOUSE & CONGRESS: ACT NOW
**WE WANT JOBS
IN THE NEW RECOVERY!**



Allow participants to benefit from work by eliminating asset building limitations, so that assets saved and acquired are held harmless. Asset development is key to stabilizing financial independence. Establish enrollee-friendly, online wage reporting, tracking, and information services.

- **The SSI program** - Modify the SSI program rules over time for all SSI youth based on CareerACCESS pilot project findings and outcomes. Sunset the program on or before 12 years, depending on objectives being met.

Summary by: World Institute on Disability (WID), National Council on Independent Living (NCIL), and PolicyWorks. Find more information at: www.ourcareeraccess.org.

Related Pending Legislation Before Congress

Achieving a Better Life Experience (ABLE) Act

The *ABLE Act of 2013-2014* will allow individuals and families to save funds in an ABLE Account to better support our health and well-being, our employment, our independent living, and our self-sufficiency over time. NCIL supports passage of the *ABLE Act* this year, which will amend Section 529 of the Internal Revenue Code to make these accounts possible for anyone applying for, or on the Supplemental Security Income program (SSI).

Research shows that living with a long-term disability means having routine, higher, out of pocket costs (Fremstad, 2009). The *ABLE Act* allows families that include someone with a disability to be able to save and pay for these needs.

Civil Rights and the Americans with Disabilities Act ←

Mental Health

Mental health has new prominence in the news and in Washington after multiple mass shootings across the nation. NCIL recognizes that mental illness diagnosis is common - half of Americans can expect a diagnosis during their lifetime. NCIL also recognizes that people with disabilities, including those diagnosed with mental illness, are more likely to become victims than perpetrators of violence.

Since 2012, the Administration and Congress have both focused on legislation to restructure federal mental health laws rather than deal with guns and violence. NCIL has concerns about many of the approaches and the lack of outreach and inclusion in these efforts. The voice of the consumer has been left out of these very important conversations and this cannot be tolerated. NCIL calls on both the Administration and Congress to include persons with disabilities in this most important policy work.



NCIL opposes any legislation or administrative action that continues or strengthens denial of rights based on a diagnosis or disability and any deprivation of liberty based on disability rather than criminal activity.

Strengthening Mental Health in Our Communities Act (H.R. 4574)

NCIL recognizes that reauthorization of Substance Abuse and Mental Health Services Administration (SAMHSA) programs is long overdue. Representative Ron Barber recently introduced *H.R. 4574*, the *Strengthening Mental Health in Our Communities Act*. NCIL supports *H.R. 4574* with the following reforms:

- a majority of consumers on state mental health planning and advisory councils (which are required to review and comment on state community mental health block grant – MHBG plans)
- that each state provide for consumer peer support organizations and / or consumer-run community mental health services in its MHBG plan; and
- that state mental health planning and advisory councils coordinate activities with Statewide Independent Living Councils under section 705 of the *Rehabilitation Act*.



Helping Families in Mental Health Crisis Act (H.R. 3717)

Representative Tim Murphy introduced *H.R. 3717*, the "*Helping Families in Mental Health Crisis Act*" in 2013. This bill would reauthorize the SAMHSA programs without the reforms NCIL supports. It also singles out people who are "disabled" (but not dangerous) for involuntary treatment, including locking them up in wards. The bill also cuts support for advocacy and mental health peer support.

NCIL opposes *H.R. 3717* and other bills that single out people for reduced rights based on disability.

Laws Affecting the ADA

ADA Notification Act of 2013 (H.R. 777)

Commerce, Justice, Science and Related Agencies Appropriations Act (H.R. 4660)

NCIL has vehemently opposed each introduction of the *ADA Notification Act* and other bills limiting our rights or enforcement of our rights. We understand that civil rights are intrinsic to all Americans and that a violation of rights cannot require 'notification' prior to protections. States should address problematic issues within state law; not create additional federal law that cannot be enforced.

More recently, the House passed *H.R. 4660* to appropriate funds for 2015 for the Departments of

Commerce and Justice, Science programs and related agencies. The Committee Report for Title II of the bill includes language under "legal activities" urging the Department of Justice to adjust its enforcement of the *Olmstead* rule under the *ADA*. The Senate must stand by the provisions of its bill, S. 2447. When the House and Senate versions are conferenced, the House Conferees should strike from the report the paragraph relating to enforcement of the *ADA*.

Violence and Abuse

Violence Against Women Act

Although the *Violence Against Women Act* was successfully reauthorized for 5 years in 2013, appropriations are done on a yearly basis. Currently the biggest threat facing survivors with disabilities are the discussions to eliminate targeted funding for specific groups, including people with disabilities. Current thinking would merge several minority groups into one funding group: "underserved populations". This action would take efforts back 12 years, when disability was listed in the underserved population category and the needs of people with disabilities were largely ignored. Those advocating for this bundling of funds and removing designated funding assume that disability issues will be addressed, but historically that did not happen and it is not happening presently.



Domestic violence services, sexual assault programs, police departments, and legal aid agencies must enhance their accessibility and challenge their discomfort working with people with disabilities. In order to put the needs of people with disabilities in the center of what they do, they must have both the commitment and the capacity to do so. A designated grant program within the Office on Violence Against Women encourages commitment and a designated funding line supports the development of resources.

