



November 19, 2020

Neil Romano  
Chairman  
National Council on Disability  
1331 F Street, N.W.  
Suite 850  
Washington, D.C. 20004

Via email [PublicComment@ncd.gov](mailto:PublicComment@ncd.gov)

Re: Public Comment; Progress Report on COVID-19.

Dear Chairman Romano,

Thank you for the opportunity to comment as part of the National Council on Disability (NCD) quarterly business meeting on Thursday, November 19, 2020. The National Association of Councils on Developmental Disabilities (NACDD) is pleased to provide the following comment on how the COVID-19 public health emergency has impacted people with IDD and changed the way Centers for Medicare and Medicaid Services (CMS) and states have responded to public health emergencies. We hope these comments are helpful for NCD's "Report on COVID-19" that is expected next year.

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.



### Impact of COVID on people with IDD.

Evidence is growing that people with IDD are exponentially more likely to contract COVID-19 and once acquired, more likely to die as a result.<sup>2</sup> The Centers for Disease Control and Prevention (CDC) also found that although disability alone may not be related to higher risk for getting COVID-19, people might be at increased risk if they 1) have limited mobility or cannot avoid coming into close contact with others, 2) have trouble understanding information or practicing preventive measures, or 3) are not able to communicate their symptoms. See CDC. “Coronavirus Disease 2019 (COVID-19): People with Disabilities.” 11 Sept. 2020.

<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>

Throughout the pandemic, DD Councils have engaged in activities to gather information from people with intellectual and developmental disabilities (IDD) and their families to better understand the impact of the pandemic. Methods used by councils to identify how people with IDD were affected by the pandemic included:

- Statewide online surveys in different languages;
- Virtual town halls/listening sessions;
- Collaboration and information sharing with state agencies and other organizations and
- Extensive story collection.

See e.g. Texas Council for Developmental Disabilities. “Texas COVID Stories,” at <https://tcdd.texas.gov/resources/covid-19-information/texas-covid-stories/> (Stories collected 3 months and again 6 months after the declaration of emergency.)

The DD Council data confirmed that the necessary “stay at home orders” to prevent spread of COVID-19 only work for people with disabilities if they can access the support they need at home. But even then, they are at risk if they depend on paid support because they cannot abide by social distancing recommendations. For example, the direct support workforce challenges that pre-dated the pandemic, coupled with a shortage of personal protective equipment (PPE), and uncertainty over Medicaid funding as states face budget deficits have made it increasingly difficult for people with disabilities. See *attached* “State Councils on Developmental Disabilities COVID-19 Report: Council Activities, Initiatives and Impact.”

Positioned to act upon emerging issues, the DD Councils use the information gained to quickly pivot their work to address these multiple identified issues. DD Councils used multiple strategies to significantly impact the issues listed above, which include but are not limited to assistance and advocacy, collaborations across state agencies, and self-advocacy organizations.



Several COVID-19 specific issues DD Councils addressed include:

- Lack of technology, internet access and training;
- Food security (e.g. TX, SC, WI, FL, HI, CA);
- Limited direct support professionals despite increased need (e.g. GA, AZ and more);
- Shortages of PPE for direct support professionals, individuals/families (e.g. MD, VA, ID, CA, MA and others);
- Lack of timely, understandable resources in plain language and alternative formats and languages (39 states and territories) (22 of them provided in different languages);
- Discriminatory hospital visitation policies and access to urgent medical care;
- Lack of educational services for students with Individualized Education Plans (e.g. AK, CA);
- First responder education to successfully support people with DD during emergency situations (e.g. NV, MO);
- State budget deficits impact on Medicaid funding; and
- Culturally and linguistically competent support for isolated tribal communities to address homelessness, addiction and other at-risk situations, not receiving needed services and supports or information. (e.g. WI support to the Ho Chunk tribe.)

*See attached "State Councils on Developmental Disabilities COVID-19 Report: Council Activities, Initiatives and Impact."*

These are just some of the ways people with IDD and families are affected and we believe their needs will increase as this pandemic continues for an unknown duration. Additional challenges will emerge as survivors are faced with the aftermath of the pandemic, especially in the areas of youth transition, employment and education loss during this time.

Key changes states have made and benefits states have gained as result of waivers and flexibilities approved by Centers for Medicare and Medicaid Services (CMS).

**CMS acted quickly to approve emergency Medicaid waivers.** DD Councils reported that the speed which some Medicaid waivers for increased access to home and community-based services (HCBS) were granted was faster than in past emergencies. In particular, there was a positive response to "blanket" 1135 waivers, CMS templates, and approvals of K waivers, during the pandemic. These waivers were helpful in many ways to expand HCBS services to people with IDD and helped keep people safe during "stay-home" orders. DD Councils report positive experience with increases to the following services:

- a. Telehealth;



- b. Virtual services (Allowing any service that can be provided with the same functional equivalency of face-to-face services to occur remotely);
- c. Remote support technology (Including equipment and connectivity to access remote services to address digital divide.);
- d. Overtime/Hazard Pay for direct care workers;
- e. Reform of onboarding and training for direct support professionals;
- f. Family members as paid support;
- g. Using electronic signatures to expedite administrative functions; and
- h. Expediting certain administrative functions (e.g. assessments) by allowing them to be done remotely.

