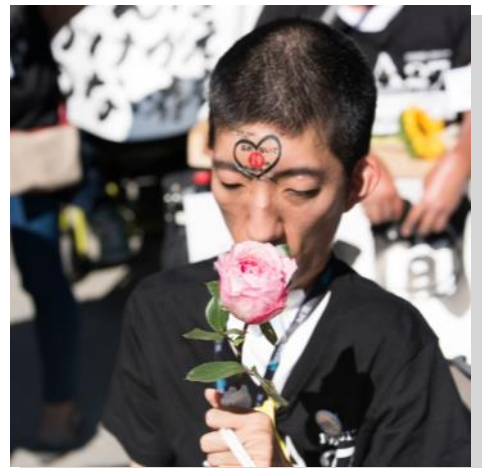




Legislative & Advocacy

Priorities Guide

Summer 2018



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 2018 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

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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.

NCIL was very excited that Congress increased IL funding by \$12 million in FY 2018. However, 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. Therefore, NCIL is requesting \$200 million in additional funding in the 2019 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 the 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.

While CILs are the only entities required to do nursing home transition, no funding has been dedicated for that purpose. In addition, the ILA and ACL have cut funding to CILs over the last several years and used the funding for other purposes, and the increase provided by Congress is not enough to effectively carry out these new core services. 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. Conversely,



Vocational Rehabilitation agencies routinely receive increases of \$365 million in COLA every year. Due to state budget constraints, state Vocational Rehabilitation agencies have returned over \$80 million to the Treasury because they are not able to match with state funds. CILs bridge the gap between Vocational Rehabilitation services and success living independently in the community. 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.

The ILA has yet to establish a system to aggregate data collected on the IL program but 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.

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 is now working with the Independent Living Administration to develop improved reporting and monitoring tools. The goal is to more effectively capture the outcomes and effectiveness of the Independent Living Program. NCIL, and CILs, want to ensure accountability through effective monitoring as well as tools that clearly demonstrate the results of investing in this unique and critical program.

NCIL respectfully requests your careful consideration to increase funds for the Independent Living line item for the 2019 budget.

Healthcare and Long-Term Services and Supports →

Disability Integration Act

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 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 co-sponsor this important legislation protecting the Constitutional and civil rights of Americans with disabilities.

Reform Medicaid, Don't Gut It!

NCIL strongly supports 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 Congress to take the time to engage NCIL and the disability community to understand the needed reforms and craft legislation that can achieve our common goals.

Independent Living and Medicaid

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.

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.



NCIL urges Congress to maintain these important provisions of the ACA by addressing the problems with the existing law rather than repealing it.

Money Follows the Person

The Money Follows the Person (MFP) demonstration program was designed to help states transition

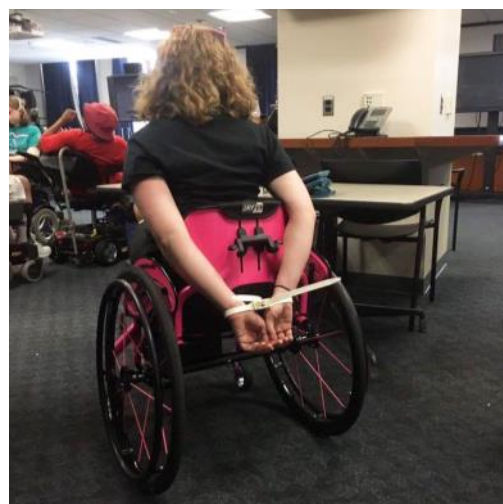
people with disabilities from institutions into the community and to assist states in rebalancing their long-term services and supports systems to increase access to home and community-based services. Since it began, 47 states have participated and over 75,000 disabled people have been liberated from institutions. On average, per-beneficiary per-month expenditures for those participating in the re-balancing demonstration declined by \$1,840 (23%) during the first year of transition from a nursing home to home and community-based LTSS, saving \$978 million. CMS also found that MFP participants are less likely to be readmitted to institutional care than other beneficiaries who transition but do not participate in the program. Unfortunately, MFP expired on September 30, 2016 and states have started to shut down their MFP programs. Congress must save and adequately fund MFP. It can do this by passing the *EMPOWER Care Act - H.R. 5306* (Guthrie-R) and S. 2227 (Portman-R).

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)

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).



Since 2015, advocates have been fighting CMS' plans to use 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 manual wheelchairs. Congress passed several temporary delays, and in June of 2017 CMS issued a new policy to permanently resolve the issue for Complex Rehab power wheelchair accessories. But, the policy didn't include manual wheelchair accessories, 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 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. 3730* (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.



