



Advocacy Priorities

Summer 2021

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Rehabilitation Act and Independent Living Funding

Independent Living Funding

The Independent Living (IL) Program has been underfunded for decades. NCIL respectfully requests that Congress increase funds by \$200 million in the 2022 budget. This amount should be split proportionally between Part C and Part B. This would bring total funding for the Independent Living Program to \$316,183,000.

Congress provided Centers for Independent Living (CILs) \$85 million in the CARES Act. These funds were to respond to the COVID-19 pandemic. We have seen CILs make a huge impact in their communities with this money.

However, that funding was only available to some CILs, and it was time-limited. Additionally, that funding was not enough to meet the increasing demand for IL services. The IL Program needs more funding so CILs can provide services to everyone who needs them.

CILs are unique organizations run by and for people with disabilities. They provide the core services and many other services to meet the needs of individuals and their communities. That often includes filling gaps left by other providers. CILs provide services to people with all types of disabilities, of all ages, and at all income levels.

For many years, all CILs were required to provide four services. These “core services” were:

- Advocacy: CILs support people to take action about things that are important to them. CILs also take action about things important to the disability community.
- Independent Living Skills Training: This helps people develop skills. These skills help people live more independently and have more control over their lives.
- Information and Referral: CILs answer people’s questions and direct them to information or services.

- Peer Counseling: This involves people with disabilities supporting each other. Sometimes this is done one-on-one. Sometimes this is done in groups.

In 2014, the Workforce Innovation and Opportunity Act (WIOA) passed into law. This law required CILs to provide three new core services:

- Institutional Transition: CILs help people with disabilities move from institutions to the community.
- Diversion: CILs help people who live in the community stay in the community.
- Youth Transition: CILs help youth with disabilities transition out of high school to college or the workplace.

The IL network is committed to providing all the core services. We have always believed the new core services are vital to achieving full inclusion. The COVID-19 pandemic has further proven how important they are. People with disabilities in congregate settings have been infected and died from COVID-19 at very high rates. Moving people into the community is more important than ever.

However, CILs have not been given any additional funding for the new core services. The CARES Act funding has allowed CILs to help people get out of dangerous congregate settings during the pandemic. It has helped CILs keep people with disabilities safe in their homes and communities. But without more permanent funding, there is no way CILs can carry out the new core services fully or effectively.

CILs believe all people with disabilities are valuable. They help people facing all sorts of discrimination. They believe people with disabilities should be able to participate in their communities. The IL Program has improved and changed how services are delivered to people with disabilities.

Statewide Independent Living Councils (SILCs) work closely with CILs. Together they develop a plan for the state's Independent Living network and services. They help figure out how to address needs that are not being met. More money for the IL Program would help states put those plans into action.

The services the Independent Living Program provides are unique and important. They are also very cost-effective. The IL Program is essential, and it does not have enough money. An additional \$200 million will help meet the needs of people with disabilities across the country.

The Independent Living Movement is founded on the belief that people with disabilities, regardless of form, share a common history and struggle. Independent Living philosophy emphasizes consumer control; the idea that

people with disabilities are the best experts on their own needs, having crucial and valuable perspective to contribute and deserve equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that affect their day-to-day lives and access to independence.



Long Term Service and Supports (LTSS)

Ending the Institutional Bias

A lot of death and illness from the COVID-19 pandemic occurred in congregate settings. Congregate settings include:

- state hospitals
- psychiatric institutions
- group homes
- developmental centers
- detention centers
- intermediate care facilities (ICFs)
- nursing facilities
- day habilitation centers
- prisons
- jails
- homeless shelters
- and more

The deaths in these facilities are avoidable. They happen because of discrimination.

The deaths in long-term care settings are the result of the institutional bias. The institutional bias makes people who need long term services and supports (LTSS) move into congregate settings to get the help they need.

The federal government has created an institutional bias in Medicaid. States are required to pay for long term care in institutions. Offering the same services in community settings is optional. Home and community based services (HCBS) are underfunded. And even funding for HCBS can still be spent on smaller congregate settings.

The institutional bias exists outside of Medicaid, too. Medicaid is the only payer for many community-based LTSS. Other payers, like Medicare and private insurance companies, will not pay for them at all.

Too many people are harmed by the institutional bias. Too many disabled people have no way to pay for the community-based services and supports they need. Too many people do not have control over their supports and services.

Black, indigenous, and other people of color (BIPOC) are especially harmed by the institutional bias. These communities have been harmed by the lack of community supports and services. They face higher rates of institutionalization and segregation.

BIPOC also make up a majority of the direct care workforce. During the pandemic, they have worked without enough protection, like masks and gloves. Disabled BIPOC and their communities have died at very high rates during the COVID-19 pandemic.

NCIL wants all people with disabilities to be valued equally. We want disabled people to be able to participate fully in their communities. The institutional bias must end.

We need Congress to:

- Significantly increase funding for HCBS;
- Ensure HCBS support individual choice and control;
- Support the direct care workforce with higher wages, benefits, and workplace protections. This must be well-thought out to include workers for people with coverage across payment systems (Medicaid, Medicare, and private pay); and
- Pass permanent reauthorization of the Money Follows the Person program.

