

PUSHING POLICY LEVERS:

**Examining the
Critical Role of
State Developmental
Disability Councils
During the COVID-19
Pandemic**



NACDD

National Association of Councils
on Developmental Disabilities

I. Defining the Problem

The COVID-19 pandemic has altered the lives of Americans with intellectual and developmental disabilities (I/DD) on many levels. In every state and territory developmental disability systems including federal agencies, state developmental disability agencies, and an array of non-profit disability membership and advocacy organizations; have pivoted to meet crisis-related needs of people with disabilities in all parts of their lives. Within these systems, state developmental disability councils (DD Councils) are critical to providing innovative solutions that will address emergency threats to health, education, employment, and community living for people with I/DD.

The World Health Organization (WHO), the Centers for Disease Control and Prevention (CDC), and a growing number of published studies have identified the increased risk of contracting COVID-19 for people with disabilities. Despite the lack of national data collection on rates of infection and death, current reporting shows that people with disabilities are experiencing a disproportional impact from the virus. Early in the pandemic, the WHO issued a technical paper acknowledging that people with disabilities were among certain populations that “may be impacted more significantly by COVID-19.”¹ Similarly, the CDC stated that while “disability alone may not be related to higher risk for contracting COVID-19,” people with disabilities might be at greater risk if they 1) have limited mobility or who cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members; 2) have trouble understanding information or practicing preventive measures, such as hand washing and social distancing; and 3) have trouble to communicating the symptoms of illness.² In November 2020, a review of private health insurance claims data found that **individuals with developmental disorders who contracted COVID-19 were three times more likely to die** compared to others, putting them at higher risk than people with any of the 15 comorbidity conditions in the study including heart failure, chronic kidney disease, liver disease and various types of cancer.³ By December 2020, the Annals of Internal Medicine, reported that people with Down Syndrome and COVID-19 face tenfold risk of dying from the virus than people without the disorder.⁴ CDC subsequently added Down Syndrome as a condition placing people at higher risk of illness.⁵

People with I/DD often rely on a complex network of services and supports to remain in their homes and communities. These systems crumbled during state lockdowns and remain compromised today. People are rightfully being asked to limit their time outside the home, but these limitations make serving people with I/DD more difficult for direct support professionals (DSPs), particularly when necessary personal protective equipment (PPE) is in short supply. The State Councils on Developmental Disabilities funded through the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) have been assessing the impact of the COVID-19 pandemic on people of all ages who have disabilities, as well as their family members. The common challenges outlined below indicate what people with disabilities and their families are navigating during this difficult time.



¹“Disability Considerations during the COVID-19 Outbreak.” World Health Organization, World Health Organization, Mar. 2020, www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1. WHO REFERENCE NUMBER: WHO/2019- nCoV/Disability/2020.1

² “People with Disabilities.” Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 2020, www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html.

³ See Diamant, Michelle. “Mounting Evidence Points To Serious COVID-19 Risk For Those With IDD.” Disability Scoop, 11 Dec. 2020, at www.disabilityscoop.com/2020/11/16/mounting-evidence-points-to-serious-covid-19-risk-for-those-with-idd/29084/ citing Makary, Marty. “Risk Factors for COVID-19 Mortality among Privately Insured Patients.” White Paper, FAIR Health, 11 Nov. 2020,

⁴ Heasley, Shaun. “People With Down Syndrome 10 Times More Likely To Die From COVID-19.” Disability Scoop, 2 Dec. 2020, www.disabilityscoop.com/2020/10/28/people-with-down-syndrome-10-times-more-likely-to-die-from-covid-19/29055/.

⁵ “Certain Medical Conditions and Risk for Severe COVID-19 Illness.” Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html.

Plain Language Communication

When the coronavirus pandemic began, few people outside of health circles knew terms that we now hear daily. PPE, “flattening the curve,” lockdowns, and community spread are just a few examples of the jargon people became familiar with as they began coping with the effects of virus spread. Understanding the origin of COVID-19, assessing the impact of the virus on the general public, learning how to practice the recommended preventive health measures, and absorbing all this new information was taxing for everyone – particularly for those with I/DD.



Imagine how overwhelming and confusing the early days of the pandemic were for people with I/DD, many of whom have trouble understanding and expressing language. People with certain disabilities, such as autism, were at greater risk for extreme anxiety and “melt-down” when they experienced abrupt changes to their routine and had to learn unfamiliar procedures to prevent virus spread.⁶ Important people in their daily lives – including family members, friends, and paid support professionals – stopped showing up, and people with I/DD were prevented from seeing others.⁷ Suddenly everyone around them became very anxious and preoccupied with cleanliness and mask-wearing, and many people were not communicating what was happening in “plain language” that people with I/DD could understand.

People with disabilities, their families, and their caregivers need information that is accessible and clearly written.⁸ Successful plain language communication should use a visually engaging format that is easy to understand, especially important if the reader has trouble understanding written words. Plain language information can be helpful for multiple audiences, including family members and DSPs so that they can convey important information to people with I/DD. Communicating critical information during an emergency in accessible, plain language is essential, so people with I/DD and their caregivers understand how to proceed safely. Developing this kind of communication is an intentional process that involves trained writers and reviewers.

Digital Divide

In March 2020, almost overnight, the United States switched from working and socializing in person to digital interaction and stay at home orders across many states. The magnitude of the shift was stunning and profound. Few people would have thought it possible to make such a quick shift before it happened. This sea-change was surprisingly effective for people who had the technology, internet bandwidth, and knowledge to benefit from it. For others, it created a profound inequality that exacerbated existing social, economic, and health disparities.



