



## Legislative & Advocacy

### Priorities Guide

Summer 2015



## *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 2015 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 & Opportunity Act* has been signed into law and is now headed into the implantation stage. *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



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## The Independent Living Program ←

NCIL is pleased with the passage of *Workforce Innovation and Opportunity Act (WIOA)* and reauthorization of the *Rehabilitation Act* contained therein. This historic bill created the Independent Living Administration (ILA), where NCIL advocates believe that the Independent Living Program will flourish. Centers for Independent Living stand ready to take on the challenges and opportunities of integrating the additions and changes included in *WIOA*. In order to effectively carry out the additional core services as authorized in this legislation and to strengthen America's Independent Living Program, it has been determined that additional funding of \$200 million will be required.



**We are requesting \$200M in additional funding in the 2016 budget for the Independent Living line item.**

Centers for Independent Living (CILs) are grassroots, advocacy-driven organizations run by and for people with disabilities. CILs envision a society in which people with disabilities are valued equally and participate fully. In order to accomplish this vision, CILs support consumers moving out of nursing homes and into the community, and advocate for individuals facing discrimination in employment, education, housing, transportation, and healthcare to ensure equal opportunity for people with disabilities as citizens of our democratic nation.

The additional core service authorized by *WIOA* in Title V is **Transition**; as defined:

- a) Facilitate the transitions of individuals with significant disabilities from nursing homes and other institutions to home and community based residences;
- b) Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individual may remain in the community; and
- c) Facilitate the transition of youth (including students) who are individuals with significant disabilities, who are eligible for individualized education programs under section 614(d) of the Individuals with Disabilities Education Act (20 U.S.C. 1414(d)), and who have completed their secondary education or otherwise left school, to post-secondary life, including employment.



The Independent Living Program has had tremendous influence for systems change in the delivery of cost-effective long-term care services using home and community-based services and transition of youth. For decades, the Independent Living Program has been woefully underfunded and has not received additional funding. Conversely, Vocational Rehabilitation agencies routinely receive

increases of \$365M in COLA every year. Due to state budget constraints, state VR agencies have returned over \$80M to the Treasury because they are not able to match with state funds. Clearly, investing in Centers for Independent Living makes sense.

This \$200M funding request will restore devastating cuts to the Independent Living Program, make up for inflation costs, address the increased demand for independent living services, and fund transition, the new core service.

According to data collected by the Rehabilitation Services Administration, during fiscal years 2008-2010, Centers for Independent Living:

- Provided the core services of advocacy, information and referral, peer support, and independent living skills training to over 3.7 million individuals with disabilities;
- Attracted over \$910 million through private, state, local, and other sources, and;
- Moved 10,711 people out of nursing homes and institutions, saving states and the federal government nearly \$194 million, not to mention improving people's quality of life.

In that same period, CILs provided other services to over 764,000 individuals with disabilities in their respective communities that included:

- Personal assistance services to nearly 260,000 people with disabilities;
- Housing, home modification, and shelter services to nearly 135,000 people seeking to secure accessible, affordable, and integrated housing;
- Assistance with assistive technology for 129,000 people with disabilities;
- Vocational and employment services to 87,000 people with disabilities;
- Transportation services to over 79,000 people with disabilities;
- Services to over 43,000 youth with disabilities, and;
- Preventative services for over 29,000 people with disabilities to prevent additional or increased severity of an existing disability.

Independent Living saves taxpayer dollars through home and community-based services (HCBS). Home and community-based services, accessed through Medicaid or the private sector, allow people with disabilities (including the ever-growing senior population) to remain in their homes rather than living in nursing homes or other institutions. HCBS Medicaid Waivers allow recipients to spend their Medicaid funds on case management, home health aides, personal care attendants, health, and other services. According to research funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and the Kaiser Commission on Medicaid and the Uninsured In 2006:

- Medicaid HCBS expenditures for personal care services, home health, and 1915c waivers were \$39 billion;



- Medicaid HCBS waiver expenditures were \$25 billion;
- Medicaid institutional costs were about \$60 billion;
- National average waiver costs per participant were \$43,039 compared with \$125,019 in institutional costs;
- After including average Community Living Costs of \$14,308 a year, waiver recipients spent \$67,672 less than a resident in a facility;
- Including average Community Living Costs (room, food and other), waiver recipients spent \$44,992 a year, compared to nursing homes costs of \$63,095 ;
- Community-based services are 29% - 21% less expensive than nursing homes, saving taxpayers \$18,103 a year per participant.



The President, OMB, and Congress want federal programs to measure their outcomes, not just their activities or outputs, and Centers for Independent Living agree. Our network of local CILs, funded by the Department of Education to help persons with disabilities remain as independent as possible, agrees that programs cannot improve unless they know their current effectiveness. On their own initiative, CILs have worked with an independent evaluator for the past four years to develop ways to measure their outcomes, and they have now succeeded. This is a rare and exciting accomplishment for a federal program.

The National Council on Independent Living has led a nationwide effort to develop outcomes, indicators, measurement tools, and ways to gather, analyze, and interpret outcome data. The Rehabilitation Services Administration within Education and all segments of the Independent Living community of practice have been closely involved at every step. CILs have field-tested their outcomes for each of the past two years. The findings from 2011 are presented below.

