



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

November 20, 2020

Vivek Murthy, co-chair  
David Kessler, co-chair  
Marcella Nunez-Smith, co-chair  
Biden-Harris Transition COVID-19 Advisory Board

*Via email*

Dear Drs. Murthy, Kessler, and Nunez-Smith,

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. CCD members represent a broad range of stakeholders – people with disabilities and their families, older adults, disability service providers and workers, healthcare professionals, and state systems that provide disability services – who advocate on behalf of adults and children with all types of disabilities, including people with physical, intellectual, developmental, and mental health disabilities, chronic health conditions, and older adults. We are writing on behalf of the Long Term Services and Supports, Health, and Rights Task Forces regarding the urgent healthcare-related issues people with disabilities are facing during the COVID-19 pandemic. We have included eight specific recommendations we believe are critical for the new Administration to take to protect the lives of people with disabilities during this pandemic, for your consideration.

For the last eight months, CCD has been advocating with federal agencies and Congress, urging them to address the dire needs of people with disabilities during COVID-19. People with disabilities have been particularly impacted by the COVID-19 pandemic. Many people with disabilities have underlying health conditions that make them high-risk for experiencing complications and even death if exposed to COVID-19. For example, a study published last week based on an analysis of national healthcare claims data found that people with intellectual and developmental disabilities are almost three times as likely to die from COVID-19 as others who are infected, and that people with chronic kidney or heart disease, cancer and other co-morbidities, and older adults have a significantly elevated risk of death.<sup>1</sup> Another study found

---

<sup>1</sup> White Paper: Risk Factors for COVID19 Mortality among Privately Insured Patients, Fair Health (Nov. 11, 2020) available at

<https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20->

that people with psychiatric disabilities are nearly twice as likely as others to die from COVID-19.<sup>2</sup>

These underlying risks are exacerbated by the fact that many people with disabilities and older adults live in a range of congregate settings – including nursing facilities, Intermediate Care Facilities, psychiatric facilities, group homes, assisted living, homeless shelters, and jails and prisons – where COVID-19 easily spreads due to rotating staff and the inability to socially distance from others. While less than one percent of people live in long-term care facilities, residents of those facilities have comprised approximately forty percent of deaths to date.<sup>3</sup> The Centers for Medicare & Medicaid Services (CMS) reports over 450,000 confirmed or suspected COVID-19 cases and 65,400 deaths in nursing homes as of November 10,<sup>4</sup> representing only a fraction of the impact in congregate settings because CMS has only required testing and reporting of COVID-19 infections and deaths from nursing facilities but not other Medicaid-funded or certified congregate settings. And while CMS has also not required reporting of race, ethnicity, or other demographic data, studies have shown that nursing facilities with more residents of color reported disproportionately more weekly new COVID-19 confirmed cases and/or deaths.<sup>5</sup> Tragically, many people with disabilities and older adults whose lives are at serious risk in these large congregate settings want to and could move to smaller, safer settings in the community if services and supports were made available to them in those settings.

People with disabilities living in the community also are facing serious issues during the COVID-19 pandemic. Many people with disabilities rely on home and community-based services (HCBS) to live safely in the community. HCBS provide people with disabilities and older adults a range of services, including in-home assistance with activities of daily living like bathing and eating, employment and day program services, and residential and housing-related supports. These supports must frequently be provided up-close and in-person—for example, there is no way to bathe someone while maintaining six feet of distance. Furthermore, most HCBS participants rely on rotating staff coming in and out of their homes and travelling between the homes of multiple service recipients, increasing risk of infection. Proper personal protective equipment (PPE) is essential to the safety of HCBS recipients and workers. The additional

---

[%20A%20FAIR%20Health%20White%20Paper.pdf](#) ); see also Margaret Turk, Scott Landes, Margaret Formica, and Katherine Goss, “Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis,” *Disability and Health Journal* (July 2020), <https://www.sciencedirect.com/science/article/pii/S1936657420300674>.

<sup>2</sup> Quanqiu Wang et al, “Increased risk of COVID-19 infection and mortality in people with mental disorders: analysis from electronic health records in the United States,” *World Psychiatry* (forthcoming 2021), <https://onlinelibrary.wiley.com/doi/epdf/10.1002/wps.20806>.

