**disABILITY LINK – Legislative and Social Policy Report – October 2020**

There is never a shortage of items to include in a legislative and policy report on disability rights, after all, there are people with disabilities in all areas of life, we are the most diverse of all so-called minority groups, anything that impacts anyone is likely to impact people with disabilities.  For the sake of brevity, disABILITY LINK will addressing a couple of pieces of legislation that affect the disability community. We can provide education on how it affects the community but cannot lobby for any type of bill.

# The Independent Living Program

We continue to work toward increasing funding for Centers for Independent Living both statewide and nationally. We participate in initiatives with NCIL and APRIL organizations. GVRA cut funding drastically to CILS. The CIL and SILC are working together to organize a letter to be sent out.

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.

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.

**Voting Accessibility**

REV Up the Vote continue monthly meeting around the Absentee Ballots and Accessible Voting Machines

REV Up the Vote at disABILITY LINK held voter registration events in July

# disABILITY LINK’s in lines with NCIL, APRIL and the IL Network’s top 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.

NCIL’s 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.

**Housing**

NCIL, APRIL, and the IL network know there is not enough housing for people with disabilities. This is even more true during these difficult times. 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.)

* 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.)

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*](https://www.congress.gov/bill/116th-congress/house-bill/6800) (*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*](https://www.congress.gov/bill/116th-congress/house-bill/2/)(*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.

**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*](https://www.congress.gov/bill/116th-congress/house-bill/7095) (*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.