#### What did we learn about Centers for Independent Living?

- 85% of at-risk clients are kept out of institutions
- 30% of institutionalized clients move back into the community
- 72% of callers receive the information they requested
- 52% of callers use a new resource they learned from the Center
- 70% of all clients have new skills, knowledge, or resources because they contacted the Center
- 51% are more independent as a result of using Center services
- 58% are now able to speak up for themselves
- Most CILs also identify barriers and problems in their communities, develop plans to address them, and successfully engage with decision-makers

NCIL respectfully requests your careful consideration to increase funds for the Independent Living line item for the 2016 budget.

## *Protecting and Expanding Our Housing Opportunities* ←

NCIL supports initiatives to increase accessible, affordable, healthy / nontoxic, decent, safe, and integrated housing. NCIL is an inclusive cross-disability organization and applies the term 'accessible' broadly, emphasizing physical accessibility, accommodations for persons with sensory disabilities (visual or hearing), mental illness, 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 (H.R. 2557)**

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 recent budgets passed by Congress has some housing programs funded under the budget levels of previous years, and represents a challenge for housing opportunities for people with disabilities. The President has proposed significant increases in 2016 allocations for housing.

As of the deadline for the policy booklet, the House of Representatives passed their Transportation, Housing and Urban Development and Related Agencies (THUD) bill, *H.R. 2557* but the Senate has yet to take up discussions on THUD appropriations. The House has made some devastating changes that NCIL opposes.

The House budget would decimate Fair Housing enforcement efforts. Funding for Private Enforcement Initiatives was eliminated. This would remove Fair Housing enforcement activities in many communities. Fair Housing complaints involving people with disabilities are nearly half of all complaints. HUD does not have sufficient funding or staff to take on all of the discrimination complaints that PEI agencies routinely investigate. Furthermore, it prohibits HUD from spending money on implementing the Affirmatively Furthering Fair Housing regulations which are necessary to move the nation toward increased integration.

The House budget underfunds the renewals of both housing choice vouchers and project-based rental assistance. It cuts the HOME budget (see Trust Fund section below) and cuts the public housing capital programs.

Advocates should work with Senators to oppose any language in the Senate version which reflects the House cuts and prohibitions. Advocates should work with both chambers to ensure that the final reconciled bill does not keep the program cuts and the diversion of the National Housing Trust Fund funding (see page 9).



## 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). The Trust Fund would benefit households with extremely low income and is targeted at renters. NCIL believes that the Trust Fund would have a major impact on housing assistance for people with disabilities. Soon after the NHTF was created, the real estate market crashed, causing the Federal Housing Finance Agency to put funding for the NHTF on hold to preserve the health of the GSEs. In December 2014, the Federal Housing Finance Agency sent a letter to Fannie Mae and Freddie Mac ordering them to start allocating funds toward the Trust Fund. Funding currently would start in 2016. Unfortunately, an amendment was inserted into the House THUD bill that would divert the Trust Fund monies into the HOME program, and furthermore, prohibit the Trust Fund from receiving any other sources of revenue. NCIL opposes any attempt to defund the Trust Fund, or to block HUD from administering the Trust Fund.



## Mortgage Interest Deduction Reform (*H.R. 1662*)

Representative Ellison introduced *H.R. 1662*, the *Common Sense Housing Investment Act*, which proposes to reform the Mortgage Interest Deduction (MID) that homeowners receive. The MID is estimated by the Office of Management and Budget to cost more than \$100 billion and is the largest housing subsidy. But its effectiveness is questionable as it benefits only households that itemize on their tax returns, and disproportionately benefits higher-income households. The bill proposed that the MID would be phased out over five years and replaced by tax credits that would impact more homeowners, including those who don't itemize on their taxes. The reform would also fund the National Housing Trust Fund and the Capital Magnet Fund. While some in Congress have expressed an interest in the MID reform, they would prefer to use the savings toward tax cuts. NCIL supports the reform of the mortgage interest deduction with some of the savings going toward affordable housing.

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

### *Universal Home Design Act* (formerly *S. 2889*)

The *Eleanor Smith Inclusive Home Design Act* and the *Universal Home Design Act* would require 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. These features will also make housing more accessible to persons with mobility disabilities, prevent unnecessary expenses for renovations, and will allow seniors to age in place, negating the need for costly institutionalization.

## Fair Housing Initiatives Program Funding (*H.R. 372*)

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. NCIL believes that there is a need to provide more support to address the housing discrimination through increased funding for education and enforcement. NCIL urges the passage of *H.R. 372*, which would increase funding for the Fair Housing Initiatives Program.

### **Moving to Work (S. 65)**

Moving to Work is a demonstration program (which has nothing to do with employment) allowing participating Public Housing Authorities (PHAs) greater flexibility in operating programs and services, with exemptions from many regulations and rules. The number of Public Housing Authorities participating in the Moving to Work demonstration program is capped at 39. 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. Of significant concern is that, according to the Center for Budget and Policy Priorities, Moving to Work agencies issue far fewer vouchers than non-Moving to Work agencies with the funding they have available.

Yet Senator Vitter introduced a bill to dramatically expand the program to 250 participating PHAs. The President's budget request proposes that another 15 PHAs be added to the program. NCIL opposes the expansion of Moving to Work until sufficient data exists to evaluate the pilot program.

*Note: The Community Integration Act (see Healthcare Section) includes language requiring that each state shall develop a statewide plan to increase the availability of affordable and accessible private and public housing stock for individuals with disabilities.*

## ***Transportation: The Lifeblood 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.

As of publication, the President and Congress agreed to a short-term two month extension that will expire on July 31, 2015. On appropriations, we are concerned with the House passage of *H.R. 2557*, the Housing and Urban Development and Related Agencies (THUD) bill, which would cut transportation funds and is now in the Senate.



