



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 21, 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

Robert Redfield, M.D.
Director, Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

By electronic mail

Dear Secretary Azar, Administrator Verma, and Director Redfield,

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 "New Nursing Homes COVID-19 Transparency Effort" [announcement](#) earlier this week.

People with disabilities and older adults are, and will be, particularly at risk for COVID-19, facing a high risk of complications and death if exposed to the virus. While the [media](#) and public have understandably focused on the outbreaks and deaths in nursing homes across the country, people with disabilities and older adults face increased risks in all institutional and congregate settings. Like nursing facilities, there have been similar outbreaks and deaths in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), including in [Illinois](#) (where the outbreak has been so significant that the National Guard has been called in), [Massachusetts](#) (where nearly half of the residents in a state-

operated ICF are infected), [Utah](#), [Texas](#), and [New Jersey](#) just to name a few; Institutions for Mental Disease (IMDs) and other psychiatric and substance use disorder treatment facilities, including in [Washington state](#), [District of Columbia](#), and [New York](#); and in group homes across the country, including across [New York](#), [Maryland](#), and [New Jersey](#).

We strongly support the steps that CMS announced earlier this week to ensure transparency and information about infections and deaths in nursing homes. These critical steps include: (1) requiring nursing homes to inform residents, their families and representatives of cases of COVID-19 in their facilities; (2) requiring nursing homes to report cases of COVID-19 directly to the Centers for Disease Control and Prevention (CDC), as well as to state and local officials; and (3) requiring nursing homes to fully cooperate with CDC surveillance efforts around COVID-19 spread. **We implore CMS to extend these same requirements to all institutional settings -- including ICF-IIDs, IMDs, substance use disorder treatment facilities, and psychiatric residential treatment facilities -- and other Medicaid-funded congregate settings where older adults and people with disabilities live, including group homes and assisted living facilities.** The need for transparency, information and data collection is equally as critical to protecting the safety and welfare of people in these settings as they are for residents of nursing homes.

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 congregate facilities, who are at serious risk during this crisis. If you have any questions, feel free to contact Alison Barkoff (abarkoff@cpr-us.org).

Sincerely,

Long-Term Services and Supports Co-Chairs

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Center for Public Representation

Nicole Jorwic
The Arc of the United States

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