Opioids and Chronic Pain

As Congress and the Administration move forward with their efforts to combat opioid addiction, people with chronic pain and other disabilities continue to be largely left out of the national conversation. The result has been increased barriers to accessing and maintaining effective pain management for people with chronic pain, discrimination against people who use opioids to manage their pain, and treatment / recovery options that are inaccessible to disabled people. In response, NCIL established a Chronic Pain / Opioids Task Force earlier this year. The major goals of the Task Force are to work to ensure that the voices of people with chronic pain and other disabilities are part of the ongoing national discussion and to develop a national advocacy strategy.

NCIL believes that any effort to reduce opioid addiction must be balanced with the needs of people with chronic pain for whom opioid medications may be medically necessary. Over 100 million Americans live with some form of chronic pain, and Congress must work with their constituents with chronic pain to ensure their efforts to address opioid addiction do not have negative consequences for them. Without taking the needs of people with chronic pain and other disabilities into account, any efforts to address opioid addiction cannot be successful.

Electronic Visit Verification (EVV)

In late 2016, EVV was passed into law as part of the *21st Century Cures Act*. NCIL opposes this new requirement and formed an EVV Task Force to coordinate a national advocacy strategy. With implementation deadlines of January 1, 2019 for personal care services and January 1, 2023 for home health services, states are in various stages of development and implementation. EVV systems vary by state, but disabled people in some states have already experienced the harmful effects of intrusive and burdensome systems.

NCIL supports H.R. 6042 (Guthrie-R), H.R. 5912 (Langevin-D), and S. 2897 (Murkowski-R). All are bills that, if passed, will delay implementation of EVV by one year. Delaying the implementation will allow more time for states to meaningfully engage consumers as they develop and roll out their systems. H.R. 5912 and S. 2897 also call for rulemaking, which will allow an additional opportunity to provide stakeholder input.

Delaying implementation alone will not solve the inherent problems of EVV. NCIL continues to strongly oppose the EVV requirement. EVV is discriminatory, and it undermines consumer direction – a key tenet of Independent Living philosophy. EVV is also a violation of the privacy of disabled people who use personal care services and home health services. Additionally, it is expensive, burdensome, and often less effective than traditional methods that have been instrumental in building consumer-directed personal assistance services nationally for the past 40 years. NCIL will continue our efforts to work with CMS and Congress to minimize the harm of EVV nationally through our grassroots Task Force.



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

Assisted Suicide →

NCIL Urges Congress to Co-Sponsor and Support *House Concurrent Resolution 80* Against Assisted Suicide Laws

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

NCIL urges all members of the U.S. House of Representatives and Senate to co-sponsor and support *House Concurrent Resolution 80*, expressing the sense of Congress that assisted suicide laws are dangerous and harmful to both people with disabilities and the general public at large. The key issues and concerns are summarized in the points and examples below.

1. There's a deadly mix between our broken, profit-driven health care 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 a rising problem. 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.



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, call the main organization that supports assisted suicide—today it's called Compassion & Choices but it used to be known as the Hemlock Society—and it 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." How could this happen if the safeguards are as strong as alleged to be? 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, until he died a natural death.

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 and no established means for finding out what happened.
- 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 assisted suicide laws do not effectively address, and that many people outlive their terminal diagnosis. Yet they still received lethal prescriptions.

Some organizations that oppose assisted suicide laws:

- American College of Medical Quality



- American College of Physicians
- American Medical Association (AMA)
- American Medical Directors Association
- American Nurses Association
- American Society of Medical Ethics
- National Hospice & Palliative Care Organization
- Physicians for Compassionate Care Educational Foundation
- Association of Programs for Rural Independent Living (APRIL)
- American Disabled for Attendant Programs Today (ADAPT)
- American Association of People with Disabilities (AAPD)
- Association for Persons with Severe Handicaps (TASH)
- Disability Rights Education & Defense Fund (DREDF)
- National Council on Independent Living
- Not Dead Yet
- Autistic Self-Advocacy Network (ASAN)
- The Arc of the U.S.
- United Spinal Association (USA)
- League of United Latin American Citizens
- Patients Rights Action Fund (PRAF)



Civil Rights and the Americans with Disabilities Act →

With each new Congress we see 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

H.R. 620 as it passed the House states its intention as: “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”.