<sup>3</sup> Kaiser Family Foundation, State Data and Policy Actions to Address Coronavirus, available at <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>; The Long-Term Care COVID19 tracking project, <https://covidtracking.com/data/longtermcare>.

<sup>4</sup> CMS COVID-19 Nursing Home Data, available at <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>.

<sup>5</sup> Yue Li et al., Racial and Ethnic Disparities in COVID-19 Infections and Deaths Across U.S. Nursing Homes, available at <https://pubmed.ncbi.nlm.nih.gov/32955105/>.

demands and restrictions during this pandemic have stretched thin states' already underfunded and fragile HCBS systems. Many HCBS providers have had to close down or completely restructure their services during the pandemic. Many have been unable to bear the significantly increased costs of operating during the pandemic, including paying for PPE, cleaning supplies, vehicle shields, and overtime to cover for sick and quarantining employees.<sup>6</sup> For people living in the community, this has translated to loss of critical services that help them stay safe during the pandemic, placing them at risk of entering institutional settings where COVID-19 is rampant. And for people fortunate enough to continue receiving HCBS services, the lack of PPE available to both HCBS providers and service recipients has placed their health at risk as staff come in and out of their homes.

Finally, people with disabilities and older adults have faced discrimination in accessing life-saving treatment during COVID-19. Many states have developed medical rationing plans to allocate care in the event of a shortage. Disability advocates – together with aging and racial justice advocates – have challenged state plans that deprioritize or even outright deny care to people with disabilities or older adults and that disproportionately impact people of color. As the federal government and states are developing priorities for COVID-19 vaccine allocation, disability advocates are concerned that people with disabilities are not being appropriately prioritized in allocation, particularly given the risks they face during this pandemic.

CCD commends President-elect Biden for immediately establishing this COVID-19 Advisory Board and for committing to establishing a COVID-19 Racial and Ethnic Disparities Task Force. As you work to develop policy priorities and action for the new Administration, we hope that you will consider the needs of people with disabilities. Below are specific recommendations that we believe are critical for the new Administration to take to protect the lives of people with disabilities during this pandemic:

- **Ensure people with disabilities are appropriately prioritized in COVID-19 vaccine allocation:** Given the high risks many people with disabilities face due to their underlying health conditions and/or from living in a congregate care setting, it is crucial that people with disabilities be prioritized in any vaccine allocation. In October, CCD released principles for vaccine allocation that we urge you to consider in the development of any vaccine allocation framework or distribution plan.<sup>7</sup> Among other things, we believe any equitable vaccine allocation plan must:
  - Prioritize people with disabilities and workers in all congregate settings;

---

<sup>6</sup> See, e.g., Avalere Report "Impact of COVID-19 on Organizations Serving Individuals with Intellectual and Developmental Disabilities," available at [https://www.ancor.org/sites/default/files/impact\\_of\\_covid-19\\_on\\_organizations\\_serving\\_individuals\\_with\\_idd.pdf](https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf) (68% of all organizations surveyed reported that they have had to close one or more service lines due to the pandemic resulting in an average loss of revenue of 32% and 52% of all organizations surveyed reported having increased staff overtime expenses).

<sup>7</sup> COVID-19 Vaccine Allocation Principles, Consortium for Citizens with Disabilities (Oct. 2020), available at <http://www.c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf>.

- Prioritize people with disabilities and workers in HCBS settings where the provider and service participant cannot effectively mitigate risks of transmission;
- Ensure that both the information and the means of distribution are accessible to people with disabilities; and
- Ensure that any allocation plan complies with federal civil rights laws and guidance that prohibit healthcare discrimination.

Recent federal vaccine allocation proposals have raised serious concerns for us. While heightened risk of infection and death from COVID-19 exists across all institutional and congregate settings, the National Academies’ framework, for example, does not equally prioritize all institutional and congregate settings and all populations within those settings.<sup>8</sup> The CDC’s Advisory Committee on Immunization Practices, meanwhile, has not yet released an allocation framework, but it appears from its recent meetings it may not prioritize residents in congregate settings at all, only staff within those settings.<sup>9</sup>