Electronic Visit Verification (EVV)

Electronic Visit Verification (EVV) is an electronic system in-home workers must use to report when they are working and what they are doing at work. NCIL is working to stop the harm EVV is causing. We want the Centers for Medicare & Medicaid Services to rescind their guidance on EVV prohibiting the use of web-based portals using dual verification. Their guidance says States cannot use web-based timesheets (like California was using) that don't track a person's location. We believe this violates

people's privacy. We have national data that clearly shows there is a statistically insignificant level of fraud in the program.

We are also working with Congress. Congress is working on the 21st Century Cures Act 2.0. We want the bill to require that GPS and biometrics will not be allowed in EVV. GPS is technology that allows the tracking of someone's location. Biometrics are personal characteristics that can be used to identify someone. Examples of this are fingerprints or voice recognition.

Congress and the Biden Administration are also working on new HCBS policies and eventually regulations. We want to make sure new HCBS programs are not required to use EVV. We want the new regulations to allow beneficiaries to "opt out" of the use of GPS and biometrics for location.



Housing

NCIL supports efforts to increase housing that is:

- Accessible to people with all disabilities
- Affordable
- Healthy / nontoxic
- Decent
- Safe
- Integrated

There is not enough housing for people with disabilities in this country. We need more affordable housing. We especially need more affordable housing for extremely low-income households (at or below 30% of Area Median Income). We need more accessible housing for people with all different kinds of disabilities. This includes people with mobility, vision, hearing, chemical and electrical sensitivities, cognitive, and all other disabilities.

Fair Housing

NCIL Supports the Housing Fairness Act of 2021 (S. 769 / H.R. 68). This would provide funding to prevent housing discrimination and enforce fair housing requirements. In 2018, over half of all housing discrimination complaints were about disability discrimination. This is unacceptable. Further, people with disabilities already face major barriers to finding housing. Increased funding is needed to improve fair housing enforcement, education, and outreach.

Visitability / Universal Design

NCIL supports increasing the accessibility of new and existing housing. This includes housing that is accessible for people with all disabilities.

This includes, but is not limited to, Visitability. Visitability is the idea that new single-family homes and town homes should be built with basic accessibility features for people with mobility disabilities. These features include:

- One zero-step entrance;
- Doors with 32 inches of clear passage; and
- One bathroom on the main floor you can get into with a wheelchair.

Some communities and states have taken the lead in promoting Visitability. NCIL supports this. We also support the Eleanor Smith Inclusive Home Design Act (which has not yet been reintroduced).

Homelessness

People with disabilities are more likely to experience homelessness. Data suggests that nearly one quarter of people experiencing homelessness have a disability. People with disabilities, particularly people with mental health disabilities and substance use disorders, can face many barriers to assistance.

NCIL supports efforts that require:

- Accessible shelters
- Mandatory training for front line staff on how to provide reasonable and necessary accommodations, including but not limited to alternatives to pat-downs and other access needs.

- Legislation that allows individuals with disabilities who are medically fragile, homeless, and unable to stay in a shelter to be eligible for coordinated entry and other housing programs. (Coordinated entry is a system to help people who are homeless access housing and support services.) Currently the Department of Housing and Urban Development's (HUD) definition does not allow someone who "couch surfs" to be added to the Coordinated Entry list. This makes these people ineligible for transitional and supportive housing placement.

Talk to your Representative and Senators about the need for more accessibility for people with disabilities who are homeless.

Public Housing

In 1998, Congress passed a law, the Faircloth Amendment, saying that Public Housing Agencies (PHAs) cannot build new public housing units that will result in them having more units. They can build new units, but they have to tear down older units so the total number stays the same (or fewer). This means PHAs cannot grow to meet the need in their communities. When you think of how some cities have grown since 1998, it is not fair that they are limited to the number of units set 30 years ago! Repeal of the Faircloth Amendment Act (H.R. 659) would end this law and allow PHAs to build more units in their communities. This would benefit low-income households with people with disabilities in many cities who desperately need subsidized units. Congress would also need to increase funding for the public housing program.

Chemical, Electrical, and other Environmental Sensitivities

For some people with some disabilities, barriers include sensitivities to things such as paint, carpeting, lawn chemicals, neighbors' activities, "smart" utility meters and other "smart" features, etc. Smart devices impacting people can include, but is not limited to:

- lighting and kitchen appliances
- Wi-Fi and routers
- electric power and distribution lines
- cell towers
- battery re-chargers for vehicles and other equipment
- 5G and other communications equipment

HUD, and particularly HUD's Office of Fair Housing and Equal Opportunity (FHEO), must proactively support reasonable accommodation requests within these barriers. HUD should encourage developers to consider these barriers in housing planning and design. Programmatic access can be appropriate; for example, allowing a resident to move to a different apartment to avoid line-of-sight exposure to a cell tower, advance

notice of carpet cleaning or pesticide spraying, etc. Ask your legislators to express their concern to HUD about these barriers and encourage HUD to work on this issue.