Across the nation, many people with I/DD are experiencing the serious consequences of being disconnected from community. Even after the lockdowns many adult day programs and other community activities remain closed for in-person interaction. The result is people with I/DD are left in their homes those with family or friends are lacking these social interaction or caregiver supports, and some others are alone. According to the National Council on Disability, people with disabilities live in poverty at more than twice the rate of people without disabilities.⁹ As a result, they may not have computers, tablets, smartphones, or access to the internet. Many of the libraries, coffee shops, and offices where they used to access technology and data streaming remain closed, or if open inaccessible to them. Examples of what people without technology and internet access miss on a daily basis include: updates about COVID-19 and current recommendations to stay safe; opportunities to stay in touch with friends and loved ones virtually; and access to digital education, telehealth visits, mental health resources, virtual exercise opportunities, live-streamed religious services, connections to community events and local government communications, and entertainment.

PPE

People with I/DD are more likely to have underlying health conditions that make them more susceptible to many diseases, including COVID-19. Given their complex needs, they are at high risk for ending up in nursing homes, state institutions, and other congregate settings if they have any illness or injury. Keeping people with I/DD from contracting illnesses in general, and COVID-19 in particular, is critical not only for the person with I/DD, but also for the community that may need those hospital beds to accommodate a spike of COVID-19 cases.



⁶ See Eshraghi, Adrien A.; Li, Crystal; Alessandri, Michael; Messinger, Daniel S., et al. “COVID-19: Overcoming the Challenges Faced by Individuals with Autism and Their Families.” The Lancet. Psychiatry, U.S. National Library of Medicine, June 2020, pubmed.ncbi.nlm.nih.gov/32445682/. (“A common feature of children on the autism spectrum is obsession with routine, and disruptions in routine linked to COVID-19 might elicit major emotional and behavioural upheaval.”)

⁷ Ibid.

⁸ See Pulrang, Andrew. “Plain Language Writing - An Essential Part Of Accessibility.” Forbes, Forbes Magazine, 23 Oct. 2020, www.forbes.com/sites/andrewpulrang/2020/10/22/plain-language-writing---an-essential-part-of-accessibility/?sh=423abe217935. (“

⁹ “Highlighting Disability / Poverty Connection, NCD Urges Congress to Alter Federal Policies That Disadvantage People with Disabilities.” NCD.gov, 13 Nov. 2017, ncd.gov/newsroom/2017/disability-poverty-connection-2017-progress-report-release.

DSPs are the unsung heroes who allow people with I/DD to live in the community, rather than congregate care settings, by providing care in the home. DSPs assist with daily living, including personal care, feeding, cooking, and cleaning. They help keep individuals safe from hazards; administer medication; accompany individuals to and from appointments and activities; and help individuals volunteer, work, or visit with friends in the community. Without DSPs, or natural supports (family members and friends) who serve in this role, many people with I/DD would be unable to live independently.

DSPs and natural supports often provide assistance that simply cannot be conducted from six feet away. Many DSPs work for more than one client in the community. Without adequate PPE, neither DSPs nor their clients are safe from COVID-19. In the early days of the pandemic, PPE was scarce and expensive in the private market, and state PPE supply chains for “essential workers” did not include DSPs. This made it more challenging for DSPs to provide supports as people with I/DD and DSPs were afraid of contracting the virus from each other without adequate PPE. In addition, if DSPs became sick, agencies had a hard time finding replacements, and people with I/DD were left on their own without these critical services.

While some states eventually added DSPs as essential workers, the lack of high-quality PPE available for DSPs remains a concern. In addition, many DSPs report that their agencies supply them with only one set of PPE per client, which is inadequate given the duration of the emergency and the danger of contracting the virus. 84% percent of DSPs said their employer provided gloves, 54% received homemade face masks, 48% received medical grade face masks or face shields, 10% received home repair style face masks. 16% percent said other personal protective equipment was provided by their employer. Many DSPs commented that they received a mask but only a limited supply (sometimes one) that was intended to last for weeks or longer.¹⁰

Medicaid: Home and Community Based Services

Medicaid beneficiaries can receive covered services in their own home or community, rather than institutions, through Home and Community-Based Services (HCBS). Most HCBS services are authorized to be performed only in person, through highly regulated providers, and at a specific rate. In March, these typical restrictions on the types of services covered, as well as the delivery methods of the services, suddenly became incompatible with the dramatic shift in the nation’s circumstances.



When the country began performing daily activities mostly virtually, the 56 State Councils on

Developmental Disabilities (DD Councils) in every state and territory worked with their state Medicaid agency to address some the following issues to ensure continued access to HCBS (not every issue was addressed in every state):

- **Covering telehealth visits**
- **Covering virtual or digital services (those that have the same functional equivalency of face-to-face services)**
- **Covering some technology costs (including equipment and internet access)**
- **Providing hazard pay for DSPs and extending overtime allowances**
- **Allowing DSPs to continue practicing for a period of time after their licenses expired**
- **Changing the training process for DSPs to allow more digital or online training**
- **Paying family members who are providing covered DSP services**
- **Using electronic signatures to expedite administrative functions**
- **Allowing certain administrative functions to be conducted remotely**

As DD Councils became aware of issues related to plain language communication, the digital divide, PPE, and HCBS access, they stepped in to learn more about how to assess and meet the needs of individuals with I/DD and their families.



¹⁰ Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., & Kleist, B. (2020). The Direct Support Workforce and COVID-19 National Survey Report 2020. Minneapolis: Institute on Community Integration, University of Minnesota.

