May 5, 2020

Honorable Alex Azar  
Secretary, U.S. Department of Health and Human Services  
200 Independence Avenue S.W.  
Washington, DC 20201

Seema Verma  
Administrator, Centers for Medicare & Medicaid Services  
200 Independence Avenue S.W.  
Washington, DC 20201

Lance Robertson  
Administrator, Administration for Community Living  
330 C St. S.W.  
Washington, D.C. 20201

By electronic mail

Re: CMS Nursing Home Initiatives

Dear Secretary Azar, Administrator Verma, and Administrator Robertson:

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. The undersigned co-chairs of the CCD Long-term Services and Supports taskforce write in response to the Administration’s recent announcement of the creation of an independent commission to address safety and quality in nursing homes.

We appreciate the Administration’s efforts to protect the health and safety of people in nursing homes, where there have been extremely high numbers of outbreaks and deaths of residents. But as we discussed in our April 21, 2020 letter to you regarding your new “Nursing Homes COVID-19 Transparency Effort,” people with disabilities and older adults face increased risks in all institutional settings, not just nursing homes. Like nursing facilities, there have been similar outbreaks and deaths in
Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), including in Illinois, Massachusetts, Utah, Texas, and New Jersey just to name a few. In Illinois, the outbreak is so significant that the National Guard has been called in, and in Massachusetts nearly half the residents (44 individuals) of a state-operated ICF have been infected. Serious outbreaks are also taking place in Institutions for Mental Disease (IMDs) and other psychiatric and substance use disorder treatment facilities, including in Washington state, District of Columbia, and New York.

The lives of people with disabilities in these settings are equally as at risk – and equally as worth protecting – as people in nursing homes. We again implore you to expand any efforts to protect the lives of people in nursing homes from COVID-19 to other Medicaid-funded institutional and congregate settings.

We know that people with disabilities and older adults are at higher risk for infection and death from COVID-19 in institutional settings. As the Administration moves forward with its safety initiatives, we encourage you to include strategies for diverting people from unnecessary admissions and transitioning people from institutions to smaller, more individualized settings in the community. This not only is critical to addressing safety concerns, but also would help vindicate the civil rights of these individuals to receive services in the community instead of in institutional settings under the Americans with Disabilities Act and the Supreme Court’s decision in Olmstead v. L.C. We encourage CMS to work with states – and for ACL to work with its disability and aging networks – to identify resources available to assist with diversion and transition activities.

We appreciate all of the important efforts the Department has taken during the COVID-19 pandemic. We urge you to act quickly to help protect the lives of ALL people with disabilities and older adults residing in institutions, who are at serious risk during this crisis. If you are willing, we would be interested in meeting with you to discuss these strategies further. Please contact Alison Barkoff (abarkoff@cpr-us.org) to schedule a meeting.

Sincerely,

Long-Term Services and Supports Co-Chairs

Alison Barkoff,  
Center for Public Representation
Nicole Jorwic  
The Arc of the United States

Julia Bascom,  
Autistic Self Advocacy Network
Jennifer Lav,  
National Health Law Program

Sarah Meek  
American Network of Community Options and Resources (ANCOR)

Cc: Calder Lynch, Deputy Administrator, CMCS  
David Wright, Director, Center for Clinical Standards and Quality, Quality and Safety Oversight Group  
Alissa DeBoy, Director, Disabled & Elderly Health Programs Group (DEHPG)  
Melissa Harris, Deputy Director, DEHPG  
Roger Severino, Director, Office of Civil Rights