Twelve years ago, before the authorization of the Disability Grant Program, little was being done to ensure equal access to safety, services, and supports for victims with disabilities. Services for victims of violence were inaccessible, providers lacked the cultural competency to work with individuals with disabilities, and misconceptions and stereotypes about victims with disabilities prevailed. Without the designated funding available through the Disability Grant Program, we fear that the progress we've made creating change will be lost, the momentum to establish welcoming, accessible, and integrated services will fade into the background, and survivors with disabilities will once again be met with architectural, attitudinal, communication and societal barriers.

Capital Punishment and People with Intellectual Disabilities

There is concern about the developing trend of states redefining the federal statute that sets the intellectual minimum standard for when the death penalty may be used in sentencing.

According to the ARC of the United States... "Earlier this year, the U.S. Supreme Court agreed to hear *Hall v. Florida*, a death penalty case concerning the definition of "mental retardation" (or

intellectual disability (ID) as it is now called) that states may use in deciding whether an individual with that disability is protected by the Court's decision in *Atkins v. Virginia*. In 2002, the Supreme Court ruled in the *Atkins v. Virginia* case that executing inmates with ID is unconstitutional.”

NCIL supports the federal law and believes that every individual with ID should be protected from the death penalty. We feel that individual state laws, which draw a hardline with IQ ceilings, are unconstitutional and should not be allowed to override federal law. This trend is dangerous and has the potential to influence the national agenda.

Human Trafficking of People with Disabilities

According to the 2012 Trafficking in Persons Report by the Department of State, “persons with disabilities remain one of the groups most at risk of being trafficked. Due to disability-based discrimination and exclusion common in many places, however, governments often ignore this risk factor or fail to make provisions for persons with disabilities as part of anti-trafficking efforts. The stigma and marginalization of a person with disabilities creates a particular vulnerability”.



The Justice Department does not track disability in trafficking statistics. It is essential that disability becomes part of the reporting statistics and that additional research be conducted on the trafficking of individuals with disabilities. The UN Convention on the Rights of Persons with Disabilities (CRPD) addresses trafficking, making ratification an essential first step towards addressing this issue.

Excessive Force by Law Enforcement Against Persons with Disabilities

Across the US, Fourth Amendment rights are being violated by law enforcement and the lives and wellbeing of people with disabilities are being put at risk.

The Center for Public Representation states that there are “significant patterns in police killings of people with psychiatric disabilities”. Reports show that as many as 50% of those shot by police officers are people with mental illnesses.

Despite DOJ's 2006 Law Enforcement Disability Awareness Initiative, law enforcement personnel are not getting the training they need to effectively respond to crimes against or committed by people with disabilities. Our justice system is not holding officers responsible for the injuries and wrongful deaths of people with disabilities. We support the efforts to increase focus on mandatory training of law enforcement on disability issues and feel there is a need for stronger consequences when abuse and harm is caused by law enforcement.

Voting Rights

Election reform continues to be one of NCIL's top priorities and will remain an essential objective of our organization and its members until all barriers to the full participation of people with disabilities in the voting process have been eliminated.

The NCIL Voting Rights Task Force agrees with the recommendations included in the National Council on Disability report “Experience of Voters with Disabilities in the 2012 Electoral Cycle”, which provided a substantive summary of interviews and recommendations to remove the many barriers people with disabilities encounter throughout the voting process. The NCIL Voting Rights Task Force adds that long lines at polling places is discrimination and a barrier to voting for Americans with disabilities.

The voting process must include:

- The right to cast a private and independent vote using reliable and accessible technology,
- Removal of all architectural and physical barriers to polling centers,
- Elimination of difficulty and discriminatory actions towards people with disabilities during the voting process and in polling sites from volunteers and personnel,
- Enforcement by the Justice Department to ensure the rights afforded by America’s voting laws,
- Elimination of staunch and discriminatory voter ID laws such as photo IDs, and
- Removal of state guardianship laws that continue to be barriers in participation of the entire voting process, from registration to casting a vote.



Healthcare and Long Term Services and Supports ←

Ending Medicaid’s Institutional Bias

- NCIL’s advocacy was instrumental in getting the Community First Choice Option included in the Patient Protection and Affordable Care Act. So far, three states (California, Maryland, and Oregon) have implemented the Community First Choice Option.

Eight other states have announced that they are selecting the Community First Choice Option, which should give seniors and people with disabilities in those states a real choice in where they receive long term services and supports:

- Arkansas
- Connecticut
- Montana
- Texas
- Colorado
- Minnesota
- New York
- Washington



This is a tremendous step forward and NCIL members are working to expand the number of states

that are selecting this option. It is clear, however, that not every state will adequately implement the Supreme Court's *Olmstead* decision and ensure that people with disabilities have the right to live and receive services in the most integrated setting. That is why NCIL has worked to develop legislation that addresses Medicaid's institutional bias and requires states to provide alternatives to institutionalization for people with disabilities.

The Community Integration Act (S. 2515) amends the Social Security Act by adding language specific to long term community based supports and services, requiring that individuals who have been deemed eligible to be placed in an institutional setting are provided services and supports they need to live in the community. This is accomplished by requiring states to provide rehabilitative services, assistance with activities of daily living, and health-related tasks to all eligible individuals. The legislation closes loopholes that allow states to limit access to community based services and supports such as waiting lists, cost caps, or other mechanisms. Finally, the legislation requires states to address the need for affordable, accessible, integrated housing.

Reform Medicaid, Don't Gut It!

Medicaid is the public funding stream that provides health coverage for low-income children and adults, as well as long term services and supports for people with disabilities and low income seniors. Over 58 million Americans rely on Medicaid services, and millions more are connected to Medicaid in some way. The House is currently considering legislation that would profoundly impact Medicaid and the systems for providing long term services and supports.