II. Stepping In

As news of the COVID-19 pandemic grew and states began implementing containment measures, the National Association of Councils on Developmental Disabilities¹¹ (NACDD) and the 56 DD Councils responded quickly. NACDD works to ensure that people with I/DD and their families have access to the critical information they need to stay safe and healthy, that health care and community service systems treat them fairly and equally, and that resources and supports are available.

In March 2020, NACDD met with the CDC's National Center on Birth Defects and Developmental Disabilities to begin developing plain language information about the COVID-19.

NACDD set up a weekly online video call, open to all DD Council members and stakeholders, which has remained in place throughout the pandemic. The calls cover a wide range of topics, including policy updates within Congress and the Administration; information sharing that might be helpful for state-level decision makers; guidance for DD Councils about how to use flexibilities under the rules of the DD Act to address COVID-19; and other useful resources developed by DD Councils or other sources including information created specifically for self-advocates, or self-care resources for Council executive directors.

In order to gather information to better understand the impact of the pandemic and the needs people were experiencing, as well as determine solutions, DD Councils:

- **Conducted statewide online surveys in different languages**
- **Conducted virtual town halls/listening sessions**
- **Collaborated and shared information with state agencies and other organizations**
- **Collected stories from people with I/DD and their families**



The information NACDD gathered from this outreach helped determine the four categories of greatest need explored in this report: plain language communication, digital divide, PPE, and HCBS.

Once DD Councils understood the needs people with I/DD and their families were experiencing, they examined the policy levers available to them to effect change. Some examples of these policy levers include:

- **State executive orders:** DD Councils in certain states prioritized communicating with governors' offices about the essential services DSPs provide people with I/DD. Given the hands-on nature of the work and the required proximity between the DSP and the person with disabilities, many DD Councils were able to influence governors to sign executive orders establishing DSPs as essential workers, which would put them in a priority category to receive PPE for their critical work.
- **Offices for civil rights:** DD Councils worked with both state and federal offices for civil rights to address issues such as hospitals excluding family members from accompanying a person with disabilities. While limiting non-patients in the hospital setting was reasonable given COVID-19, preventing people with I/DD from having a caregiver with them during an experience as confusing and scary as being in the hospital was unacceptable. DD Councils successfully worked with offices for civil rights in multiple jurisdictions to get permission for one person to accompany an individual with I/DD during a hospital stay.
- **Medicaid Appendix K waivers:** Medicaid has numerous waivers that allow for certain exceptions to Medicaid requirements. One category of waivers is known as the 1915 (c) Waiver Appendix K waivers (Appendix K waivers) that are implemented during emergency situations (such as hurricanes, earthquakes, floods, public health emergencies, etc.).¹² These emergencies are time-limited and allow for flexibility within Medicaid requirements to get people the care they need when the ordinary requirements are difficult or impossible to meet. NACDD established a task force on waivers where participants shared information about how to initiate waivers in states. Appendix K waivers have been a very useful tool for assisting people with I/DD during the pandemic. NACDD successfully advocated that the Centers for Medicare & Medicaid Services (CMS) should extend these waivers past the original termination dates to better reflect the continuing need for these emergency Medicaid services because of the unexpected longevity of the pandemic. In late December, days before K waivers were set to expire, CMS issued guidance extending the termination of Appendix K submissions in response to the coronavirus pandemic to no later than six months after the expiration of the public health emergency.

¹¹ For more information about NACDD, please see Appendix A.

¹² "Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers." Medicaid, www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html.

With no time to waste at the beginning of the pandemic, DD Councils leveraged partnerships, staff and member expertise, and fiscal resources to implement a wide array of activities and strategies to help their constituents. This included conducting outreach, disseminating information, sharing resources to help communities respond (including information about COVID safety, economic resources, health care options, emergency preparedness, voting options, and assistance with education and workforce issues, among others), advocating for new policies, and conducting demonstration projects to build capacity and inform systems change.

NACDD has been in communication with all 56 DD Councils constantly and is sharing the Councils' best ideas and greatest successes across the DD Council network. This includes plain language resources of all types, information on telehealth, videos that explain complex concepts in simplified terms to people with I/DD, resources to share with federal and state decision makers, and much more.

III. Drilling Down

DD Councils made a tremendous impact in these four areas—plain language communication, digital divide, PPE, and HCBS—that profoundly affect people with I/DD and their families. Examples of this impact follow.

Plain Language Communication

Many DD Councils dedicated themselves to creating and quickly disseminating updated information about COVID-19 in easy-to-read, plain language, some of which is available in multiple languages, to help individuals and families as they navigate the pandemic.



Green Mountain Self-Advocates and the New York Council

Green Mountain Self-Advocates (GMSA) is a nonprofit organization, run by people with I/DD and their allies in Vermont. GMSA educates peers to take control over their own lives, make decisions, solve problems, and speak for themselves. GMSA values plain language communication for people with I/DD and their families, and they have developed standards for other organizations to follow when developing plain language resources to communicate important information.

GMSA put together a series of COVID-19 documents in plain language to help communicate critical information to people with I/DD and their families.¹³ The contents include:

Part 1: Basic COVID-19 Information by and for People With Disabilities

Part 2: Tips for Working with Support Staff During COVID-19

Part 3: Sample Advocacy Letter About Patients with Intellectual Disabilities Having a Support Person with them when in the Hospital

Part 4: COVID-19 Medical Information Form for People with Disabilities

Part 5: How People On SSI And SSDI Get a Stimulus Check

Part 6: Getting Unemployment Benefits During the Coronavirus Emergency

Part 7: Developmental Services During the Coronavirus Outbreak

Part 8: Coronavirus Plain Language Glossary or Words to Know

Part 9: Know Your Rights: Bringing a Supporter to a Hospital or Doctor's Office



Many DD Councils adopted the GMSA plain language tools for their own constituents. The NY Council went further and worked with GMSA and translators to translate some of the GMSA COVID-19 resources into languages commonly spoken in New York – including Spanish, Chinese, Russian, Haitian Creole, Bengali, Korean, and Yiddish. The NY Council then shared those multi-lingual resources with the entire DD Council network. Community groups of populations speaking these languages were very grateful for the plain language resources in their native tongues, helping people with I/DD and their families who speak English as a second language stay informed about crucial COVID-19 information.



