



Advocacy Priorities & Talking Points Guide

Summer 2020

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Rehabilitation Act / Independent Living Funding



Congress gave Centers for Independent Living (CILs) \$85 million. They did this in the *CARES (Coronavirus Aid, Relief, and Economic Security) Act*. This money was to help respond to the COVID-19 pandemic. NCIL advocated with the Independent Living Administration (ILA). We educated Congress. We said CILs need funding to meet disabled people’s needs during COVID-19. We are grateful to Congress for this funding. And we are already seeing CILs make an impact in their communities.

However, this funding was only for CILs that receive a Part C grant. Some CILs only get Part B or state funding.

The federal government gives Part C funding directly to CILs. The federal government gives Part B funding to the state. Some CILs then get Part B funding from the state. CILs that get only Part B or other state funding could not get the new funding.

States are now working on their budgets. Many states are facing budget gaps. Many have less money coming in than they need. Some states are proposing cuts to funding for Independent Living. These cuts would be harmful to CILs that rely on state funding.

CILs need more funding to provide all the core services to all who need them. NCIL figured out that the Independent Living program needs \$200 million more. This needs to include more funding for both Part C and Part B.

CILs are organizations. People with disabilities run them. They believe all people with disabilities are valuable. They believe we should be able to participate fully in our communities. CILs help people move out of institutions. They help people move into the community. CILs advocate for people with disabilities facing discrimination. This can be discrimination in employment or education. It can be discrimination in housing, transportation, healthcare, and more. CILs help people in all these areas and more. This helps people with disabilities have more opportunities.

Statewide Independent Living Councils (SILCs) work closely with CILs. They develop the state's independent living network and services plan. When needs are not being met, they figure out how to address them. More money would help states put those plans into action. More money would help expand the network of CILs. It would help the network address the states' needs and priorities.

The Independent Living Program has made a big impact in the US. It has impacted the long term care system. It has improved home and community based services (HCBS) delivery. And it has affected transition services for youth. Most CILs also find other problems in their communities. They come up with plans to deal with the problems. They work with decision-makers to put the plans into action. CILs also help fill gaps between other programs.

The Independent Living Program has not had enough money for a long time. Giving money to Centers for Independent Living makes sense. There is an increasing demand for Independent Living services. This \$200 million request will help meet that need.

Healthcare / Long Term Services and Supports (LTSS)



A lot of death and illness from COVID-19 has been in congregate facilities. Congregate facilities include:

- state hospitals
- psychiatric institutions
- intermediate care facilities (ICFs)
- nursing homes
- group homes
- developmental centers
- day habilitation centers

- detention centers
- prisons
- jails.

It includes more places, too.

The deaths in all these facilities happened because of discrimination. Deaths in long-term care settings are the result of an Institutional Bias. The Institutional Bias pushes many disabled people into congregate facilities. People get forced there to get the long term services and supports (LTSS) they need.

The government has created an Institutional Bias in Medicaid. They require states to pay for LTSS in institutions. Offering the same services in community settings is optional.

Large institutions regularly get funding increases. Home and community based services (HCBS) are underfunded. Sometimes smaller congregate facilities get funding for HCBS. This is instead of supporting individual choice in living arrangements.

The government made it easier to institutionalize people during the pandemic. People can be automatically transferred from hospitals to congregate facilities. This is allowed even if facilities are unlicensed in their state. Getting supports and services to keep people at home has gotten harder.

The Money Follows the Person (MFP) program is very successful. It supports moving people from institutions to the community. It has helped over 91,000 people move to the community. However, MFP is surviving on minimal support. It is not getting the longer-term extensions it needs.

People make judgments about disabled people and our lives. They think our lives have less value. That creates threats to our lives.

States have developed new rules during the pandemic. They have developed practices that harm disabled people. We might have life-saving treatment denied. We might have equipment we need denied or removed. These are only the most recent threats we face. Systems often deny disabled people care that can save or extend our lives. States also keep trying to expand physician assisted suicide and similar efforts. We need a commitment to the value of disabled lives.

