

June 3, 2020

For the disability community, COVID-19 impacts are viewed and felt on two distinct but related fronts: a health emergency in which our lives are at disproportion risk where the impacts of existing health system disparities have been laid bare; and an economic disaster that touches not only access to employment and resources to meet basic needs, but fracturing and undermining the service system structures that are so crucial to ensure that people with disabilities have access to full lives.

What are some of the key challenges your members/constituencies have faced during this crisis? (e.g. accessibility, travel, work from home, technology, food, unemployment, education, policy, research, etc.)

## Health Crisis

* The delay in guidance regarding the risk to and steps for mitigation of COVID-19 and the disability community was stark:
* On January 30th, the World Health Organization (WHO) announced the outbreak of a

novel coronavirus disease, COVID-19

* It was not until March 26th that WHO provided guidance for risks to people with disability (PWD) ([World Health Organization](https://www.who.int/docs/default-source/inaugural-who-partners-forum/english-covid-19-disability-briefing.pdf?sfvrsn=8a1aa727_1&download=true))
* On April 7th, the [Centers for Disease Control and Prevention](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html) articulated disability populations were at increased risk of infection from and adverse outcomes of COVID-19
* On May 28th, the CDC provided critical guidance:
	+ [Guidance for Direct Service Providers](https://www.cdc.gov/coronavirus/2019-ncov/hcp/direct-service-providers.html)
	+ [Guidance for Group Homes for Individuals with Disabilities](https://www.cdc.gov/coronavirus/2019-ncov/community/group-homes.html)
	+ [Guidance for Direct Service Providers, Caregivers, Parents, and People with Developmental and Behavioral Disorders](https://www.cdc.gov/coronavirus/2019-ncov/hcp/developmental-behavioral-disorders.html)
	+ [People with Developmental and Behavioral Disorders](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-developmental-behavioral-disabilities.html)
* The continued lack of access to PPE and training on its use for non-medical, congregate settings and delivery of direct support in home and community services continues to be a primary and critical safety barrier:
	+ While primarily funded by Medicaid, direct disability supports are provided *outside of* our health system. By definition they are non-medical in nature. This means that these service providers have not been a part of distribution efforts for PPE and that staff have not historically been trained on correct PPE use
		- PPE is critical for safe care and service provision in all settings
		- Training of PPE use for staff is needed as a part of public health response
		- Training for PWD is needed to support self-advocacy and self-management of direct service experience
* Discrimination regarding access to treatment in the face of shortages:
	+ The outbreak has highlighted the limited number of ICU beds and ventilators around the country. The inadequacy of our health care system uncovered both existing and newly developed policies that would limit access to care based on disability status
		- Health care rationing – state tracker <https://www.centerforpublicrep.org/covid-19-medical-rationing/>
		- The Department of Health and Human Services Office of Civil Rights has updated a bulletin on[Civil Rights Laws and HIPAA Flexibilities that apply during the COVID-19 Emergency](https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html) making clear this discrimination is unacceptable
			* An [early case resolution with Alabama removing discriminatory ventilator triaging guidelines](https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html)
			* The Center for Dignity in Healthcare for People with Disabilities, developed two factsheets that address the rights of people with disabilities in healthcare settings. One factsheet was created for people with disabilities and their family members; the other was created to inform healthcare professionals and personnel about the rights of people with disabilities in the healthcare setting:
			* Factsheet for People with Disabilities: <https://www.ucucedd.org/wp-content/uploads/2020/04/COVID-19-Fact-sheet-for-PWD-002.jpg>
			* Factsheet for Healthcare Personnel: <https://www.ucucedd.org/wp-content/uploads/2020/04/Safeguards-against-Discrimination-flyer-for-healthcare-professionals_ThinkEquitable.jpg>
* Failure to include disability status in data monitoring of the crisis. While national and state data collection and reporting on rates of infection and death does not adequately or accurately reflect the impacts on people with disabilities, we are seeing news stories that reflect the disproportionate impact:
	+ [Nearly half of developmentally disabled at state home infected with coronavirus](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.wcvb.com_article_nearly-2Dhalf-2Dof-2Ddevelopmentally-2Ddisabled-2Dat-2Dstate-2Dhome-2Din-2Dmassachusetts-2Dinfected-2Dwith-2Dcoronavirus_32178605-3Ffbclid-3DIwAR0tYMf1Fh2Ap0c4ioMAr-2D4PljrebC009Af2kZ20xULAW1nAkFkcSgTvGnA&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=pdCZE-3d_KAF68g-WNWsRrWspT__AGongW5FfAUiyZo&e=) (MA)
	+ [Group homes for disabled adults grapple with the spread of coronavirus](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.washingtonpost.com_local_group-2Dhomes-2Dfor-2Ddisabled-2Dadults-2Dgrapple-2Dwith-2Dthe-2Dspread-2Dof-2Dcoronavirus_2020_04_18_ac2ecae2-2D7ff2-2D11ea-2Da3ee-2D13e1ae0a3571-5Fstory.html&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=3cg0waHUUlM8WV6PjcjKUobZt9j89XmKVmkWNnvOijU&e=) (DC, MD, VA)
	+ [Illinois National Guard activated for COVID-19 response at Park Forest developmental center with more than 100 cases](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.chicagotribune.com_suburbs_daily-2Dsouthtown_ct-2Dsta-2Dillinois-2Dnational-2Dguard-2Dludeman-2Dcenter-2Dst-2D0419-2D20200417-2Devmpvn4bfbegtia2njinmdbf54-2Dstory.html-3Ffbclid-3DIwAR3YO5TCtXoh3mMHBoXrFjFGjj5TyGr-5FbcIOE3xw5RMO5bRsgfR749mqnpQ&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=-fu5vnl4B-Co67gxjs-FJQhhXTMnaVMYt3lN3MZGaSI&e=) (IL)
	+ [It’s time to recognize the essential value of direct support professionals](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.minnpost.com_community-2Dvoices_2020_04_its-2Dtime-2Dto-2Drecognize-2Dthe-2Dessential-2Dvalue-2Dof-2Ddirect-2Dsupport-2Dprofessionals_-3Ffbclid-3DIwAR2nMdeopCYtVj4sgNSsnGA5o2p8MHqRKezNiiMH9SUcyckpDtIiOnh2MUU&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=YbO-SivwvCpXKqLCH4sxctvvErFOOG0XuC_qqlOZrCY&e=) (MN)
	+ [‘It’s Hit Our Front Door’: Homes for the Disabled See a Surge of Covid-19](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.nytimes.com_2020_04_08_nyregion_coronavirus-2Ddisabilities-2Dgroup-2Dhomes.html-3Ffbclid-3DIwAR0oFLCIFeGfE9H2vrfMMEN6WZZdIOBiKraJN1erYXHwADqpd68uvcMg0NM&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=w2C8R-0GbuX_9Kuf-Pef5AHvuXDlxWKw1v_-WBfIMoU&e=) (NY)
	+ [Coronavirus Hits Texas Living Center For Disabled Persons](https://urldefense.proofpoint.com/v2/url?u=https-3A__www.npr.org_2020_03_30_823742198_coronavirus-2Dhits-2Dtexas-2Dliving-2Dcenter-2Dfor-2Ddisabled-2Dpersons&d=DwMFAg&c=L93KkjKsAC98uTvC4KvQDdTDRzAeWDDRmG6S3YXllH0&r=6fUtb-coZej2vQDCW7eZ-JhpTmaMWl43ZButep8_-t8&m=RSuOIGHS4iRhP0ACqisqDR2XfBmzOYvNBaLn5GxMWmI&s=tB7Sjz6a115P3isCEKHGBMXIbpwYsuYVn2k4MEPxyEQ&e=) (TX)
* Discrimination in terms of support and communication systems in acute care settings:
* Complaints have been filed with the Office for Civil Rights at the U.S. Department of Health and Human Services regarding how visitor policies due to COVID-19 have denied access to communication and support needed by many elderly and disabled people to make informed medical decisions, sometimes resulting in incorrect care or long-lasting harm.
* Around the country, hospital policies vary. Many ban all visitors; some states and some hospitals do make exceptions for some patients who can't speak. The Center for Public Representation, Autistic Self Advocacy Network, Communication FIRST, and The Arc have released an [Evaluation Framework for Hospital Visitor Policies](https://www.centerforpublicrep.org/wp-content/uploads/Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies_5-14-20_Final.pdf). This guidance provides stakeholders with the legal framework for required reasonable modifications to state and hospital no-visitor policies, identifies a number of criteria for evaluating visitor policies, and provides examples from state policies.
* Transition to telehealth access issues. There has been a rapid expansion in the availability of many health care services by telehealth. CMS [lifted several restrictions](https://edit.cms.gov/files/document/medicare-telehealth-frequently-asked-questions-faqs-31720.pdf) on [who can receive telehealth and the types of services they can receive](https://www.kff.org/medicare/issue-brief/faqs-on-medicare-coverage-and-costs-related-to-covid-19-testing-and-treatment/). This shift, while positive for many, may have limited reach and creates a set of equity and accessibility considerations:
	+ NCI Data Highlight – on access to cell/smartphones among people with IDD:  <https://www.nationalcoreindicators.org/upload/aidd/Data_Highlight_Cell_Phones.pdf>
	+ Internet connections are spotty or absent in some parts of the country. As covered in a report from Michigan State University <https://www.canr.msu.edu/news/rural-broadband-investment-urgently-needed-in-the-covid-19-crisis>
		- Some providers are initiating programs to provide Wi-Fi hot spots for patients in remote locations, for instance in some rural areas.