Civil Rights and the Americans with Disabilities Act

2021 is the 31st anniversary of the Americans with Disabilities Act (ADA), but there are still many threats to our rights.

ACCESS Act

Another bill has been introduced that could weaken the ADA. This bill is called the ADA Compliance for Customer Entry to Stores and Services Act (H.R. 77). For short, it is called the ACCESS Act.

The ACCESS Act is similar to bills that have been introduced before. It does not increase access. In fact, it would create barriers to enforcing the ADA. Therefore, it would weaken our civil rights.

For example: if a disabled person wants to challenge specific barriers in court, they must do a lot of things first. They must provide the business with written notice. The notice must include very specific information. Then, they have to wait up to 60 days for the business to write a plan to address the barrier. Then, they have to wait up to another 60 days for the business to fix the issue or make “substantial progress”.

The ACCESS Act could also weaken website access requirements. It requires other tools to be studied as possible alternatives to accessible websites. These tools include a telephone number and “accessibility widgets”. Accessibility widgets make websites more accessible for some people, but they also tend to interfere with technology some disabled people need, like screen readers.

The bill doesn't look like it will pass this year. But we still can't ignore it. Lawmakers keep introducing similar bills every year. Eventually one of these bills will pass if we don't advocate against these threats.

Parenting Rights

NCIL supports the rights of disabled parents and disabled people who want to become parents. People with all disabilities have the right to have and raise children. They have the right to receive reproductive assistance. They have the right to become foster or adoptive parents. Congress and the Courts have repeatedly protected these rights. These rights are also protected under the laws like the ADA and Section 504 of the Rehabilitation Act of 1973. The ADA says: "No individual shall be discriminated against on the basis of disability". Yet, people with disabilities continue to be denied these rights. People with disabilities are denied the right to become a parent. Parents with disabilities continue to lose custody of their children just because they are disabled. Many states have laws that include disability as a reason for denying parental rights. We will continue working to fight these.

Alternatives to Guardianship

NCIL does not support the use of guardianship for people with disabilities. Guardianship is when a judge decides a person can't make their own decisions. The judge then chooses a guardian for the person. The guardian may be a person's parent, someone else they know, or someone they don't know. Adults under guardianship do not have the right to make most of their own decisions. Their guardian gets to make decisions about their life. This can include getting a job, how they live, and who they spend their time with. They can even decide if a person can get married or start a family. Guardianship can be permanent and is hard to remove.

Some parents think their child with a disability must have a guardian. They may think their child is not able to make their own decisions. Their child's school or doctors may have told them to get guardianship when their child turns 18. Parents do not always know guardianship is not the only option. Many families are also encouraged to get guardianship for older relatives who develop disabilities.

NCIL believes people with disabilities must have the right to make decisions and control their own lives. Guardianship takes away people's freedom and choice. Centers for Independent Living (CILs) can and must help people avoid guardianship.

NCIL supports some alternatives to guardianship. One good alternative is supported decision-making (SDM). SDM allows a person with a disability to choose a person, or people, they trust to help them make decisions. This person can be a family member or friend. The disabled person can get the support they need, but they stay in control of the final decision. SDM helps people keep their rights.

NCIL also supports the use of a power of attorney (POA). A POA allows a person to choose someone to make legal decisions for them. The person they choose could be a friend, family member, or other trusted person. The disabled person decides to have a POA, and they can take that power away at any time.

All legislation about adults with disabilities should presume competence and avoid guardianship.

Immigration

NCIL opposes attacks on immigrants' rights. We have fought many policies that harm immigrants. Some of these policies separated families, many who have still not been reunited. Some of these policies threatened long-standing programs and protections. Some of these policies discriminated mostly against disabled immigrants and immigrants of color. NCIL is encouraged by the Biden Administration's proposals to get rid of harmful policies still in place and expand the immigration system. We continue to follow these issues closely. NCIL supports transforming our immigration system into one that is fair and humane.

Voting Rights

NCIL's work around voting rights can be found on page 23.



Transportation

People rely on transportation to participate in their communities. People with disabilities still face barriers and discrimination, especially to air travel. Transportation must be accessible, affordable, and safe. All types of transportation must have accessible options.

Air Travel

NCIL supports the Air Carrier Access Amendments Act of 2021 (ACAAA) (S. 642 / H.R. 1696). The Air Carrier Access Act of 1986 was passed to stop discrimination against people with disabilities in air travel. But people with disabilities still face a lot of discrimination and barriers. The ACAAA would strengthen the original protections and make air travel more equitable. It would require better accessibility of aircraft, airports, websites, and kiosks. It also includes a process for people with disabilities to file complaints if they are discriminated against.

Self-Driving Cars

Self-driving cars, also known as autonomous cars, are not being designed accessibly. Accessibility must be included from the beginning. Otherwise, people with disabilities will be left behind. Legislation is needed to ensure self-driving cars are being built to be inclusive.