COVID-19 has especially harmed Black, indigenous, and other people of color (BIPOC) and their communities. The lack of community-based services and supports has harmed them. Black and brown disabled people have died at very high rates. They have died in high rates in all types of congregate facilities. BIPOC also make up a majority of the direct care industry. They have worked with little or no personal protective equipment (PPE). PPE are things like masks and gloves. These communities are dying at high rates from COVID-19.

People are having a hard time getting the medications they need. This includes all types of medications, including controlled substances. Controlled substances are more tightly controlled by the government. This includes medications like opioids that people take for pain. It includes some other medications people need. People need access to all their medications. There are new policies that limit access and create barriers. These policies harm disabled people who rely on these medications.

Other policies have limited visitors in the hospital. People need support in the hospital for many reasons. They may need help to communicate. They may have other support needs. People who need help in the hospital are at risk because of these policies.

We need to end the Institutional Bias. To do that, we need a shift in resources. We also need a shift in the way people value our lives. We call on Congress to make these shifts. They need to do this for their constituents, their families, and their communities.

We call on Congress to:

- END THE INSTITUTIONAL BIAS in long term services and supports.
- Increase funding for Home and Community Based Services (HCBS) programs. This includes dedicated HCBS funding in the next COVID-19 package in Congress. We need a major investment in HCBS. It must support individual control and choice. This will ensure supports are available for people across the lifespan.
- Pass long term reauthorization of the Money Follows the Person program. A reauthorization of a law updates the law and says it will continue.
- Protect our rights. This includes preventing involuntary institutionalization. It includes banning discrimination in medical decision-making. And it includes banning discrimination in medical rationing.
- Ensure access to PPE for disabled people and our support workers.
- Ensure access to medications, supplies, and equipment for all people. This includes people who rely on controlled substances.

Electronic Visit Verification (EVV)

NCIL wants Congress to delay the requirement for EVV. We want it delayed from January 2021 until 2022. We want it delayed nationally. NCIL is working with members of Congress. We are supporting legislation that includes this change. This is the *COVID-19 Recovery for Seniors and People with Disabilities Act (S. 3740)*.



Congress is working on a bill called the *21st Century Cures Act 2.0*. Congress wrote a paper that explains their plan for the bill. This paper said Congress would not allow GPS

and biometrics in EVV. GPS is technology that allows the tracking of someone's location. Biometrics are personal features that are used to identify someone. Examples of biometrics are fingerprints or voice recognition.

We will keep working to make sure that language is in the final bill. We will focus on the House Energy & Commerce Committee. Strong advocacy has been successful to make change. Strong advocacy is also what will bring success in the future.

Americans with Disabilities Act / Civil Rights



This is the 30th anniversary of the *Americans with Disabilities Act (ADA)*. But there are still threats to our rights. For example, another bill has been introduced that could weaken the ADA. This bill is the *ACCESS Act (H.R. 4099)*.

The *ACCESS Act* is similar to previous bills. It would create barriers to *ADA* enforcement. It would set our rights back.

The *ACCESS Act* does not increase access. In fact, it creates more barriers. If a disabled person wants to challenge specific barriers in court, they have to do many things. First, they must provide specific notification. They then have to wait up to 60 days for the business to write a plan. Then they must wait 60 days more for the business to fix the issue or make progress.

The *ACCESS Act* could also weaken website access requirements.

The bill will probably not pass this year. But we still cannot ignore it. Lawmakers keep introducing similar bills every year. Eventually one of these bills will pass if we do not fight them.

We are also facing the COVID-19 pandemic. COVID-19 has highlighted how disabled people are discriminated against. This is especially true for disabled black, indigenous, or other people of color (BIPOC).

The ADA/Civil Rights Subcommittee is working with other Subcommittees. We urge you to review the Healthcare / LTSS and Emergency Preparedness sections.

Housing

When you meet with your Members of Congress, you should focus on certain things. You should talk about how there is not enough housing for people with disabilities. This is even more true during these difficult times. You should talk about the need for housing that people can afford. We



need more housing for extremely low-income households. These households make at or below 30% of the “Area Median Income”. (The Area Median Income is the middle amount of money people make in a region. In a region, half of families make more than the median. Half of families make less.)