## Economic and systems crisis

* Loss of employment and day services:
	+ From March to April, the number of [employed working-age people with disabilities decreased by 950,000 (from 4,772,000 to 3,827,000), a 20 percent reduction, while the number of employed working-age people without disabilities decreased by 14 percent (from 140,135,000 to 120,804,000)](https://researchondisability.org/home/ntide/ntide-news-item/2020/05/21/ntide-may-2020-special-report-workers-with-disabilities-in-the-covid-economy)
* Transition to virtual education in K-12 and higher education:
* Schools are suspended and classrooms are converted to virtual learning environments with high likelihood of extending into the Fall of 2020.
	+ Emerging guidance on reopening points to distinct reality that students with disabilities will not return to in-person education at same rates as typically developing peers
		- <https://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2020/200515-reopening-schools.pdf>
	+ The discrepancy in the delivery of a free and appropriate public education is pronounced between what is available to typically developing children versus those requiring special education. This is starting to be documented in formal complaints.
		- Fairfax, Virginia:<https://www.washingtonpost.com/local/education/virginia-investigates-complaints-that-fairfaxs-online-learning-fails-disabled-students/2020/05/18/377f7fd2-992b-11ea-a282-386f56d579e6_story.html?fbclid=IwAR0T3dPZkTGjHwpmVaLU-lQA1Q51LK1SvVY687HRvr4K9ggPKwwnFfX7S28>
* Reductions to transportation infrastructure:
	+ Reduced public transportation, rider services, and paratransit (door-to-door) service. [CDC guidance](https://www.cdc.gov/coronavirus/2019-ncov/community/transportation/index.html) on these services indicates continued risk and lack of safe access for people with disabilities
	+ Many people with disabilities rely on public transportation systems, which in many places now offer limited service and represent an exposure risk

What does post-Covid-19 look like regarding issues specific to the disability community?  (e.g. employment, travel, technology, work from home, medical care, accessibility, policy, research, etc.)

The timeframe of “post-COVID-19” will look dramatically different for the disability community. As states and localities begin to reopen, many people with disabilities are among those for whom healthcare guidance states that continued sheltering in place is needed. The expectation is that will remain true until a vaccine has been developed and widely deployed. This marked new segregation is a result of complex sets of factors facing people with disabilities for the duration of the pandemic.

Access to employment will vary based on the ability for essential job tasks to be completed remotely and on the effective implementation of accommodations in the workplace. The ability to return to work will also vary widely by job sector. People with disabilities are overrepresented in the service industry employee population, which has been hardest hit by the pandemic. Of note, lack of OSHA guidance on workforce safety standards creates challenges to navigating the workplace safely as states reopen.

