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 2019 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. Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs) 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

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, NCIL 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 of 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. NCIL believes that people with disabilities are the best experts on their own needs and have crucial and valuable perspective to contribute, 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.
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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 and an additional $3 million in FY 2019. 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 2020 budget for the Independent Living line item.

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

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
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 those dollars with state funds. CILs bridge the gap between Vocational Rehabilitation services and success living independently in the community. 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, CILs 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 worked with an independent evaluator for a period of 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.

NCIL 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.

Research into the return on investment of CIL services is also needed. NCIL has been advocating with universities and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to conduct such research.

NCIL respectfully requests your careful consideration to increase funds for the Independent Living line item for the 2020 budget.
Healthcare and Long-Term Services and Supports

**Disability Integration Act (H.R. 555 and S. 117)**

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 and civil rights to liberty and freedom. The Disability Integration Act – *H.R. 555* (Sensenbrenner-R) and *S. 117* (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 and due to our strong advocacy, a *majority of members of all applicable House committees and the full House of Representatives* are cosponsors of the legislation. NCIL and more than 700 other aging, disability, social justice and faith-based organizations have called on the *House of Representatives to pass the Disability Integration Act before July 26, 2019*, and we urge every member of Congress to co-sponsor this important legislation protecting the Constitutional and civil rights of disabled Americans.

**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.

• **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 per 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;
- established the Community First Choice Option (1915k), a Medicaid option that incentivizes states through an enhanced Federal Medicaid Assistance Percentage (FMAP) to provide LTSS in the community instead of nursing facilities and institutions; and
- authorized accessibility standards for Diagnostic Medical Equipment so people with disabilities could get access to preventative healthcare screenings and appropriate diagnostic testing.

As Congress continues to consider changes to the healthcare system, NCIL continues to urge that these important provisions be maintained. Further, any effort to expand healthcare coverage and service, including establishing universal healthcare, must include the services and supports needed by disabled people, including home and community based LTSS, and be done in conjunction with authentic disability-led organizations like NCIL. It is also critically important that members of Congress not allow discussions about these changes in healthcare policy to replace or undercut efforts to advance the civil and Constitutional right of disabled Americans to live in freedom as embodied in the Disability Integration Act.

**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 88,000 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. The Centers for Medicare & Medicaid Services (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. Although the program expired, states have been drawing down their unspent funds, and as those funds have run out, they have been shutting down their MFP programs. With the recent
extension only providing enough funding to keep the program alive for three months, and an additional bill providing only $20 million through September, Congress must now adequately fund MFP. Congress can do this by extending the program for five years by passing the EMPOWER Care Act - H.R. 1342 (Dingell-D) and S. 548 (Portman-R). This gives the independent living community time to develop a permanent solution that modernizes the program and funds Centers for Independent Living to do this work.

**Durable Medical Equipment (DME) and Complex Rehabilitation Technology (CRT)**

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.

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 2019 - H.R. 2408 (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 apply 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 2019 – S. 1223 (Casey-D) and the Protecting Access to Wheelchairs Act – H.R. 2293 (Larson-D), which provide permanent solutions.

**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.

Chronic Pain and Opioids

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. People with chronic pain and other disabilities continue to be left out of the national conversation, which has resulted in increased barriers to accessing and maintaining effective pain management, discrimination against people who use opioids to manage their pain, and treatment / recovery options that are inaccessible to disabled people. NCIL has been working to ensure that the voices of people with chronic pain and other disabilities are part of the ongoing national discussion and to develop and implement a national advocacy strategy.

Policy responses to the opioid crisis have focused largely on limiting prescription opioids, which has made it increasingly difficult for people who use opioids to manage their conditions to access needed medication. People are seeing their medication forcibly reduced or eliminated; some are being denied medical care altogether. When moving forward with these efforts, legislators must understand the impact of the current policy focus and start to direct their efforts toward comprehensive pain care. They must also work with their constituents with chronic pain and NCIL to ensure their efforts to address opioid addiction do not have negative consequences. Without taking the needs of people with chronic pain and other disabilities into account, any efforts to address
Electronic Visit Verification (EVV)

In late 2016, EVV was passed into law as part of the 21st Century Cures Act. NCIL opposed this new requirement and formed an EVV Task Force to coordinate a national advocacy strategy in April 2018. 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 are experiencing the harmful effects of these intrusive and burdensome systems.