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 March, the House passed HR 749 (Passenger Rail Reform and Investment Act of 2015) supporting Amtrak which not sits in the Senate.

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.

NCIL strongly supports high speed rail, including Amtrak and regional high speed rail systems. However, they continue to be out of compliance with the *Americans with Disabilities Act of 1990 (ADA)* in that many stations and vehicles are not up to ADA standards. These companies are not government entities, but receive federal subsidies and as such must comply with Section 504 of the *Rehabilitation Act of 1973* as amended, as well as the *ADA of 1990* as amended. Amtrak and others have received subsidies, technical assistance, and directives in this area. NCIL believes that as we approach the 25th anniversary of the *ADA*, no further excuses should be tolerated for delaying accessibility or other compliance measures.



→ **Livable communities:** Safe and accessible rights-of-way are essential elements of community life. All pedestrians must be able to travel safely 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 (including TNCs):** Legislation and regulations are needed to increase the number and availability of accessible vehicles within the private transportation industry, including taxis, limousines, shuttle service, car rentals, buses, trains and now, Transportation Networking Companies (TNCs, also known as Ride Sharing).

The most recent transportation option that the disability community and others are taking a close look at is Ride Sharing (not to be confused with shared ride), also known as Transportation Networking Companies (TNCs). This is both an interesting and challenging development that can increase transportation options, but also raises concerns. Because of the limits on transit and other transportation options utilized by the disability community (i.e., crossing county lines, lack of

accessible vehicles, limits on non-traditional hours of services such as evenings, weekends, and holidays), TNCs are important. They provide options for many people with disabilities and other communities. The problem has been that a number of TNCs have not voluntarily offered accessible vehicles across the board and continue to fight accessibility requirements in many regions. This continues to leave people with a wide variety of disabilities and older Americans who use wheelchairs, scooters, and service animals without options. This is not acceptable to NCIL.

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. This can include vehicles running on compressed natural gas (CNGs), hybrid vehicles, etc. NCIL believes that our policymakers should support American companies by providing incentives and subsidies toward the development of new universally designed, wheelchair accessible, energy efficient transportation vehicles.

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 and TNC 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 114th 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 114th Congress)

*Moving Ahead for Progress in the 21st Century (MAP-21)* 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.

## **Federal Aviation Administration (FAA) Reauthorization**

Airports and air travel have long been a challenge for people with disabilities. Everything in the airport up to the ticket counter is covered under the *ADA*, but everything beyond the ticket counter is under the FAA. NCIL supports FAA Reauthorization which addresses the concerns of people with disabilities, including policies and practices promoting cultural competency and inclusion of persons with disabilities similar to non-disabled passengers. See the two issues outlines below for additional information.

## **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, is the appropriate technical standard 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*** (previously S. 556; Not Yet Introduced in the 114th Congress)

Previously sponsored by now retired 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.

This legislation 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.

## *Employment and Economic Equity* ←

NCIL works with Americans with disabilities who use Social Security's two main disability benefit programs to live independently and work in their communities, Social Security Disability Insurance, and the Supplemental Security Income program (SSI). Both programs are in need of structural reform and each program can serve widely different populations, which underlie some of the reasons for two sets of recommendations this year.

### **Social Security Disability Insurance: SSDI Beneficiaries and Employment**

*NCIL salutes each one of the 1.2 million SSDI beneficiaries in 2013 who had a job, out of 8.4 million SSDI beneficiaries that year. Most of them unfortunately earned very low wages that were below federal poverty guidelines. NCIL believes Congress must address this crisis this year.*

NCIL members have spent the first six months of 2015 carefully shaping recommendations which we believe will better support more SSDI disability beneficiaries and their employment activities.

#### **NCIL members recommend and support:**

- For SSDI beneficiaries who work, SSDI should disregard 50% of Substantial Gainful Activity earnings (\$545 in 2015) per month as a Career Expense Disregard. Earnings above this amount should reduce the SSDI benefit check by \$1.00 for every \$3.00 in earnings, commonly called a 3/1 benefit offset.
- For current SSDI beneficiaries, SSDI should eliminate work incentive rules, in particular, the Trial Work Period (TWP) and the Extended Period of Eligibility (EPE). Eliminate earned income as a reason for ceasing entitlement to SSDI benefits.
- Earnings in the SSDI program should be counted in the month in which they are paid.



- The Social Security Administration (SSA) should be required to prioritize telephonic and digital forms of real-time wage reporting procedures, similar to what they currently use for SSI.
- SSDI eligibility should only be terminated due to medical improvement, as determined in the current medical Continuing Disability Review (CDR) process.

### **Supplemental Security Income program: SSI Recipients and Employment**

In a 2015 letter to President Obama, the National Council on Disability asks:

*“What would a fundamental restructuring of the SSI and SSDI system require to align it with the goals of the Americans with Disabilities Act (ADA), which celebrates its 25th anniversary this year?”*

- NCD’s Securing the Social Contract: Reforming Social Security Disability Report (January 2015)

### **Updates on an Important NCIL Response: The CareerACCESS Policy Initiative**

NCIL’s Board of Directors has adopted a strong statement of support for CareerACCESS. NCIL Members passed a 2014 Resolution calling on NCIL to advocate for reform of the current Social Security definition of disability.