Wisconsin Plain Language COVID-19 Toolkit

Based on a needs assessment in Wisconsin, the Wisconsin Council created the “COVID 19 Toolkit: Stay Healthy, Stay Safe, Stay Connected” for people with disabilities, families, caregivers, and providers.¹⁴ The toolkit includes fillable forms, tips, links to information, and activities in sections that cover how to stay healthy, safe, and connected; as well as several rights documents addressing living situations, employment, and re-opening in plain language. Self-advocates reviewed the toolkit and made the language even more user-friendly. Examples of content descriptions in plain language include:

¹³ “A Self-Advocate's Guide to COVID-19: Green Mountain Self-Advocates.” A Self-Advocate's Guide to COVID-19 | Green Mountain Self-Advocates, 2020, gmsavt.org/3665-2/.

¹⁴ “COVID-19 Resource Toolkit.” Wisconsin Board for People with Developmental Disabilities, 2020, wi-bpdd.org/index.php/covid-19/.

- **Learn how to keep yourself healthy from COVID-19 and what to do if you do get sick. Go through the “My Safer at Home Plan” to be sure you have everything you need to stay healthy.**
- **Learn how to stay safe in your home and your rights. Learn how to tell someone if you are abused and neglected and to make a plan of action if you feel unsafe. Find out what other resources are out there to help you.**
- **Learn how to stay connected to your family and friends during this time. Learn about social distancing and how to be safer at home. Get ideas on activities you can do to feel better, learn something new, and keep yourself busy.**

The Wisconsin Council leveraged significant investments of time from its state managed care and provider network, which provided input and agreed to pilot the toolkit with participants. The Council disseminated the toolkit to people with I/DD through its listserv of 8,000 participants, social media posts, and weekly video chats featuring self-advocates and experts sharing components from the toolkit. They also encouraged their Department of Health Services, a large managed care organization, and multiple providers to share the toolkit with participants and post it on their websites. Additional providers and managed care organizations delivered the toolkit to over 100 participants, presenting it both one-on-one and in small groups.

The Board for People with Developmental Disabilities (BPDD) has been a critical partner in Wisconsin, collaborating with our state oversight teams for the Home and Community-Based Services (HCBS) waiver programs during the COVID-19 pandemic.

Kiva Graves, Director Bureau of Quality and Oversight Division of Medicaid Services

Digital Divide

Every DD Council discovered that people with I/DD who lacked technology equipment, internet access, or the training to use technology were experiencing much greater hardship than their peers who were connected digitally. Several DD Councils focused on this issue and made progress connecting individuals with disabilities to services, information, family, and each other.



Maine – Providing iPads to Connect

When it became clear that state stay-at-home orders would continue for an unknown length of time, members of the Maine Council were grateful to remain connected virtually, but they also realized that many people they served may not be connected at all. There were also new challenges for staff or Council members as some had experience using video conferencing software and could help their members while others did not, or did not have experience assisting or training others remotely. This reinforced that the digital divide involves not only technology hardware, but training.

The Maine Council dedicated itself to increasing the virtual engagement of Mainers with I/DD, including with social media platforms, virtual self-advocacy, virtual direct support services, virtual learning, and meaningful social engagement. The Council brainstormed with members of the University Centers for Excellence in Developmental Disabilities Education and the director of Maine CITE (the agency tasked with making assistive technology more available to Maine children, adults and seniors, funded by the Administration for Community Living (ACL) and administered through Maine Department of Education) about how to operationalize the concept.

The Council decided to distribute tablets, because tablets connect automatically with internet wi-fi, are portable, and can be easily cleaned without damage. While they recognized that this may not be the optimal solution for every user, they felt that the relative simplicity of dealing with a single type of device would enable them to move quickly. The Council chose to invest in iPads, despite their higher cost, because they are easy to use, have Apple technical support (in person and remote) to help users learn to navigate iPads, include numerous intrinsic accessibility features, and have a long lifespan. The Council was able to obtain 148 iPads through Apple at a discount, at a time when consumer electronics were in short supply.

The Maine Council worked with partners to develop a rubric to evaluate applications, as they had three applicants for each available device. Maine CITE connected the Council with Spurwink AllTech, an organization that connects individuals with disabilities to technological solutions related to learning and employment. AllTech set up the iPads (put them in their cases, charged them, loaded them with useful apps, and prepared them for user access) and shipped them. This partnership made set-up and shipping quick and efficient, and users could connect immediately upon receiving the devices.



The Maine Council received outstanding feedback about the impact of the program. User comments include:

I have more access to people, friends, staff and resources.

The self-advocate has made significant strides in using these apps to communicate and advocate. We leave the app open so she can access the images any time to make requests. Staff also assist her to Skype with her mother whenever she taps her mom's picture. This has seemed to give her more confidence that she will get what she wants when using the iPad. This iPad has given her a voice that she did not have/use with the previous communication system we had.

You can see their faces and you know who you are talking too. I like to see who I am talking to.

I am so happy that I got it. I had nothing before. I love my iPad.

I can see my family now, because they don't go out to visit with the disease.

I'm a lot more social than I used to be.