NCIL supports the position of Senator Tammy Duckworth and 42 other Senators who have pledged to protect the *ADA*. “No American should be forced to endure discrimination for any length of time so that places of public accommodation may learn how to follow a seminal, bipartisan civil rights law that was enacted in 1990.”

We strongly oppose the bill's requirement that a very specific written notice to be provided to the owner or operator of the inaccessible business. The bill 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 allowing a total of 180 days for the owner or operator to "remove the barrier or make substantial progress in removing the barrier".

Businesses have had almost 28 years to remove access barriers and remedy non-compliance with the Americans with Disabilities Act. They 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 it allows businesses to continue with their wait-and-see approach and to only resolve access issues after someone 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 temporary and permanent housing should be designed and constructed to be 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. After years of near-stagnant funding in the face of increasing costs of

providing housing assistance and the higher need for housing assistance, last year's increase of nearly 10% was very welcome and a much needed boost to housing assistance programs. However, the dire deficit forecast partially caused by the large tax cut bill will increase pressure for cuts to non-defense discretionary spending programs such as housing.

Secretary Carson has submitted a FY19 budget request from HUD that is below FY 18 final numbers. The submitted request would see cuts to voucher programs, zero out Community Development Block Grants, reduce homeless assistance, and cut funding for Sections 811 and 202 programs, among others.

Strong advocacy is needed to demonstrate the importance of housing programs for people with disabilities. Advocates must fight for every penny the housing programs need to maintain funding of commitments.

NCIL opposes “reform” efforts that would unfairly increase rent on people who depend on housing assistance.

There have been separate proposals from HUD under Secretary Carson and from Representative Ross which would allow public housing authorities to increase rent on extremely low income households, among other initiatives. Despite the claim for simplicity and transparency, both proposals would sow confusion as multiple housing authorities could have different rent structures with different ways to calculate rents owed by households. In both cases, the “reform” efforts are designed to increase the rents that the poorest households pay, including the elimination of deductions in rent calculations. People with disabilities would be no longer able to deduct their disability and medical expenses, and the child care deduction will also be eliminated. ANY rent increases would further push low income individuals out of already dire housing options.



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 in 2017, 55 percent of all complaints were on basis of disability. 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 *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 all 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 supports the *Affordable Housing Credit Improvement Act of 2017 (H.R. 1661 and S. 548)* and proposes it be amended for increased wheelchair accessibility.

Many cities and regions suffer from a shortage of affordable and housing accessible for persons with mobility disabilities. 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 mobility disabilities. A bipartisan push to expand the LIHTC program has been underway, introduced as *H.R. 1661* and *S. 548*; both named “*Affordable Housing Credit Improvement Act of 2017*”. The recent tax bill increased the LIHTC allocation authority by 12.5% for 2018-2021, but a permanent large increase is still needed for the staggering demand.

NCIL supports the program and the additional tax credits proposed, but NCIL believes that given the desperate need for mobility accessible units, the LIHTC program has to do better on accessibility. A 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 provide sufficient funding for subsidized and accessible housing, one way to increase the number of accessible units (by Fair Housing standards) is by expanding the LIHTC program. The LIHTC program should adopt a minimum of 5% mobility accessibility and 2% sensory accessibility standard of Section 504 requirements.

NCIL supports the *Rent Relief Act of 2017 (H.R. 3670)*

This bill would provide a tax credit against the tax on the rent a household pays, capped at 150% of HUD’s Fair Market Rent. The tax credit percentage is pro-rated according to income, starting at 100% for those under \$25,000, then 75% for those between \$25,000 and \$50,000, 50% for between \$50,000 and \$75,000, and so forth until no credit is given those with income over \$125,000. People who live in subsidized housing can claim one month’s rent on their taxes. This would greatly assist low-income households with a larger tax refund (or a diminished tax liability).

NCIL supports the *Ending Homelessness Act of 2017 (H.R. 2076)*

This bill would provide for more funding between 2018 and 2022 for emergency relief for homelessness, rental assistance for those who are homeless, and homeless outreach and



coordination services. The bill also provides additional funding through the Housing Trust Fund. It would also provide funding to HUD to expand the Healthcare and Housing (H2) Systems Integration Initiative by assisting states and localities in coordinating Medicaid programs, behavioral health providers, housing providers, and finance support services to ensure homeless individuals receive services. Multiple studies have shown that unsheltered homeless individuals with disabilities are responsible for a disproportionate percentage of healthcare costs; in South Carolina, data showed that just 5% of the homeless population were responsible for nearly half of all the Medicaid charges; and 50% of the homeless population accumulated 97% of the charges. Housing has been shown to be the most effective way to reduce the healthcare costs.