- **Expand requirements for mandatory COVID-19 reporting and testing to all Medicaid funded or certified congregate settings:** As discussed above, people with disabilities and older adults in ALL institutional and congregate settings face a significantly increased risk of COVID-19 infection and death. Since this spring, CMS has announced several initiatives and regulations focused exclusively on safety in nursing homes. In May, CMS issued Interim Final Regulations<sup>10</sup> requiring nursing facilities to report COVID-19 infections and deaths and notify residents and their families or representatives. CCD submitted comments urging CMS to expand these requirements to all Medicaid-funded or certified institutional and congregate settings.<sup>11</sup> CMS recently issued Interim Final Regulations<sup>12</sup> requiring testing of staff and residents in nursing facilities. Despite the preamble specifically mentioning that

---

<sup>8</sup> Comment Letter on Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine, Consortium for Citizens with Disabilities (Sept. 4, 2020), available at <http://c-c-d.org/fichiers/CCD-Vaccine-Allocation-Comments-9-4-20.pdf>.

<sup>9</sup> Materials from recent ACIP meetings are available here: <https://www.cdc.gov/vaccines/acip/meetings/index.html>.

<sup>10</sup> “Medicare and Medicaid Programs, Basic Health Program, and Exchanges; Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency and Delay of Certain Reporting Requirements for the Skilled Nursing Facility Quality Reporting Program” (May 8, 2020), available at <https://www.federalregister.gov/documents/2020/05/08/2020-09608/medicare-and-medicaid-programs-basic-health-program-and-exchanges-additional-policy-and-regulatory>.

<sup>11</sup> See July 7, 2020 Comment from CCD to Secretary Azar, available at <http://www.c-c-d.org/fichiers/Nursing-Home-Reg-Comments-final-7-7-20.pdf>. We also encouraged CMS to require such data be reported by race, ethnicity, primary language, disability status, age, sex, sexual orientation and gender identity, as discussed in more detail below.

<sup>12</sup> “Medicare and Medicaid Programs, Clinical Laboratory Improvement Amendments (CLIA), and Patient Protection and Affordable Care Act; Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency,” published Sept. 2, 2020 at <https://www.federalregister.gov/documents/2020/09/02/2020-19150/medicare-and-medicaid-programs-clinical-laboratory-improvement-amendments-clia-and-patient>.

people in all types of long term care facilities are high risk,<sup>13</sup> the regulation only applies to nursing facilities. Again, CCD submitted comments urging CMS to expand this requirement to all Medicaid-funded or certified settings.<sup>14</sup> In October, Senators Murray, Hassan, and Warren sent a letter to CMS raising similar concerns and asking, among other things, for these regulations to be expanded to all congregate care settings.<sup>15</sup> Finally, CCD members have been urging CMS to issue guidance about visitation in congregate care settings, including the circumstances under which in-person support may be required under civil rights laws. In September, CMS issued guidance about visitation in nursing homes,<sup>16</sup> again failing to provide guidance to residents of similarly-situated institutional and congregate settings. We encourage CMS to expand this guidance, with some improvements, to all institutional and congregate settings.<sup>17</sup>

- **Ensure all service providers and participants have access to PPE:** Having access to PPE is critical in the fight against COVID-19. Yet eight months into the pandemic, people with disabilities and their service providers still do not have consistent and reliable access to PPE. We recommend that CMS develop a nationwide strategy, in collaboration with states, to ensure that all Medicaid and Medicare providers and participants have access to PPE. It is critical that any PPE initiative not only focus on institutional settings like nursing homes, but also include HCBS participants and the providers who come into close contact with them while providing services. We also urge your Advisory Board to consider all action to address this urgent issue, including recommending invoking the Defense Production Act.
- **Develop a national strategy to facilitate transition of people with disabilities and older adults out of institutional and large congregate facilities into community settings:** More than forty percent of COVID-related deaths in the United States have been people in institutional settings,<sup>18</sup> with even more deaths in other types of congregate facilities. Yet

---

<sup>13</sup> See 85 Fed. Reg. 54820, 54851 (noting that high risk populations identified by the CDC include “[r]esidents of LTC facilities, including nursing homes, Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICF/IIDs), inpatient psychiatric and substance abuse treatment facilities including institutions for mental disorders (IMD) and Psychiatric Residential Treatment Facilities (PRTF), assisted living facilities, group homes for individuals with developmental disabilities and board-and-care facilities).