You should explain:

- the need for more accessible housing;
- the importance of having housing choices;
- the need to invest in housing voucher programs. (Voucher programs help people who do not have a lot of money get housing.)

You should share stories about:

- the people you work with;
- the calls you get;
- how difficult it is for people to find housing.

The House of Representatives has passed two important bills. One of the bills is a COVID-19 recovery bill. It is called the [*HEROES Act*](#) (*H.R. 6800*). The *HEROES Act* includes \$200 billion for affordable housing. The House has also passed another bill. This is an infrastructure bill. (Infrastructure is structures and systems that make our cities, states, and country work. This includes things like roads and public transportation. This also includes things like housing, schools, and the internet.) The bill is called the [*Moving Forward Act*](#) (*H.R. 2*). It includes \$100 billion for affordable housing. It includes new and increased housing tax credits.

The Senate has not taken action on either bill (at the time of writing). We expect the Senate to negotiate with the House.

Reach out to your Senators to talk about the importance of those two bills. Ask for their support. Ask them to support the housing funding. If your Representative voted for those bills, thank them for their support.

Transportation

Transportation must be accessible. Accessible means it has to work for people with disabilities. It also has to be safe and not cost too much. Transportation includes buses, planes, cars, and more. All transportation should be accessible to people with disabilities. This is important so people with disabilities can do things everyone else can. This includes going to work or school. It includes meeting with friends. It includes many other things.



Here are some very important things for people with disabilities:

- The House of Representatives passed the [INVEST Act](#) (*H.R. 7095*). This is the “big transportation bill”. It is also known as the “surface transportation bill”. Congress passes one every 5 years. It is an important bill. It provides money for building and fixing roads and bridges. It also helps pay for public transportation and things like bike and walking paths. The Senate has not yet taken action (at time of writing). We need to work with legislators and advocates. We need to make sure this new law works for everyone.
- Medicaid pays for rides to the doctor for many disabled people. We need Congress to protect that so states cannot take it away.
- People with disabilities can have a very hard time on airplanes and trains. Wheelchair users can face unique problems. We must make this easier for people with all disabilities.
- There must be more accessible taxis and services like Uber (when you use a smartphone to get a ride). Everyone must be able to use them.

All these things will make America’s transportation fairer. With these changes, people with disabilities will have more choices. People with disabilities need the same choices as everyone else.

Mental Health

This country disregards people with disabilities. This has put us at more danger during the COVID-19 pandemic. Our systems force people with disabilities to live in congregate settings. They are at risk of death, injury, and further disability. They are more at risk because of COVID-19.



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

We knew how urgent it is to get people out of congregate settings. COVID-19 has only made this more urgent. We urgently need to invest in community services and supports. This includes housing. This includes peer support services. It includes other voluntary community mental health services. It includes other voluntary community substance use disorder services.

NCIL opposes denying people their rights because of their disability. This includes:

- Efforts to institutionalize more people. This includes repealing the IMD exclusion. IMD stands for Institutes for Mental Disease. IMDs are institutions with more than

16 beds that mostly serve people with mental health diagnoses. The IMD exclusion blocks Medicaid from paying for treatment in IMDs for people between 21 and 64 years old. Repealing with IMD exclusion would increase institutionalization.

- Efforts to increase forced treatment. This includes involuntary electroshock. This includes Involuntary Outpatient Commitment (IOC). IOC is also known as Assisted Outpatient Treatment (AOT). IOC / AOT is when a court requires someone to follow a treatment plan. It is an outpatient plan. This can include medication. It can include where a person can live. It can also include what activities a person must participate in.
- Efforts to increase prevention methods that discriminate against people. This includes databases of diagnosis or treatments. This also includes the use of “threat assessments” in schools.

Education & IDEA

Individuals with Disabilities Education Act (IDEA)

IDEA is a civil rights law. It is known as the special education law. It guarantees special education and services to disabled students. NCIL believes IDEA is a good law. We believe it is a necessary law. IDEA must be fully implemented and enforced.