*See attached* Letter to Seema Verma, Administrator, Centers for Medicaid and Medicare. 2 Oct. 2020. (NACDD Recommendations on HCBS Long Term Care Waivers.) and London, Rachael. NACDD Points for Consideration – Appendix K. Undated.

Issues and concerns raised by DD Councils regarding state and federal response and emergency Medicaid waivers.

COVID-19 exposed systemic problems and gaps in HCBS that created dangerous conditions for people with IDD who risked exposure to the virus to access community services. NACDD identified several concerns with the response efforts including:

- 1. Lack of stakeholder input and failure to weigh stakeholder input on the needs of people with IDD remains a great concern.** Many DD Councils reported a serious lack of coordination between stakeholders and state and federal agencies responding to the emergency. There needs to be more stakeholder engagement broadly and states should be required to provide to CMS the full array of requests recommended by advocates. For example, in Tennessee there were many families providing care for family members with IDD who were frustrated that the state agency because they did not take seriously the request to be paid for providing care. The state legislature is considering changes to the state plan to allow for payment. However, it will be too late for COVID relief.

NACDD recommendations to CMS included ensuring that states are using meaningful stakeholder input to ensure the state has sufficiently weighed the impact these waivers have on people with lived-experience with disability. CMS could accomplish this by requiring DD Councils' input in each state's Medicaid waiver renewal process, as Councils represent the perspective of citizens of their states who use (or need) HCBS.



- 2. Potential risks as a result of the changes and waivers approved during the public health emergency.** NACDD is concerned that some providers are not following person-centered planning or compliance with the Home and Community Based Services regulations that enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities. NACDD recommends that states must require and enforce person-centered planning in HCBS waiver services, especially during public emergencies. CMS should expect that states have enhanced and modernized the mechanisms in place to identify and enforce effective person-centered planning. For example, Tennessee’s DD Council reported that the lack of oversight for hiring providers and provider quality assurance was concerning. These concerns were voiced generally by other DD Councils. *See attached* Letter to Seema Verma, Administrator, Centers for Medicaid and Medicare. (Provides several examples of concerns resulting from approved waivers.)
  
- 3. Concern that innovation and improved HCBS services will end when the public health emergency is over.** There is overwhelming concern that the HCBS field will regress and discard innovations. Within the context of the entire state landscape, here are some concerns that may have consequences for HCBS long after COVID-19. For example, CMS and states should be urged to continue all flexibilities that have shown a benefit to people with IDD by amending their Medicaid state plan.
  
- 4. Internet connectivity and access to technology are critical to Medicaid services and community living during COVID-19, however, we are concerned that many HCBS recipients are not able to access the internet.** The rise in rates of COVID-19 cases, hospitalizations and deaths bring a new urgency to making sure people with IDD are receiving quality HCBS safely in person and through the expansion of services provided remotely through the internet. Reliable fast internet connection, technological equipment to access the internet, and knowledge needed to use web-based interfaces or other applications are and will continue to be necessities, and are essential for HCBS participants to access government, public services, job opportunities, etc.

Under HCBS waivers, some technology purchases have been covered, but not routine and ongoing internet connection or smart phone plans. Many state agencies have been moving information and processes online so customers can self-serve and states can leverage efficiencies. For HCBS participants, many of whom may also be non-drivers—there can be an advantage to being able to take care of business from home. But for people who lack connectivity, online information and processes become a barrier.



Emergency waiver flexibilities like telehealth and virtual services presume the participant has sufficient access to the internet and technology. HCBS participants lose the opportunities and advantages these new methods of service delivery offer when they do not have connectivity. In many cases the traditional service delivery model has barriers of its own for HCBS participants (time, distance, transportation and mobility barriers, etc.).

Job listings assume applicants have an e-mail account and can submit online applications. As virtual work spaces become more common, many employment opportunities could open up for people with disabilities, but these depend on reliable connectivity and equipment.

The recent Electronic Visit Verification requirements are challenging for many HCBS participants, and even more so for the many people who live in areas with poor internet connections and cell phone service or whose low incomes cannot accommodate internet connections or robust cell phone plans.

CMS must move quickly to modernize delivery of services to clarify that access to the internet and devices for all HCBS waiver recipients as part of the proper and efficient operation of the state Medicaid plan. This action will insure HCBS waiver recipients are protected in the case of future “stay home” orders during public health emergencies and improve the lives of people with IDD so they can self-direct these services.