Discussions with key Congressional staff and interested state agencies continue this year. NCIL is working with the World Institute on Disability and PolicyWorks to secure wider support and funding for CareerACCESS pilot projects in up to five states. For current details and the CareerACCESS blog, use the QR Code below on your smart phone, visit [ourcareeraccess.org](http://ourcareeraccess.org), or email Justin Harford at [justinh@freed.org](mailto:justinh@freed.org).



### **NCIL Asks Congress: Reform SSI for Career Building Young Adults!**

**The NCIL Ask:** NCIL requests Congress (through the House Ways and Means Committee and the Senate Finance Committee) for funds to start and continue CareerACCESS pilot projects in up to 5 states that will serve young adults who meet SSI medical rules for disability, while eliminating the requirement for applicants to prove an inability to work.

Since 1956, young adults with disabilities must prove their inability to work to be eligible for Social Security disability programs. Current SSI rules relegate millions of individuals with disabilities to lives of poverty to remain eligible for cash benefits and health care.

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

CareerACCESS can revolutionize how young adults eligible for Social Security's SSI program (Supplemental Security Income) find and use employment support services, while



maintaining disability cash benefits and building their own assets.

CareerACCESS pilot pilots will build on innovative practices to increase employment rates for young adults with disabilities, and over time, provide an effective alternative to the current SSI benefits program.

### **Current Pilot Project Features and Directions**

Piloted in up to 5 states, CareerACCESS will serve young adults 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 young adults up to age 30.

#### **Features:**

**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 into CareerACCESS, an alternate benefit program to SSI. Eligible applicants must meet or equal the current medical rules in Social Security's Listing of Impairments, excluding the test for work incapacity.

Applicants who decide they are not ready for CareerACCESS can choose to apply for the current SSI program in a pilot state.

**Supports** - Design a mix of new and existing supports by using blended and braided funding from the Department of Education, Health and Human Services, Department of Labor, and Social Security, to serve young adults with disabilities who are in compliance with an Individualized Career Plan (ICP) that meets federal rules and standards.

The individual will review and update the ICP with the key support partners needed to comply with project rules. If a participant becomes non-compliant for any reason, they may exit to the traditional SSI program.

**Simplification** - Test simplification of SSI work rules allowing CareerACCESS participants to keep their federal SSI stipend (\$733 for an individual, \$1100 for a couple). The cash benefit stays the same until the participant's earnings and stipend combined are more than 250% of the 2015 federal poverty level. When the participant reaches that level, the young adult will have \$2,452 per month to work with. For income amounts above this level, the cash stipend (\$733) will be reduced \$1 for every \$3 in earnings.

**Cash and Counseling** – The cash stipend rules allow for 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 career planning and coaching, navigating systems, benefits planning, asset development, and health care access.

**Financial Planning** - Allow participants to benefit from work by eliminating asset building limitations;



assets acquired and saved during the project, including ABLE Accounts, are held harmless. Asset development and portability after exit from the project 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 at or before 12 years, depending on objectives being met as regularly reported to Congress.

Summary by: World Institute on Disability (WID), National Council on Independent Living (NCIL), and PolicyWorks. Current information at: [www.ourcareeraccess.org](http://www.ourcareeraccess.org).

## *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, five states (California, Maryland, Montana, Oregon, and Texas) have implemented the Community First Choice Option.

NCIL members are working to expand the number of states that are selecting this option. It is clear, however, that without federal legislation every state will not 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. It is also possible for states to implement CFC, secure the extra federal funds, and continue to maintain policies that limit access to services or fail to provide a real alternative to institutionalization. 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.

NCIL is working on the next generation of the *Community Integration Act*, which, instead of focusing on changing Medicaid, strengthens the ADA's integration mandate in order to accelerate *Olmstead* implementation by:



1. clarifying that every individual who is eligible for Long Term Services and Supports (LTSS) has a federally protected right to a real choice in how they receive services and supports;
2. assuring that states and other LTSS funders provide services and supports in a manner that allows individuals with disabilities to live in the most integrated setting – including their own home, have maximum control over their services and supports, and lead an independent life;
3. establishing a comprehensive state planning requirement, comparable to the transition planning process required under the ADA, that includes enforceable benchmarks;

4. requiring states to address the need for affordable, accessible, integrated housing that is independent of service delivery; and
5. establishing stronger, targeted enforcement mechanisms.

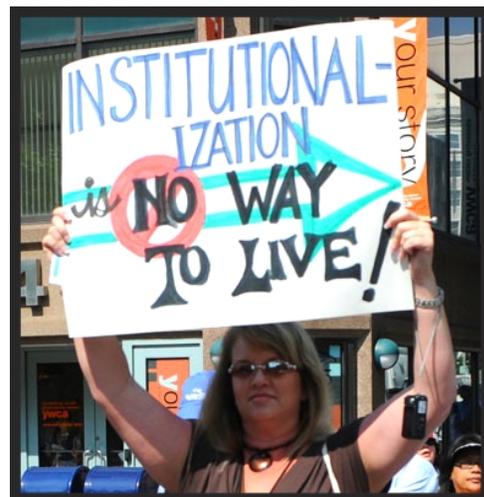
### **Reform Medicaid, Don't Gut It!**

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 71 million Americans rely on Medicaid services, and millions more are connected to Medicaid in some way. Congress is currently considering legislation that would profoundly impact Medicaid and the systems for providing long-term services and supports. Instead of gutting Medicaid, 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; and
- **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.