Private Transportation

Strong rules and laws are needed to increase the number and availability of accessible vehicles in the private transportation industry. This includes, but is not limited to:

- Taxis
- Car rentals
- Transportation networking companies (TNCs) like Uber and Lyft
- Shuttle services
- Limousines
- Boats
- Bike rental services

TNCs (also called “Ride Hailing Services”) may help solve some of our community’s transportation needs. They are also creating new barriers. Both TNCs and taxis continue to fight against complying with the Americans with Disabilities Act. And accessible transportation is woefully lacking. People with disabilities must be involved in all discussions and decisions about TNCs and other modes of transportation.

Amtrak & High Speed Rail

Amtrak and other rail systems must continue to improve station, vehicle, and service accessibility. They must do this equitably. Recent settlements with the Department of Justice and Amtrak have spurred them into a more concerted effort, but it will still take years before all facilities are accessible.

Surface Transportation

Congress is working on their big “Surface Transportation bill”. This bill funds things like roads, bridges, highways, bike paths, and public transportation. This is usually passed every five years. Last year, Congress passed a one-year extension. That funding expires on September 30, 2021. We need to work with legislators and advocates. We need to make sure this new law works for everyone, including older adults and people with disabilities.

Websites and Reservations Systems and Mobile Apps

Many websites for making reservations for transportation services are not accessible and do not meet current accessibility standards. This is especially true for people who are blind or have low vision. Many are not equitable for people with disabilities, requiring them to make a call to get information, make a reservation, or get a discount. There are other forms of discrimination as well. This is also true of the mobile apps now used by many transportation businesses.



Healthcare

Expanding Coverage

The Biden Administration and Congress have talked about expanding healthcare coverage and services. NCIL supports helping more people get healthcare coverage. We also support expanding access to community based long term services and supports (LTSS). Any efforts to expand healthcare, including universal coverage or a public option, must include the needs of the disability community, including expanding access to LTSS. We also want to make sure healthcare coverage lets disabled people get the equipment and supplies they need to live independently.

Prohibiting Healthcare Discrimination

There is a lot of discrimination against people with disabilities in healthcare. This has serious consequences, like substandard care and less access to needed services. The COVID-19 pandemic highlighted this for us. States and hospitals created new rules that discriminated against disabled people. They developed plans for “medical rationing” that determined who does and does not get treatment and care. Some disabled people were denied treatment altogether.

Black, indigenous, and other people of color (BIPOC) have died at alarming rates during the pandemic. LGBTQIA+ people and many other marginalized groups have also faced discrimination. Discrimination in healthcare has always had deadly consequences. During the pandemic, it has meant drastically higher infection and death rates.

NCIL supports strong enforcement of nondiscrimination laws. We also support new laws to address discriminatory practices. Some of our biggest areas of concern include:

- Medical equipment in clinics, offices, and facilities that is not accessible;
- Failure to communicate or provide information in accessible formats;
- Discrimination involving pressure to refuse life-sustaining treatment;
- Discriminatory “futile care” policies allowing healthcare providers to decide not to give life-saving treatment to someone even if they want it;
- Discrimination in organ transplants; and
- Quality Adjusted Life Years (QALYs). Insurance companies use QALYs to decide how much – or whether – to pay for certain treatments and services. Different disabilities and health conditions are given different number values. These are used to calculate the “value” of the treatment or service.

Chronic Pain and Opioids

Efforts to reduce opioid addiction must consider the needs of people with chronic pain. Some people with chronic pain need opioid medications. Because of some of the new laws, people with pain face more barriers to pain management. Many of these new laws focus on limiting opioid prescriptions. This has made it difficult for some people to get needed medication. Some people have been forced to reduce or stop their medication very quickly. Other people have been denied medical care completely.

Congress must understand the impact of recent laws. They must focus on comprehensive care for both pain and substance use. People with pain need access to the full range of the options that are available. Congress must work with people with pain and people with substance use disorders.

Opposing Assisted Suicide

Assisted suicide laws pose major dangers to people with disabilities. [Every national disability organization with a position on assisted suicide opposes it.](#) Many national medical organizations also oppose it. This includes the American Medical Association and the American College of Physicians. Many states have repeatedly refused to pass assisted suicide laws as well. The reasons we oppose it include:

When assisted suicide is legal, it is the cheapest treatment available. This is attractive in our profit-driven healthcare system. This is dangerous.

Terminal diagnoses are often wrong, and it is nearly impossible to know how long someone has left to live. Assisted suicide laws lead people to lose good years of their lives.

If one doctor says “no,” people can “doctor-shop” (go from doctor to doctor) until they find one who will say “yes”.

The “safeguards” do not protect people. There is no independent witness when the lethal drugs are taken. There is no real enforcement, and no one is charged with investigating. Therefore, there is no protection against abuse or coercion.

Many other pressures exist that can cause people with compromised health to hasten their death.

Evidence shows that assisted suicide laws lead to “suicide contagion,” driving up the general suicide rate.

We already have the right to good end-of-life pain relief. This includes palliative sedation, if needed. Palliative sedation uses medication to decrease awareness to relieve suffering.

