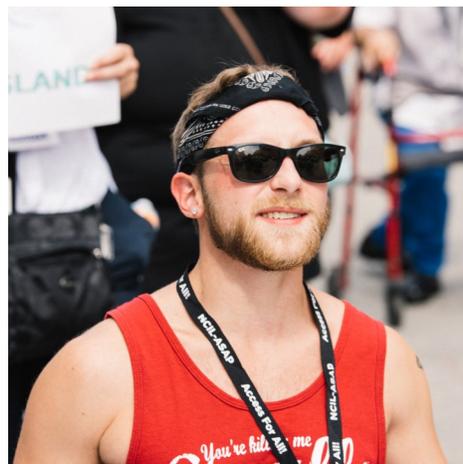
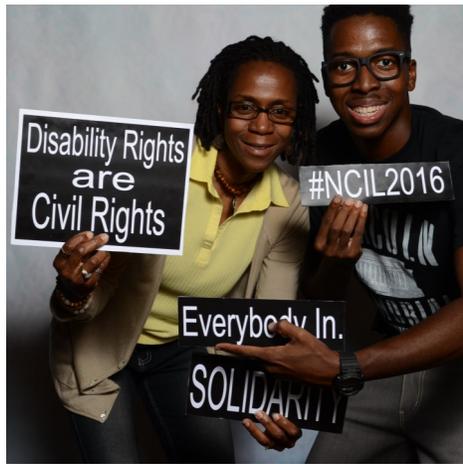




# Legislative & Advocacy

## Priorities Guide

Summer 2017



# A Message from the Executive Director

I am pleased to announce the release of the summer edition of the National Council on Independent Living's 2017 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. 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.



Kelly Buckland  
Executive Director



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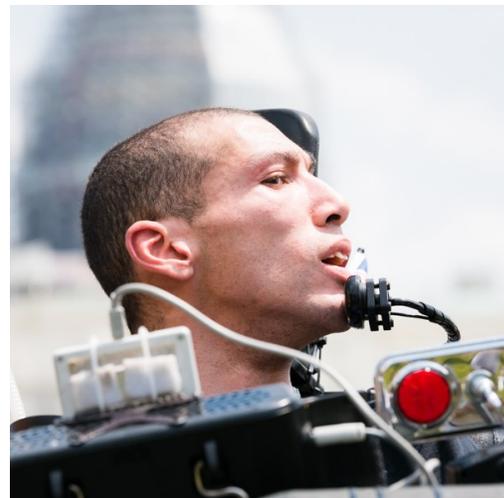
## The Independent Living Program →

NCIL continues to work with the Independent Living Administration (ILA) to actualize the significant changes created by the *Workforce Innovation and Opportunity Act (WIOA)* and reauthorization of the *Rehabilitation Act* contained therein. The ILA, within the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services, has worked very closely with NCIL as new regulations have been developed. The regulations are one piece of the various and numerous tasks required to implement the changes required by *WIOA* and many more are in process.

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.

NCIL is requesting \$200 million in additional funding in the 2018 budget for the Independent Living line item.

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.



SILCs (Statewide Independent Living Councils) are essential CIL partners in developing a plan for a statewide network of CILs. Increased funding is essential to the implementation of those state plans.

The additional core services authorized by *WIOA* in Title V are labeled **Transition**; as defined:

- a) Facilitate the transition 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 (HCBS) 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 \$365 million in COLA every year. Due to state budget constraints, state VR agencies have returned over \$80 million to the Treasury because they are not able to match with state funds. Clearly, investing in Centers for Independent Living makes sense.

This \$200 million funding request will restore devastating cuts to the Independent Living Program, offset inflation costs, address the increased demand for Independent Living services, and fund the new transition services.

According to data collected by the Rehabilitation Services Administration, during fiscal years 2012-2014, Centers for Independent Living:

- Provided the core services of advocacy, information and referral, peer support, and independent living skills training to nearly 5 million individuals with disabilities;
- Attracted over \$2.26 billion through private, state, local, and other sources, and;
- Moved 13,030 people out of nursing homes and institutions, saving states and the Federal government over \$500 million, AND improving the individuals' quality of life.

In that same period, Centers provided other services to hundreds of thousands of individuals with disabilities in their respective communities that included:

- Personal assistance services to nearly 184,240 people with disabilities;
- Assistance to 145,937 people in securing accessible, affordable, and integrated housing;
- Assistance with Assistive Technology for 171,441 people with disabilities;
- Vocational and employment services to 96,492 people with disabilities;
- Advocacy to significantly increase access and opportunities to fully participate in community life;
- Transportation services to over 103,175 people with disabilities, and;
- Services to over 35,137 youth with disabilities.

Independent Living saves taxpayer dollars through home and community-based services. 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 1915(c) 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;



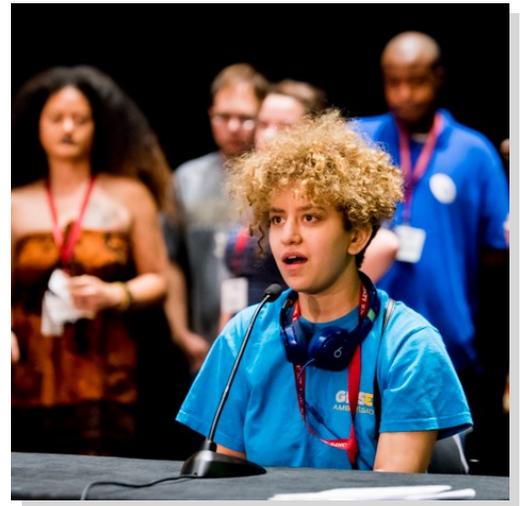
- Including average Community Living Costs (room, food and other), waiver recipients spent \$44,992 a year, compared to nursing homes costs of \$63,095;
- Community-based services are 21% - 29% less expensive than nursing homes, saving taxpayers \$18,103 a year per participant.

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 Health and Human Services 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 five 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 led a nationwide effort to develop outcomes, indicators, measurement tools, and ways to gather, analyze, and interpret outcome data. The Rehabilitation Services Administration and all segments of the Independent Living community of practice were closely involved at every step. CILs field-tested their outcomes over the course of three 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 2018 budget.

## Healthcare and Long-Term Services and Supports →

### ***Disability Integration Act: H.R. 2472 and S. 910***

Even though community-based services are overall more cost effective and the Supreme Court's *Olmstead* decision requires community integration, Americans with disabilities are regularly forced

into institutions and denied their Constitutional right to liberty. The Disability Integration Act – *H.R. 2472* (Sensenbrenner-R) and *S. 910* (Schumer-D) – is bi-partisan, bi-cameral legislation that addresses this injustice by:

- clarifying in statute 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;
- 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;
- establishing a comprehensive state planning requirement, comparable to the transition planning process required under the ADA, that includes benchmarks while providing states with the time they need to comply with the law;
- ensuring that there is an adequate workforce to support community integration;
- requiring states to address the need for affordable, accessible, integrated housing that is independent of service delivery; and
- establishing stronger, targeted enforcement mechanisms.



NCIL worked extensively with ADAPT and others in crafting this legislation. We urge every member of Congress to cosponsor this important legislation protecting the Constitutional and civil rights of Americans with disabilities.