<sup>14</sup> See Nov. 2, 2020 Comment from CCD to Administrator Verma, available at <http://www.c-c-d.org/fichiers/CCD-LTSS-Testing-IFR-comments-11-2-20-submitted.pdf>; see also April 27, 2020 letter from CCD to Secretary Azar, available at <http://www.c-c-d.org/fichiers/COVID-disability-data-collection-letter-2020-4-27.pdf>.

<sup>15</sup> Oct. 14, 2020 Letter from Senators Murray, Hassan and Warren to Administrator Verma, available at <https://www.help.senate.gov/imo/media/doc/Congregate%20Care%20Letter%20HELP%20October%2014%202020.pdf>.

<sup>16</sup> CMS “Nursing Home Visitation – COVID-19” (Sept. 17, 2020), available at <https://www.cms.gov/files/document/qso-20-39-nh.pdf>.

<sup>17</sup> Sept. 30, 2020 Letter to Centers for Medicare & Medicaid Services, available at <https://www.centerforpublicrep.org/wp-content/uploads/Letter-to-CMS-ACL-OCR-re-visitation-guidance-9.30.20-final.pdf>.

<sup>18</sup> See *supra* n. 3.

transitions out of institutional and other congregate care facilities have not been accelerated but instead have largely ground to a halt due to the challenges faced by community services systems. It is urgent, particularly as new surges of COVID-19 continue, that the federal government develop and implement a national strategy to facilitate the transition of people with disabilities and older adults out of, and diversion of their admission to, congregate care facilities in order to enable individuals to avoid the risks of transmission in these facilities, as well as to reduce facilities' census sufficiently to allow physical distancing. Such a strategy requires thoughtful planning and resources to help community providers meet individuals' needs safely in the community and to ensure that these providers can safely enter congregate facilities where necessary to assist individuals in considering, planning, and effectuating transition. While efforts to reduce the census in jails and prisons in response to COVID-19 outbreaks have also been insufficient and have left far too many people at risk, the decarceration efforts that have dramatically reduced the census in some jails and prisons demonstrate that similar efforts can and should be undertaken in congregate care facilities.

- **Provide further guidance and increased enforcement regarding non-discrimination requirements in access to COVID-19 treatment:** As the pandemic began emerging in the United States, states began developing or updating existing “crisis standards of care” for rationing medical care in the event of a shortage. Many of these plans explicitly exclude or deprioritize people with disabilities and older adults from life-saving treatment and use criteria that disproportionately harm Black, Indigenous, and people of color (BIPOC). Members of CCD have filed legal complaints with HHS’ Office for Civil Rights alleging these plans violate federal civil rights laws.<sup>19</sup> CCD, along with the National Council on Disability and members of Congress, urged OCR to issue guidance.<sup>20</sup> We are grateful for the work that OCR has done to date – issuing a March 28, 2020 bulletin<sup>21</sup> that makes clear that disability rights laws apply during this public health emergency and working with several states to revise their crisis standards of care to comply with federal civil rights laws.<sup>22</sup> But there is an urgent need for more to be done. We encourage you to consider having OCR issue additional guidance or emergency regulations providing more detail to covered entities about their legal obligations, to promptly resolve pending and new complaints, and to continue to prioritize enforcement of the law regarding illegal medical rationing plans.

---

<sup>19</sup> Disability advocates have filed approximately a dozen complaints with HHS OCR about discriminatory crisis standards of care. See <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.

<sup>20</sup> March 20, 2020 Letter from CCD to OCR, available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>.

<sup>21</sup> Office of Civil Rights “Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19),” (March 28, 2020), available at [https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt\\_0asYiXi91XW4rnAKW8kxcog](https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog).

<sup>22</sup> See OCR announcements of resolutions of complaints in Utah, Tennessee, Pennsylvania and Alabama regarding their crisis standards of care, available at <https://www.hhs.gov/civil-rights/newsroom/index.html>.

