



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 27, 2020

Hon. Alex Azar
Secretary, U.S. Dept of Health and Human Services
200 Independence Ave., SW
Washington DC 20201

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

Hon. Seema Verma
Administrator, Centers for Medicare & Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

Re: COVID-19 data collection and reporting concerning people
with disabilities

Dear Secretary Azar, Director Redfield, and Administrator Verma:

The undersigned national disability organizations write to you as the co-chairs of the Consortium for Citizens with Disabilities (CCD) Rights Task Force to urge you to collect and report data concerning the impact of COVID-19 on people 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.

We have been extremely concerned about the particularly dramatic way in which the pandemic has affected people with disabilities. In states around the country, COVID-19 has had devastating effects on people with disabilities not only due to vulnerabilities to the virus related to underlying disabilities, but also due to the dangers posed by the widespread continued reliance of our disability service systems on institutional and congregate living settings. The pandemic has ravaged nursing homes, psychiatric hospitals, institutions for people with intellectual and developmental disabilities, board and care homes, and other confined, congregate settings.

Each day brings new stories of outbreaks and deaths in these facilities. For example, the *Wall Street Journal* has reported that more than 10,000 deaths from COVID-19 in the United States

have occurred among residents of nursing homes and long-term care facilities.¹ The *New York Times* has chronicled thousands of deaths of nursing home residents across the country, including 55 deaths at the Cobble Hill Health Center in Brooklyn, 70 deaths at the Andover Subacute and Rehabilitation Center II in New Jersey—with the remaining 420 residents either testing positive or sick with fevers and coughs, at least 46 deaths at the Canterbury Rehabilitation & Healthcare Center in Richmond, Virginia, and outbreaks and deaths in hundreds of other facilities.² Significant outbreaks have also occurred in psychiatric hospitals,³ institutions for people with intellectual and developmental disabilities,⁴ board and care homes,⁵ and group homes.⁶ Many of

¹ Jon Kamp & Anna Wilde Mathews, *Coronavirus Deaths in U.S. Nursing, Long-Term Care Facilities Top 10,000*, Wall Street Journal, Apr. 22, 2020, <https://www.wsj.com/articles/coronavirus-deaths-in-u-s-nursing-long-term-care-facilities-top-10-000-11587586237>.

² Tracey Tully et al, *70 Died in a Nursing Home as Body Bags Piled Up. This is What Went Wrong*, New York Times, Apr. 19, 2020, <https://www.nytimes.com/2020/04/19/nyregion/coronavirus-nj-andover-nursing-home-deaths.html>, Farah Stockman et al., ‘*They’re Death Pits*’: *Virus Claims at Least 7,000 Lives in U.S. Nursing Homes*, New York Times, Apr. 17, 2020, <https://www.nytimes.com/2020/04/17/us/coronavirus-nursing-homes.html?smid=fb-share&fbclid=IwAR3NEUzyunz7H-gR2O1GHyugBU8Ew1Mxv36UVax2t-URmEVDy2YXlxmGUtk>, Simon Romero et al., *Virginia Nursing Home Had Plenty of Coronavirus Patients but Few Tests*, New York Times, Apr. 15, 2020, <https://www.nytimes.com/2020/04/15/us/virginia-nursing-home-coronavirus.html?smid=fb-share&fbclid=IwAR3SedNpBtsqZvuWg2nBlzZBz4UIYih9gYMwK6mzIlnI37pCZoed8BogM4g>.

³ See, e.g., Ethan Geringer-Sameth, *10 Dead, Hundreds Infected as State Psychiatric Facilities Become Another Crisis Point in Coronavirus Outbreak*, Gotham Gazette, Apr. 17, 2020, https://www.gothamgazette.com/state/9321-ten-dead-hundreds-infected-new-york-state-psychiatric-facilities-crisis-coronavirus-outbreak?fbclid=IwAR1Q3q2yXN2fvGE4rk3Trw3A4fXhjEgk4_9_CA4KUZcxJiQnNJs5tDhdgtc; Evan Lambert, *4 patients at St. Elizabeths Hospital dead after contracting COVID-19*, Fox 5 Washington DC, Apr. 13, 2020, <https://www.fox5dc.com/news/4-patients-at-st-elizabeths-hospital-dead-after-contracting-covid-19-officials>.