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

Although NCIL strongly opposes the *American Health Care Act (AHCA) - H.R. 1628*, we strongly support reform of Medicaid LTSS in order to better serve people with disabilities and low income communities. Instead of capping or cutting Medicaid through Block Grants or Per Capita Caps and giving states “flexibility” allowing them to deny Americans with disabilities their freedom, Congress should work with NCIL and the disability community to 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 while improving quality; 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.

Such reform efforts require thoughtful planning. NCIL urges the Senate to take the time needed to engage NCIL and the disability community to understand the needed reforms and craft legislation that can achieve our common goals.

## Healthcare

Although the *Affordable Care Act* is flawed, it does provide critically important access to health insurance for Americans with disabilities. Additionally, the ACA addressed other critical healthcare issues for people with disabilities. Specifically, the ACA:

- prohibited discrimination against people with pre-existing conditions by insurance companies;
- required that insurance plans provide essential benefits to ensure that people have the coverage they need;
- extended Money Follows the Person (MFP), a Republican New Freedom initiative that is liberating thousands of disabled people from institutions (unfortunately, the MFP program is ending because of Congressional inaction);
- established the Community First Choice Option (1915k), a Medicaid option that incentivizes states through an enhanced FMAP to provide LTSS in the community instead of nursing facilities and institutions;
- authorized accessibility standards for Diagnostic Medical Equipment so people with disabilities could get access to preventative healthcare screenings and appropriate diagnostic testing.



As Senators consider their own version of healthcare legislation, NCIL urges every Senator to maintain these important provisions of the ACA by addressing the problems with the existing law rather than repealing it. It is important to note that although proponents of the AHCA felt that they addressed the needs of people with disabilities and pre-existing conditions, the House plan would allow elimination of essential benefits needed by such individuals, result in increased premiums for such individuals making coverage unaffordable, and allow insurance companies to cap benefits, rendering coverage useless.

## Durable Medical Equipment (DME)

NCIL supports access to DME and opposes efforts to cut funding or restrict access, as this is a hindrance to the independence and integration of disabled people and seniors.

**Complex Rehabilitation Technology (CRT):** 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 2017 - H.R. 750 (Sensenbrenner-R).*

Unless Congress acts, CMS plans on using information obtained through the Durable Medical Equipment (DME) competitive bidding program (CBP) and inappropriately applying that to cut payments for accessories used on Complex Rehab wheelchairs. Congress has passed temporary delays in 2015 and 2016, but the current delay expired on June 30, so further action is needed. Complex Rehab “accessories” are really critical components on wheelchairs, including pressure relieving cushions, positioning supports, tilt/recline systems, and specialty drive controls. CMS’ action violates the intent of Congress when it passed the *Medicare Improvements for Patients and Providers Act (MIPPA)* in 2008 requiring CMS to exempt Complex Rehab power wheelchairs and accessories from the CBP. The negative impact would extend well beyond Medicare beneficiaries to also hurt people with disabilities in Medicaid and private insurance programs. NCIL supports the *Protecting Beneficiary Access to Complex Rehab Technology Act of 2017 - H.R. 1361 (Zeldin-R)* and *S. 486 (Casey-D)*, which provides a permanent solution.

## **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:

- discrimination due to inaccessibility of medical and diagnostic equipment or failure to provide effective communication and access to information to individuals with communication and sensory disabilities;
- 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 disabled people;
- 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 →

## *Talking Points Against Legalization of Assisted Suicide and Examples of Problem Cases*

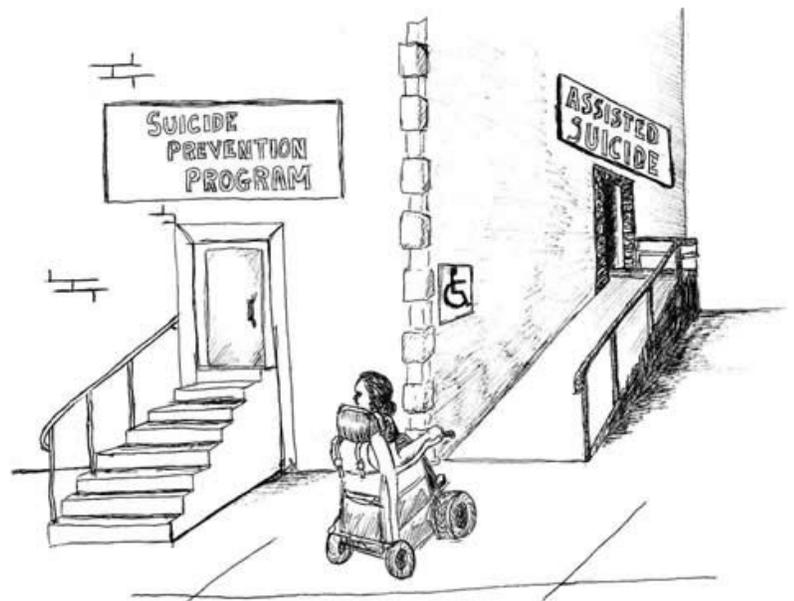
**Our concern is social justice. If assisted suicide is legal, some people's lives will be ended without their consent, through mistakes and abuse. No safeguards have ever been enacted or even proposed, that can prevent this outcome, which can never be undone.**

1. There's a **deadly mix between our broken, profit-driven healthcare system and legalizing assisted suicide**, which will be the cheapest so-called treatment. Direct coercion is not even necessary. If insurers deny, or even merely delay, expensive live-saving treatment, the person will be steered toward assisted suicide. Will insurers do the right thing, or the cheap thing?

**Barbara Wagner and Randy Stroup**, Oregonians with cancer, were both informed by the Oregon Health Plan that the Plan wouldn't pay for their chemotherapy, but would pay for their assisted suicide. Though called a free choice, for these patients, assisted suicide would have been a phony form of freedom.

2. **Elder abuse**, and abuse of people with disabilities, are rising problems. Where assisted suicide is legal, an heir (someone who stands to inherit from the patient) or abusive caregiver may steer someone towards assisted suicide, witness the request, pick up the lethal dose, and even give the drug — no witnesses are required at the death, so who would know?

**Thomas Middleton** was diagnosed with Lou Gehrig's disease, moved into the home of Tami Sawyer in July 2008, and died by assisted suicide later that very month. Two days after Thomas Middleton died, Sawyer listed his property for sale and deposited \$90,000 into her own account. After a Federal investigation into real estate fraud, Sawyer was indicted for first-degree criminal mistreatment and aggravated theft. But the Oregon state agency responsible for the assisted suicide law took no action.



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

3. **Importantly, there is an alternative**: anyone dying in discomfort that is not otherwise relievable, may legally today, receive **palliative sedation**, wherein the patient is sedated to the point where the discomfort is relieved while the dying process takes place. So we already have a legal solution to any uncomfortable deaths that does not endanger others the way an assisted suicide law does.
4. **Diagnoses of terminal illness are often wrong**, leading people to give up on treatment and lose good years of their lives, and endangering people with disabilities, people with chronic illness, and other people misdiagnosed as terminally ill.