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 →

Economic competitiveness and success in the 21st century are dependent upon creative ‘outside-the-box’ ideas and solutions to provide everyone, including individuals with disabilities, with affordable accessible transportation that connects 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 both public and private transportation.

To have vibrant livable communities, all modes of transportation must be accessible. Biking and walking are important options for transportation that improve health and well-being and reduce congestion. Safe and accessible transportation is critical to improve employment opportunities and connect people with programs, services and recreational opportunities. Accessible bike programs are available only in a few areas and advocates should seek out local, county, state, and Federal guidance, especially from local and state bicycle-pedestrian groups to increase accessible bike programs across America. People, 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.

Self-Driving / Autonomous Vehicles

Self-Driving cars (also called autonomous vehicles or AVs) are coming. In fact, some are already in use here and in other countries. The potential of AVs to increase transportation options for people with disabilities is one of the greatest benefits of this technology and possibly the most dramatic change in transportation in the century. However, right now market forces are driving (pun intended) the process, which is likely to have a negative rather than positive impact for people with disabilities. Even though people in rural areas (where there is less public transit) could benefit more than people in metropolitan areas, market forces are moving to deploy these vehicles in urban areas.



Last year the House of Representatives passed *H.R. 3388* (the *SELF DRIVE Act*) and the Senate introduced *S. 1885* (the *AV START Act*). Neither bill requires universal design in AVs nor do they mandate that people with disabilities will be able to access this technology. Advocates testified at hearings requesting that universal design language be included and it was not. There are no readily available wheelchair accessible vehicles. People who use wheelchairs or scooters have to modify vehicles which greatly increases the cost of transportation for this population. Congress needs to fix this. Profitability for manufacturers will continue to drive this process unless Congress steps in and balances the need for innovation with the greater public good of access for all. Access and safety must be the top priorities.

Airlines and Air Travel Issues

Bills for Federal Aviation Administration (FAA) Reauthorization (*H.R. 4* and *S. 1418*) are starting to move in Congress. This is must-pass legislation by September 30, 2018 to avoid a shutdown of the nation's airports. It now appears that FAA Reauthorization bills will include much of what is in House and Senate versions of the *Air Carrier Access Amendments Act*. *S.1318* was introduced in 2017 by Senator Tammy Baldwin (D-WI), and *H.R. 5004* was introduced by Representative James Langevin (D-RI) in February of this year. Provisions in these bills would address some of the concerns of the disability community, including policies and practices promoting cultural competency for airline personnel and private contractors. Airlines would also be required to meet accessibility standards, including safe and effective boarding and deplaning procedures; visually accessible announcements; and better options for stowage of assistive devices. Other provisions would require the Secretary of Transportation to work with stakeholders to develop an Airline Passengers with Disabilities Bill of Rights and create a U.S. Department of Transportation Advisory Committee on the Air Travel Needs of Passengers with Disabilities.

The Trump Administration, through DOT, announced a one year delay on data collection that covered lost or damaged wheelchairs, scooters, and mishandled assistive technology on airlines. Leading disability organizations have opposed further delay of data collection. Advocacy groups have filed a lawsuit that is pending.

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.

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. In August 2017, Amtrak released the report “ADA Stations Program Five Year Strategic Plan.”

Although long overdue, this plan is an important step to improving accessibility. Amtrak also created a position of Vice-President for Passenger Accessibility. However, there is still a lot of work to do. On many trains, people with disabilities do not get the same level of service as others. For example, wheelchair users and others who cannot climb steps are limited to the lower level of the bi-level cars and cannot access the dining cars or the sightseer lounges. Advocates need to continue to push Amtrak for greater accessibility.

And in an ironic twist of events, while some stations have recently been made accessible, the ticket agent position has been eliminated. This creates other barriers for people with disabilities. There will be not assistance for baggage handling or boarding assistance. This cost saving move by Amtrak will disproportionately impact people with disabilities.

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 services, car rentals, buses, trains, boats and more recently, ride hailing services, also known as Transportation Networking Companies (TNCs).

Ride Hailing services 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, and overcharged members of the disability community.

Few TNCs offer accessible vehicles 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 (first and last mile). 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.

Traditional taxi services still do not have enough accessible vehicles. And even though the *ADA* has been in place for over 25 years, some taxi companies are fighting against local mandates to increase the number of accessible taxis in their fleet.