The system of supports to facilitate employment: state vocational rehabilitation agencies, community-based employment programs, and independent living services, are adapting to the situation. They are assisting clients with acute needs for technology, personal protective equipment (PPE), and food and shelter, as well as addressing the escalating need for employment services. Their needs for support and access to resources to adapt and transition is a growing concern. Capacity and resource constraints are very real.

The safety of and contraction of available transportation services is an additional factor that will impact employment disproportionately for people with disabilities, particularly those whose disability prevents them from driving, as both public and private transportation options are significantly diminished due to the virus.

Technology is now a priority for all areas of life: employment, interviews and training, education, telehealth and telerehabilitation. This creates ongoing challenges for both service providers and their clients, many with immediate needs for computer hardware and software and home internet access. Meeting the needs for accessible remote access to work and services may increase the likelihood of returning to full lives for people with disabilities, critically allowing access to health care, and offsetting the negative effects of social isolation.

What are some promising solutions or continued needs you’ve identified as a result of the above?

AUCD and the entire disability community and system has pivoted to respond to the crisis -- seeking to build upon research and experience to innovate in every way possible to meet the needs, save lives and ensure the human and civil rights of people with disabilities to ensure that our communities continue to benefit from all.

Between March 6th and April 24th, four COVID-19 Emergency Supplemental Funding Packages have become law. This massive policy change and federal investment responds to both the public health and economic emergency we are now facing.

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| [Coronavirus Preparedness and Response Supplemental Appropriations Act](https://www.congress.gov/bill/116th-congress/house-bill/6074) | Rebalanced funds that were moved from programs like NIDILRR and emergency heat funding when the crisis began.  |
| [Families First Coronavirus Response Act](https://www.congress.gov/bill/116th-congress/house-bill/6201) | Enhanced Unemployment Insurance to people unable to work -- including some access for caregivers of individuals with IDD. Increased funding for food security programs. |
| [Coronavirus Aid, Relief, and Economic Security Act (or CARES Act)](https://www.congress.gov/bill/116th-congress/house-bill/6074) | * Medicaid funding for direct support professionals to assist disabled individuals in the hospital
* Inclusion of those receiving SSI/SSDI in $1,200 stimulus payments
* $85 million for Centers for Independent Living
* $50 million for Aging and Disability Resource Centers
* Extension of Money Follows the Person and Spousal Impoverishment through November 30, 2020
 |
| [Paycheck Protection Program and Heath Care Enhancement Act](https://www.congress.gov/bill/116th-congress/house-bill/266?q=%7B%22search%22%3A%5B%22%5Cu2022%5CtH.R.+266%22%5D%7D&s=1&r=2) | $75 billion to help hospitals treat COVID-19 patients and address drops in revenue |

While [small provisions](https://www.aucd.org/docs/urc/COVIDFAQ2.0.pdf) were included to meet some of the pressing needs of individuals with IDD, the trillions of dollars invested to date do not meet or in many cases even address the needs of people with disabilities or the systems and workforce supporting them. An immediate need remains for Congress to expand Home and Community-Based Services (HCBS) to help keep people with I/DD in their homes and communities – and out of institutions and other dangerous congregate settings, where people are dying in greater numbers due to exposure to the virus. By investing in HCBS, we can also pay the workforce that supports people with I/DD to live as independently as possible in communities and support this workforce with training and access to adequate personal protective equipment.

The developmental disabilities (DD) system designated under the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), known as the University Centers for Excellence in Developmental Disabilities (UCEDDs), the State Councils on Developmental Disabilities (DDCs), and the Protection and Advocacy agencies (P&As) nationally and in every state and territory has pivoted to meet crisis-related needs and are continuing the critical work to meet the needs of people with disabilities in all parts of life – health, education, employment, and community living. While the Coronavirus Aid, Relief, and Economic Security (CARES) Act provided $955 million for the Administration for Community Living (ACL), none of the funding was directed to people with intellectual and developmental disabilities. A targeted investment in the DD system is needed to address the complex and pressing needs of the crisis and to ensure an adequate system remains in place for recovery.