**Jeanette Hall** of Oregon was diagnosed with cancer in 2000 and told she had six months to a year to live. She knew about the assisted suicide law, and asked her doctor about it, but he encouraged her not to give up. Eleven years later, she wrote, “I am so happy to be alive! If my doctor had believed in assisted suicide, I would be dead.”

5. **Doctor-shopping:** It’s become common knowledge in Oregon that if your doctor says no, you can call the main organization supporting assisted suicide: Compassion & Choices (formerly the Hemlock Society), which will refer you to assisted-suicide-friendly doctors. They have been involved in between 75% and 90% of Oregon’s reported assisted suicides. Shopping for another doctor who says ‘yes’ will get around the law’s weak safeguards.

Take the case of Oregon patient **Kate Cheney**, who was 85. Her doctor refused to prescribe lethal drugs, because he thought the request actually resulted from pressure by her adult daughter who felt burdened with care giving. So the family found another doctor, and Ms. Cheney soon used the lethal prescription and died. We call this “doctor shopping.”

6. **People with depression and other psychiatric disabilities are at significant risk.** **Michael Freeland**, age 64, had a 43-year medical history of acute depression and suicide attempts. Yet when Freeland saw a doctor about arranging an assisted suicide, the physician said he didn’t think that a psychiatric consultation was “necessary.” But when Freeland chanced to find improved medical and suicide prevention services, he was able to reconcile with his estranged daughter and lived two years post-diagnosis. How did that happen if the safeguards are so strong?
7. **Financial and emotional pressures** can also make people choose death. Family pressures are often hidden.
8. **Oversight & data collection are grossly insufficient.**
  - The reporting requirements lack teeth.
  - Non-compliance is not monitored.
  - There is no investigation of abuse, nor even a way to report it. The system does not report abuse because it’s set up not to find any abuse, and not to show abuse, even when it does exist.

**Wendy Melcher** died in August 2005 after two Oregon nurses, Rebecca Cain and Diana Corson, gave her overdoses of morphine and phenobarbital. They claimed Melcher had requested an assisted suicide, but they administered the drugs without her doctor’s knowledge, in clear violation of Oregon’s law. No criminal charges were filed against the two nurses.

- There are a small number of penalties with no way to enforce them; no established means for finding out what happened.
- Underlying data is destroyed annually: most egregious of all, the State of Oregon has acknowledged that after each annual report is published, the underlying data is destroyed, so no outside party can conduct objective research.
- The Washington State assisted suicide law, and many current proposals in other states, require physicians signing the death certificate to list the underlying terminal illness as the cause of death, not the taking of lethal drugs, even if the patient was not experiencing any symptoms from the illness at the time. Many doctors see this as requiring them to falsify the death certificate, and it makes accurate data impossible to collect.

9. **People with disabilities endangered.** Supporters of doctor-prescribed suicide always say this proposal won't affect people with disabilities. But it will, **whether or not they realize it.** Terminal illnesses are almost always disabling in some way, particularly in the latter stages. And people with terminal illnesses are particularly vulnerable to risk. Oregon data also shows that the top five reasons people request assisted are disability-related concerns that have not been effectively addressed, and that many people outlive their terminal diagnosis.

See more at the DREDF assisted suicide web page: [dredf.org/public-policy/assisted-suicide/](http://dredf.org/public-policy/assisted-suicide/)

## Civil Rights and the Americans with Disabilities Act →

Once again, with a new Congress, we see new attacks on the *Americans with Disabilities Act*. Each of the past few years, these attacks have intensified yet have failed to move forward. But we cannot take for granted that it will be the same in this Congress. Pressures on Congress have grown, particularly in states that allow monetary damages for ADA-related lawsuits.

Because of the increase of “drive-by lawsuits,” as they are labeled by the business community, legislators from those same states are filing legislation that requires notification and cure periods. Legislators are receiving a lot of feedback from those who support the bill in the business community. We must make sure Members of Congress understand the disastrous effect this bill will have on the civil rights of Americans with disabilities.

### ***ADA Education and Reform Act of 2017: H.R. 620***

This bill is similar to ADA notification legislation introduced in the 114th Congress. *H.R. 620* states its intention: “to amend the *Americans with Disabilities Act of 1990* to promote compliance through education, to clarify the requirements for demand letters, to provide for a notice and cure period before the commencement of a private civil action, and for other purposes”.

We agree with the portion of the bill that would include the disability community in the design of any training or education.

We strongly disagree with the section requiring a very specific written notice be provided to the owner or operator of the accommodation. This section states that “the written notice required under subparagraph (B) must also specify in detail the circumstances under which an individual was actually denied access to a public accommodation, including the address of property, the specific sections of the *Americans with Disabilities Act* alleged to have been violated, whether a request for assistance in removing an architectural barrier to access was made, and whether the barrier to access was a permanent or temporary barrier”.

We similarly disagree with the provisions allowing 60 days for the owner or operator to provide “a written description outlining improvements that will be made to remove the barrier” and 120 additional days to “remove the barrier or make substantial progress in removing the barrier”.



Businesses have had 27 years to remedy non-compliance with the *Americans with Disabilities Act*. It should not require a notice and cure period to resolve issues that should have been rectified years ago. This legislation puts the onus on the disability community to monitor access and allows businesses to continue with their wait-and-see-if anyone-notices approach and to only resolve issues of access if anyone actually issues a complaint.

## Housing →

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 health disabilities, developmental and intellectual disabilities as well as 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. Housing is a key component in rebalancing our long term care system. Diverting individuals with disabilities from nursing homes and other institutions and transitioning them to the community saves money. Housing challenges also are seen with many veterans returning with disabilities, with the high rate of homelessness among people with disabilities, and with the aging of the population. NCIL believes that all housing should be designed and constructed accessible to and usable by all.

The demand for housing that people with disabilities can actually use has far outgrown the available supply, and the shortage will only get worse with our nation's aging population and the corresponding increase in the number of people with disabilities. Congress has to act to ensure that there will be an adequate supply of housing, both private and public.

### **NCIL opposes cuts to housing and other domestic programs designed to assist low to moderate-income households, including those with disabilities.**

Nationally, housing affordability continues to be a serious challenge for households that include a person with a disability. Despite years of near-stagnant funding in the face of increasing costs of providing housing assistance and the higher need for housing assistance, the Trump Administration has proposed a 15% cut to the budget for the U.S. Department of Housing and Urban Development. Under the President's proposed budget, the Community Development Block Grants (CDBG) and the HOME programs would be eliminated, even though both have had longstanding bipartisan support. Although Congress' FY17 budget numbers for HUD and USDA programs did not have any significant changes from previous years, an earlier budget document could be an ominous omen. The House Budget Committee plan, approved on March 16, 2016, proposed to cut programs for low and moderate-income people by about \$3.7 trillion over the next decade. Those potential cuts would have reversed a long tradition of bipartisan support in Congress for housing programs. *Strong advocacy is needed to demonstrate the importance of housing programs for people with disabilities.*

## **NCIL supports the *Housing Fairness Act of 2017: H.R. 149***

Systemic discrimination is not the only housing issue that people with disabilities encounter in communities. The National Fair Housing Alliance has reported that over half of all fair housing complaints since 2010 are disability-related! This is unacceptable for a group that already faces formidable barriers to finding housing. Increased funding is needed for HUD's Fair Housing Initiatives Program to improve the effectiveness of fair housing enforcement, education, and outreach.