The Maine Council also learned that users with I/DD exceeded both their own and other's expectations in being able to use technology effectively. The director of a self-advocacy organization reported that several individuals, who had absolutely refused to participate in any activity that was not in-person, finally tried a virtual connection with their iPad and it went really well. The director of an adult developmental disability services organization reported telehealth services went much better than expected and were well-received by participants because of the iPads.

Kansas – Staying Connected with Smartphones

The Kansas Council decided to focus on the digital divide when a self-advocate member of the Council said connecting with others by video “kept him out of a dark place.” His mother confirmed that he got his “spark back” by connecting with others virtually. Council members knew how many other people with I/DD were missing these connections, who lacked technology, internet access, or the training to use it.

The Council's “Access to Technology” project provided 50 smartphones with 6-12 months of prepaid cellular service to Kansans with I/DD who did not have the technology or internet access required to video chat with others. A committee selected the recipients from a population of approximately 13,000 people with I/DD who needed this kind of assistance. The phones help people stay in touch with family, receive virtual and telehealth services, connect socially with peer supports, attend virtual conferences, and learn more about how to stay safe during the pandemic.

The Kansas Council chose phones over tablets because some communities do not have internet service, but most communities have cell phone service. They were able to purchase the phones at a discount and get other in-kind services so they could serve more people through the project. Two self-advocates who are members of the Kansas Council will create training videos about how to use the phone and certain apps, as well as how to be safe when using the internet.

People with I/DD were some of the first people to lose their jobs and now they are isolated. Isolation sometimes comes with abuse, neglect, and exploitation,” said Steve Gieber, the Kansas Council’s executive director. “If we don’t help our citizens stay connected with others, then people are really at risk of bad things happening.

Lessons Learned to Increase Connections

NACDD heard from self-advocate leaders during our Self-Advocate Discussion Series, a monthly discussion with self-advocates from across the country, that people with I/DD want to see a hybrid lifestyle of online and in-person activities become part of the solution for addressing healthcare and community access needs in the future. People with I/DD want to continue to connect with friends, family, caregivers and medical professionals via technology and traditional in-person opportunities.

NACDD also heard from organizations such as People on the Go (POG), a Maryland advocacy organization for people with I/DD, that people with I/DD who were previously reluctant to attend group activities or those who could not always secure transportation to get to meetings and activities, have enjoyed being able to attend such activities online, and wish to continue to do so in the future.

Personal Protective Equipment (PPE)

At the beginning of the pandemic, most people did not even know what the term PPE meant - much less have access to adequate protective equipment like face masks and disposable gloves to ward off infection. The lack of PPE was concerning worldwide, but it was devastating for people with I/DD and their families who rely on DSPs to enter their home and help with activities of daily living, manage health care needs like medication, or support people with I/DD in community activities (virtually or in person). DD Councils focused on prioritizing PPE for people with complex disabilities and those who care for them.



Massachusetts – Partnering to Distribute PPE

The Massachusetts Council was already concerned about protecting medically fragile children with disabilities from the coronavirus when Council members learned about a teenager with cerebral palsy and respiratory issues who needed help. This young woman requires round-the-clock care from DSPs to survive, and both the woman's family and her caregivers were scared about COVID-19 transmission without appropriate PPE. Her mother put in perspective that any infection is serious for her daughter when she said, "When kids with complex needs have even a respiratory infection, they need an ICU bed and a ventilator. How do we avoid filling up the ICU units and taking beds away from patients seeking COVID treatment? How do we get basic supplies and PPE to remain safe at home, and not clog the healthcare system?" For a period of time in March 2020, the young woman's mother tried to provide all her care without help from DSPs, but that was unsustainable given the complexity of her needs.

The Massachusetts Council worked with a local television news station on a news story about the critical need for families of people with I/DD and DSPs to have adequate PPE. Harvard Business School students, who were members of a student group working to get face masks to health care workers and vulnerable populations, saw the story and reached out to help. The student group – the PPEople First Procurement Team – delivered significant quantities of PPE to the Massachusetts Council, which coordinated distribution of masks and gloves through Family to Family Resource Centers, DD agencies, food resource centers, and homeless shelters, as well as by directly mailing them to families. By the end of May 2020, 4,100 masks and 1,000 pairs of gloves had reached families.

One parent said, **Thank you – you've saved my daughter's life.**



California – Leveraging State and Local Relationships to Create a PPE Pipeline

The California Council recognized quickly that people with I/DD were likely to be disproportionately impacted by COVID-19 and requested that the governor make PPE (including cloth masks, paper masks, medical grade masks (N95 masks), face shields, gloves, gowns, and sanitizer) available for all workers who support people with I/DD in their homes. The governor agreed and the state relied on the Council to lead a massive effort to distribute PPE to provider agencies, as well as directly to individuals with I/DD, their families, and DSPs.

The California Council developed a plan to: 1) identify people with I/DD who were most at risk; and 2) distribute PPE through a statewide network that included over 400 community-based partner organizations in urban, rural, and tribal communities. The Council worked from their headquarters and 12 regional offices in California, distributing over 100 million pieces of state-supplied PPE through October 2020. A few examples of these partnerships include:

- **The Council's Sacramento regional office hosted a three-day, drive-through PPE distribution event. Local school districts, churches, self advocacy organizations, providers, and community non-profits advertised and supported the event to make the distribution process efficient and safe.**
- **CA Council members, staff, and their families delivered PPE to Navajo Wellness Centers in California. The CDC reports that American Indians and Alaska Natives are testing positive for COVID-19 at 3.5 times the rate of non-Hispanic whites.¹⁵**
- **The CA Council worked with Access Services of Los Angeles, the paratransit service for individuals with disabilities, to distribute thousands of pieces of PPE to their employees and riders.**



[Because of State Council on Developmental Disabilities] we were able to distribute the PPE resources to the most vulnerable in our community. Thank you.