In late 2018, the EVV “delay” bill was passed in the House and Senate by unanimous consent and signed by the President to extend implementation to January 1, 2020. NCIL is not satisfied with implementation by CMS of the “sense of Congress” language that encourages robust stakeholder involvement. In fact, they held only one national call. In March, the NCIL EVV Task Force arranged for and held a lengthy teleconference with CMS and explained our position and called for more stakeholder involvement as well as guidance to the states reinforcing the need to redouble their efforts in engaging disabled consumer employers and attendants. We will continue to engage CMS.

Legislatively, NCIL has joined with ADAPT, who made some headway with Rep. DeGette to file legislation “permanently delaying” implementation of EVV in the 116th Congress. Since that time, she has agreed to file a stand-alone bill that will prohibit the use of GPS and biometrics in the provision of EVV.

Another destructive consequence of EVV is the effect that it is having on the consumer directed personal care services workforce. It is creating a severe worker shortage in states where EVV has already been implemented. Workers are refusing to be geo-tracked and have their privacy rights violated and, as a result, are leaving their current positions or not choosing to provide personal care for persons with disabilities. There have been several instances where disabled personal care employers have had to spend time in a nursing home due to worker shortages.

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, oppressive, 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.
Assisted Suicide

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

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

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

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

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

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

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

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

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

6. **People with depression and other psychiatric disabilities are at significant risk.** Michael Freeland, age 64, had a 43-year medical history of acute depression and suicide attempts. Yet when Freeland saw a doctor about arranging an assisted suicide, the physician said he didn’t think that a psychiatric consultation was “necessary.” But when Freeland chanced to find improved medical and suicide prevention services, he was able to reconcile with his estranged daughter and lived two years post-diagnosis. How did that happen if the safeguards are so strong?

7. **Financial and emotional pressures** can also make people choose death. Family pressures are often hidden.

8. **Oversight & data collection are grossly insufficient.**
   - The reporting requirements lack teeth.
   - Non-compliance is not monitored.
   - There is no investigation of abuse, nor even a way to report it. The system does not report abuse because it’s set up not to find any abuse, and not to show abuse, even when it does exist.

   Wendy Melcher died in August 2005 after two Oregon nurses, Rebecca Cain and Diana Corson, gave her overdoses of morphine and phenobarbital. They claimed Melcher had requested an assisted suicide, but they administered the drugs without her doctor’s knowledge, in clear violation of Oregon’s law. No criminal charges were filed against the two nurses.
   - There are a small number of penalties with no way to enforce them and no established means
for finding out what happened.

- Underlying data is destroyed annually: most egregious of all, the State of Oregon has acknowledged that after each annual report is published, the underlying data is destroyed, so no outside party can conduct objective research.

- The Washington State assisted suicide law, and many current proposals in other states, require physicians signing the death certificate to list the underlying terminal illness as the cause of death, not the taking of lethal drugs, even if the patient was not experiencing any symptoms from the illness at the time. Many doctors see this as requiring them to falsify the death certificate, and it makes accurate data impossible to collect.

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

See more at the DREDF assisted suicide web page: dredf.org/public-policy/assisted-suicide.

### Civil Rights and the Americans with Disabilities Act

#### ADA Notification

For people with disabilities, access to our communities and the supports and services that allow us to remain independent is a civil right. Unfortunately, not everyone agrees, and the *Americans with Disabilities Act (ADA)* has repeatedly come under attack. Over the past several years, these attacks have intensified, yet have failed to gain the support necessary to become law. Nevertheless, we cannot take for granted that the same will be true in this Congress. Pressures on Senators and Representatives 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 states are filing legislation that requires notification and cure periods. Legislators are receiving a lot of feedback from businesses in support of these ‘ADA notification bills.’ We must make sure Members of Congress understand the disastrous effect these bills will have on the civil rights of Americans with disabilities.

In the last Congress, *H.R. 620* passed the House. Congress stated 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”.

We are happy to report as of publication of this document, an ADA Notification bill has yet to be introduced during this Congress, although rumors indicate that it could happen.