Medicaid Transportation

Transportation is a covered benefit under state Medicaid plans that are approved by the Centers for Medicare & Medicaid. With the continuing and increasing push for Medicaid Managed Care for both behavioral health and long term care, transportation is an issue that advocates will want to watch on Federal and state levels. A bill (*H.R. 1394*) was introduced that would allow states to make Medicaid transportation optional! NCIL opposes this or similar legislation because it will create more barriers to healthcare services for many people, including people with disabilities. This could also negatively impact public transit because some basic infrastructure is supported by Medicaid dollars.

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.

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.

Transportation Policy Watch List

NCIL also supports the following legislation and policy:

- Public Policy Change: Increase weight levels on transit lifts to 1000 pounds
- *Allowing Local Control of Federal Transit Funds Act* (Not yet introduced in the 115th Congress)
- Public policy supporting ADA compliance with vehicles for water travel

NCIL also encourages its members to be active on all levels in addressing transportation concerns.

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.

Note: The *Disability Integration Act* (see Healthcare Section) is the best way to ensure integrated care for persons with psychiatric disabilities.



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 to 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 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 (Public Law 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**. The House Energy and Commerce Committee, which holds jurisdiction,

has agreed to listen to and consider this proposal. Upon request, further information was sent to the Committee.

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 chief Social Security actuary has completed culling and analyzing data and House Social Security Subcommittee of Ways and Means has been re-approached for further consideration. Currently, realistic avenues to move forward are being considered. As expected, any programmatic costs are small. Indeed, savings could be achieved by simplifying SSA rules and by the resulting increased socioeconomic productivity.

A cohesive one-pager has been crafted laying out both policy proposals and is ready for distribution.

The *ABLE Act*: The Same Barriers Block Our Way Forward!

In 2018, the *ABLE Act* still continues to be an important policy priority for NCIL. Over 45 states have opted to enact ABLE legislation with many (33 at last count) actively launching programs. Other states are having ABLE legislation heard in their own statehouses in 2018.

In previous years, it was NCIL's preference that the three policy enhancements listed below should be considered a "package" and it was NCIL's desire to see all three passed together. However, this idea has been largely ignored by elected officials. At the date of this drafting, a version of the *ABLE to Work Act* and the *Financial Planning Act* have been included in and passed with the *Tax Cuts and Jobs bill*, becoming law (*Public Law 115-97*) in December 2017. Also included in *Public Law 115-97* was a provision to allow contributions to ABLE Act accounts to qualify for the Federal Retirement Tax Credit. The *Age Adjustment Act* was NOT included due to cost.

The *ABLE Age Adjustment Act* (*H.R. 1874* and *S. 817*) would raise the age limit for eligibility for ABLE accounts to individuals disabled before age 46 (current legislation limit is age 26). Introduced April 4, 2017 by Representative Tony Cardenas (D-CA), it was referred first to House Ways and Means and then to the Committee on Finance. It has 28 co-sponsors but has experienced the same reticence from elected officials as in years past. Thus, NCIL's advocacy efforts in this regard continue to be substantial in order to see it to fruition. A reinvigorated initiative, which NCIL supports, has been developed in 2018 to advocate for passage.

The *ABLE to Work Act* (*H.R. 1896* and *S. 818*) 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 ABLÉ accounts. Introduced by Representative Cathy McMorris-Rodgers (R-WA) on April 4, 2017, this legislation would allow individuals and families to save more money in an ABLÉ account if the beneficiary works and earns income. With 47 co-sponsors, it was first referred to the House Ways and Means Committee, then to the Committee on Finance, and was placed on Senate Legislative Calendar under General Orders, Calendar No. 269 in November 2017. Incorporated into the tax bill, it became *Public Law 115-97* in December 2017, though it included language which was opposed by some disability groups, including NCIL, as confusing and likely to discourage employment rather than encourage it.

The *ABLE Financial Planning Act (H.R. 1897 and S. 1)* will allow families to rollover savings from a Section 529 college savings plan, penalty-free, to an ABLÉ account. *H.R. 1897* was introduced April 4, 2017 by Representative Cathy McMorris-Rodgers (R-WA) and first referred to the House Ways and Means Committee, then to the Committee on Finance, and placed on Senate Legislative Calendar under General Orders, Calendar No. 269 in November 2017. Incorporated into the tax bill, it became *Public Law 115-97* in December 2017.

Eliminating Subminimum Wages: The *TIME* Act

In 2018, 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. Since then little has been done in its regard.