## **NCIL supports the *Common Sense Housing Investment Act of 2017: H.R. 948***

Each year, 75% of almost \$200 billion in housing assistance dollars spent by the Federal government is used toward homeownership subsidies. The largest housing subsidy is the home mortgage interest deduction, which is used by homeowners who can benefit from itemized deductions on their taxes. Although homeowners at different income levels can take advantage of the deduction, half of all homeowners do not benefit. Those with pricey homes use bigger deductions. Frustratingly, homeowners with incomes over \$100,000 receive eight out of every ten dollars for mortgage interest deductions, which is more assistance than low-income households receive from HUD! In short, those who need the assistance the least receive the most, making this a very ineffective program.

A proposed reform would provide a nonrefundable tax credit for homeowners and cap the amount of the tax write-off from \$1 million to \$500,000. Because it will be a tax credit, it will impact more homeowners and is a more effective policy while saving money. The reform would also fund the National Housing Trust Fund and the Capital Magnet Fund through the savings, building potentially 2.4 million new affordable housing units over the next decade! More homeowners can use the mortgage interest credit, AND more affordable units are built, with zero new cost to the Federal budget!

It is likely that the home mortgage interest deduction will be discussed as part of a more broad tax reform. If that occurs, tell legislators that you support the proposal in *H.R. 948*, and that savings from housing tax reform should be used toward housing assistance for people with extremely low incomes.

## **NCIL supports the *Eleanor Smith Inclusive Home Design Act (formerly H.R. 3260)***

Housing affordability is only part of the solution. There has to be greater physical accessibility in the nation's housing stock, both for private and Federally-subsidized housing. Currently, there are no national accessibility standards for privately owned single-family (1 to 3 units) housing. Some communities and states have taken the lead in promoting single-family home accessibility standards, commonly known as Visitability. Visitability is the idea that new single-family homes should be constructed with basic accessibility features to allow a guest with a mobility disability to visit. Equally important, these same features, if required in new construction, would provide accessibility for potential homeowners or renters with disabilities and enhance the likelihood of seniors being able to age in place, and would reduce the need for costly home modifications or significant renovation. The previous Congressional Sessions have seen a proposal that would require that newly constructed,



Federally-assisted single family houses and town houses conform to Visitability standards. The basic design features referenced by the bill refers to the International Codes Commission's accessibility standards for a voluntary Type C unit.

**NCIL proposes that reforms to the LIHTC program should require that LIHTC properties follow a 15% requirement for accessible units in both single-family housing and multifamily housing, as well as 100% Visitability requirement for single-family housing.**

Many cities and regions suffer from a shortage of affordable and accessible housing. This is one of the few sources, and the primary source, of "new money" for housing that can be affordable with other subsidies. Many Low Income Housing Tax Credit (LIHTC) properties are multi-family housing, which fall under the *Fair Housing Act* design and construction requirements. Even though there are no Section 504 obligations for greater accessibility, it has been beneficial for many people with disabilities. A bipartisan push to expand the LIHTC program has been underway, introduced as S. 548 and H.R. 1661, both named "*Affordable Housing Credit Improvement Act of 2017*".

NCIL supports the program and the additional tax credits proposed, but NCIL believes that given the desperate need for accessible units, the LIHTC program has to do better on accessibility. A recent study in the Housing Policy Debate, "The Characteristics and Unmet Housing Program Needs of Disabled HUD-Assisted Households" by Casey Dawkins and Mark Miller, found that hundreds of thousands of people with disabilities were in housing that did not meet their accessibility needs. Startlingly, in public housing, seventy percent of residents did not receive a requested disability-related reasonable accommodation, and ninety percent of public housing residents with disabilities did not live in accessible units.

*Since Congress has consistently chosen to not significantly increase funding for subsidized housing, one way to increase the number of accessible units is by expanding the LIHTC program.*

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



## Transportation →

In today's society, economic competitiveness and success in the 21st century are dependent upon revolutionary ideas and solutions providing Americans, including individuals with disabilities, with accessible transportation systems that connect our cities, suburbs, rural areas, regions, and states. *NCIL strongly supports and advocates for the integration of individuals with disabilities into society through universal (accessible) design in in both public and private transportation systems. In doing so, America honors, for 27 years, the equal access intent of the Americans with Disabilities Act (ADA). We encourage the Trump Administration to provide appropriate enforcement through the Department of Justice.*

Given the wide variety of pedestrian transportation options, 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. Increased investment in the current transportation system alone won't 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. We must embrace innovative ideas that serve to enhance and maximize community integration, connectivity, and independence.

We believe 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 includes vehicles running on compressed natural gas (CNGs) and hybrid vehicles. NCIL supports public policy promoting American companies by providing incentives and subsidies toward the development of new universally designed, wheelchair accessible, energy efficient transportation vehicles. This encompasses transportation for air, land, and waterways.

In order to maximize continuity and efficiency of transportation, a coordinated plan is required that involves representatives from all impacted stakeholders, including the disability community.

**Amtrak / High Speed Rail Systems:** NCIL strongly supports high speed rail, including Amtrak and other regional high speed rail systems. However, they often continue to be out of compliance with *ADA* standards. These companies are not government entities, but receive Federal and other governmental subsidies and as such must comply with Section 504 of the *Rehabilitation Act*, as well as the *ADA*. In addition to subsidies, they have received technical assistance and directives in this area. NCIL believes that as we have passed the 26th anniversary of the *ADA*, no further excuses should be tolerated for delays on compliance. See *H.R. 749, the Passenger Rail Reform and Investment Act of 2015* (new version to be reintroduced in 115th Congress) for more details on Amtrak reforms.

**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. As states and communities increase their bicycle lanes and related supports, it is important the disability community is at the table. In addition, advocates should seek out local, county, state, and Federal guidance, especially from local and state Bicycle-Pedestrian Coordinators where major changes are taking place. For more information concerning livable communities or 'Complete Streets,' see *H.R. 2071, the Safe Streets Act of 2015* (new version to be reintroduced in 115th Congress).

**Private transportation services:** 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, boats and more recently, Transportation Networking Companies (TNCs).

TNCs, also known as Ride Sharing, are both an interesting and challenging development that can increase transportation options, but also raise 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 can be important. They provide options for many people with disabilities. Unfortunately, TNC drivers have often discriminated against people with disabilities, not provided appropriate treatment of service animals (including trunk placement), and overcharged members of the disability community (i.e. price gouging). TNCs don't offer 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. Some states are looking to contract with TNCs to reduce costs and in some cases, seek to address other disability services gaps. NCIL believes that with the right policies and practices, TNCs can be part of solving some of our community's transportation needs. Some efforts between TNCs and the disability community are proving helpful, but great challenges remain. NCIL encourages advocates to be at the table on all levels when public policies and practices on TNCs are being discussed.

**Transportation Funding:** In December 2015, Congress passed and President Obama signed the *Fixing America's Surface Transportation (FAST) Act*. The *FAST Act* is a five year agreement that will have funding for all modes of transportation with three years of guaranteed funding. President Trump has indicated an interest in increasing investment in transportation, but it's not clear how much, which sectors, (public and / or private), or which modes.