NCIL appreciated the support of Senator Tammy Duckworth and the 42 other Senators in the 115th Congress who pledged to protect the ADA in a letter to Senate Majority Leader Mitch McConnell. We strongly agree that “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.” During the 116th Congress, NCIL will continue to monitor and evaluate any legislation that does not support our basic civil right as persons with disabilities to fully participate in society.

**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, modifications in rules and procedures, 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 and recognizes the value of choice, independence and freedom of people with disabilities. NCIL believes that all temporary and permanent housing, including housing provided by the Federal Emergency Management Agency (FEMA), should be designed and constructed to be accessible to and usable by all.

Housing challenges also are seen with many veterans with disabilities, with a high rate of disabilities among people who are experiencing homelessness, and with the aging of the population. 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. HUD stated in 2017 that approximately one in six renter households with worst-case housing needs (paying more than 50% of income toward rent, living in severely inadequate conditions, or both) includes a person with a disability. This has increased 28% since 2013. Policymakers and Congress must act to ensure that there will be an adequate supply of housing, both private and public. Both the Technical Assistance Collaborative and the National Low Income Housing Coalition have extensively documented the housing costs that put housing out of reach for many people, and the shortage of affordable housing
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. Housing appropriations simply have not kept pace with demand, and people with disabilities have been overlooked, with stagnant funding for Section 811, Mainstream Vouchers, Housing for Persons with AIDS, and Fair Housing Enforcement. There have also been attempts to defund the Community Block Development Grants (CDGB) and HOME funds. NCIL is pleased by the proposed House budget, which is a step in the right direction.

At the time of writing, the House Appropriations Subcommittee on Transportation and Housing and Urban Development (THUD) passed the House THUD budget, but it has not come up to a vote in the full House yet. The Senate has yet to release their version. Advocates should be aware of the status of housing funding in both chambers before meeting with their legislators. The growing deficit after the large tax cut bill will increase pressure for cuts to non-defense discretionary spending programs such as housing. Sequestration is also a factor as the Budget Control Act agreed to by both parties in 2011 would trigger automatic spending cuts unless both parties agree to a temporary bipartisan budget agreement.

Strong advocacy is needed to demonstrate the importance of housing programs for people with disabilities. Advocates must fight for every penny that housing programs need to maintain funding of commitments, to meet current and future needs.

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 Congress, 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 increase the rents that the poorest households pay, including the elimination of deductions in rent calculations. People with disabilities would no longer be able to deduct their disability and medical expenses, and the childcare deduction will also be eliminated. ANY rent increases would further push low income individuals out of already dire housing options.

**Housing Choice Voucher Mobility Demonstration Act of 2019 (H.R. 1122)**

An issue in many communities for many people is how difficult it is to actually move to a different municipality with the housing choice voucher. This bill authorizes a mobility demonstration program to allow Public Housing Authorities to work together on a regional basis. The purpose is to encourage low income families to move to lower-poverty areas and to expand access to opportunity areas in which they can have access to jobs and better educational opportunities. It would include
financial support for moving costs, counseling, support services, and landlord outreach. This bill passed the House 387-22 on a bipartisan basis and now is in the Senate Committee on Banking, Housing, and Urban Affairs, along with a similar bill, S. 291.

Congress already funded the Voucher Mobility Demonstration program when it passed the Consolidated Appropriations Act (H.J. Res 31), but this bill is needed to ensure the program continues in the upcoming years. To persuade Senators to support it, we can point to the fact this is a bipartisan bill, and that Congress has already supported the pilot program in appropriations.

**Hardest Hit Housing Act of 2019 (H.R. 2295)**

Public Housing Agencies have not received sufficient funds to keep up with maintenance and updating costs, resulting in a capital funds backlog of over $26 billion (the 2019 budget allocated nearly $2.78 billion dollars for capital funds). This bill attempts to reduce this backlog by adding $4 billion over 5 years toward capital funds for the largest public housing agencies that own or administer more than 10,000 public housing units. We believe there are only seven such agencies that qualify.

This bill also would allocate $5 million to Neighborworks for mortgage foreclosure mitigation activities to 15 states with the highest rate of defaults and foreclosures. Finally, it would add 20,000 new vouchers for rental assistance for five years.