### **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 and 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. Consequently, NCIL supports the *Medicare DMEPOS Competitive Bidding Improvement Act of 2015 (H.R. 284; S. 148)*.

Additionally, Medicare currently does not have unique coverage for the more complex needs of individuals with disabilities and chronic medical conditions that require medically necessary individually configured products and services. We believe the creation of a separate recognition of CRT will result in decreased Medicare expenditures by averting hospitalizations due to conditions such as severe pressure sores and blood clots. In the interest of quality healthcare and optimal functionality for individuals with disabilities and chronic medical conditions, recognition of a separate category for CRT is needed, so NCIL supports the *Ensuring Access to Quality Complex Rehabilitation Technology Act of 2015 (H.R. 1516; S. 1013)*.



### **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:

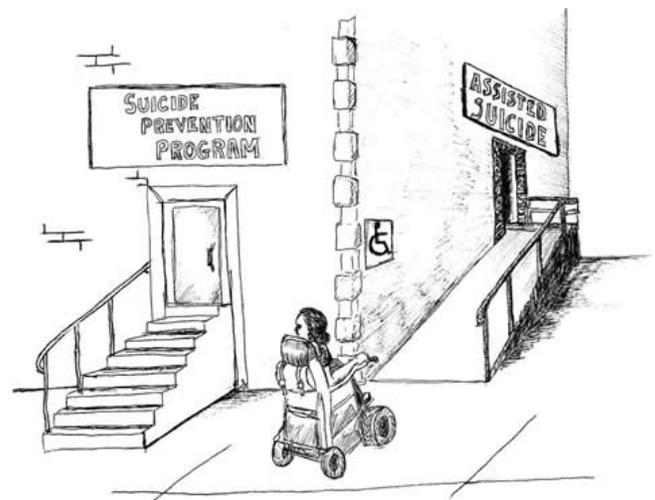
- discrimination in policies and procedures concerning decisions to withhold or withdraw life-sustaining treatment, including but not limited to advance care planning that discourages the choice to receive life-sustaining treatment based on messages suggesting that it is “better to be dead than disabled”;
- 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;
- discrimination in organ transplant eligibility, organ procurement policies and related services; 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.



*Illustration by Amy Hasbrouck and Elissa Small for Second Thoughts*

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 2015, disability rights and independent living advocates have been instrumental in defeating assisted suicide legislation in Alaska, Colorado, Connecticut, Maine, Maryland, Nevada, Rhode Island and Tennessee, with efforts continuing in California, New Jersey and the District of Columbia.

# *Civil Rights and the Americans with Disabilities Act* ←

## **Laws Affecting the ADA**

We celebrate the 25th Anniversary of enactment of the ADA this year. One impact of this anniversary is that most members of Congress were not around when the ADA was passed. Of current Members of Congress, only 17 Senators and 22 Representatives voted for the ADA. It is crucial that we educate our members on why we continue to need civil rights protections and strengthening of existing protections.

### ***ACCESS: The ADA Compliance for Customer Entry to Stores & Services Act (H.R. 241)***

### ***Labor, Health & Human Services, Education and Related Agencies Appropriations Act (S. 1695)***

Some members of Congress continue outright assault on key protections of the ADA. These include Rep. Ken Calvert's (R-CA) ironically named "ACCESS" bill. This legislation would amend the ADA to prohibit commencing suit for discrimination based on the failure to remove a structural barrier to entry into an existing public accommodation unless the owner or operator of such accommodation: is provided a written notice specific enough to identify such barrier; and has either failed to provide the person with a description outlining improvements that will be made or provided such description and failed to remove the barrier.



This bill is much like the *ADA Notification Act* and other bills NCIL has vehemently opposed each time introduced if limiting our rights or enforcement of our rights. We understand that civil rights are intrinsic to all Americans and a violation of rights cannot require 'notification' prior to protection. States should address problematic issues within state law; not create additional federal law limiting enforcement of civil rights.

In addition to direct assault on the ADA, Members of Congress have introduced amendments and other legislation to limit rights under the ADA. Examples include appropriations provisions such as the one in House Appropriations Bill to appropriate funds for 2016 for the Departments of Labor, Health & Human Services, Education and related agencies. The Committee Report for the bill appropriates funds for grants to encourage involuntary mental health treatment (called "Assisted Outpatient Treatment" or "AOT"). When the House and Senate versions of the "Labor HHS" funding bill are conferenced, the conferees should strike funding for AOT/involuntary outpatient commitment.

The Administration has joined in efforts to undermine protections of the ADA. The Equal Employment Opportunity Commission proposed a rule recently that would allow insurers and other health plans, including employer plans, to subject people with disabilities to significant penalties for refusing to participate in wellness programs. This rule undermines the provisions of the ADA prohibiting employers from requiring applicants and employees to undergo medical exams unrelated to work requirements and from requiring disclosure of disability. It would allow employers to discover

key information about a person's disability. If the Administration does not reverse course on this rule, Congress should require the administration to protect this important principle.

### **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.

According to a recent article in the Washington Post, 125 fatal shootings by police in the first six months of 2015 were experiencing signs of mental illness.

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. However, we know that issues related to many disabilities result in inappropriate use of force and cause injury or death to people with disabilities.

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.