One bill in particular, *H.R. 567, the State Flexibility Act*, would essentially gut Medicaid by converting it into a program of block grants. This bill aims to make Medicaid more efficient by allowing states greater flexibility in how they can use federal funds, but because of the current economic climate, it would instead result in severe cuts to programs and services that are essential for seniors and people with disabilities. This is an unacceptable piece of legislation that will likely die in the Senate if it ever passes the House, and we strongly oppose it.

Congress should implement real Medicaid reform by:

- **Expanding the use of community-based services:** studies have demonstrated that by reducing the over-reliance on institutions and nursing facilities and shifting toward more cost-effective community-based services, states can contain Medicaid spending.
- **Demedicalizing services:** by reducing the reliance on costly medical personnel to provide assistance by allowing attendants to perform these tasks, states could use the same amount of Medicaid funding to support more seniors and people with disabilities living in their own homes.
- **Expanding consumer directed service options:** by empowering people to manage their own services and reducing the need for administrative overhead, states can also reduce Medicaid Expenditures.



→ **Reorganizing Medicaid services to eliminate wasteful bureaucracy:** the current system wastefully organizes services based on diagnosis and age, even though people may have the same functional needs. By organizing services based on functional needs, states can eliminate redundant and needlessly expensive bureaucracies and reduce Medicaid expenditures.

NCIL strongly supports reform of long-term services and supports in order to take the pressure off Medicaid, so that it can better serve the needs of people with disabilities and low income communities. Such reforms should also help ensure that people with disabilities who work are able to get and keep the long-term services and supports they need to be independent. Without such reforms, the Medicaid program will continue to bear the load of long-term service needs for many Americans, who will be forced into a lifetime of poverty to qualify for this assistance.

NCIL will continue to support a plan that addresses these concerns, but cautions that we must not pursue public policy that ensures individuals served in such a program have the opportunity to live in the community while Medicaid recipients are relegated to nursing facilities and other institutions.

Prohibiting Discrimination Based on Disability in Healthcare

Comprehensive implementation and enforcement of nondiscrimination laws, regulations, and principles will help reduce healthcare disparities based on disability and reduce the impact of societal prejudice and negative stereotypes on access to quality healthcare. Discrimination based on disability should be addressed through a combination of protection and advocacy enforcement efforts, regulatory development focused on preventing disability-based discrimination, and policy work guided by the principle “nothing about us without us.” Among the most urgent areas of concern are:

- discrimination in organ transplants and related services;
- discrimination in policies and procedures concerning decisions to withhold or withdraw life-sustaining treatment, including but not limited to advance care planning that discourages the choice to receive life-sustaining treatment based on messages suggesting that it is “better to be dead than disabled”;
- discriminatory “futile care” policies allowing healthcare providers to use quality of life judgments to overrule the decision to receive life-sustaining treatment made by individual, surrogate, or advance directive;
- discriminatory relaxing of constitutional and statutory constraints on the power of guardians to withhold or withdraw life-sustaining treatment from people with disabilities; and
- discriminatory rush to judgment and denial of life sustaining treatment of newly injured persons based on hasty and unsupportable diagnosis of “persistent vegetative state” (PVS) earlier than 90 days for an anoxic brain injury, or one year for a traumatic brain injury, and before careful testing consistent with guidance from research studies on misdiagnosis of PVS.



Assisted Suicide

NCIL has long opposed the legalization of assisted suicide. Equal rights include equal suicide prevention. Oregon, Washington and, recently, Vermont have statutes legalizing assisted suicide. The Montana Supreme Court has declared that the victim's consent to assisted suicide can be a defense to homicide charges, and a New Mexico district court has declared assisted suicide a state right, but the state is appealing that ruling.

In Oregon and Washington, data indicates that people request assisted suicide for reasons directly related to disability-based oppression, such as feelings of loss of autonomy and dignity, and feelings of being a burden on others. These factors are the direct result of both negative stereotypes and public policies that deny people the consumer-controlled long term services and supports that they need to feel respected and valued throughout life to a natural death.



Assisted suicide laws set up a double standard whereby most suicidal people get suicide prevention while certain others get suicide assistance. For those who are old, ill, or "disabled enough", society will not only agree that suicide is appropriate but will provide the lethal means to complete the act. This form of discrimination violates the *ADA* and must be opposed.

During 2014, disability rights and independent living advocates have been instrumental in defeating assisted suicide legislation in Connecticut, New Hampshire, Massachusetts and New Jersey.

Competitive Bidding

The Centers for Medicare and Medicaid Services (CMS) created the Competitive Bidding program for purchasing Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS). The program establishes rates for certain categories of equipment, but it does not require vendors to fulfill their contracts. It was intended to cut costs and reduce billing discrepancies. It has instead resulted in a lack of local providers and delays in deliveries, which have lengthened hospital stays and driven costs up.

Critically missing is an independent evaluation of the program's impact on beneficiary health. With the program set to apply competitive bidding prices to the rest of the nation in 2016, Members of Congress need a much better understanding of the impact this program has had if changes should be made to ensure improved care outcomes and system efficiency. NCIL believes a full review of the program should be available before the program expands nationally in 2016 to avoid preventing people with disabilities from having access to vendors of critically needed supplies, especially in the rural areas of our nation.