Although the NCIL Housing Subcommittee was concerned about the fact that the capital funds part of this bill would target only large public housing agencies with more than 10,000 units, we believe that focusing money on them will reduce the overall backlog and free up money in the regular appropriations budget for other housing agencies.

**Housing Fairness Act of 2019 (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, 56.7 percent of all individual discrimination complaints were based on 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.

**Eleanor Smith Inclusive Home Design Act (formerly H.R. 6509)**

Housing affordability is only part of the solution. There has to be greater architectural and policy accessibility integrated into 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. This bill 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.

Note: The Disability Integration Act, H.R. 555 and S. 117 (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 and healthy communities, we must recognize the social determinants of health. People with disabilities are frequently isolated due to limited or non-existent transportation services. Mounting evidence shows that social connections are crucial to maintaining health. Transportation services must be expanded to allow for social activities.

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, health, and independence.

Self-Driving / Autonomous Vehicles

Advocates and policymakers must make sure that these vehicles are fully accessible. In previous years, Congress has held hearings on Autonomous Vehicles (AVs), but legislative activity has
stalled. This provides an opportunity for renewed advocacy in this important area. 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 the process (pun intended), 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.

One major concern as AVs continue to develop is that there are no readily available wheelchair accessible vehicles. People who use wheelchairs or scooters have to modify a vehicle, 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. Safety must be the top priority.

### Airlines and Air Travel Issues

With the passage of the *Federal Aviation Administration Reauthorization*, progress has been made for air travel for people with disabilities. The new law requires the FAA to have an advisory committee for air travel for people with disabilities. Airlines are also required to collect data and report on the number of assistive devices that they transport and how many are damaged or lost. Revisions to Transportation Security Agency (TSA) officer training (regarding people with disabilities) are included in the reauthorization. Yet there remain significant barriers to air travel for people with disabilities. In March, Senator Tammy Baldwin (D-WI) introduced the Air *Carrier Amendments Act of 2019* (*S. 669*), and Representative James Langevin (D-RI) introduced the same bill (*H.R. 1549*) in the House. NCIL supports this legislation, which will give people with disabilities equal access to air travel.

In the past year, several airlines have restricted travel with a service animal or emotional support animal. This has created a burden for many people with disabilities. Advocates must continue to monitor the situation closely. Curbside check-in has also been curtailed in some areas, also creating barriers at airports.

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.

Since the release (August 2017), of Amtrak’s “ADA Stations Program Five Year Strategic Plan,” some progress has been made. Amtrak has been providing quarterly updates, but it has been agonizingly slow. There are still too many stations and rail cars that are not accessible. 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. Accessible signage and safety information is not available on all trains. 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.

Although Uber recently announced expansion of wheelchair accessible vehicles (WAVs), in some larger metropolitan areas, the number is still disproportionately out of balance. These companies also continue to fight against the Americans with Disabilities Act 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 Services (CMS). With the continuing and increasing push for Medicaid Managed Care, transportation is an issue that advocates will want to watch on federal and state levels. In past years, there have been attempts to make Medicaid Transportation optional. Currently, an amendment to the Fiscal Year 2020 Labor-HHS-Education Funding Bill introduced by Representative Rosa DeLauro (D-CT) included a general provision to maintain support for nonemergency medical transportation services for Medicaid beneficiaries who lack access to transportation to healthcare facilities. The amendment was adopted by voice vote. It is hoped that the full house will support this measure. Lack of Medicaid transportation would negatively impact the very people that can least afford it. Advocates will need to monitor the situation closely and be watchful that Congress or the Administration try to eliminate Medicaid Transportation via administrative rulemaking.

**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 with funding for all modes of transportation and three years of guaranteed funding. 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.

Recent discussions between Congress and the President have stalled regarding infrastructure and rebuilding our nation’s crumbling roadways. While there is an immediate need to rebuild our roads and bridges, we must also work on long-term sustainable funding. Without a sustainable funding mechanism, we will never be able to move into the next century.

**Transportation Policy Watch List**

NCIL also supports the following legislation and policy:

- New transportation mode: Monitor the proliferation of e-scooters and the potential barriers / impediments to persons with disabilities.