While many transportation advocates wanted a longer term, more robust transportation funding package to address all modes with inflationary indexed increases, this was viewed as the best that could be done under the current political circumstances since it resulted in guaranteed additional funding for states. States generally receive close to half of their transportation funding through the Federal government.

NCIL supports full appropriation of Congressional funding agreed to in prior authorizations. We oppose cuts that impact people with disabilities, including those that support them living in the community.

The *Transportation – Housing & Urban Development (THUD) Appropriations* bills are key to transportation funding, including Community Development Block Grant (CDBG) dollars, which are often blended with other government funds for local curb cuts and other accessible community projects.

**Medicaid Transportation:** Transportation is a covered benefit under state Medicaid plans that are approved by the Centers for Medicare & Medicaid. Medicaid or Medical Assistance Transportation Programs are grouped under paratransit, but have different funding streams. With the continuing increased push for Medicaid Managed Care for both behavioral health and long term care, transportation is an issue that advocates will want to watch on state and county / regional levels. Medicaid Managed Care Organizations (MCOs) should be reminded that they have responsibilities for transportation that must adhere to Federal and state rules as well as their MCO contracts.



## **Airlines and Air Travel Issues**

**Federal Aviation Administration (FAA) Reauthorization:** In July 2016, Congress passed and

President Obama signed a short term *FAA Reauthorization* extension that is now set to expire in September 2017. Two changes of interest are that the Federal DOT is to report back to Congress on findings regarding disability-related complaints and the air travel industry is to incorporate ‘best practice’ models to address disability related concerns by July 2017. Airports and air travel have long been a challenge for people with disabilities. Airports are subject to either *ADA Title II* or *Title III* and if Federal funding is involved, *Section 504 of the Rehabilitation Act of 1973*. Airlines are subject to the *Air Carrier Access Act (ACAA)*, which covers airline owned, leased, or controlled space, including airport facilities; airplanes; and airline websites. NCIL supports an *FAA Reauthorization* that addresses the concerns of the disability community, including policies and practices promoting cultural competency and inclusion of persons with disabilities similar to other passengers.

***Air Carrier Access Amendments Act*** (bill number not yet assigned in 115th Congress): The *Air Carrier Access Amendments Act* would require domestic and foreign air carriers to ensure airplanes are designed to accommodate people with disabilities, including wheelchair users. Airlines would also be required to meet accessibility standards, including safe and effective boarding and deplaning equipment and procedures; visually accessible announcements; and better options for stowage of assistive devices. It would also require airlines to eliminate gaps in service to people with disabilities. The legislation would strengthen *ACAA* enforcement by requiring referral of certain complaints to the U.S. Department of Justice and conferring a private right of action.



***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 prior proposed rules by DOT. 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.



NCIL continues to work with other advocates on DOT-OST-2015-0246, also known as a “Reg Neg” and other issues noted in this section addressing accommodations for air travelers with disabilities.

## Transportation Budget / Policy Watch List

NCIL also supports the following legislation and policy:

- Public Policy Change: Increase weight levels on transit lifts to 1000 pounds
- Public policy around driverless cars
- *Allowing Local Control of Federal Transit Funds Act*
- Public policy supporting ADA compliance with vehicles for water travel

### NCIL opposes:

- **H.R. 1394** or related policy and budget efforts “to amend title XIX of the *Social Security Act* to permit states to refuse to provide Medicaid Transportation” (Non-Emergency Medical Transportation, also known as NEMT). In addition to *H.R. 1394*, HHS Secretary Tom Price sent a letter that could potentially permit states to opt out of providing these Federally-mandated services.
- The Trump Administration, through DOT, announced a one year delay on data collection that covered lost or damaged wheelchairs, scooters, and mishandled baggage on airlines. Some Senators have sent letters opposing the delay to address these air travel concerns. Leading disability organizations have opposed further delay of data collection on lost or damaged wheelchairs, scooters, and mishandled baggage.
- Proposed elimination or extreme reduction in Community Development Block Grants (CDBG) as proposed by Trump Administration.

NCIL also encourages its members to be active on all levels in addressing transportation concerns, particularly since most venues are utilizing some Federal dollars: Metropolitan Planning Organizations (MPOs), Rural Transit Planning Organizations (RTPOs), county / local transit, airport, state Department of Transportation (DOT) boards and other boards where transportation issues often don't include representatives from the disability community.



## Mental Health →

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 with mental health labels, are more likely to become victims than perpetrators of violence. NCIL continues to oppose all legislation or administrative action that denies rights based on a diagnosis or disability and any deprivations of liberty based on disability rather than criminal activity. Legislation must also assure continued support for mental health peer support and advocacy.

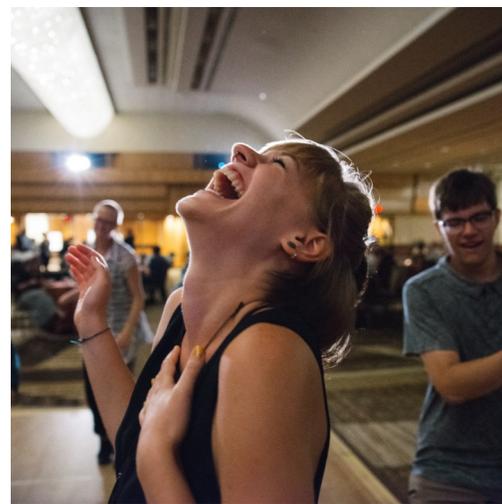
People with psychiatric disabilities have been left out of many mental health policy discussions. Their experience is crucial and must be represented, at least in equal proportion to other stakeholders, in these discussions.

NCIL opposes two current bills: the *Mental Health and Substance Abuse Treatment Accessibility Act of 2017 (H.R. 1253)* and the *Medicaid Coverage for Addiction Recovery Expansion Act (S. 1169)*. Both bills encourage more institutionalization of people with disabilities. *H.R. 1253* would provide Federal loans and loan guarantees for more psychiatric and substance use treatment beds.

The Senate bill would modify the Medicaid Institution for Mental Disease (IMD) exclusion. This policy, in effect since the beginning of the Medicaid program, excludes Medicaid payment for mental health and substance use services in facilities with more than sixteen beds, except for patients younger than 22 or at least 65 years of age. If passed, the bill would allow Medicaid to pay for sixty consecutive days of inpatient treatment in larger facilities.

The IMD exclusion was included in Medicaid from the beginning to prevent a Federal take-over of state support for institutions seen as warehousing people with mental health disabilities. Proponents of *S. 1169* claim that it would expand access to much needed treatment for opioid addiction. However, the bill would actually do little to expand access to treatment while posing a significant threat to civil liberties. The legislation does not require states to make suitable outpatient treatment available and would not prevent someone from being subject to involuntary treatment – institutionalized against their will. The Act's sponsor, Sen. Durbin (D-IL) states that, if enacted, eighteen additional facilities in Illinois would become available.

Members who have assisted consumers to reintegrate back into the community from some of these facilities find it hard to imagine that any of these facilities would be the least bit helpful or an appropriate placement for anyone seeking treatment for an opioid addiction.