- 5. Challenges to HCBS Provider network had a negative impact and caused much anxiety among people with IDD.** DD Councils are concerned that providers of many types of HCBS services may close because of COVID, and that state budget shortfalls directly related to the COVID crisis may result in additional cuts that providers cannot weather. Provider capacity was already limited or insufficient for certain HCBS service types (community-based employment, personal care, psychology etc.) and/or for certain geographical areas. In some places there are few or even no provider choices. Councils are concerned that this existing problem—a crisis already for some services—will be exacerbated and that HCBS participants will be underserved, unserved, or family/natural supports will be expected in ways that are unsustainable and undesired by both participant and caregiver.

DD Councils are also concerned that small providers and providers of community integrated services could be at a disadvantage as states reduce Medicaid budgets. Innovative providers are essential to continue the progress towards inclusion,



integration, and equal opportunity for people with disabilities. Many states have struggled to shift congregate/facility-based models that have high fixed costs to community-based models that may cost more on the front end but are far less expensive long term. In states where facility-based models are well established, it may seem easy to pay for fewer, larger providers which results in less choice for HCBS participants wanting community-based options and more reliance on congregate settings which is counterproductive to CMS rebalancing goals.

6. **Need to improve outreach to Transition Age Youth to use services.** As a result of the pandemic and the flexibilities, DD Councils have reported a significant decrease in the number of transition age youth being able to access (find) a provider for day supports. Because assessments and other transition services can be done virtually, and because most day services are being provided in residential settings, many providers have been less inclined to take on "new" folks.
  
7. **Need for an improved Medicaid waiver modification and renewal process in state processes.** CMS negotiations with the state Medicaid agency are not synced with legislative timelines. Modifying permanent waivers to include elements of what states have implemented under emergency waivers is a long process. It is likely there will be a significant gap between when the flexibility granted under an emergency waiver expires and when the same flexibility can be implemented again as part of the permanent waiver.

Some states have a legislative review process that is required before any waiver modifications can be started. In cases where the legislature must approve the final waiver submission, the entire process may or may not move forward in the end even with CMS permission. Governors and state Medicaid agencies may also have staffing or other budgetary reasons that impact whether a waiver will be modified. Political realities impact the innovation of the HCBS service system.

These processes are so technical between CMS and State Medicaid Agencies that it makes it difficult for stakeholders to meaningfully understand and follow. CMS and SMAs should reform their approach to monitoring risk to meaningfully engage the average citizen experiencing the system and be responsive to their experiences. CMS's process should include meaningful input from stakeholders in addition to state Medicaid agencies. CMS's process should include a review of input from State DD Councils to their Medicaid Agencies. If the Medicaid agencies did not include the input in their waiver requests, CMS should facilitate further stakeholder input.





NACDD comments reflect a compilation of comments from our Medicaid Waiver Task Force Members and individual DD Councils. We strongly advise speaking with the following experts in our network to assist you with data collection from state stakeholders:

- Tami Jackson, Public Policy Analyst and Legislative Liaison  
Wisconsin Board for People with Developmental Disabilities and  
NACDD Medicaid Waivers Task Force Chair  
(608) 266-0979 (office) | (608) 228-7285 (cell)  
[Tamara.jackson@wisconsin.gov](mailto:Tamara.jackson@wisconsin.gov)
- Beth Stalvey, Executive Director  
Texas Developmental Disabilities Council  
(512) 437-5432  
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- Erica S. McFadden, PhD, MSW, Executive Director  
Arizona Developmental Disabilities Planning Council  
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- Rachel London, Esq., Executive Director  
Maryland Developmental Disabilities Council  
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- Lauren Percy, Director of Public Policy  
Tennessee Council on Developmental Disabilities  
615-741-5019  
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- Kristin Vandagriff, Executive Director  
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- Aaron Carruthers, Executive Director  
California State Developmental Disabilities Council  
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We also recommend that you speak with stakeholders who have lived-experience with Medicaid waiver implementation in their states. A good place to get expertise, survey data, and stories is with state advisory groups. For example, in Tennessee, every waiver program has





advisory groups of people who use the services. State DD Councils can put you in touch with these advisory committees upon request.

In conclusion, NACDD looks forward to NCD's upcoming report on COVID-19. Please feel free to contact Erin Prangley at [eprangley@nacdd.org](mailto:eprangley@nacdd.org) for additional information.

Sincerely,

Erin Prangley  
 Director, Policy  
 National Association of Councils on Developmental Disabilities

#### Attachments

Meltzer, Donna. Letter to Seema Verma, Administrator, Centers for Medicaid and Medicare. 2 Oct. 2020. (NACDD Recommendations on HCBS Long Term Care Waivers.)

Meltzer, Donna. Letter to Seema Verma, Administrator, Centers for Medicaid and Medicare. 20 Jul. 2020. (NACDD Recommendations for Unwinding Medicaid Emergency Waivers in the States.)

London, Rachael. NACDD Points for Consideration – Appendix K. Undated.

National Association of Councils on Developmental Disabilities. *State Councils on Developmental Disabilities COVID-19 Report: Council Activities, Initiatives and Impact*. July 2020. <https://secureservercdn.net/198.71.233.87/718.d58.myftpupload.com/wp-content/uploads/2020/09/COVID-19-Report-2020.pdf>