- Public Policy Change: Increase weight levels on transit lifts to 1000 pounds.
Public policy supporting ADA compliance with vehicles for water travel.

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 opposed two 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), in the last Congress. Neither have been reintroduced in the 116th Congress, but we continue to oppose these and any other bills that encourage more institutionalization of people with disabilities. H.R. 1253 would have provided Federal loans and loan guarantees for more psychiatric and substance use treatment beds. S. 1169 would have modified the Medicaid Institution for Mental Disease (IMD) exclusion by allowing Medicaid to pay for sixty consecutive days of inpatient treatment in larger facilities.

The IMD exclusion, 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. 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 and other similar bills claim that it would expand access to much needed treatment for opioid addiction. However, these bills would actually do little to expand access to treatment while posing a significant threat to civil liberties. S. 1169 in particular did 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, Senator Durbin (D-IL) stated 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: Respond, Innovate, Succeed, and Empower (RISE) Act (H.R. 3086 and S. 1585)**

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: Keeping All Students Safe Act (KASSA)**

Restrainting 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 listened to and considered 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.

Please note that discrete stand-alone legislation (H.R. 7101), encompassing both policy proposals, was introduced in the House in October, 2018 and is expected to be re-introduced in the 116th Congress in both House and Senate.

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

In 2019, the ABLE Act still continues to be an important policy priority for NCIL. Over 45 states have opted to enact ABLE legislation with many (41 at last count) actively launching programs. Other states had hearings on ABLE legislation in their 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. The ABLE to Work Act and the Financial Planning Act passed with the Tax Cuts and Jobs bill, which became Public Law 115-97 in December 2017. Also included in Public Law 115-97 was a provision to allow contributions to ABLE accounts to qualify for the Federal Retirement Tax Credit. The ABLE Age Adjustment Act was not included due to cost.

The ABLE Age Adjustment Act (H.R. 1814 and S. 651) has been re-introduced as stand-alone legislation on a bicameral and bipartisan basis in the 116th Congress. It would raise the age limit for eligibility for ABLE accounts to individuals disabled before age 46 (current legislation limit is age 26). NCIL’s advocacy efforts in this regard continue to be substantial in order to see this initiative to fruition. Momentum appears to be building in Congress and with regard to number of national organizations currently supporting this initiative.

Building upon previous fortifications to the original ABLE Act, the ABLE Age Adjustment Act would heighten equity - making tax-free ABLE accounts available to, for example, military veterans whose disability was established after age 26.

Eliminating Subminimum Wages

Unfortunately, the Transitioning to Integrated and Meaningful Employment (TIME) Act did not move forward during multiple Congresses, despite significant degree of interest and bipartisan support.

However, similar initiatives have been introduced in the 116th Congress to eliminate / phase-out sheltered workshops and subminimum wages. The Transformation to Competitive Employment Act (H.R. 873 and S. 260) would do that. Also note that the Raise the Wage Act (H.R. 582 and S. 150) contains such clauses as a section of the larger bill.
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! NCIL continues to work with WID and PolicyWorks to bring about implementation of the goals of CareerACCESS. Visit www.ourcareeraccess.org for more information.

Disability Employment Tax Credit Expansion

NCIL supports the concept of a re-introduced bill, the Disability Employment Incentive Act (S. 255), to expand the disability employment tax credits for employers who hire people with disabilities. This bill will increase the maximum (Work Opportunity) tax credit and expand to more categories of people with disabilities (such as SSDI and SSI beneficiaries). It will also add credits for removing architectural and transportation barriers to employment for people with disabilities and seniors.

Social Security Online Tools Innovation Act

NCIL supports the creation of an online tools platform to assist beneficiaries with disabilities to better manage their benefits vis-à-vis employment. Unfortunately, legislation did not pass Congress in the 115th Congress, despite passing House Ways and Means unanimously. It has not yet been re-introduced in any form in the 116th Congress.

NCIL also supports access to employment training information (e.g. Vocational Rehabilitation material) to those people with disabilities initially denied benefits upon application.