In 2019, the [National Council on Disability released a report on Assisted Suicide](#). The report examined the effect of the country’s assisted suicide laws on people with disabilities. The report found that the laws’ safeguards are ineffective. It also found that there is no oversight of abuses or mistakes. Many of those [abuses have been documented by the Disability Rights Education and Defense Fund \(DREDF\)](#).



Employment / Social Security

It has been more than 30 years since the Americans with Disabilities Act passed. However, people with disabilities have not made much progress with employment. People with disabilities are still employed at lower rates than nondisabled people. 19.3% of people with disabilities are employed. 66.3% of nondisabled people are employed. This is a huge difference. People with disabilities are also two times as likely to work part time as nondisabled people.

COVID Recovery

Things have gotten worse since the COVID-19 pandemic began. Workers with disabilities have lost their jobs more than nondisabled workers. The inequality during COVID-19 is even worse for young people with disabilities. It is also worse for disabled people of color. People with disabilities have lost almost 1 million jobs. Having a job can be a path out of poverty.

There are things we need to think about when the country starts recovering from COVID-19. People with disabilities should be considered fairly for jobs. They should be considered based on their to ability to do the responsibilities of the job.

The COVID-19 pandemic has shown us that working remotely can be effective. This should benefit some workers with disabilities. This can help us make the best use of our skills and reduce some barriers to employment.

Removing Barriers to Employment for Older Workers

NCIL has developed two proposals. Both proposals would get rid of barriers to work for older people with disabilities.

Proposal #1 – Get Rid of the Medicaid Buy-In (MBI) Age Limit: Some of the services and supports disabled people need are only available through Medicaid. Some people with disabilities are not eligible for Medicaid because they earn too much money. MBI helps more people with disabilities access needed services and supports. But right now, people in some states are only eligible until they turn 65. Our proposal would get rid of this age limit imposed by the Medicaid Buy-In (MBI) under the Ticket to Work legislation.

Proposal #2 – Get Rid of “Disabled Adult Child” (DAC) Employment Restrictions: Some people with disabilities are in a group Social Security calls Disabled Adult Children (DAC). These people were disabled before age 22 and meet other requirements. They receive Social Security Disability Insurance (SSDI) benefits. DACs are the only group that receives SSDI and is not allowed to work above substantial gainful activity (SGA) after retirement age. (Substantial gainful activity is work that brings in a specific amount of money. For example, the SGA for non-blind people this year is \$1310. People who earn more than \$1310 are working above SGA.) Our second proposal would change this and allow DACs to work above SGA after retirement age. This would make the rules the same for all Social Security beneficiaries.

Action: In 2018, both proposals were introduced in one bill. It had support from both Republicans and Democrats. In 2019, a bill was introduced with just proposal #1. This was reintroduced this year. It is called the Supporting and Empowering the Nation to Improve Outcomes that Reaffirm Careers, Activities, and Recreation for the Elderly (SENIOR CARE) Act (S. 1476). NCIL supports this bill. We also hope proposal #2 will

be introduced again. This bill needs more co-sponsors and support from other disability organizations to pass!

ABLE Age Adjustment Act

Many benefits people with disabilities rely on limit how much money people can have or save. ABLE Accounts are special accounts that allow people with disabilities to save their money for disability-related expenses. This can include things like housing, transportation, healthcare, and more. Money put in an ABLE Account does not affect eligibility for benefits, like Medicaid or SNAP (food stamps).

Right now, only people who were disabled before turning 26 are eligible for an ABLE Account. The ABLE Age Adjustment Act (S. 331 / H.R. 1219) would change that. If this bill passes, people who were disabled before turning 46 would be eligible for ABLE Accounts. This change would help millions of people and help stabilize the program by increasing the number of people using these accounts. This bill needs more co-sponsors in order to pass!

Competitive Integrated Employment

NCIL opposes paying people with disability subminimum wages. NCIL also opposes the segregation of disabled employees in sheltered workshops or elsewhere. Sheltered workshops are 95% of the 14(c) certificate holders. These certificates allow employers to pay disabled people subminimum wages.

NCIL supports efforts to advance competitive integrated employment. Competitive refers to jobs where disabled and nondisabled people work for the same wages, benefits, and opportunities. Integrated refers to jobs in the community where disabled and nondisabled people work together doing the same, or similar, jobs.

NCIL supports the Transformation to Competitive Integrated Employment Act (H.R. 2373). This bill would phase out the use of 14(c) certificates. It would provide grants to states and employers to support competitive integrated employment.

All these initiatives will help people with disabilities work their way out of poverty while benefitting the country's economy as a whole. They will help the country's productivity.

SSI Restoration Act

Supplemental Security Income (SSI) provides financial assistance to older adults and people with disabilities with little to no income or assets. Much of the program has not been updated since it began in 1972. Because of that, many people who rely on SSI live in poverty and struggle to meet their basic needs.