Earlier this year, the Supreme Court failed to address a claim raised that law enforcement officers must consider the needs of people with disabilities when planning and training for use of force. This failure, in *Sheehan v. San Francisco*, of the federal government to address these issues means that we will continue to have to work with local government to ensure that the lives of people with disabilities are protected.

We must build support within Congress and the Administration to ensure that police protect and serve people with disabilities rather than kill them.

### **Mental Health**

Mental health continues to have prominence in the news and in Washington after another year of multiple mass shootings across the nation. NCIL recognizes that mental health disabilities are common - half of Americans can expect a diagnosis during their lifetime. NCIL also recognizes that people with disabilities, including those diagnosed with mental health disabilities, 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 these approaches and the lack of outreach and inclusion in such efforts. The voice of mental health consumers has been left out of these very important conversations and we cannot tolerate this.



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.*

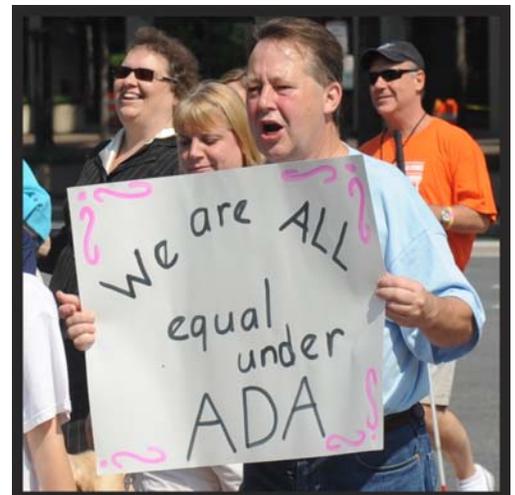
NCIL recognizes that reauthorization of Substance Abuse and Mental Health Services Administration (SAMHSA) programs is long overdue. Important services for people with mental health, substance abuse and other disabilities are funded through these programs. NCIL supports such legislation with the following 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) and
- that each state provide for consumer peer support organizations and / or consumer-run community mental health services in its MHBG plan.

In addition, advocates must be certain that any such legislation doesn't single out people who have a disability but are not dangerous for involuntary treatment. In addition, the legislation should assure continued support for advocacy and mental health peer support.

The "*Helping Families in Mental Health Crisis Act of 2015*" (H.R. 2646) has been introduced by Representative Murphy. This bill addresses SAMHSA programs. Unfortunately, instead of appropriate reforms, the bill includes provisions that threaten civil rights of persons diagnosed with "mental illness." Among protections attacked in the bill are privacy of health care information and restrictions on advocacy by state "protection and advocacy" systems. The bill also increases funding for inpatient mental health services under Medicare and Medicaid without ensuring that community services are available and prevents SAMHSA from funding evidence-based programs such as peer support programs.

NCIL opposes H.R. 2646 and other bills that single out people for reduced rights based on disability.



### **Protecting the Rights of Parents with Disabilities and Their Children**

There is a historical bias against parents with disabilities and their children. Nearly every state has child custody and guardianship laws that classify parents with disabilities and authorize removal and detention of their children or termination of their parenting rights on the basis of disability.

There are significant barriers for parents with disabilities, including attitudinal barriers, lack of information about parenting adaptations, lack of funding for adaptive technology, exclusion from public policy considerations, lack of disability expertise in service systems, access to reproductive

health, and lack of respect for home and family.

In the coming year, NCIL's ADA / Civil Rights Subcommittee will plan and implement a national campaign for federal legislation to protect the rights of parents with disabilities and their children. The Subcommittee encourages all NCIL members to become a part of this most important work.

## Violence and Abuse

The *Violence Against Women Act* was signed into law in September of 1994. It has been reauthorized three times since, in 2000, 2005, and 2013. This law created the first U.S. federal legislation acknowledging domestic violence and sexual assault as crimes. It is also provided federal resources to encourage community-coordinated responses to take action against violence.

In September of 2014, President Obama issued a proclamation in recognition of the 20th year anniversary of VAWA. In the proclamation he states, "On the anniversary of this landmark legislation, we rededicate ourselves to strengthening the protections it first codified, and we reaffirm the basic human right to be free from violence and abuse."

Although the *Violence Against Women Act* was successfully reauthorized in 2013, appropriations are done on a yearly basis. We must continue to work diligently on behalf of survivors with disabilities and continue the efforts to recognize this group with targeted funding. Some entities have pushed for a return to a category for underserved populations, thus eliminating targeted funding for specific groups, including people with disabilities. Currently, for example, a designated grant program exists within the Office of Violence Against Women entitled "Training and Services to End Violence Against Women with Disabilities." We must continue to work for people with disabilities to be funded as a designated grant program in this critical legislation. Before this designation, 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. As we know from our work with the *ADA*, change only happens with continued advocacy. While great strides have been made, domestic violence services, sexual assault programs, police departments, and legal aid agencies must continue to enhance their accessibility and challenge their stereotypes when working with people with disabilities.

We must continue the momentum to educate our policy makers and our membership so that we can work together to establish welcoming, accessible, and integrated services. There have been a number of initiatives that are being emphasized with the latest reauthorization including more resources that are being directed at sexual assault and support services. One of these is happening on the college campuses around the country. Stay informed about what is happening and continue to ensure that as new efforts are undertaken, people with disabilities are included. Our goal is that



survivors with disabilities will also have the basic human right to be free from violence and abuse.