Family Leave Initiative

There have been proposals mentioned in Congress regarding creation of a Family Leave benefit under Social Security. However, at this time, the proposals entailed voluntary subscription and forfeiture of retirement benefits. Although the idea of a Family Leave provision is supported, there has been concern about forfeiture of one part of a benefit to pay
Various other germane bills introduced or pending introduction in the 116th Congress, relating directly or indirectly to enhancing employment and economic opportunities for people with disabilities, are being monitored by NCIL. NCIL has been offering and will continue to offer input.

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 when they are provided with 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 is encouraged by the recent Congressional hearing titled, “Aging and Disability in the 21st Century: How Technology Can Help Maintain health and Quality of Life.” As stated in the hearing, “Assistive technology provides an opportunity for millions of individuals to live independently, improving the lives of older Americans and 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, autonomy and a satisfying life.

The AT Act was last reauthorized in 2004 and efforts to introduce a 21st Century reauthorization are underway. The new legislation will address increasing access to assistive technology, including expanding access and capacity for what are now known as the Alternative Financing Programs (AFPs).

NCIL supports the 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’ recent support of the AT Act by appropriating additional funding for both the state AT projects and the AFPs.
NCIL also supports Congressional efforts to increase access and information about alternative communication devices to individuals who need this technology so they can be full participants in every aspect of their lives.

Note: You can find information on NCIL’s advocacy around Complex Rehabilitation Technology in the Healthcare Section.

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 & Recovery

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

The NCIL Emergency Planning Subcommittee is alarmed that people with disabilities and older adults are 2 to 4 times more likely to die or be injured in disasters.

Recent reports reveal how current disaster infrastructure systematically fails the 61 million disabled individuals and 48 million adults over 65 across the United States (see ncil.org/epreports). Together,
these reports detail the range of barriers people with disabilities encounter during disasters, including emergency notification, evacuation, sheltering, response, registering for FEMA disaster assistance, housing, and long-term recovery. These barriers are not an inevitable part of disability or aging; rather, they are the result of the failure to comply with civil rights obligations and excluding disability and aging communities in disaster planning, response, recovery, research, and oversight.

FEMA’s Office of Disability Integration and Coordination, the Administration for Community Living and Office of the Assistant Secretary for Preparedness and Response (ASPR) have refused to work with disability-led organizations. FEMA’s Disability Coordinator has a statutory obligation to engage with NCIL and our partners.

Excluding disability and aging communities from disaster response planning and response results in ineffective response and recovery, unnecessary hardship, institutionalization, violation of civil rights, and disproportionate loss of lives.

There were 122 major disasters in 2017 and 2018, with over $306 billion dollars spent in 2017 alone. Both years were historic in the number of lives lost, lives uprooted, damages incurred, people misplaced, and costs involved. Of those who died in Hurricane Maria, 70% were 70 years old or older and most had “chronic health conditions” which is medical model speak for disability.

Despite federal requirements to comply with disability civil rights law in the expenditure of every disaster dollar, the Federal government, states and local governments continue to rely on volunteers, donations, and charity to meet their obligations to people with disabilities in disasters. Disability leaders have fought to end the charity model of disability program and service delivery for decades.

The NCIL Emergency Planning Subcommittee strongly recommends that legislators and the Independent Living community take action to require monitoring and enforcement of disability civil rights law and improve our emergency preparedness, response, and recovery for people with disabilities, including our aging population.

Recommendations to Congress:

1. Support, sponsor, pass and fund the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI) and the Disaster Relief Medicaid Act (DRMA).

**REAADI for Disasters Act (S. 1755)**

Creates a network of regional disability-led technical assistance centers that will provide research, training, and technical assistance to states and local emergency planners to better involve and support the disability and aging community during disaster preparedness activities.

- Establishes a National Commission on Disability Rights and Disasters to study the needs of disaster-impacted individuals with disabilities, older adults and others with access and functional needs.
• Requires a review of the spending of disaster funds to ensure people with disabilities and older adults have access to services and that buildings and structures reconstructed following disasters are accessible, as required by the *Rehabilitation Act of 1973*, as amended and the *Americans with Disabilities Act of 1990*, as amended.

• Creates a grant program to pilot innovative national strategies to advance inclusion of people with disabilities and older adults in disaster preparation, response, recovery, and mitigation; and

• Requires the Department of Justice to examine how civil rights of people with disabilities and older adults are treated during and following disasters.