Because of the problems we have already seen, NCIL has supported a number of measures aimed at ending the CMS Competitive Bidding program, and supports similar measures in this Congress. Such legislation can help eliminate the dangers created by this program, but it will never pass unless members of the House and Senate understand that the program is actually reducing access and support for their constituents with disabilities.

Transportation: The Life Blood of Society ←

In today's society, economic competitiveness and success in the 21st century is dependent upon revolutionary ideas and solutions providing Americans, including individuals with disabilities, with accessible transportation systems that connect our cities, regions, and rural areas.

NCIL strongly supports and advocates the integration of individuals with disabilities into society through the design of universally accessible transportation systems and pedestrian safety initiatives.

NCIL demands that all new and innovative public and private transportation systems that transfer passengers with disabilities be universally accessible.

Given the wide variety of pedestrian transportation options, pedestrian safety and rights-of-way must be designed to maximize accessibility to all community-based services, programs, activities, and employment opportunities that are available to the general public.



There are three areas of concentration that will maximize societal and community integration, involvement, and participation by individuals with disabilities:

- **Rural passenger transportation systems, including transportation systems between one municipality and another, must be of universal and accessible design:** NCIL strongly supports increased availability and access to affordable and accessible rural transportation options that connect municipalities to one another.

In order to maximize continuity and efficiency of such a transportation system, a coordinated plan is required. Within such a coordinated plan, this rule of accessibility must also apply to small airplanes and any other method of passenger transportation.

- **Livable communities:** Safe and accessible rights-of-way are essential elements of community life. All pedestrians must be able to travel in safety with accessible rights-of-way. It is of equal imperative to maximize accessibility and safety for pedestrians as it is for passengers.
- **Private transportation services:** Legislation is needed to increase the number and availability of accessible vehicles within the private transportation industry, including taxis, limousines, shuttle service, car rentals, buses, trains, etc.

Increased investment in the current transportation system alone will not solve the problems that affect the lack of continuous, seamless, accessible and affordable transportation services.

Americans, especially individuals with disabilities, are negatively affected on a daily basis by the lack of accessible and affordable transportation.

Americans with disabilities demand transportation options that are affordable and accessible. We must embrace innovative ideas that serve to enhance and maximize community integration, connectivity, and independence.

NCIL believes that Congress must move toward a 21st century system that focuses on

accountability and results while creating jobs, providing access to opportunity for all Americans (including individuals with disabilities), reducing carbon emissions and our dependence on foreign oil, and improving America's economic competitiveness.

When America honors the equal access intent of the *Americans with Disabilities Act* by ensuring accessible and affordable public and private transportation systems, people with disabilities will have the same travel options available to everyone else, allowing them to attend school, maintain employment, attend social and faith functions, travel within the communities of their choice, and fully participate in the American Dream.

Toward maximizing accessible transportation within the private transportation industry, NCIL supports a federal standard requiring all taxi fleets in America to be wheelchair accessible and universally designed as soon as feasibly possible and encourages the Access Board to develop and adopt a minimum standard of universal design for all taxicabs.

Allowing Local Control of Federal Transit Funds Act (Not Yet Introduced in the 113th Congress)

Local transit systems need and require flexibility with federal funds through an incentive program where state and local governments will be able to use a percentage of their funds for operations. NCIL supports this legislative idea because it will reduce fare increases and cuts to vital public transportation services, which are widely used by people with disabilities.

Moving Ahead for Progress in the 21st Century (Not Yet Introduced in the 113th Congress)

Moving Ahead for Progress in the 21st Century (MAP21) authorizes funds for highways, highway safety & transit programs, and paratransit, including fixed route and demand-responsive services. Reauthorization of this legislation is critical for the provision of equal access to public and private transportation in accordance with the *Americans with Disabilities Act*.

Non-Discrimination on the Basis of Disability in Air Travel

NCIL is pleased to see that the *Air Carrier Access Act* might cover kiosks owned by airports in addition to those owned by carriers under new proposed rules by the Department of Transportation. However, this proposal should include an explanation that public airports otherwise covered by the *ADA* or the *Rehabilitation Act* are still accountable under those laws, which may be enforced by private parties.

NCIL supports many of the DOT's substantive accessibility proposals for both websites and kiosks. We agree that the Website Content Accessibility Guidelines (WCAG) 2.0, Level AA, are the appropriate technical standards for websites. However, we strongly believe that it must be paired with a performance standard to maximize accessibility and usability. Technical standards alone will not ensure usability. NCIL recommends adding a performance standard that will guarantee that individuals with disabilities have the same access and website experience as users without disabilities and substantially similar ease of use. Mandates for accessibility of websites and kiosks are long overdue. Simultaneously, DOT must not make the same mistake by neglecting to include mobile devices and apps. It is imperative that we ensure access to the most advanced and

accessible communication technologies.

Air Carrier Access Amendments Act (S. 556)

Sponsored by Senator Tom Harkin, the *Air Carrier Access Amendments Act* requires domestic and foreign air carriers to ensure that all visually displayed entertainment programming available to flight passengers is accessible to individuals with disabilities, including by making available open captioning (openly displaying text on a shared video monitor), closed captioning (displaying text through an individual video monitor), and video description (audio-narrated descriptions through individual or shared monitors) for individuals who are deaf, hard of hearing, blind, or visually impaired, as the case may be.

It requires in addition that all individual video displays to flight passengers of entertainment programming or information that are operated primarily by use of touchscreens or other contact-sensitive controls include a mechanism allowing individuals with disabilities to operate such displays independently in accordance with standards the Architectural and Transportation Barriers Compliance Board shall establish.