Tribal Temporary Assistance for Needy Families Organization.

¹⁵ "CDC Data Show Disproportionate COVID-19 Impact in American Indian/Alaska Native Populations." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 19 Aug. 2020, www.cdc.gov/media/releases/2020/p0819-covid-19-impact-american-indian-alaska-native.html.

Medicaid: HCBS

In March, NACDD created the Emergency Waiver Task Force, comprised of stakeholders from DD Councils working with state DD agencies, to determine the best solutions to pandemic-related issues associated with Medicaid coverage. Before the pandemic, NACDD advocated for CMS to consider telehealth as an allowable Medicaid expense as this flexibility is important to people with I/DD and their families; NACDD called on CMS to allow telehealth waivers providing overtime and hazard pay for DSPs and to allow more flexibility for where HCBS services are performed, but CMS declined to give states flexibility to do so under Medicaid. However, given the magnitude of challenges associated with the pandemic, however, CMS was willing to be more flexible. Certain DD Councils made significant progress with their state Medicaid agencies to enact emergency Appendix K waivers with flexibility to meet the needs of people with I/DD and their families.



Arizona – Supporting Families through Medicaid Flexibility

As COVID-19 began to spread in mid-March, the Arizona Council convened a virtual town-hall listening session to learn about struggles individuals and families faced, gaps in service systems, and resources people needed. The meeting was so well received that it became a weekly discussion attended by 90-140 people each week through late summer, after which it continued more intermittently. The Arizona Council hosted this meeting with two University Centers for Excellence in Developmental Disabilities, the Arizona state disability protection and advocacy agency, the Arc of Arizona, and the Native American Disability Law Center. Participating Medicaid agency staff were able to listen to families talk about their needs directly, which made it easier for the Arizona Council to collaborate with Medicaid to quickly approve Appendix K waivers to address critical issues.

The Arizona Council identified several significant barriers to service delivery and discussed them with the state Medicaid agency, the governor's office, the department of health services, and the state division of developmental disabilities (Arizona DDD). Medicaid ultimately granted the following flexibilities for up to six months after the end of the public health emergency:

- **Arizona DDD vendors may temporarily provide physical and occupational therapy, employment, day program, and other habilitative services using telehealth methods during the COVID-19 pandemic.**
- **Arizona DDD vendors may temporarily provide in-home services to support remote learning for children with disabilities.**

Telehealth services example: A service provider in rural Arizona offered active habilitation services for severely/chronically disabled adults who did not qualify for physical therapy. These one-to-one sessions were vital to help patients develop and retain the highest-level functionality and quality of life. When the pandemic began, people with I/DD and their families were very concerned about losing recently acquired functionality, and they strongly advocated to continue these habilitation services. With the intervention of the Arizona Council, Medicaid granted telehealth habilitation services. Providers led patients through regular exercise, skill-building movements, and corrective and specialized exercise using video conference platforms. Today, the provider is serving new patients in this part of rural Arizona, and families are asking that these telehealth options be made permanent, because they expand the limited number of options available in a very rural area.



In-home education support example: Prior to the pandemic, children with disabilities received educational services in school. When schools closed, there was no support to help these school-aged children learn how to use a computer, take part in their class, and receive other critical services. The Arizona Council quickly realized that with school curriculum going virtual, parents, teachers, and students with disabilities needed help managing the technology and making sure that the curriculum could be accessed in the home. The Arizona Council was able to work with Medicaid to allow educational support and technology training for families and students with disabilities in their homes. Services took a month to get up and running, but now children and families are getting what they need. The flexibility used for this service was intended to kick in quickly and be used to ensure children with disabilities would not fall behind.



In addition, the Arizona Council was successful in getting the state to establish protocols for protecting the health of DSPs and people with I/DD, as well as addressing DSP workforce shortages through retainer payments, increasing rates, and expediting approval of substitute personnel.



Tennessee – Creating Flexibility through Appendix K Waivers

The Tennessee Council conducted a needs assessment of its constituents in March 2020. Participants indicated they were concerned about losing (or never having) health insurance; safe access to DSPs, therapists, and specialists; and respite for primary caregivers. Reports from other disability organizations, including the listening sessions hosted by the ACL, confirmed these concerns from Tennessee constituents were consistent with national trends.

Members of the Tennessee Council worked with the governor's office and leaders of key state agencies to provide the following issues through Appendix K waivers:

- Received state approval to apply for a waiver to pause non-voluntary disenrollment from Medicaid, including HCBS, during the pandemic.¹⁶ Expanded telehealth and remote support coordination and approved “homebound” services in HCBS.
- Approved measures that make it easier for providers to keep and onboard DSPs, including temporary rate increases, additional time for background checks and CPR certifications, and allowing medication administration to be supervised remotely.

The Tennessee Council also hosted a webinar for graduates of the Partners in Policymaking course about the Appendix K waivers used in Tennessee and across the nation. The language in the Appendix K waivers established by the Tennessee Council could be used as a starting point for waivers that meet the needs of people with I/DD in future emergencies.

This fund helped my daughter with access to her therapies via teleconference by using the iPad we purchased. [It] also provided educational games ... and an increase in family interactions, due to Zoom or Facetime. Tennessee Family.

[Our daughter] loves school, loves learning, and loves her teachers and friends. This quarantine has been so hard on her, because she thrives on social interaction. This iPad will allow her to continue to connect with family and friends, which will lessen her anxiety and stress level. Tennessee Family.