Provides for contracting with Centers for Independent Living to:

1. prepare for hazards;
2. provide personal assistance services during response and recovery periods;
3. identify accessible emergency shelters and adapt emergency shelters to be accessible;
4. develop accessible media, including media using American Sign Language; and
5. meet other needs for individuals with disabilities, older adults, and individuals with access and functional needs.

**Disaster Relief Medicaid Act (S. 1754)**

• Ensures uninterrupted access to Medicaid services when recipients must evacuate across state lines during an area included in a Presidential Disaster Declaration.

• Provides states with resources to support the Medicaid needs of individuals forced to relocate.

• Limited time 100% Federal match for displaced individuals, technical assistance and support to develop innovative state strategies to respond to an influx of out-of-state individuals.

• Creates a grant to help states develop an emergency response corps to provide home and community-based services.

2. NCIL opposes reliance on charity, volunteers and donations to meet the legal obligations of the *Rehabilitation Act* and the *Americans with Disabilities Act* and calls on Congress for immediate enforcement of laws and associated funding to meet the disaster related needs of all people with disabilities.

3. Monitor and enforce Red Cross obligations for providing equal access to all programs and services before, during and after disasters in the most integrated setting appropriate to the needs of disaster impacted people with disabilities, without exception.
4. The Department of Justice (DOJ) and the Department of Homeland Security (DHS) must both monitor and enforce the *Rehabilitation Act of 1973* and the *Americans with Disabilities Act of 1990* as amended, ensuring people with disabilities and older adults have full and equal access to disaster services. This includes ensuring people with disabilities and older adults are provided services in integrated settings and requiring the Department of Health and Human Services and the Centers for Medicare and Medicaid Services cease issuing waivers that allow states to expedite the admission of disaster-impacted people with disabilities and older adults into nursing homes and other institutions.

5. 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 (Veterans Affairs Supportive Housing) 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 116th 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 2019 (H.R. 2094 and S. 1034)** would 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 was introduced in the last
Congress 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 in many forms – through systemic oppression and from predators and individual abusers.

We must continue to push to be included in laws and grant programs to end the violence and to receive the support victims with disabilities need for healing.

Current federal bills to follow include:

**Hate Crime Victim Assistance Act (H.R. 223)**

Introduced by Representative Velazquez (D-NY-7), this bill is an amendment to the *Omnibus Crime Control and Safe Streets Act of 1968* to establish grants to reduce the incidence of hate crimes. Hate crimes have been on the rise across the United States.

**Police Training and Independent Review Act (H.R. 125)**

Introduced by Representative Cohen (D-TN-9), this bill would require state law enforcement officers to fulfill a training session on sensitivity each fiscal year. Training required on ethnic and racial bias, cultural diversity, and police interaction with people with disabilities, mental health conditions, and new immigrants.

**Trafficking Victims Protection Act of 2000 Amendment (H.R. 467)**

This bill was introduced by Representative Kinzinger (R-IL-16) in order to encourage a victim-centered approach to combating human trafficking, and for other purposes.

**Violence Against Women Act (H.R. 6545)**

The *Violence Against Women Act (VAWA)* lapsed December 21, 2018 and is currently unauthorized. Representative Sheila Jackson Lee (D-TX-18) is expected to re-introduce VAWA for reauthorization very early in the 116th Congress, with bipartisan support and as a priority.

**Violence Against Women Act Amendment (H.R. 505)**

This amendment was introduced by Representative Calvert (R-CA-42) to reauthorize the grant
program for education, training, and enhanced services to end violence against and abuse of women with disabilities.

**Office on Violence Against Women Authorization (H.R. 600 and S. 171)**

This bill was introduced by Representative Emmer (R-MN-6) in the House and Senator Klobuchar (D-MN) in the Senate to improve the handling of crimes of domestic violence, dating violence, sexual assault, and stalking by incorporating a trauma-informed approach into the initial response to and investigation of such crimes.

**#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 116th 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.

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.

Centers for Independent Living provide Peer Support; Information and Referral; Individual and Systems Advocacy; Independent Living Skills Training; and Transition Services.

Find your local CIL or SILC by visiting ncil.org.