S. 556 Makes certain penalties under the *Americans with Disabilities Act of 1990* available to persons aggrieved by an air carrier's failure to comply with this Act. For these reasons, NCIL strongly supports this legislation.

Protecting and Expanding Our Housing Opportunities ←

NCIL supports initiatives to increase accessible, affordable, healthy / non-toxic, decent, safe, and integrated housing. NCIL is a cross-disability organization and applies the term 'accessible' broadly, emphasizing physical accessibility, accommodations for persons with sensory (visual or hearing), emotional, developmental and intellectual disabilities, and persons with chemical and electrical sensitivities. The need for housing that accommodates a wide-range of disabilities is increasing due to community living options replacing costly and unjust institutionalization, many veterans returning with disabilities, the high rate of homelessness among people with disabilities, and aging of the population.



Housing Funding

Housing affordability continues to be a serious challenge for many households with a person with a disability across the country, and funding has not kept up with the increasing number of people seeking housing assistance. In the face of increasing costs of providing housing assistance and the higher need for housing assistance, funding has been stagnant - or worse.

The Fiscal Year 2015 appropriations process is underway at the time of the draft of this section, and

may not be fully agreed upon yet. It is likely that there will need to be agreement between the House of Representatives and the Senate on the final numbers. The proposed appropriations numbers by the President, the House, and the Senate all are under the budget levels of past years, and represent a challenge for advocates fighting for increased housing opportunities.

An area of concern is the continuing loss of tenant-based vouchers. The Center on Budget and Policy Priorities project, using December 2012 numbers of vouchers, a cumulative loss of 80,000 vouchers under the House budget, and 76,000 vouchers under the Senate budget. In a time of economic hardship, the loss of rental assistance funding hurts many families and individuals. Another area of concern is the lack of funding for Fair Housing programs with the President requesting \$71 million. The Senate would keep it at the FY14 level, \$66 million, but the House cut this deeply to \$46 million. Discrimination against persons with disabilities continues to be a top cause of Fair Housing complaints.

Funding for the National Housing Trust Fund

Congress created the National Housing Trust Fund (NHTF) in 2008 with initial funding intended to come from a very small amount (0.042%) of new business purchases of Fannie Mae and Freddie Mac (the Government Sponsored Enterprises, or GSEs). Soon after the NHTF was created, the real estate market crashed. The law allowed for putting funding for the NHTF on hold if necessary to preserve the health of the GSEs. To date no funding has been forthcoming, but because the GSEs are now making record profits, advocates are pressing them to begin contributing to the NHTF. No Congressional action is required for the GSEs to begin funding the NHTF. Advocates should support *H.R. 1213, the Common Sense Housing Investment Act* (more information below).

Full funding of the NHTF has been a NCIL priority since its inception. The NHTF will create and preserve housing principally for extremely low income Americans, which disproportionately includes households with a member who has a disability.

Common Sense Housing Investment Act (H.R. 1213)

H.R. 1213 would capitalize the NHTF through reforms to the Mortgage Interest Deduction (MID) that homeowners receive if they itemize on their tax returns. Currently the deduction, estimated by the Office of Management and Budget to cost more than \$100 billion, is the largest housing subsidy. Yet the MID disproportionately benefits households that least need a subsidy. The reforms, as introduced by Representative Ellison of Minnesota, would convert the MID to a 15% nonrefundable tax credit on the interest paid by homeowners who have mortgages up to \$500,000 on their primary residence and one other house. The Mortgage Interest Deduction itself would be phased out over five years as it is replaced by the tax credit. This means more homeowners (maybe as many as 16 million more) with mortgages would benefit because those who do not file itemized tax returns would get a tax break too.

The bill would also lower the cap on mortgage eligibility for the tax break from \$1 million to \$500,000, creating an estimated \$200 billion over ten years that could be directed toward the NHTF and other housing programs. NCIL joins the National Low Income Housing Coalition and other

housing advocates in the United for Homes campaign to support this legislation, which would benefit extremely low income households.



Eleanor Smith Inclusive Home Design Act (H.R. 2352)

The *Eleanor Smith Inclusive Home Design Act* requires that newly constructed, federally assisted single family houses and town houses conform to visitable standards, which include enough accessibility for a guest with mobility disabilities to visit. Those units would conform to ANSI 1005 Type C Visitable Units. These features will also make housing available to persons with mobility disabilities, prevent unnecessary expenses for renovations, and will allow seniors to age in place, negating the need for costly institutionalization.

Housing Fairness Act of 2013 (H.R. 285)

NCIL opposes housing discrimination, particularly as it pertains to individuals with disabilities. According to the National Fair Housing Alliance, 44% of all housing discrimination complaints were connected to disability concerns in 2011. This legislation would provide more support to address the housing discrimination through increased funding for education and enforcement. It also would put in place stronger reporting requirements for HUD. NCIL supports *H.R. 285*.

Moving to Work (H.R. 4868; Possible Amendment to Senate Appropriations)

Moving to Work is a demonstration program allowing participating Public Housing Authorities (PHAs) greater flexibility in operating programs and services, with exemptions from many regulations and rules. There are 38 PHAs participating in the Moving to Work pilot demonstration. Yet even though the demonstration program has been authorized since 1996, there never has been a thorough examination of the Moving to Work programs, with a lack of sufficient data to evaluate it. The lack of data has been a concern of HUD's Inspector General and the Government Accountability Office. Yet Senators Sherrod Brown (D-OH), Michael Bennet (D-CO), and Rob Portman (R-OH) are attempting to file an amendment to the Senate HUD funding bill to expand the number of Moving to Work agencies by ten. Moving to Work Expansion was also introduced in the House on June 12 by Representative Stivers. NCIL opposes the expansion of Moving to Work until sufficient data exists to evaluate the pilot program.