As in 2017, what 2018 will bring for *TIME* remains to be seen, though NCIL and the 17 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.

There are currently initiatives in Congress apart from *TIME* to eliminate sheltered workshops and subminimum wages. NCIL is following closely.

Concern About Medicaid Work Rules

NCIL is concerned that implementing work rules for Medicaid beneficiaries will negatively impact people with disabilities. Some people with disabilities may be required to navigate through burdensome bureaucratic requirements and may lose Medicaid coverage and supports needed for employment. Paradoxically, some people with disabilities may thus cease employment.

The CareerACCESS Policy Initiative

NCIL continues to strongly support CareerACCESS pilot projects in at least two states. CareerACCESS remains a ready model for assisting young adults on SSI to make the successful transition from benefits to building careers. To focus more on the program elements of the CareerACCESS initiative, the project has expanded within a broader effort called WID E3



(wid.org/wid-e3), an employment and economic empowerment strategy. The shift was in part due to funding challenges in launching the pilot projects. Vermont continues to be the lead state in such a potential collaboration, which would not necessarily rely upon Federal funding. NCIL 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! Visit www.ourcareeraccess.org for more information.

Technology →

NCIL strongly advocates for the expansion and accessibility of generic, mainstream technologies (including assistive technology) that enables and enhances independence for people with disabilities. NCIL supports the integration of principles of universal design, inclusion, consumer control and consumer choice, and peer support as these technologies are developed and become available. People with disabilities are best served by being provided opportunities for information and “hands-on” experiences to technology. NCIL encourages the use of universal design to make technology inclusive, accessible, and more affordable to people with disabilities. NCIL supports legislation and advocacy efforts that develop and provide enforcement measures for access standards for existing and emerging technologies.

Assistive Technology Act

NCIL supports funding and reauthorization of the *Assistive Technology Act (AT Act)* because these programs help individuals with disabilities learn about, try, and acquire assistive technology that will promote and enhance independence and a satisfying life.

The *AT Act* was last reauthorized in 2004 and many of the state AT programs have not yet received the \$410,000 minimum grant award that was authorized by the Act. Additionally, many of the states and territories do not have an Alternative Financing Program (AFP); and for many that do, the programs are small and need access to capital and operational monies. By supporting AFPs and increasing their funding, Congress will make it possible for states to build and expand their programming.

NCIL supports the renewed commitment that Congress has expressed that the AFPs expand and emphasize consumer choice and control within these programs. Congress has also directed the AFPs to incorporate credit-building activities, including financial education and asset building programs. These assurances support NCIL’s work towards greater financial stability, independence, and opportunity for individuals with disabilities.

NCIL is encouraged by Congress’ support of the *AT Act* in 2018 – providing new dollars to coordinate and expand reuse programs (along with the Centers for Medicare and Medicaid Services) and by appropriating a new \$2 million dollars to expand and support AFPs.

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 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 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 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.

Emergency Preparedness & Response →

The NCIL Emergency Preparedness Subcommittee addresses the need for people with disabilities to be involved in the development, assessment, and implementation of emergency preparedness and all stages of a disaster. The Subcommittee educates and advocates for the needs of people with disabilities at all stages of a disaster. We work with FEMA, other agencies and partners, and the NCIL membership to address the needs of persons with disabilities before, during, and after a disaster at the Federal, state, and local levels.

The 2017 Hurricane Season was historic in the number of lives lost, lives uprooted, damages incurred, people misplaced, and costs involved. We must improve our emergency preparedness, response, and recovery for people with disabilities, including our aging population.

The following are our recommendations to Congress and are based on the testimony of NCIL Emergency Preparedness Subcommittee member Paul Timmons before the Senate Special Committee on Aging in November, 2017. Paul is CEO of Portlight Strategies and Founding Board member of the Partnership for Inclusive Disaster Strategies.

NCIL endorses these recommendations and has requested that the House Homeland Security Committee seriously consider them.

Recommendations:

1. Create an inclusive disaster relief fund for Centers for Independent Living (CILs) and other consumer-controlled community disability and aging organizations to engage in emergency preparedness, response, recovery, and mitigation. Invest 1 billion dollars over five years to serve the people of their community before, during, and after disasters. Those who are aging and those with disabilities are the experts on housing, access to health maintenance services, accessible transportation, getting people back to work, and keeping people out of facilities. Currently, CILs and other consumer-directed agencies receive no funding to do their emergency preparedness and disaster response, recovery, and mitigation work. Funding for these efforts should not



compete with first responders, public health, and state and local emergency managers. So it is essential to fund preparation and response work through separate sources.