NCIL supports modernizing the SSI program through the SSI Restoration Act (S. 2065 / H.R. 3824). This bill would make important changes to the program, including, but not

limited to: raising the income and asset limits, increasing the benefit amount, eliminating cuts when people receive in-kind support (like help with groceries or a place to stay), and getting rid of several marriage penalties.



Emergency Preparedness

The NCIL Emergency Planning Subcommittee addresses emergency preparedness, response, and recovery. People with disabilities need to be involved in all parts of a disaster. We need to help develop, assess, and implement plans and responses. We need to be involved in emergency preparedness. We need to be involved in disaster response. We need to be involved in recovery.

Since March 2020, we have been dealing with the COVID-19 pandemic. Other disasters have not stopped.

Since 1980, every U.S. state has had at least one billion-dollar disaster. For each of the past five years the U.S. has had 10 or more billion-dollar disasters. This means the damage cost was at least one billion dollars.

People with disabilities and older adults are usually 2 to 4 times more likely to die or be injured in disasters. That number has been much higher during the COVID-19 pandemic. Many people are dying in congregate settings. That number is tragic. It highlights what we have known for decades: congregate settings are deadly.

NCIL educates and advocates for the needs of people with disabilities at all stages of a disaster. We work with many agencies and partners. Many offices of the government have refused to work with organizations led by people with disabilities. NCIL strongly recommends that lawmakers and the Independent Living community take action. We need disability civil rights laws to be monitored. We need those laws to be enforced. We need to improve our emergency preparedness, response, and recovery for people with disabilities.

Our recommendations for Congress:

1. There are two important bills. The first is the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI). The second is the Disaster Relief Medicaid Act (DRMA). Members of Congress should support and sponsor them. These should pass into law.

REAADI does a lot of important things. One thing it would do is create a network of technical assistance centers. These centers will provide research, training, and assistance to states. They will also provide that to local emergency planners. These centers will be disability-led. This will help better involve and support the disability and aging communities during disaster preparedness activities.

DRMA also does a lot of important things. One thing it would do is ensure people who need to evacuate their state during an emergency can still access Medicaid. It would also provide resources to states.

You can read more about both bills at reaadi.com.

2. Congress must enforce the laws to meet the needs of people with disabilities during disasters. This includes providing funding to disability organizations to meet those needs.

3. The Red Cross must provide equal access to all programs and services equal to their Disability Integration (DI) staff's efforts. This must happen before, during, and after disasters. This must be done in the most integrated setting appropriate. This is practiced by Red Cross (DI) and must be done without exception. Congress must monitor and enforce this.

4. The rights of people with disabilities must be protected during disasters. This includes:

- Ensuring access to disaster services;
- Ensuring people with disabilities and older adults are provided services in integrated settings;
- Making HHS and the Centers for Medicare and Medicaid Services stop allowing states to institutionalize people more easily; and
- Ensuring the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 are monitored and enforced.

The agencies responsible for accomplishing these goals are:

- The Department of Justice (DOJ);
- The Department of Homeland Security (DHS); and

- The Department of Health and Human Services (HHS).

5. Congress should direct FEMA (Federal Emergency Management Agency) and ACL (Administration for Community Living) to put together a coordinated effort. The effort should focus on ongoing planning, preparation, and implementation. This effort should include:

- Federal agencies
- States
- Community-based organizations
- Business, public health, and other sectors
- People with disabilities and older adults in leadership roles

We encourage everyone to visit NCIL's COVID-19 page: ncil.org/covid-19. We also encourage everyone to visit the Partnership for Inclusive Disaster Strategies (PIDS) website for resources on COVID-19 and disability: disasterstrategies.org/covid-19-resources.



Voting Rights

Voting Accessibility

Disabled people face major barriers to voting. Our goal is for all people with disabilities to vote in all elections. All people with disabilities must be able to vote privately and independently. All voters must have access to both in-person and remote voting. Both must have accessible options. This is even more urgent during the COVID-19 pandemic.

We have a strategy to reach this goal:

- We will help with education and get-out-the-vote campaigns. We will help with voter registration. We will develop plans and provide resources. We will train leaders. We will work with other organizations. We will do this in primaries and

elections at all levels of government.

- We will encourage and educate people with disabilities to run for public office and hold appointed positions.
- We will work with the disability community to advocate for Federal funding. This funding should expand voting options. This includes accessible remote voting options for everyone. Both accessibility and security of voting must be improved.
- We will advocate to ensure any new voting technology is accessible and easy to use.

We also must keep the access that we already have. We will make sure voter websites are accessible and easy-to-use. This includes election offices, campaigns, and organizations who are educating voters. Each must also provide materials in alternative formats.

Fighting Voter Suppression

NCIL is committed to fighting laws that make it harder for people to vote. We will fight laws that limit early voting and curbside voting. We will fight against laws that require strict voter identification to vote. We will fight laws that make it harder for people of color to vote.

For the People Act (S. 1 / H.R. 1)

People across the country face many barriers to voting. The For the People Act (S. 1 / H.R. 1) would get rid of some of these barriers. Some of these pieces will specifically expand access for people with disabilities. NCIL supports the many pieces of the bill that will expand voting access.