Veterans Issues ←

NCIL supports efforts to provide all Veterans and their families with services and benefits in the most effective and efficient manner possible in recognition of their service and sacrifice. Specifically, NCIL supports:

- Reform by the VA and Congress for the Veterans Health Administration (VHA) to process appointments in a timely manner.

- Reform by the VA and Congress for the Veterans Benefits Administration (VBA) claims process to ensure consistency, true reforms with timely processing, and adjudication of claims.
- A focus by the Department of Defense (DOD), VA, and Congress to provide proper supports for veterans who have PTSD, Traumatic Brain Injury, and mental health issues as a result of service.
- Transition from military to civilian life involves the veteran's ability to work competitively. Congress must provide funding for education, employment, and training programs to meet increasing needs.
- Congress must ensure that the Veterans Health Administration (VHA) receives appropriate and sufficient funding for veterans' healthcare while sustaining quality and satisfaction. This would include continued expansion of community-based living options such as Veterans Directed Home and Community Based Services, Medical Foster Homes, and the *Family Caregivers Act*.
- Our President and Congress should continue to address the issue of current homeless Veterans and support efforts to prevent homelessness.
- Congress must ensure that existing benefits received by veterans and their families are not reduced. There should be no reduction in future benefits for veterans and their families.
- Since September 2001 there have been benefits created specifically for post-9/11 military members and deservedly so. It is time to examine the availability of those benefits for veterans who served pre-9/11.
- There are factors affecting the daily living of families and veterans that require the services they need to be available in the communities where they live. There needs to be continued effort by Congress, DOD, and the VA to engage and collaborate with community-based organizations like Centers for Independent Living, which stand ready to continue serving veterans and their families.

NCIL supports the following bills from the 113th Congress and urges swift action on these measures.

Workable Solutions: Reducing the Backlog and Creating Better Access

- The *Quicker Veterans Benefits Delivery Act (H.R. 1980)* will establish workable solutions by maximizing the use of private medical evidence to conserve VA resources and allowing the VA the authority to award partial or temporary benefits when clearly supported by evidence. *H.R. 1980* is awaiting House action in Subcommittee.
- The *Disabled Veterans' Access to Medical Exams Improvement Act (H.R. 2423)* provides VA contract physicians the ability to conduct disability examinations at any location in any state on behalf of the VA. This legislation extends the 2013 sunset date to 2016 and expands the successful pilot program to five more regional offices. This legislation was passed by the House as Section 201 of *H.R. 2189* and is awaiting Senate action.
- The *Access to Veterans Benefits Improvement Act (H.R. 733)* provides access to VA case-tracking information for accredited individuals tasked with helping veterans. VA trained and accredited County Veteran Service Officers (CVSOs) have explained that they cannot answer simple questions about VA actions because they lack access. This will ease the administrative

burden on VA employees, allowing their focus to remain on claims processing. This legislation was passed by the House as Section 3 of *H.R. 1405* and is awaiting Senate action.

Providing Reservists Improved Opportunities for Careers in the Federal Workforce

- The *Military Reserve Jobs Act of 2013 (H.R. 2785)* provides qualified members of the Military Reserve Components a tiered preference in hiring for civil service jobs. For many veterans, careers with the federal government present a fantastic opportunity to continue their lifelong mission of public service. *H.R. 2785* is awaiting House action in Committee.

Fighting for Those Improperly Discharged by DOD with False Psychiatric Disorders

- The *Servicemembers Mental Health Review Act (H.R. 975)* will force DOD to review and correct improper personality disorder discharges for over 31,000 veterans and ensure those with PTSD get the mental health care they need and benefits they have earned. *H.R. 975* is awaiting House action in Subcommittee.



Righting Two Wrongs for Military Retirees

- The *Military Retirement Restoration Act (H.R. 3793)* repeals the onerous cost-of-living-adjustment (COLA) cuts for military retirees under age 62 that were proposed by Representative Paul Ryan (R-WI) and included in the budget agreement. *H.R. 3793* is awaiting House action in Subcommittee.
- Legislation to honor service of the Guard-Reserve Retirees (*H.R. 679*) would grant full “veteran” status to members of the Guard and Reserve components who served at least 20 years but have not been called up for federal active duty. This recognition does not entitle members additional benefits; it simply legitimizes the honor they have earned. This legislation was passed by the House as Section 2 of *H.R. 1405* and is awaiting Senate action.

Doing What’s Right for Our Navy Veterans Exposed to Agent Orange

- The *Blue Water Navy Ship Accountability Act (H.R. 1494)* directs DOD to review the logs of each Navy ship operating in the waters near Vietnam between January 1962 and May 1975. This will ease the burden of wrongfully denied claims for Vietnam Veterans with presumptive Agent Orange conditions because of classified logs. This legislation was passed by the House as Section 301 of *H.R. 2189* and is awaiting Senate action.
- The *Blue Water Navy Vietnam Veterans Act of 2013 (H.R. 543)* clarifies presumptions related to veterans who served in the Republic of Vietnam by including its territorial seas for the VA’s service connection to Agent Orange. *H.R. 543* is awaiting House action in Subcommittee.