IV. Moving Forward

The entire world is learning important lessons related to COVID-19 about emergency and pandemic preparedness and the benefits and limitations of accessing so much of our lives in a digital environment. As we enter the second year of the public health emergency created by the pandemic, NACDD, the DD Councils, and people with I/DD and their families are taking stock of what has gone well and what has gone badly with our response. These lessons learned and best practices will help us be more prepared for pandemics or other types of emergencies in the future.

We already know a few things:

- Future emergencies will come.
- Effective emergency preparedness for with people with I/DD is complex and requires additional planning.
- People at the lower end of the economic spectrum – which disproportionately includes people with I/DD – experience more challenges in everyday life than people with more financial resources, and this disparity is exacerbated significantly during an emergency.

Here are some recommendations about how we can take the best solutions from 2020 and make continued progress towards effective emergency preparedness for people with I/DD in future emergencies.

Plain Language Communication

Communicating in plain language is always essential, but it is even more important in an emergency when health and safety are threatened. Our country was not well prepared to share detailed health precautions in plain language when the COVID-19 pandemic began. Many DD Councils learned best practices about communicating in plain language from GMSA and other plain language experts, but we need to put more resources and planning to anticipate and respond to the critical needs for people with I/DD before the next emergency happens.

¹⁶ This waiver was ultimately superseded by the Families First Act which required states to pause disenrollment in order to accept additional funding. See Solomon, Judith, et al. “Medicaid Protections in Families First Act Critical to Protecting Health Coverage.” Center on Budget and Policy Priorities, 17 Apr. 2020, www.cbpp.org/research/health/medicaid-protections-in-families-first-act-critical-to-protecting-health-coverage. (Explains how Families First Act prevents states from cutting coverage while the FMAP increase is in place and ensures that they use the extra federal dollars to keep their Medicaid programs intact.)

NACDD recommends the following:

- **Government and healthcare systems should develop a repository for accessible, plain language communications about emergency response before emergencies take place. All efforts should be coordinated with stakeholders including people with I/DD, NACDD, DD Councils, providers, plain language experts, and other advocacy groups.**
- **Government and healthcare systems should facilitate the effective dissemination of emergency communications to people with I/DD through a broad variety of mediums including flyers, videos, webinars, translation services for public emergency announcements, and more. Stakeholders including people with I/DD, NACDD, DD Councils, DSP provider networks plain language experts, and other disability groups must be consulted to determine the best delivery methods, as these can change rapidly as we have seen throughout the course of this ongoing pandemic. Emergency plain language communications must be available in the most commonly spoken languages in each state or territory to ensure that all people with I/DD and their families have a clear understanding about how to respond and access resources in an emergency.**
- **Federal and state emergency planning authorities must proactively engage stakeholders from the I/DD community in their regular course of business, including activities related to emergency planning and recovering from emergencies.**



Proactive collaboration by government, healthcare systems and stakeholders from the I/DD community will help people with I/DD and their families across the nation stay better informed when any emergency arises.

Digital Divide

In many emergencies, access to technology and digital data (internet or cellular service), as well as the training to effectively use the technology, will be critical to help people stay safe. People with disabilities live in poverty at more than twice the rate of people without disabilities and while they make up approximately 12 percent of the U.S. working-age population, they account for more than half of those living in long-term poverty.¹⁷ Living in poverty is one factor that may limit access to technology.¹⁸ A survey conducted by NACDD of the 56 DD Councils early in the pandemic placed need for the technology hardware (phones and tablets), financial assistance to pay for internet access, and training on how to use technology at the top of the list problems to solve during this pandemic. As the pandemic continues and isolation grows, these technological needs will only grow. Addressing this disparity is not only expensive, but it involves infrastructure systems that may not be in place in very rural areas.

NACDD recommends the following:

- **Medicaid managed care organizations and DSP provider organizations should evaluate how to cover technology hardware, coverage for internet access, and training for people with I/DD to ensure access to technology on a daily basis and during emergencies. Additional training to DSPs on how to use technology is important because they can help train individuals with I/DD on how to use basic technology. Using technology should result in cost efficiencies and improved access to services and supports for people with I/DD.**
- **CMS can drive state innovation by clearly stating that HCBS waiver recipients must have access to telehealth and internet access. CMS can further support innovation by instructing State Medicaid Agencies that devices to access the internet, training to access all Medicaid services provided over the internet (including telehealth), and all activities necessary to fully participate in the online “virtual” community, should be allowable costs under Medicaid. Covered services should include access to both phone and internet (Smartphone plans can provide connectivity for both) and provide a mechanism for low-income participants to support the costs of acquiring technology and devices.**
- **In addition to including these services under current Medicaid policies, policy makers at the national and levels should evaluate how to provide internet access to people with I/DD. This may be accomplished through government grant making authorities or expanding existing programs such as the federal Emergency Broadband program to identify and prioritize low-income people with I/DD for the service.**



Implementing these recommendations will enable people with I/DD to participate more fully in “virtual” community living access supports through HCBS, communicate more effectively with their health providers and other community networks, participate in telehealth visits, and stay safer and more resilient during emergencies.

¹⁷ See “National Disability Policy: A Progress Report - October 2017.” NCD.gov, 19 Mar. 2018 at page 21, [ncd.gov/progressreport/2017/national-disability-policy-progress-report-october-2017](https://www.ncd.gov/progressreport/2017/national-disability-policy-progress-report-october-2017).

¹⁸ See Anderson, Monica, and Madhumitha Kumar. “Digital Divide Persists Even as Lower-Income Americans Make Gains in Tech Adoption.” Pew Research Center, Pew Research Center, 30 May 2020, www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/.