### **Human Trafficking of People with Disabilities**

Human trafficking is the illegal trading of human beings for commercial sexual exploitation or forced labor. It is modern day slavery, where people profit from the control and exploitation of others, and it is a fast growing criminal enterprise. Human trafficking is an abuse of human rights. Due to the very nature of human trafficking activities, it is very difficult to come up with accurate statistics on trafficking especially as it relates to people with disabilities. According to the Department of State, while the victims may sometimes be kept behind locked doors, they are often hidden right in front of us. For example, construction sites, restaurants, elder care centers, nail salons, agricultural fields, and hotels. The traffickers' use of coercion is so powerful that even if outreach is done to victims, they may be too fearful to accept help.

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.

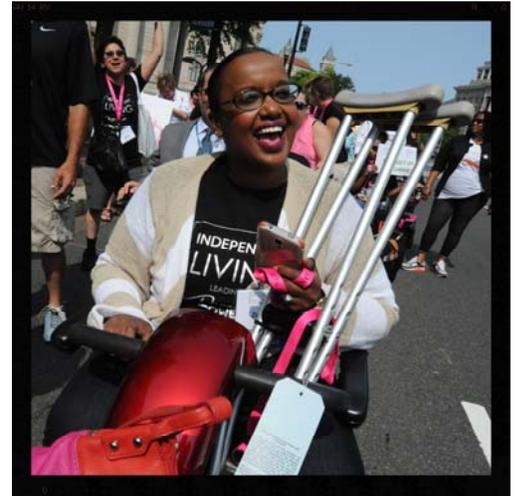


### **Elder Justice, Adult Protective Services, and People with Disabilities**

The Elder Justice movement is organized and vocal in relation to violence and abuse. The bipartisan *Elder Justice Act (EJA)* was introduced in 2002 and enacted into law in 2010, as part of the *Patient Protection and Affordable Care Act (PPACA)*. It addresses a series of provisions designed to address some of the weaknesses in federal and state efforts to prevent and respond to abuse, neglect, and exploitation of older people. It is the first comprehensive legislation to address elder abuse. The field of elder justice has some momentum. After a few years without an appropriation, money for this act has begun flowing. Included in this is additional support for Adult Protective Services (APS). Many of you know that people with disabilities often are fearful of APS involvement. This seems to depend on which state it is, whether supports are in place after investigations, procedures that are in place, and who all this applies to. Some states have APS systems that are more proactive primarily due to significant advocacy in reaction to difficulties. All of this brings up issues that are worth noting.



It is imperative that we ensure the protection of rights, while addressing abuse, neglect and exploitation. Of primary concern is that unlike child abuse, each state defines and sets parameters for who is included in their state Adult Protective Services legislation, the procedures that are used, and whether supports can be obtained. This creates complications when looking at the overall system and in developing better federal policy. As this legislation is implemented, considering our move to the Administration for Community Living, it is imperative that we continue to raise these concerns. This legislation could make some positive changes, and we need to make sure that rights stay at the forefront, that stereotypes of people with disabilities do not drive policy, and that we join with our colleagues in the elder justice movement to ensure that improvements are made to these systems that can address some of these fears.



### **Capital Punishment and People with Intellectual Disabilities**

In a 2002 Supreme Court ruling, *Atkins v. Virginia*, the U.S. Supreme Court recognized the risk of wrongful execution faced by persons with intellectual disability (formerly referred to as “mental retardation”). It banned the execution of persons with intellectual disability as cruel and unusual punishment under the 8th Amendment. In the 2014 Supreme Court ruling, *Hall v. Florida*, the U.S. Supreme Court again reinforced its earlier decision that people with intellectual disabilities not be executed. It required that consideration of evidence beyond IQ tests be taken into account when determining intellectual disability.

Despite these rulings, several states (most recently Georgia) have moved forward with an execution of a person with intellectual disability. This trend in some states is disturbing, especially since the Supreme Court has held that doing so is unconstitutional and in violation of federal law.

We support the federal law and believe that every individual with intellectual disability should be protected from the death penalty. We feel that individual state laws that 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. More information on this issue can be found at the Arc’s National Center on Criminal Justice & Disability and at the Death Penalty Information Center. Information for this brief was taken from these sources.

### **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. NCIL looks forward to the day when Americans with Disabilities are a powerful voting bloc. To reach this goal, we have a three pronged strategy:

- We work to improve the accessibility of all parts of the voting process, this includes federal funding to improve accessibility, accuracy and security in voting.
- We encourage people with disabilities to run for public office, and

→ We help to organize robust voter registration and education drives.

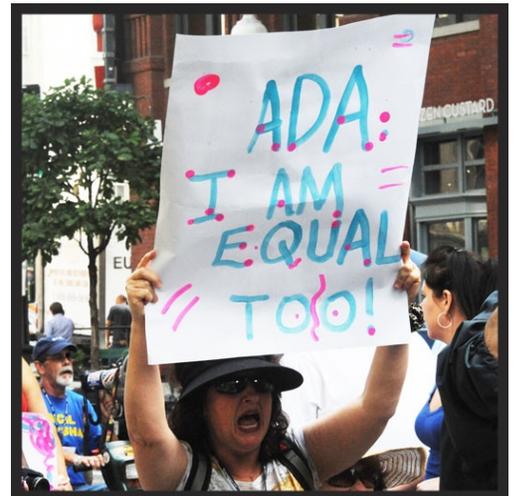
The voting process must include:

- 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 to the entire voting process, from registration to casting a vote.