Protecting Children of Veterans Who Gave up So Much for Our Country

- The *Children’s Protection Act of 2013 (H.R. 288)* allows children of veterans eligible for medical care under the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) to continue coverage up to age 26. The Patient Protection and Affordable Care Act left a coverage gap for children of eligible veterans from 23 to 26 years of age. *H.R. 288* is awaiting House action in Committee.

Education ←

All students with disabilities have the right to an equal education. Furthermore, students with disabilities must be assured a high quality education that provides the opportunity to acquire the same knowledge and skills as their peers through participation in the general curriculum and access to teachers qualified to teach students with diverse learning needs.

Implementation and enforcement of the *Individuals with Disabilities Education Act (IDEA)* and the *Elementary and Secondary Education Act (ESEA)* must be improved.

Reauthorization of *ESEA* provides Congress with the opportunity to reaffirm and strengthen provisions that will ensure that all students receive a quality education. Specific items that need strengthening include:

- Empowerment of students with disabilities with information about education rights, services, and expectations
- Integration of academic instruction, school activities, and planning to promote successful transition from school to adult life
- Accountability standards focused on improving the graduation rate of students with disabilities
- Integration of *IDEA*, *ESEA*, and Section 504 of the *Rehabilitation Act* requirements
- Development of standards to ensure all students have full, meaningful access to quality instruction in the regular curriculum
- Assessment programs aligned with the curriculum and used as a means to make schools accountable to students and their families
- Requirements for disaggregation of assessment data and use of the data to improve educational opportunities

Keeping All Students Safe Act (H.R. 1893)

Restraining and secluding students must be ended. The Government Accountability Office reported widespread misuse of restraint and seclusion. The *Keeping All Students Safe Act, H.R. 1893*, will protect from restraint and seclusion, specifically:

- ban restraint / seclusion except in emergencies where someone is in danger of physical harm;
- require that parent notification if a student is restrained / secluded on the same day that the event occurred;
- ban restraints that impede breathing, mechanical restraints, and chemical restraints; and
- prevent restraint / seclusion from being used when less restrictive alternative would eliminate any danger.



Available and Accessible Technology ←

NCIL strongly advocates for access to mainstream and assistive technologies (AT) that enable and enhance independence for people with disabilities through supporting the principles of Universal Design, inclusion, consumer control, and peer support as they apply to the use, development, and delivery of mainstream and assistive technologies.

People with disabilities are best served by available and affordable “hands-on” exposure to technology. NCIL encourages the use of Universal Design to make technology inclusive and accessible to people with disabilities and supports legislation and efforts that develop and enforce access standards in existing and emerging technologies.

Assistive Technology Act (Not Yet Introduced in the 113th Congress)

NCIL supports funding of the *Assistive Technology Act* by Congress because it assists consumers in learning about, experimenting with, and acquiring assistive technology in pursuit of their independence.

Ten years after the 2004 amendments, many of the state AT Programs, not including the territories, have yet to receive the \$410,000 minimum grant award authorized in the *Assistive Technology Act*. Many states have no alternative finance program or have a limited program. By supporting the Alternative Financing Programs and increasing its funding, Congress can help people with disabilities purchase the technology they need.

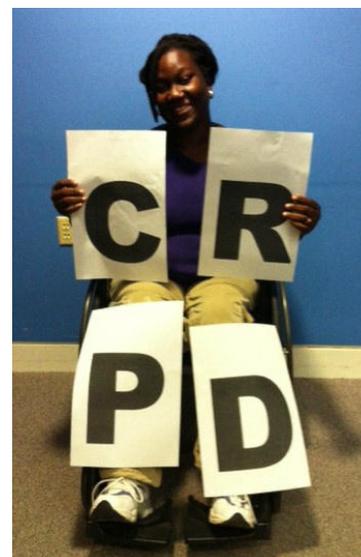
NCIL was encouraged by Congress’s support of the *Assistive Technology Act* by infusing an additional two million dollars into the *Act* to support Alternative Finance Programs and strengthen consumer control measures for new entities competing for those funds.



Convention on the Rights of Persons with Disabilities ←

Status of the CRPD in the United States

The United States signed the Convention on the Rights of Persons with Disabilities treaty in 2009 and transmitted it to the U.S. Senate for their advice and consent for ratification in May of 2012. The U.S. International Council on Disabilities (USICD) has led the community’s call for ratification (expressed by over 800 disability, faith, business, and veteran organizations), rallying Senate support, and working with leaders like Senator Bob Dole to ensure bipartisanship and secure the 2/3 Senate vote needed. On December 4, 2012, the United States



Senate considered the ratification of the CRPD but fell short of the super-majority vote required, much due to falsehoods spread by opponents of human rights treaties.

In 2013, a new process in the Senate Foreign Relations Committee was initiated under Chairman Robert Menendez' leadership. Two successful hearings were conducted that explored multiple topics both within the treaty and concerning broader U.S. foreign policymaking. Following these two successful hearings, active discussions ensued between the Committee Ranking Member and Chairman to develop consensus language for a package of reservations, understandings, and declarations (RUDs) to attach to our ratification. USICD's close monitoring of the process encouraged us that though this would be a lengthy process, it was one that was moving forward.

The community was therefore angered and dismayed by a statement by Ranking Member Corker on the eve of the Christmas recess of his unwillingness to support the treaty, citing his belief that no RUDs would bring him comfort with ratification. This was particularly surprising because legal scholars invited by Senator Corker to testify at the hearings stated that federalism and other concerns expressed by Senator Corker could be adequately addressed by appropriate RUDs.