- **Require robust data collection about COVID-19:** Data collection is crucial to the development of any plan to address COVID-19. COVID-19 has highlighted the long-standing systemic inequities in our healthcare system not just for people with disabilities but also for BIPOC who have been hospitalized at higher rates due to COVID-19.<sup>23</sup> To ensure that the COVID-19 response is addressing the needs of all people, we urge the Administration to require the collection of data with stratification of reporting by key demographic groups, including disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, residential setting, and treatment setting. This will help identify disparities in access to and quality of care, which is desperately needed to improve the response to this pandemic.
- **Provide additional funding to HCBS providers through the provider relief fund:** Congress created the Provider Relief Fund in the CARES Act. However, the rollout of funds to Medicaid and CHIP providers has been problematic, with inconsistent and inadequate communication from HHS. Many Medicaid HCBS disability and aging providers were left out or prevented from accessing the full amount of funding they are due because of lack of information and flexibility from HHS. While some of those issues were eventually resolved, others still remain. Moreover, the provider relief funds disbursed so far are not nearly enough to sustain HCBS providers, many of whom have had to close their doors. Without provider capacity in the community to provide HCBS to people with disabilities and aging adults, the Medicaid HCBS system will falter. We recommend that the incoming Administration restructure the approach to make sure that provider relief funds reach the providers who need them most, especially in the HCBS network. The Administration should engage with HCBS providers to better understand and address the barriers to their participation and should make use of the already existing fiscal relationships between Medicaid providers and states to ensure a more smooth distribution of funds.
- **Work with Congress to pass a COVID-19 relief package:** CCD has been urging Congress to pass a desperately needed fourth COVID-19 relief package since the spring. We were pleased that the HEROES Act, passed by the House in May and then again in October, included many of the most important priorities of the disability community, including dedicated funding for states' Medicaid HCBS systems, hazard pay for essential workers (including direct care workers), additional recovery rebates, education funding, and additional funding for nutrition and housing assistance programs. We have been advocating with the Senate to pass a bill that similarly meets the needs of people with disabilities and does not include harmful provisions, like liability shields for negligent nursing homes or that

---

<sup>23</sup> See, e.g., Kaiser Family Foundation “Racial Disparities in COVID-19: Key Findings from Available Data and Analysis” (Aug. 17, 2020), available at <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-key-findings-available-data-analysis/>.

would allow employers to discriminate against workers with disabilities.<sup>24</sup> We encourage President-elect Biden to make working with Congress on this critically-needed relief package a priority.

We appreciate the urgency of the task facing the COVID-19 Advisory Board, particularly as the number of COVID-19 cases are increasing across the country. We would welcome the opportunity to be a resource to you – and to the new Administration as this work continues – to ensure that the needs of people with disabilities and older adults are addressed. If you are taking meeting requests at this time, we would like to schedule a meeting to discuss the issues in this letter with you. Please contact Alison Barkoff ([abarkoff@cpr-us.org](mailto:abarkoff@cpr-us.org) or 202-854-1270) for follow up and questions regarding this letter.

Sincerely,

Alison Barkoff  
Center for Public Representation

Jennifer Lav  
National Health Law Program

Julia Bascom  
Autistic Self Advocacy Network

Nicole Jorwic  
The Arc of the United States

Dan Berland  
National Association of Directors  
of Developmental Disabilities Services

Sarah Meek  
American Network of Community Options  
and Resources

Co-chairs, CCD Long Term Services and Supports Task Force

Natalie Kean  
Justice in Aging

Erin Shea  
Center for Public Representation

David Machledt  
National Health Law Program

Rachel Patterson  
Epilepsy Foundation

Co-Chairs, CCD Health Task Force

Kelly Buckland  
National Council on Independent Living

Jennifer Mathis  
Bazelon Center for Mental Health Law

Samatha Crane  
Autistic Self Advocacy Network

Allison Nichol  
Epilepsy Foundation

---

<sup>24</sup> See July 30, 2020 Letter from CCD to Senate and House leadership, available at <http://www.c-c-d.org/fichiers/CCD-Rights-LTSS-Health-letter-re-senate-covid-package-7-30-20-final.pdf>; June 15, 2020 letter from CCD to Senate leadership, available at <http://www.c-c-d.org/fichiers/National-and-State-Sign-on-COVID-19-Senate-Letter.pdf>.



Stephen Lieberman  
United Spinal Association

Co-Chairs, CCD Rights Task Force

Cc: Chiquita Brooks-LaSure, Team Lead  
Robert Gordon, Team Lead  
Department of Health and Human Services Agency Review Team  
Ben Wakana, Transition Team