## Education →

### ***Individuals with Disabilities Education Act (IDEA)***

NCIL believes that *IDEA* as a civil rights law is a good and necessary law that must be fully implemented and aggressively enforced. Amendments to *IDEA* must ensure that students with disabilities are afforded the following:

- An educational program that includes the development of self-advocacy skills, information about their rights, and opportunities to connect with adult role models with disabilities;
- Full access and benefit of education, including academics, extracurricular activities, physical education and social opportunities;
- Appropriate assessments and necessary technology and supports in order to participate in the learning process actively with peers;
- An equal opportunity to be appropriately challenged in their educational endeavors;
- Schools that are accountable for the success of all students; and
- Due process rights when their civil rights are being denied, regardless of financial resources.

## College Accessibility for Students with Disabilities

Students with disabilities are enrolling in college in record numbers. Students often find it difficult to locate information about college requirements for accommodations and specific disability programs at colleges. Colleges are not prepared to adequately accommodate students. Federal legislation is needed to:

- Require colleges to accept an IEP or 504 plan as evidence of disability when a student is seeking accommodations in college;
- Establish information on disability services to be provided in one place and make that place publically known; and
- Establish a technical assistance center for college staff to learn about the needs of students and the responsibilities of faculty.

## Restraint and Seclusion of Students Must End

Restraining and secluding students causes harm and is proven to be ineffective. Yet restraint and seclusion remains a practice in many schools. The Government Accountability Office reported widespread misuse of restraint and seclusion. Federal legislation is needed to:

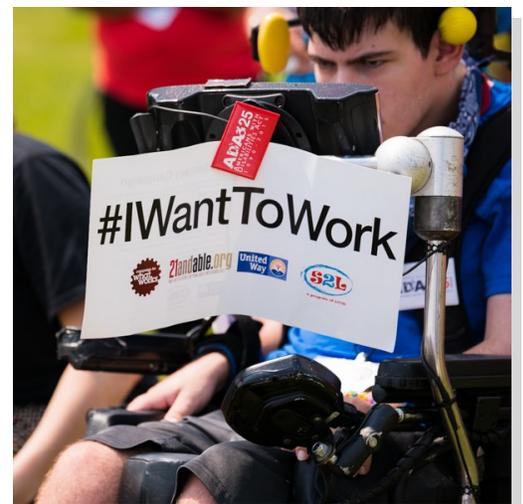
- ban restraint / seclusion except in emergencies where someone is in danger of physical harm;
- require that parent notification if a student is restrained / secluded on the same day that the event occurred;
- ban restraints that impede breathing, mechanical restraints, and chemical restraints; and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

## Employment & Economic Equity →

### Congress: Amend the Current Law for Baby Boomers with Jobs!

NCIL maintains its strong requests to Congress to eliminate the age 65 limit for Medicaid Buy-In eligibility for workers as currently found in the *Ticket to Work and Work Incentives Improvement Act* (PL 106-170). We know many workers with a disability need to retain Medicaid to pay for personal assistance services, for example, which in turn help pay for their continued independence, integration, and economic and community contributions.

This idea, with the help of partners in DC, has been put into proper legislative language and is ready to move forward! NCIL requests Congress to align this law with the same Medicaid Buy-In language in the *Balanced Budget Act of 1997*, allowing for continued Medicaid Buy-In eligibility for workers with a disability age 65 and older. The two laws need to read as one on this matter to support **all workers with disabilities**.



## **Congress: Create An Equal Playing Field and Remove Barriers to Employment for Older Workers!**

NCIL also asks Congress to change Social Security rules and regulations (POMS) to eliminate earnings limitations for CDB / childhood disability beneficiaries (who draw benefits attributable to another's account) upon reaching full Social Security retirement age (currently 66) to equate with rules of SSDI beneficiaries who have established their own account. This would eliminate such work disincentives as Substantial Gainful Employment (SGA) requirements for this group, encouraging all aging workers to continue to work if they so choose. Like its partner policy idea listed above, this has been put into proper legislative language and is also ready to move forward given the opportunity!

### **The *ABLE Act*: Now More Than Ever!**

In 2017, the *ABLE Act* still continues to be an important policy priority for NCIL. Over 45 states have opted to enable ABLE legislation with many (18 at last count with more to come) actively launching programs. Other states are having ABLE legislation heard in their own statehouses in 2017.

**The *ABLE Age Adjustment Act* (S. 817)** would raise the age limit for eligibility for ABLE accounts to individuals disabled before age 46. The current legislation limit is age 26. S. 817 was introduced April 4, 2017 by Sen. R. Casey (D-PA) and has been referred to the Committee on Finance.

**The *ABLE to Work Act* (S. 818)**, which builds on the success of the *ABLE Act* by making it possible for individuals with disabilities to increase their ABLE accounts in various ways. This will encourage individuals to work without impacting their Federal benefits or current ABLE accounts. This legislation would allow individuals and families to save more money in an ABLE account if the beneficiary works and earns income. S. 818 was introduced April 4, 2017 by Sen. Richard Burr (R-NC) and has been referred to the Committee on Finance.

**The *ABLE Financial Planning Act* (H.R. 1897)** would allow families to rollover savings from a Section 529 college savings plan to an ABLE account. H.R. 1897 was introduced April 4, 2017 by Rep. Cathy McMorris-Rodgers (R-WA) and referred to the House Ways and Means Committee.

As in previous years, the three are considered a "package" and it is NCILs wish to see all three passed together. However, this idea has been largely ignored and at the date of this drafting there remains a push to move the other two bills without moving the *ABLE Age Adjustment Act*.

### **Eliminating Subminimum Wages: *The TIME Act***

In 2017, the *Transitioning to Integrated and Meaningful Employment (TIME) Act* still commands considerable interest by NCIL, Congress, DOL, and a myriad of advocacy groups across the nation.

H.R. 1377 was introduced by Rep. Gregg Harper (R-MS) on March 7, 2017 and referred to the House Committee on Education and the Workforce.

What 2017 will bring for *TIME* remains to be seen, though NCIL and the eight co-sponsors of the Act continue to direct Congress and the Secretary of Labor to discontinue issuing to any new profit, non-profit, or governmental entity special wage certificates (which permit individuals with disabilities,



including individuals employed in agriculture, to be paid at lower than minimum wages). This bill requires a three-year phase-out of all certificates.

### **The CareerACCESS Policy Initiative**

NCIL strongly supports the Congressional funding needed now to allow at least two states to pilot CareerACCESS projects by 2018 for young adults with a disability building careers. The three states to date with the strongest NCIL member interest in launching the pilot projects are Vermont, Michigan, and Massachusetts. Pennsylvania is in discussions as of Spring 2017. Visit [www.ourcareeraccess.org](http://www.ourcareeraccess.org) for more information.

NCIL, its members, and the Americans we work with and for can move closer to the middle class and true economic integration with these economic policies and laws in place!

### 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.

Thirteen 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 do not have an Alternative Financing Program (AFP); and for many that do, their programs are small. By supporting AFPs and increasing their funding, Congress will make it possible for states to build and expand their programming. This will make it possible for people with disabilities to participate in financial education, develop money management skills and purchase assistive technology that supports greater productivity, financial stability and independence.