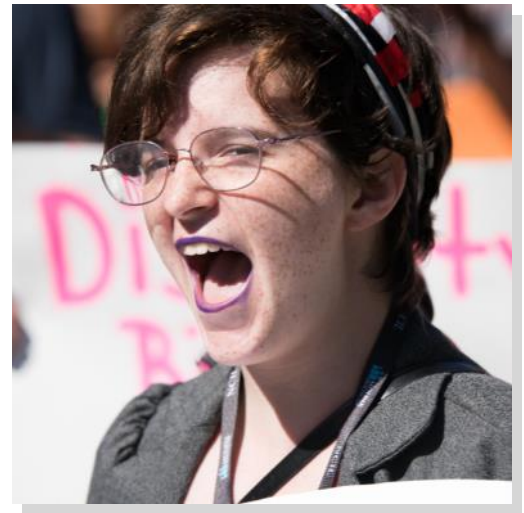
2. Establish a National Center for Excellence in Inclusive Disability and Aging Emergency Management. The initial focus of the Center should include community engagement, leadership, training and exercise development, studying the use of volunteers to determine efficacy in sheltering services to individuals with disabilities and older adults, reviewing the *Post Katrina Emergency Management Reform Act* to better define state and Federal government obligations to plan for, respond to, recover from, and mitigate all hazards in compliance with disability civil rights laws.

3. Direct the US Department of Justice, and provide the Department with resources, to monitor and enforce the use of all disaster funds to ensure compliance with the civil rights requirements of the *Rehabilitation Act of 1973*, as amended and the *Americans with Disabilities Act of 1990*, as amended.

4. Provide Department of Homeland Security grant funds to specifically fund qualified and experienced statewide Access and Functional Needs Coordinators for all states and territories. Several states, including California and Mississippi, have already taken this step and these coordinators are serving as statewide subject matter experts across preparedness, response, recovery, and mitigation. They are coordinating whole community collaboration among disability leaders, community organizations, first responders, emergency managers, public health and safety, private sector, and other stakeholders and establishing best practices. In addition, consider the establishment of an American Independence Corps, similar to FEMA Corps, made up of at least 5,000 citizen members with and without disabilities to carry out planning and preparation activities in each state, DC, and territory year-round.

5. Exempt the cost of disability-related repairs and replacement from the FEMA Individuals and Households maximum Grant ceiling (currently \$33,300). Disability-related repairs and replacement of durable medical equipment and other disability items includes replacing wheelchairs, customized vehicles, medical devices, entrance ramps, elevator installation to meet home elevation requirements, and other items that provide equal access for people with disabilities in recovering from a disaster.

6. Finally, direct FEMA and the Administration for Community Living to lead a coordinated effort across Federal government agencies, the states, community-based organizations, foundations, and other sectors, with those who are aging and people with disabilities in leadership roles, aimed at achieving on-going planning, preparation, and implementation of these recommendations.



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.
- Offering Veteran spouses the ability to receive Veteran Caregiver and Veteran-Directed Home & Community Based Services if they are being cared for by the Veteran.
- 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. This will not be resolved by passage of *H.R. 4457, the Veterans Empowerment Act*, as Veterans would then be required to make co-pays for which they lack financial resources. In addition, services would be hindered by the inability of the VA and community partners to share medical records.

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. This includes destigmatizing mental illness and streamlining processes so that Veterans do not have such a difficult time receiving help.
- 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 these benefits need to be available 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. This includes having HUD-VASH vouchers more readily available for those Veterans living in rural areas.

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, 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 2017 (S. 423)* and the *CHAMPVA Children's Protection Act of 2017 (H.R. 92)* allow children of Veterans eligible for medical care under the CHAMPVA program 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 →

People with disabilities experience violence at higher rates, and in 2018, continue to be under-represented in national violent crime statistics and hate crime reports.

We must push to be recognized in national conversations and receive victim support. These two laws are important this year:

- **The Violence Against Women's Act (VAWA)** will expire in September 2018. VAWA funds violence-response programs (shelters, hotlines, and collaborative grants with Centers for Independent Living). The Senate is holding hearings this year to reauthorize VAWA. Senators need to hear from victims and survivors with disabilities about their needs for support from VAWA-funded programs. Thankfully VAWA has been funded for FY2018, due to the strong support of Senators Leahy and Grassley.
- **The Combating Human Trafficking in Commercial Vehicles Act (Public Law 115-99)** passed into law January 2018. Thank Representatives for their continued support in ending human trafficking of people with disabilities.