In addition, election offices must have accessible websites and provide alternative formats for all voter education materials. We support modernizing and improving the nation's voter registration system, including a robust implementation of the agency-based registration requirements of the National Voter Registration Act.

- We support a strong and vital U.S. Election Assistance Commission that continues to improve accessibility of the entire voting process.
- We support the recommendations of The President's Commission on Election Administration.



## *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***

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.



## ***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***

Restraining and secluding students must be ended. The Government Accountability Office reported widespread misuse of restraint and seclusion. The *Keeping All Students Safe Act* 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.



### ***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 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.
- 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.



## 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.

# *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 within the Committee's membership and other bipartisan Senate supporters to develop consensus language for a package of reservations, understandings, and declarations (RUDs), to attach to our ratification. This resolution for ratification passed out of the Senate Foreign Relations Committee in July 2014.

Unfortunately, the Senate's progress on the issue ended there, and no vote for ratification was called during the final 6 months of the 113th Congress.

Now in a new Congress, the CRPD must again be passed from the Senate Foreign Relations Committee. The national coalition for ratification, including our allies in the veterans, business, faith and civil rights communities, remains committed to ratification of the CRPD. At this time, the United States Senate is developing its agenda and it appears unlikely that the CRPD would be considered during this 114th Congress. As advocates from the local to national levels, we must continue to pursue opportunities to elevate the CRPD and the global disability community in the minds of policymakers and our constituents through education on the issues, inclusion of international perspectives in disability rights advocacy, and enforcing disability rights principles in U.S. foreign affairs.

## **The Treaty Needs Our Commitment**

Grassroots support will continue to be vital in order to ensure widespread Senate awareness of the one billion persons with disabilities in the world, our human rights, the need to tear down barriers



and support freedom and inclusion of all people, and support the implementation of the Convention both in the United States and around the world. NCIL supports U.S. ratification of the CRPD, and will continue working with USICD and the coalition in this advocacy.

USICD offers a speakers bureau that connects CRPD presenters to diverse audiences. Anyone who is interested in a presentation on the treaty can contact David Morrissey [dmorrissey@usidc.org](mailto:dmorrissey@usidc.org) to plan a presentation. Please consider including the CRPD in your organization's work.



## *Legislation NCIL Supports*

- Increased funding for America's Independent Living Program
- *Common Sense Housing Investment Act (H.R. 1213 - 113th Congress)*
- *Eleanor Smith Inclusive Home Design Act (H.R. 2352 - 113th Congress)*
- *Universal Home Design Act (S. 2889 - 113th Congress)*
- Fair Housing Initiatives Program Funding (*H.R. 372*)
- *Allowing Local Control of Federal Transit Funds Act* (Not Yet Introduced in the 114th Congress)
- *Moving Ahead for Progress in the 21st Century* (Not Yet Introduced in the 114th Congress)
- *Air Carrier Access Amendments Act* (Not Yet Introduced in the 114th Congress)
- *Community Integration Act (S. 2515 - 113th Congress)*
- *Assistive Technology Act*
- *Keeping All Students Safe Act (H.R. 1893)*
- Legislation to Support Veterans from the 113th Congress:
  - *The Quicker Veterans Benefits Delivery Act*
  - *The Disabled Veterans' Access to Medical Exams Improvement Act*
  - *The Access to Veterans Benefits Improvement Act*
  - *The Military Reserve Jobs Act of 2013*
  - *The Servicemembers Mental Health Review Act*
  - *The Military Retirement Restoration Act*
  - *Legislation to honor service of the Guard-Reserve Retirees*
  - *The Blue Water Navy Ship Accountability Act*
  - *The Blue Water Navy Vietnam Veterans Act of 2013*
  - *The Children's Protection Act of 2013*

- Reauthorization of:
  - *Elementary and Secondary Education Act*
  - Federal Aviation Administration (FAA)
  - Substance Abuse and Mental Health Services Administration (SAMSHA) - NCIL supports reauthorization only with the requirements listed on page 23 of this booklet.
- Ratification of:
  - UN Convention on the Rights of Persons with Disabilities

## *Legislation NCIL Opposes*

- *Pay Back the Taxpayers Act of 2015 (H.R. 574)*
- *Moving to Work (S. 65)*
- *State Flexibility Act (H.R. 567)*
- *ACCESS: The ADA Compliance for Customer Entry to Stores & Services Act of 2015 (H.R. 241)*
- 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.

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

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.



### **The Independent Living Program**

Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization. Centers for Independent Living Provide:

- Peer Support
- Information and Referral
- Individual and Systems Advocacy
- Independent Living Skills Training

America is home to:

- 403 Centers for Independent Living (CILs)
- 330 branch offices
- 56 Statewide Independent Living Councils (SILCs)

The Independent Living Movement is founded in the belief that people with disabilities, regardless of the form, have a common history and a shared struggle, that we are a community and a culture that will advance further banded together politically.

Independent Living philosophy emphasizes consumer control, the idea that people with disabilities are the best experts on their own needs, having crucial and valuable perspective to contribute and deserving of equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that powerfully affect their day-to-day lives and access to independence.

Find your local CIL or SILC by visiting [ncil.org](http://ncil.org).



2013 H Street, NW / 6th Floor • Washington, D.C. 20006

voice: (202) 207-0334 • fax: (202) 207-0341 • tty: (202) 207-0340

website: [www.ncil.org](http://www.ncil.org) • email: [ncil@ncil.org](mailto:ncil@ncil.org)