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.



## Voting Rights →

NCIL's top three voting priorities are: election reform to maintain accessibility in the voting processes; disability engagement in the development of new and innovative voting technology; and ensured accessibility and increased disability participation during the entire election cycle to build electoral power. These will remain essential objectives of our organization and its members until all barriers to the full electoral participation of people with disabilities 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 multi-tiered grassroots strategy:

- We will work to improve disability community engagement and accessibility of all policy regulating the voting process; this includes Federal funding to improve accessibility, accuracy, and security in voting.
- We will advocate with policy makers, technology makers, and election officials to ensure that any new voting technology has been created to serve the most universal access needs of all voters with disabilities.
- We will work to train leaders, develop strategic plans, foster collaborations, and provide resources and help for disability community-driven non-partisan voter registration, education, and get-out-the-vote campaigns in primaries and general elections at the local, regional, state, and national levels.
- We will work to encourage and recruit people with disabilities to run for public office and hold appointed positions in government.

In order to achieve these ends, we must set a high standard of integrity for the voting process, which must include:

- the right to read and mark a ballot privately and independently;
- the right to access reliable and accessible voting technology and equipment;
- the elimination of difficulty and discriminatory actions and attitudes towards people with disabilities during the registration, education, and voting processes by election volunteers and personnel;
- the removal of all architectural and physical barriers to polling centers;
- enforcement by the Justice Department to ensure the rights afforded to all citizens by America's voting laws are upheld equally for voters with disabilities;
- the elimination of regressive and discriminatory voter ID laws that require a photo ID to cast a ballot; and
- the removal of state guardianship laws that continue to be barriers in participation to the entire voting process, from registration to casting a vote, for many people with disabilities.

In addition to these goals and standards, we must work to maintain the access we have achieved so



far. We seek to make sure all election officials, campaigns, and organizations engaging in voter education have accessible websites and provide alternative formats for all voter education materials as spelled out in the *Americans with Disabilities Act*. 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 promote a strong and vital partnership with the U.S. Election Assistance Commission that continues to improve accessibility of the entire voting process. Finally, we continue to engage the President's Commission on Election Administration and support its recommendations to increase access and protect equality for voters with disabilities. Details can be found at: [bipartisanpolicy.org/the-presidential-commission-on-election-administration](http://bipartisanpolicy.org/the-presidential-commission-on-election-administration).

## 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. Specifically, NCIL supports:

### **Veterans Health Administration (VHA)**

- Reform by the VA and Congress for the VHA to process appointments in a timely manner.
- Congress must ensure that the 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 Veteran Directed Home and Community Based Services and Medical Foster Homes.

### **Veterans Benefit Administration (VBA)**

- Reform by the VA and Congress for the 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 due to 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 benefits received by veterans and their families are not reduced.
- Since 2011, benefits have been created for post-9/11 military members and deservedly so. It's time to examine the availability of those benefits for veterans who served pre-9/11.



## **Veteran Homelessness Prevention**

- Our President and Congress should continue to address the issue of homeless veterans and support efforts to prevent homelessness.

## **Veterans & Centers for Independent Living**

- There are factors affecting the daily lives of families and veterans that require needed services 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 115th Congress and urges swift action on these measures:**

### **Healthcare Reform Must Help CHAMPVA Beneficiaries**

The Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) is a comprehensive health insurance program in which the VA shares the cost of covered healthcare services for eligible beneficiaries. Beneficiaries include dependents of veterans with catastrophic service-connected disabilities who are under the age of 23, if enrolled in an accredited school as a full-time student, or under age 18 if not so enrolled. The *CHAMPVA Children's Care Protection Act of 2015 (S. 170)* and the *Veterans Dependents' Parity Act (H.R. 220)* allow 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.

### **Social Security Caregiver Credit Legislation and Veterans**

Social Security retirement benefits are based upon a person's earnings in the workplace and when someone must drop out of the workforce to care for a loved one, this can have an adverse impact on their future financial security in the form of lower benefits. Legislation has been introduced to allow people who provide at least 80 hours a month of unpaid assistance for a relative with disabilities to continue earning Social Security credits. Why is this important to veterans with disabilities? A VA law specifically excludes counting the caregiver stipend for purposes of earnings credit under Social Security. Efforts are underway to extend the VA caregiver benefit to all veteran caregivers so that this legislation does not inadvertently exclude caregivers of veterans with disabilities.

## Violence and Abuse →

As reported in *The Hill* on January 19th, the Trump budget is closely following a blueprint that was laid out by the conservative Heritage Foundation last year. Staff from this think tank organization has moved to assist in the Administration's transition. At the Department of Justice, the blueprint calls for the elimination of *Violence Against Women Act* Grants and the Legal Services Corporation and reducing funding for DOJ's Civil Rights Division.

### **Violence Against Women Act Grants**

The *Violence Against Women Act (VAWA)* grants create and support comprehensive, effective, and

cost saving responses to the crimes of domestic violence, dating violence, sexual assault and stalking in thousands of communities across the United States. Currently, a designated grant program exists within the Office of Violence Against Women and funded by VAWA entitled “Training and Services to End Violence Against Women with Disabilities.” Since its inception, nearly 60 communities have been funded to create sustainable change by addressing gaps in services, accessibility, and safety in order to better serve individuals with disabilities who have been impacted by domestic violence, sexual assault, and stalking. We must support this critical legislation for the benefit of victims of domestic violence, sexual assault, dating violence, and stalking. Once secured, we must continue to push for people with disabilities to be funded as a designated grant program in this continuing work.

### **Legal Aid**

Another target is the Legal Services Corporation (LSC). This is an independent nonprofit established by Congress in 1974 to provide financial support for civil legal aid to low-income Americans. LSC promotes equal access to justice by providing funding to independent non-profit legal aid programs in every state. These grantees serve thousands of low-income individuals, children, families, seniors, and veterans.

### **Civil Rights Division, Department of Justice**

Also included in the blueprint is reducing funding for the Civil Rights Division. It is unclear what this would involve, but in this climate, it is imperative not only to maintain current civil rights division efforts but to look at mechanisms to ensure the civil rights of all Americans in the future, especially those with disabilities.

Together, the *Violence Against Women Act (VAWA)* programs, the legal aid grants from the Legal Services Corporation and the Civil Rights Division of DOJ support the needs of victims of violence and other civil rights. We urge you to act now to protect VAWA funding from these and any other proposed cuts.

### **Cascading Effects**

In addition to the points made above, the issue of violence and abuse are woven into the issues addressed in other parts of this document.

Repeal of *Affordable Care Act (ACA)* and associated block grants for Medicaid create a situation in which individuals with disabilities may lose their choice to live independently in the community. Institutional settings, such as nursing homes, are a breeding ground for neglect and abuse. The risk to health and safety of individuals with disabilities therefore is directly affected by the actions being taken by Congress and the White House.

The changes within the Education Department, including the possible elimination or moving money from public to school choice programs may have a drastic effect on the safety of students with disabilities. The *Individuals with Disabilities Education Act (IDEA)* mandates that schools investigate and respond to incidents of bullying, plus Individualized Education Plans (IEPs) have been used as a tool in combating bullying. Seclusion and restraint policies are guided by Federal mandates in response to the states’ inability to ensure the safety of students. These Federal protections are essential and must not be reverted back to the state.