However, NCIL is very concerned that the bill includes a requirement to use paper ballots in both in-person and remote voting. Paper ballots are inaccessible to many people with disabilities. This “paper ballot mandate” means that their right to a private and independent ballot will be violated.

NCIL supports expanding voter access for all Americans. While we support many of the important efforts in the For the People Act, it must be amended to include the disability community’s access needs. At the time of writing, the House has passed this bill, and it is being considered in the Senate.



Mental Health

Mental health disabilities are common. Half of Americans will get a mental health diagnosis at some time in their life. But people with mental health disabilities are left out of policy discussions about mental health. This exclusion has resulted in discrimination and other harm.

Mental Health and Violence

Many recent proposals to curb gun violence have falsely linked mental health and violence. People with disabilities are far more likely to be victims than perpetrators of violence. NCIL opposes this false linking of mental health disabilities and gun violence. We oppose all efforts to deny people's rights based on diagnosis or disability. We oppose the use of discriminatory and harmful violence prevention methods. This includes the use of databases based on diagnosis or treatment. It also includes the use of "threat assessments". These practices harm disabled people and people of color, and they do not prevent violence. For these reasons, NCIL strongly opposes the Behavioral Intervention Guidelines Act of 2021 (S. 1383 / H.R. 2877).

Forced "Treatment"

NCIL supports disabled people's right to control their services and supports. NCIL opposes forced or coerced "treatment". This includes involuntary institutionalization and forced drugging. It also includes Involuntary Outpatient Commitment "IOC" (also known as Assisted Outpatient Treatment "AOT").

Institutionalization

The media has focused a lot on COVID-19 deaths in nursing homes. We know that psychiatric facilities and other congregate settings are just as deadly. COVID-19 has made clear the dangers of these settings. These are dangers the disability community was already aware of.

People with disabilities are often forced to live in congregate settings. There continue to be many efforts to increase beds in congregate settings. There continue to be efforts to create new inpatient facilities. One such effort focuses on repealing the IMD exclusion. (The IMD exclusion limits Medicaid coverage for inpatient mental health services. NCIL opposes repealing the IMD exclusion.)

These settings put people at more risk of death, injury, and further disability. This was true before COVID-19. COVID-19 has shown the world how urgent it is to get people out of these settings. We must invest in community services and supports. This includes housing. This includes peer support services. This includes other voluntary community mental health services. And this includes other voluntary community services for substance use disorders.



Education

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a civil rights law. It says students with disabilities have the right to a free and appropriate public education. NCIL believes IDEA must be fully implemented. We believe it must be strongly enforced. Students should have an education that includes:

- The development of self-advocacy skills;
- Information about their rights;
- Opportunities to connect with adults with disabilities;
- Full access to all parts of their education. This includes academics, extracurricular activities, physical education, and social activities;
- The right assessments, technology, and supports to participate with their peers;

- An equal opportunity to be challenged;
- Schools that are accountable for the success of all students; and
- Due process rights when their rights are denied. Due process is a formal way to resolve disagreements with the school.

During COVID-19 students must continue to have an educational program that supports them. It must appropriately challenge them. They must continue to have access to assessments. They must have access to supports and technology they need. They must also have access to due process if their right to an education is not provided.

Restraint and Seclusion of Students

Restraint and seclusion cause harm. They are traumatic. But many schools continue to restrain and seclude students. Both restraint and seclusion are disproportionately used on students with disabilities and students of color. The use of restraint and seclusion should be banned. The Keeping All Students Safe Act (S. 1858 / H.R. 3474) would ban almost all seclusion and restraint. Schools would only be allowed to use physical restraint when someone is in immediate and unpreventable danger of physical harm. In those cases, restraints that make it hard to breathe or threaten the person's life (like prone or supine restraint) cannot be used. Action is still needed to pass this bill and fully ban these practices. NCIL strongly supports this bill.

College Accessibility for Students with Disabilities

Students with disabilities often have a hard time finding information they need from colleges. It is hard to find information about requirements for accommodations. It is hard to find information about disability programs. Colleges are not prepared to accommodate students in typical times. The COVID-19 pandemic has made this worse. Federal legislation is needed. Legislation should require colleges to accept an IEP or 504 plan as proof of disability. It should also enforce 504 accommodation requirements. NCIL supports the Respond, Innovate, Succeed, and Empower Act (also known as the RISE Act). The RISE Act would accomplish many of these things. It has not been reintroduced yet.



Technology

People with disabilities need more opportunities to access assistive technology (AT) devices and services. This includes devices that are generic and mainstream. This also includes personalized devices. All these devices can increase independence. They can increase self-determination. They can increase inclusion. And they can increase full participation.

There are many important things to consider when developing new technology:

- Universal design
- Inclusion
- Consumer control
- Consumer choice
- Peer support

These are also important when technologies become available in the marketplace. People with disabilities are best served when they have access to information, “hands-on” trial experiences, and supports. These can all help ensure the technology works for them. NCIL is encouraged by new devices that have incorporated universal design.