During COVID-19, students must 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 the supports and technology they need to participate. If schools violate their rights, they must have access to due process. Due process is a formal way to resolve disputes with the school.

Restraint and Seclusion

Restraining and secluding students causes harm. It is ineffective. But many schools continue to restrain and seclude students. We need Congress to ban the use of restraint and seclusion except in emergencies. Emergencies are when someone is in immediate and unpreventable danger of physical harm. Those will be very rare situations. When that happens, schools must not use restraints that can make it hard to breathe. Schools must never use mechanical restraints. Schools must notify parents right away when restraint or seclusion is used. We need Congress to act.

College Accessibility

It is hard for disabled students to find information from colleges. It is hard to find information about requirements for accommodations. And 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. We need federal legislation to help. It should require colleges to accept an IEP or 504 plan as proof of disability. It should also enforce 504 accommodation requirements.

Employment / Social Security

It has been 30 years since the *Americans with Disabilities Act (ADA)* passed. Americans with disabilities have not made much progress with employment. The employment rate for people with disabilities is very low. It is much lower than for nondisabled people. The employment rate for people with disabilities is 19.3%. The employment rate for nondisabled people is 66.3%. This is a big difference. These numbers are from the Office of Disability Employment Policy.



Disabled people also work part-time more than nondisabled people. We are two times as likely to work part-time.

Things have gotten worse since the COVID-19 pandemic began. Workers with disabilities have lost their jobs more than nondisabled workers. People with disabilities have lost almost 1 million jobs! Having a job can be a path out of poverty.

The inequality during COVID-19 is worse for young disabled people. It is also worse for people of color with disabilities.

We are starting to think about the country's recovery from COVID-19. There are things we need to think about for people with disabilities. Employers should consider us fairly for jobs. They should consider people based on their ability to do the job responsibilities.

The COVID-19 pandemic has shown us that working remotely can be effective. This should benefit workers with disabilities. This can help us make the best use of our skills. It can also help reduce barriers, like transportation.

We need to advocate in our states. We need to advocate for Vocational Rehabilitation programs. They need their full share of federal funding. They also must address the new requirement to support youth employment.

NCIL has worked with members of Congress to propose bills. The bills would get rid of barriers to work for people with disabilities. They are cost-effective. Congress introduced two bills in December 2019. They are bipartisan. That means both Republicans and Democrats support them.

The bills are called the *Supporting and Empowering the Nation to Improve Outcomes that Reaffirm Careers, Activities, and Recreation for the Elderly (SENIOR CARE) Act* (H.R. 5429 and S. 3010).

The bills would remove barriers for older workers with disabilities. They remove the 65-year-old age limit in the Medicaid Buy-In program. This age limit is in the *Ticket to Work and Work Incentives Improvement Act* (1999).

Some disabled people work and earn too much to get Medicaid coverage. Medicaid Buy-In programs allow some of those people to get Medicaid. This is important because Medicaid pays for long term services and supports. Other insurance providers do not.

The *SENIOR CARE Act* would remove the 65-year-old age limit. It would allow disabled people over 65 to stay eligible for Medicaid Buy-in. Those who keep working past 65 would keep their Medicaid eligibility.

NCIL has another proposal, too. It would get rid of rules that discriminate against “childhood disability beneficiaries” (CDB). (CDB is a category from the Social Security Administration. These are people who have been disabled since childhood. They get benefits on a parent’s earnings record.)

We need support from Congress for these proposals.

NCIL also supports the *ABLE Age Adjustment Act* (H.R. 1814 and S. 651). This bill is also bipartisan. This bill would change who is eligible for ABLE Accounts from age 26 to age 46. Right now, only people who became disabled by 26 are eligible. This bill would allow people who became disabled by 46 to use the accounts too.

All of these initiatives will help the economy of this country. They will help the country be more productive. They will help people get out of poverty.

Technology

People with disabilities need more access to 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. They can increase participation.