The community coalition immediately launched a campaign to rebut his arguments, to activate grassroots pressure on the Senator to return to the negotiating table, and to elevate in the media leading advocates so that we keep attention on this important treaty.

Advocates understand that other potential supporters of the treaty are not following Senator Corker's lead, but rather are waiting to see the final package of RUDs before making a decision. Committee Chairman Menendez has told his Senate colleagues that the treaty remains a priority for him and that he intends to move it forward to a mark-up and vote out of Committee and to the full Senate in 2014.

The campaign for ratification is strong because of disability and allied supporters across the country. Now is the time we must show this strength by calling our Senators to express our support and by expanding our grassroots activities. Letters to the editor, local educational activities, training your Center's members on the treaty: these are excellent ways to keep the movement alive.

The website www.disabilitytreaty.org is easy to share with our friends and family. It provides one-stop resources for taking action!



The Treaty Needs *Your* Voice

Grassroots support will continue to be vital in order to ensure widespread Senate support to ratify this landmark treaty. NCIL supports the U.S. ratification of the CRPD, and is actively working with USICD to raise awareness and understanding of this treaty.

Together, the disability community has renewed their call for U.S. ratification and is working on a stronger, even more robust campaign in 2014.

USICD offers a speakers bureau that connects CRPD presenters to diverse audiences. Anyone who is interested in a presentation on the treaty or would like to be involved in the grassroots effort to advocate for ratification is encouraged to contact USICD's Disability Rights Program Coordinator, Eileen Dombrowski at edombrowski@usidc.org or visit www.disabilitytreaty.org.



Legislation NCIL Supports

- Achieving a Better Life Experience (ABLE) Act
- Strengthening Mental Health in Our Communities Act (H.R. 4574)
- The Community Integration Act (S. 2515)
- Allowing Local Control of Federal Transit Funds Act (Not Yet Introduced in the 113th Congress)
- Moving Ahead for Progress in the 21st Century (Not Yet Introduced in the 113th Congress)
- Non-Discrimination on the Basis of Disability in Air Travel
- Air Carrier Access Amendments Act (S. 556)
- Common Sense Housing Investment Act (H.R. 1213)
- Eleanor Smith Inclusive Home Design Act (H.R. 2352)
- Housing Fairness Act of 2013 (H.R. 285)
- Legislation to Support Veterans from the 113th Congress:
 - The Quicker Veterans Benefits Delivery Act (H.R. 1980)
 - The Disabled Veterans' Access to Medical Exams Improvement Act (H.R. 2423)

- The Access to Veterans Benefits Improvement Act (H.R. 733)
- The Military Reserve Jobs Act of 2013 (H.R. 2785)
- The Servicemembers Mental Health Review Act (H.R. 975)
- The Military Retirement Restoration Act (H.R. 3793)
- Legislation to honor service of the Guard-Reserve Retirees (H.R. 679)
- The Blue Water Navy Ship Accountability Act (H.R. 1494)
- The Blue Water Navy Vietnam Veterans Act of 2013 (H.R. 543)
- The Children’s Protection Act of 2013 (H.R. 288)
- Keeping All Students Safe Act (H.R. 1893)
- Assistive Technology Act (Not Yet Introduced in the 113th Congress)
- Reauthorization of:
 - Elementary and Secondary Education Act
 - Substance Abuse and Mental Health Services Administration (SAMSHA) NCIL supports reauthorization only with the requirements listed on page 8 of this booklet.

Legislation NCIL Opposes

- Helping Families in Mental Health Crisis Act (H.R. 3717)
- State Flexibility Act (H.R. 567)
- ADA Notification Act of 2013 (H.R. 777)
- Commerce, Justice, Science and Related Agencies Appropriations Act (H.R. 4660)
- Moving to Work (H.R. 4868; Possible Amendment to Senate Appropriations) - NCIL opposes the expansion of Moving to Work until sufficient data exists to evaluate the pilot program.
- Any legislation that:
 - Attempts to abolish the National Housing Trust Fund
 - Continues or strengthens lists of people with mental illness and any deprivation of liberty based on disability rather than criminal activity
 - Block Grants Medicaid
 - Legalizes assisted suicide
 - Requires photo identification to vote

About the National Council on Independent Living

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

Mission

NCIL advances Independent Living and the rights of people with disabilities.

Vision

The National Council on Independent Living envisions a world in which people with disabilities are valued equally and participate fully.

History

Founded in 1982, the National Council on Independent Living is one of America's leading and the oldest cross-disability, national grassroots organization run by and for people with disabilities.

We represent Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other disability rights organizations serving hundreds of thousands people with disabilities in every state and territory of the country.

An outcome of the national Disability Rights and Independent Living Movements, NCIL was founded to embody the values of disability culture and Independent Living philosophy, which creates a new social paradigm and emphasizes that people with disabilities are the best experts on their own needs, that they have crucial and valuable perspective to contribute to society, and are deserving of equal opportunity to decide how to live, work, and take part in their communities.

Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to affect change.

NCIL promotes a national advocacy agenda set by its membership and provides input and testimony on national disability policy.

NCIL works with people with disabilities and other important community organizations concerned with the civil and human rights of the disability community to advocate for crucial legislation that gives legal standing to the rights of people with disabilities and expands the possibility for full integration and equal opportunity.



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