NCIL also supports the creations coming from the “Makers Community”. These can be devices made from 3-D printers. These can also be devices made from cardboard and other easily-found materials.

Assistive Technology Act

Congress has committed to expanding consumer choice and control in state Assistive Technology (AT) programs and Alternative Financing Programs (AFPs). (AFPs help people with disabilities pay for the AT they need.) NCIL supports this. Congress has also directed the AFPs to incorporate credit-building activities. This can include things like financial education and providing information about other funding sources.

NCIL is monitoring the reauthorization of the Assistive Technology Act. NCIL supports changes that:

- Provide separate authorization and funding to create and expand AFPs throughout the U.S. and territories.
- Incorporate consumer control and consumer direction throughout state AT program activities. This includes the Advisory Committee and the development and management of AFPs. These changes will mean people with disabilities have more power and control.



Violence and Abuse

The COVID-19 pandemic has put a spotlight on violence in our society. It has shown us violence of racism borne of white supremacy. It has highlighted the violence of oppression and the violence of institutionalization.

Black, Brown, Indigenous and other People of Color (BIPOC) have died at much higher rates. There are many reasons for this. This includes short- and long-term lack of access to quality healthcare and poor treatment from the medical and prison industrial complexes.

People with disabilities in congregate settings are also victims of sexual assault and caregiver violence. Getting out of these places is important. These settings account for at least 40% of COVID-19 deaths in the U.S.

Federal and state funding must get people out of institutions. This is often called transition. This funding must also help people stay out of institutions. This is called diversion. This will help end the violence and death because of institutionalization. Funding must also increase access to healthcare for all BIPOC.

People who have been victims of violence should be able to receive the services they want and need. This includes victims of sexual assault. This includes victims of domestic assault. This includes victims of caregiver violence. They should be able to receive culturally-specific services. In order for that to happen, the Senate needs to reauthorize the [Violence Against Women Act](#) (VAWA), which passed the House in March 2021.

People with disabilities experience serious violent crime (sexual assault, robbery and aggravated assault) at three times the rate of people without disabilities*. During a crisis like a pandemic, personal violence increases. Hotlines and online chat support services are still in service. You can contact one of them to speak with someone who is trained to help.

- Deaf Abused Women's Network (DAWN) for legal, medical, system advocacy, and survivor support services. Video Phone: 202.559.5366 or deafdawn.org
- National Domestic Violence Hotline: 800-799-7233 or 800-787-3224 (TTY) or www.thehotline.org
- National Sexual Assault Hotline: 800.656.HOPE (4673) or chat online at online.rainn.org

* U.S. Department of Justice, Bureau of Justice Statistics 2017



Veterans

NCIL supports efforts to provide all Veterans and their families with services and benefits in the most effective and efficient manner possible.

Veterans Health Administration (VHA)

NCIL supports:

- Reform by the Veterans Administration (VA) and Congress for the VHA. This reform must ensure appointments are processed in a timeline manner.
- Veteran Spouses: Offering Veteran spouses the ability to receive services if they are being cared for by a Veteran. These include Veteran Caregiver Services and Veteran-Directed Home and Community Based Services (HCBS).
- Veteran Healthcare: The VHA needs enough funding for Veterans' healthcare. Congress must provide this funding. This includes expanding community-based options like Veteran-Directed HCBS.

Veterans Benefit Administration (VBA)

NCIL supports:

- Reform by the VA and Congress for the VBA claims process. This reform must ensure consistency, timely processing, and adjudication of claims.
- Proper support: Veterans with post-traumatic stress disorder (PTSD), traumatic brain injury (TBI), and mental health disabilities due to service need to be able to access support. The Department of Defense (DOD), the VA, and Congress need to ensure this. This includes destigmatizing mental illness. It also includes making processes easier so finding and getting help is not so difficult.
- Employment: Employment opportunities help Veterans transition from military to civilian life. Congress must provide funding. This must support education, employment, and training programs.
- Benefits: Congress must not reduce benefits for Veterans and their families.
- Pre-9/11 Veterans: Benefits have been created for post-9/11 military members. These benefits must be available to pre-9/11 Veterans, too.

Veteran Homelessness Prevention

The President and Congress must support efforts to prevent Veteran homelessness. This includes making HUD-VASH (Veterans Affairs Supportive Housing) vouchers more available to Veterans in rural areas. These vouchers provide housing and support services to Veterans.

Veterans and Centers for Independent Living

Veterans need to be able to access services in the communities where they live. Congress, DOD, and the VA need to engage and collaborate with community-based organizations, like Centers for Independent Living (CILs). This collaboration will ensure Veterans and their families can access the services and supports they need.

Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)

CHAMPVA is a comprehensive health insurance program. The VA shares the cost of covered healthcare services for people who are eligible. NCIL supports the CHAMPVA Children's Care Protection Act of 2021 (S. 727 / H.R. 1801). This bill would allow children of eligible Veterans to continue coverage up to age 26. The Affordable Care Act left a gap for children of eligible Veterans from ages 23-26.





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