NCIL is watching the reauthorization of the *Assistive Technology Act*. This is called the *21st Century Assistive Technology Act* (S. 1835). A reauthorization of a law updates the law and says it will continue. NCIL will support this bill if Congress makes some changes:

- Provide a separate funding stream for Alternative Financing Programs (AFPs). This funding should help create and expand AFPs. Assistive technology can be very expensive. AFPs help people with disabilities pay for AT devices and services.
- Incorporate consumer control and consumer direction. Both of these things mean people with disabilities have more power and control. This needs to happen throughout the AT program activities. This includes the Advisory Committee. And this includes the Alternative Financing Programs.

Voting Rights

Our goal is full accessibility of elections. All people with disabilities should be able to vote privately and independently. This is even more urgent during the COVID-19 pandemic. People are facing major barriers to voting.



All voters must have access to both in-person and remote voting. Both of these must have accessible options.

We have a strategy to reach this goal.

- We will advocate for federal funding. We will work with others in the disability community for this. This funding should expand voting options. This includes accessible remote voting options for everyone. We must improve both accessibility and security of voting.
- We will train leaders. We will work with other organizations. We will provide resources. We will help with voter registration. We will help with education and get-out-the-vote campaigns. We will do this in elections at all levels of government.
- We will advocate with policymakers. We will advocate with technology makers. And we will advocate with election officials. New voting technology should be accessible and easy-to-use. We will make sure of this.
- We want people with disabilities to run for public office. We want people with disabilities to hold appointed positions. We will encourage and educate people to be able to do this.

We also must maintain the access we have. We will make sure websites voters use are accessible and easy-to-use. This includes websites from election officials. This includes campaign websites and websites of organizations that are educating voters.

They must also provide materials in alternative formats. This includes formats like large-print and recorded materials. The *Americans with Disabilities Act (ADA)* requires this.

We support improving the country's voter registration system. This includes strong implementation of the *National Voter Registration Act (NVRA)* requirements. The NVRA made new requirements for states. These were meant to make it easier for people to register and stay registered to vote.

We support a strong partnership with the U.S. Election Assistance Commission (EAC). The EAC is an independent agency of the government. They develop a lot of election-related guidelines. They serve as a clearinghouse of information and have other election-related responsibilities. Our partnership continues to improve voting accessibility.

Emergency Preparedness

For each of the past five years, the U.S. has had 10 or more billion-dollar disasters. This means the damage cost at least one billion dollars. There were 101 disasters declared by the federal government in 2019. Fourteen were billion-dollar disasters.



Since 1980, every U.S. state has had at least one billion-dollar disaster. 2020 is on track to be another record-breaking year. [Read more at climate.gov](https://www.climate.gov).

Now we are dealing with the COVID-19 pandemic. We have to deal with that while responding to other disasters.

Many people are dying in institutions. The number of people dying is enormous. It highlights a reality we have known for decades.

Disabled people and older adults are always at risk during disasters. They are usually 2 to 4 times more likely to get hurt or die in disasters. That number has been much higher during the COVID-19 pandemic.

We encourage everyone to visit our NCIL COVID-19 page: ncil.org/covid-19. We also encourage everyone to visit the [Partnership for Inclusive Disaster Strategies \(PIDS\) web page](#).

The NCIL Emergency Preparedness Subcommittee addresses emergency preparedness, response, and recovery. People with disabilities must be involved in all parts of disasters. 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 find ways to limit harm to our community. And we need to be involved in recovery.

NCIL educates and advocates for the needs of people with disabilities at all stages of a disaster. We work with FEMA. FEMA is an agency of the government. They help

coordinate the response to disasters in the U.S. We work with the Red Cross. They provide emergency assistance and disaster relief. They also do disaster preparedness education. We also work with other agencies and partners. Disabled people have needs before, during, and after disasters. We work with them to address all of these. This is at all levels: local, state, tribal, territorial, and federal.

Some offices have refused to work with organizations led by people with disabilities. This includes FEMA's Office of Disability Integration and Coordination. This includes the Administration for Community Living (ACL). This includes the Office of the Assistant Secretary for Preparedness and Response (ASPR). They have refused to work with us even though FEMA's Disability Coordinator is required to. They are required to engage and consult with NCIL and our partners.