Hate crimes against people with disabilities have always been underreported so the actual impact of this election on this is not clear, but what is known is that there has been a spike in hate crimes since the election. The hateful rhetoric used during the campaign and continuing since the election puts people in already marginalized groups at risk for being victimized.

The United States also has a history of banning people with disabilities from entering this country. Recent travel bans and deportation rules include a focus on banning and deporting individuals based on their need for support. This targets individuals with disabilities and puts them at risk. The deportation orders have already made it difficult for victims to come forward seeking help. Going to the police or court puts victims at risk of coming into the view of officials, who may deport them or break up families - leaving children born in this country “orphaned” to the system.

## Aging & Disability Resource Centers →

Aging & Disability Resource Centers (ADRCs) must embrace our principle of “nothing about us without us” at the national level (by working with NCIL), at the state level (by working with Statewide Independent Living Councils - SILCs), and at the local level (by working with Centers for Independent Living - CILs). This includes a commitment to consumer control, consumer direction, self-determination, autonomy, and dignity of risk for all consumers. It also means that policy decisions about serving people with disabilities must include the disability community.

- All ADRCs must serve seniors and people of all disabilities of all ages from day one and every day. Existing ADRCs that have not adhered to this and all key elements are not truly ADRCs because they are not cross-age and cross-disability.
- All ADRCs must implement the “No Wrong Door” model versus the “Single Point of Entry” model.
- All ADRCs’ design, development, and implementation are required to include a mandatory partnership between the senior agencies and CILs & SILCs, unless one entity chooses not to participate.

Specifically, NCIL’s ADRC Subcommittee will work with Administration for Community Living (ACL) / Independent Living Administration (ILA) on the development of the guidelines that reinforce this partnership at the Federal, state and local levels.

## 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 and a 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 the 115th 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. 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. Each of us can play a role in educating ourselves and others. Each of us can let politicians know the treaty's value, what it means to us, and why ratification is the best choice, especially if we want the U.S. to be the strongest voice in promoting disability rights around the world.

### **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 Opposes

- ADA Compliance for Customer Entry to Stores and Services (ACCESS) Act
- ADA Education and Reform Act
- American Health Care Act (AHCA)
- Correcting Obstructions to Mediate, Prevent, and Limit Inaccessibility (COMPLI) Act
- H.R. 1394 or related policy and budget efforts "to amend title XIX of the Social Security Act to permit states to refuse to provide Medicaid Transportation"
- Local Zoning Decisions Protection Act
- Mental Health and Substance Abuse Treatment Accessibility Act
- Medicaid Coverage for Addiction Recovery Expansion Act

## Legislation NCIL Supports ✓

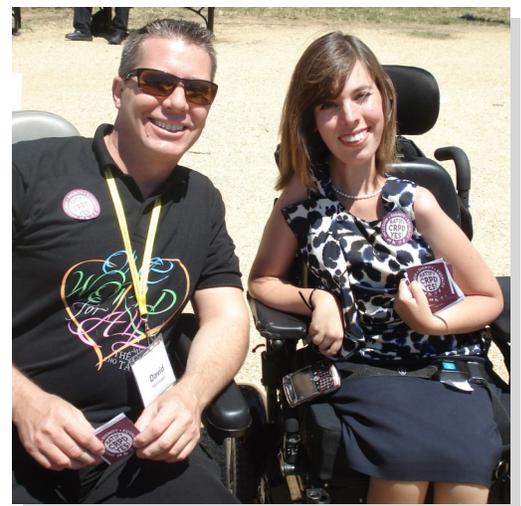
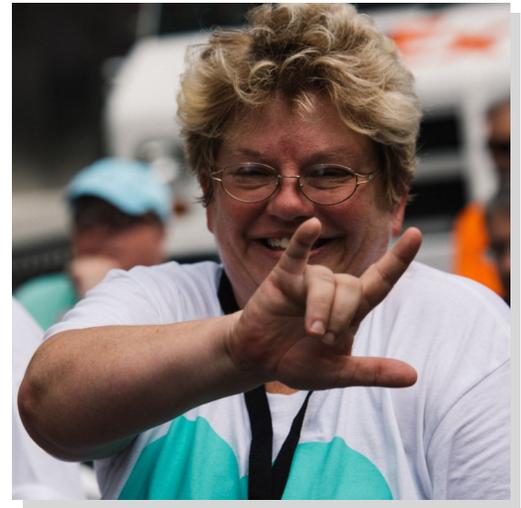
- Air Carrier Access Amendments Act
- Allowing Local Control of Federal Transit Funds Act
- ABLE Age Adjustment Act
- ABLE Financial Planning Act
- ABLE to Work Act
- Access to Veterans Benefits Improvement Act
- Blue Water Navy Vietnam Veterans Act
- CHAMPVA Children's Care Protection Act
- Common Sense Housing Investment Act
- Disability Integration Act
- Disabled Veterans' Access to Medical Exams Improvement Act
- Eleanor Smith Inclusive Home Design Act
- Ensuring Access to Quality Complex Rehabilitation Technology Act
- Housing Fairness Act
- Keeping All Students Safe Act
- Lead-Safe Housing for Kids Act
- Lori Jackson Domestic Violence Survivor Protection Act
- Medicare DMEPOS Competitive Bidding Improvement Act
- Military Reserve Jobs Act
- Mortgage Interest Deduction Reform
- Passenger Rail Reform and Investment Act
- Pet and Women Safety Act
- Protecting Domestic Violence and Stalking Victims Act
- Quicker Veterans Benefits Delivery Act
- Safe Streets Act
- Security and Financial Empowerment Act
- Stop Child Abuse in Residential Programs for Teens Act
- Transit Accessibility Innovation Act
- Transition to Independence Act
- Transitioning to Integrated and Meaningful Employment (TIME) Act
- Veterans Dependents' Parity Act

### Full funding of:

- Assistive Technology Act

### Ratification of:

- Convention on the Rights of Persons with Disabilities Treaty



# 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 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.



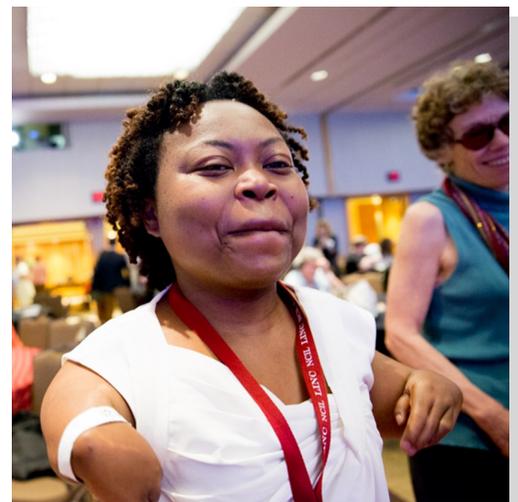
Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to affect change. NCIL promotes a national advocacy agenda set by its membership and provides input and testimony on national disability policy.

## America's 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
- Transition

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





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