PPE or Emergency Equipment

During this pandemic, PPE has been essential for everyone to reduce the chances of contracting COVID-19. Given the vulnerabilities of people with I/DD, leaving the house is very dangerous without PPE, and even receiving care from DSPs in their own homes requires PPE for themselves, the caregivers, and family members. Not all emergencies will require PPE in the same way this pandemic does, but each emergency may require “emergency equipment” of one sort or another.

NACDD recommends the following:

- **Policymakers must ensure that DD Councils have a seat at the table to develop state and local emergency preparedness plans that include people with disabilities for all types of emergencies, including planning for emergency equipment.**
- **Federal appropriations must include sufficient resources for DD Councils to engage in grant making for training, technical assistance, and development of tool kits for individuals with I/DD, families, and caregivers to help them prepare for potential emergencies (such as fires, floods, hurricanes, power outages, pandemics, etc.).**
- **Managed care providers and DSP provider organizations must provide adequate PPE for their DSPs. Many DSPs do not have access to the volume of gloves and masks necessary for their work, and they rely on individuals with I/DD to provide extra supplies. Medicaid should include PPEs as an allowable expense because it is medically necessary medical equipment. Managed care providers and DSP provider organizations should conduct due diligence to ensure all PPEs are effective based on the best scientific data available. CDC and government agencies should provide updated guidance for what they consider to be effective PPE for any given public health emergency.**



It is critical for government, health care systems, and DSP provider organizations to work collaboratively to protect people with I/DD, their families, and their DSPs by including them in the priority supply chain for PPE. Coordinating with DD Councils and other state and local stakeholder groups can be an effective way to identify where people with I/DD are in most need and distribution of PPE during emergencies.

Medicaid: HCBS

DD Councils and state Medicaid agencies made rapid progress in many states to implement new Medicaid service and delivery options that helped people with I/DD stay safe at home. Many of these changes significantly benefit Medicaid beneficiaries, provide effective and cost-saving digital or online service options, reduce reliance on congregate settings, and offer flexible options that Medicaid may consider making permanent after the emergency is lifted (including telehealth, virtual workspaces, remote learning, internet connection, and technology as critical service system infrastructure, etc.).

Appendix K waivers typically cover emergencies that have a shorter lifespan, such as hurricanes and tornadoes. The COVID-19 pandemic is providing an unexpected opportunity to pilot some of these changes over the course of a year or more. CMS and state Medicaid agencies are considering which elements of Appendix K waivers and other public health emergency waivers should be made permanent elements of state Medicaid plans after the emergency is lifted. A key concern is making sure participants are able to freely choose services and service delivery methods that benefit them and do not feel forced into choices that increase social isolation, reduce community integration, or negatively impact participant rights.

NACDD recommends the following:

- **CMS should ensure that states are using meaningful stakeholder input as state Medicaid agencies decide which aspects of the Appendix K Waivers to maintain. Councils often play a leadership role in stakeholder input. CMS should solicit and review input from the DD Councils in each state's Medicaid waiver renewal process, as DD Council represent the perspective of citizens of their states who use (or need) HCBS.**
- **CMS, ACL, state DD agencies and state Medicaid directors should collaborate to provide best practice and lessons learned to create greater and safer opportunities for people with I/DD as states work to rebalance services. The considerations for whether an Appendix K waiver should be maintained hinges on effective person-centered planning. NACDD created a list of K waiver HCBS services employed during the public health emergency and an analysis of their effectiveness and considerations for keeping these services after the emergency.¹⁹ NACDD will continue to work with all stakeholders to ensure that individuals with I/DD who are not using Medicaid also have access to critical technology and information required not only during an emergency, but throughout the year, in order to successfully live independently in the community.**



¹⁹ Meltzer, Donna. "To Seema Verma, Administrator, Centers for Medicaid and Medicare." 2 October 2020. <https://www.nacdd.org/nacdd-on-medicare-and-appendix-k/>

Conclusion

Eventually, the COVID-19 pandemic will no longer be a public health emergency. At that time, many people will go back to their typical pre-pandemic life including jobs, day programs, other in-person gatherings, meetings, and appointments. But we all are forever changed because of our response to the COVID-19 public health emergency.

We must correct the mistakes that made the situation more dangerous for people with I/DD, such as lack of plain language information, disruption of HCBS services, and failure to plan for PPE for people with I/DD, their families, and DSPs. At the same time, we cannot squander the opportunity to keep and build on desirable changes that have improved HCBS, access to community, telehealth, and more because of modernizing delivery of services through online technology.

People with I/DD want the same access to options and choices to participate in the digital community as people without disabilities. This is especially true during public health emergencies where access to information, HCBS and other supports, and technology can sometimes make the difference between life and death. Collectively we want to continue making more healthcare services, including mental health, accessible online for those in congregate as well as home-based settings. Having options and choices for where, when, and how to receive care will continue to evolve. We plan to work with our partners to examine and plan for post-pandemic success.

About NACDD

NACDD is the national association for the 56 Councils on Developmental Disabilities (DD Councils) across the United States and its territories. NACDD provides technical assistance to all DD Councils through a contract with the Administration on Community Living; advocates for the national public policy agenda; advocates for DD Councils' appropriations in Congress; and convenes DD Councils for leadership and development training.

The DD Councils are authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The overall purpose of the DD Act is to ensure people with developmental disabilities and their families are included in all aspects of community life. The DD Act requires that DD Council members are appointed by the state/territory's governor to advocate to elected officials and that 60% of members must have a developmental disability or be a family member to a person with developmental disability. These requirements put DD Councils in a unique position to provide critical stakeholder input to all levels of state and federal government.



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