We need to take action. We need our lawmakers to take action. We need them to monitor disability civil rights laws. We need the laws to be enforced. We need to improve emergency preparedness, response, and recovery.

Our work with peer organizations has had positive outcomes. Our federal partners have noticed our best practices. They supported giving more money to the Independent Living network. We got additional funding from Congress in the *CARES Act*. They gave us funding to support and increase our work in response to COVID-19.

We have recommendations for Congress:

1. There are two very important bills. One is the *Real Emergency Access for Aging and Disability Inclusion for Disasters (REAADI) Act*. The other is the *Disaster Relief Medicaid Act (DRMA)*. We need our Members of Congress to support and sponsor them. They should pass them. They should fund them.

REAADI does many important things. One thing it would do is create a network of technical assistance centers. There will be one center in each region. These centers will be disability-led. They will provide research, training, and assistance to states. They will provide those things to local emergency planners. This will help better involve and support the disability community during disaster activities.

DRMA does many important things too. It would help people who need to evacuate their state in an emergency. It would make sure those people can continue to access Medicaid. And it would provide resources to states.

You can read more about both bills, including summaries and bill text, at reaadi.com.

2. Congress must enforce laws that meet disabled people's needs during disasters. They must do this now. This includes the *Rehabilitation Act* and the *Americans with Disabilities Act (ADA)*. They must fund qualified disability organizations to meet those needs.

3. The Red Cross must provide equal access to all programs and services. This must happen before, during, and after disasters. They must provide these in the most integrated setting appropriate. They must do this without exception. Congress must monitor and enforce this.

4. The federal government must monitor and enforce the *Rehabilitation Act* and the *ADA*. The Department of Justice (DOJ) must do this. The Department of Homeland Security (DHS) must do this. And the Department of Health and Human Services (HHS) must do this. Disabled people must have full and equal access to disaster services. They must ensure this. They must protect our rights. This means ensuring disabled people can be served in integrated settings. People are being institutionalized more easily during COVID-19. HHS and the Centers for Medicare and Medicaid Services (CMS) have allowed this. This must stop.

5. Congress should direct FEMA and ACL to convene and fund a coordinated effort. This effort should bring together federal agencies. It should bring together states. It should bring together community-based organizations. And it should bring together business, public health and other sectors. People with disabilities and older adults should have leadership roles. The effort should focus on all of our recommendations. The goal should be ongoing planning, preparation, and implementation.

Violence & Abuse

The COVID-19 pandemic has highlighted a lot of violence in our society. It has highlighted the violence of racism. It has highlighted the violence of oppression. And it has highlighted the violence of institutionalization.



[Black, indigenous and other people of color \(BIPOC\) are dying from COVID-19 at four and five times higher rates.](#) This includes from short- and long-term lack access to quality healthcare.

People in congregate settings are also victims of sexual assault. They are victims of caregiver violence. Getting out of congregate settings is important.

These settings account for at least 40% of COVID-19 deaths in the US.

Federal and state funding must get people out of institutions. Transition is the name of this process. This funding must help people stay out of institutions. Diversion is the name of this process. This will help end the violence and death from 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. And this includes victims of caregiver violence. They should be able to receive culturally-specific services.

The Senate needs to strengthen the *Violence Against Women Act (VAWA)*. They need to vote to reauthorize it.

People with disabilities experience two times the rate of violence as people without disabilities. During a crisis like COVID-19, personal violence increases. Hotlines and online chat support services are still in service. You can contact one of them to speak with someone trained to help.

- Deaf Abused Women's Network (DAWN). They provide legal, medical, system advocacy, and survivor support services. Video Phone: 202-55-.5366 or deafdawn.org
- National Domestic Violence Hotline: 800-799-7233 or 800-787-3224 TTY or www.thehotline.org
- National Sexual Assault Hotline: 800-65-.HOPE (4673) or chat online at online.rainn.org.