- Department of Transportation (DOT) will designate an official to coordinate human trafficking prevention efforts and take into account the unique challenges of combating human trafficking within different transportation modes.
- DOT is establishing an advisory committee to make recommendations on actions it can take to help combat human trafficking and develop recommended best practices for states and state and local transportation stakeholders.

Victimization of People with Disabilities is Increasing

Oppression, in its many forms, is violence. The health and safety of individuals with disabilities is at risk due to the actions being taken by Congress and the White House.

- Medicaid cuts will impact how individuals with disabilities live independently in the community. Institutional settings (nursing homes, hospitals) with their history of abuse, will create new victims.
- Department of Education cuts will have a devastating impact on the safety of students with disabilities. A repeal of the *Individuals with Disabilities Education Act (IDEA)* will remove schools' responsibility to investigate and respond to incidents of bullying. Federal mandates on seclusion and restraint policies for states ensure the safety of students. These Federal protections must not be reverted back to the state level.
- Department of Homeland Security travel bans and deportation rules include a focus on banning and deporting individuals based on their need for support. This targets individuals with disabilities. Deportation orders decrease the ability for victims to come forward seeking help. Victims now put themselves and families at risk when reporting crimes of violence or seeking medical attention. We oppose the deportation of immigrants and refugees and their families.

#MeToo and the Congressional Resolution on Sexual Violence

We are at a critical moment that is reshaping the way we discuss sexual violence as a society. However, current narratives are not comprehensive of the various communities affected by rape culture. Survivors of sexual violence at the margins of the margins are unapologetically coming forward to say "Me Too", and yet are dismissed by the establishment and mainstream media.

This is why NCIL endorsed a bicameral Congressional Resolution affirming Congress' commitment to holistic solutions to sexual violence that account for the experiences of diverse and at-risk populations of survivors. Senator Booker and Representative Watson Coleman's resolutions, *Senate Resolution 487* and *House Resolution 854* respectively, hold our legislators accountable for strengthening laws that will protect all survivors of sexual violence.

The preambulatory clauses of the resolution highlight the reality that sexual violence is a weapon of oppression wielded by those in power. As a result, marginalized communities experience higher rates of sexual violence while receiving the fewest resources for justice and healing. The clauses navigate the compounded burdens survivors of disenfranchised communities carry. This includes



the overrepresentation of transgender and queer folks, people with disabilities, people of color and young survivors of sexual violence in the juvenile justice system. The resolution also confronts the dangerous legislative efforts to increase law enforcement's role during a time of prioritized mass detention and deportation, as well as police brutality against unarmed Black people and people with disabilities.

This resolution then calls on Congress to listen to, learn from, and create change to protect and support all survivors, not a privileged few. The resolution also calls on Congress to resist rollbacks on protections for survivors, including poor reinterpretations of Title VII and IX as they pertain to transgender students and workers, and legislation that undermines the *Americans with Disabilities Act*. This is an attempt to build a path forward by calling for the allocation of resources to address the unique needs of diverse survivor populations as well as for disaggregated research initiatives that further highlight the particularities of ethnic groups beyond larger identity categories.

This resolution is another opportunity to stand with survivors and mobilize other policymakers to not only hear survivors' voices, but to take holistic actions on the matter.

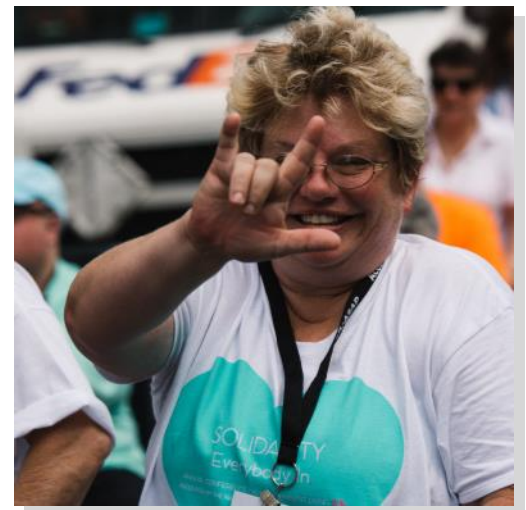


Aging & Disability Resource Centers →

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 plans to continue working with the Administration for Community Living (ACL) and the Independent Living Administration (ILA) in order to develop 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@usicd.org to plan a presentation. Please consider including the CRPD in your organization's work.

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.





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