⁴ See, e.g., Elisha Sauers, *16 test positive for coronavirus at center for disabled in Chesapeake*, The Virginian-Pilot, Apr. 22, 2020, https://www.pilotonline.com/news/health/vp-nw-coronavirus-chesapeake-outbreak-20200422-2nm4x3cysnaitctdjta72uqxku-story.html?fbclid=IwAR0bYoTwdR3uWsJJyySYw53YDRaSqF5i8r4EQHts05ky4YohecnJM-Wxd_8; Allie Morris, *Officials report 31 new coronavirus cases at the Denton County State Supported Living Center*, Dallas Morning News, Mar. 27, 2020, <https://www.dallasnews.com/news/public-health/2020/03/27/officials-report-31-new-coronavirus-cases-at-the-denton-county-state-supported-living-center/>

⁵ Joaquin Sapien, *Now that the Coronavirus is Inside this Adult Home for the Elderly or Mentally Ill, It May Be Impossible to Stop*, ProPublica, Apr. 2, 2020, <https://www.propublica.org/article/now-that-coronavirus-is-inside-this-adult-home-for-the-elderly-or-mentally-ill-it-may-be-impossible-to-stop>.

⁶ Danny Hakim, *‘It’s Hit Our Front Door’: Homes for the Disabled See a Surge of Covid-19*, New York Times, Apr. 8, 2020, https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html?fbclid=IwAR3IK8KrUVrnL1YtTmCv7ZnhwpzjMpxjm5OKbHVE7A10ePMltX_WFaLKxd_8; Rebecca Tan, *Group Homes for Disabled Adults Grapple with the Spread of Coronavirus*, Washington

these facilities have no personal protective equipment for either staff or residents, and no plan for what to do in the event of an outbreak.

The effects of the pandemic exacerbate the civil rights concerns already present with the widespread overreliance on institutional care for people with disabilities. The Americans with Disabilities Act's integration mandate and the Supreme Court's *Olmstead* decision prohibit the needless institutionalization and segregation of people with disabilities. Now, people with disabilities are not only isolated and segregated in institutional settings but at risk of death in those settings. And transitions out of these institutions have largely come to a halt due to the pandemic.

In many cases, information concerning COVID-19 testing, cases, and deaths in these facilities remains hidden from the public. At the Andover nursing home in New Jersey, where 70 residents died, information about the spread of COVID-19 became public only after police discovered 17 bodies in a holding room following an anonymous tip.⁷ In Texas, despite the pleas for information of family members restricted from visiting relatives in state institutions for individuals with intellectual and developmental disabilities, state officials have refused to disclose data concerning the number of cases among staff and residents of these facilities.⁸

Information about COVID-19 testing, cases, and deaths of people with disabilities in institutional facilities as well as in community settings is critically important for those individuals, for their families, for staff, and for the public. Further, this information is important to collect and report on a national basis in order to better understand the impact of the virus on people with disabilities and to inform strategies to prevent its spread—including strategies to improve compliance with the ADA's integration mandate in the current environment. According to one New York study, people with disabilities in group homes and similar facilities in and near New York City were more than five times as likely as others to become infected and nearly five times as likely to die from the coronavirus.⁹

The federal government has the ability to collect information from states and service providers concerning the impact of the virus on people with disabilities. We implore you to collect and report publicly the following information:

Post, Apr. 18, 2020, https://www.washingtonpost.com/local/group-homes-for-disabled-adults-grapple-with-the-spread-of-coronavirus/2020/04/18/ac2ecae2-7ff2-11ea-a3ee-13e1ae0a3571_story.html?fbclid=IwAR0WU5a3kDvVSxrgmvdVfcuoy-LxYzDBAGE_jwQng5MK05uHkhrtMR7IsBw.

⁷ Tully, *supra* note 2.

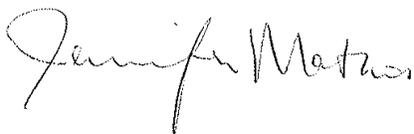
⁸ Sami Sparber, *Texas will not release information about coronavirus clusters in state-run homes for Texans with disabilities*, Texas Tribune, Apr. 22, 2020, <https://www.texastribune.org/2020/04/22/coronavirus-texas-sslc-disabilities/?fbclid=IwAR2kOY4u-jWw0JE2kquBFcHFu9sK1m582f0a4mmvhBEh4as40A8EdUeLK-0>.

⁹ Hakim, *supra* note 6.

- Numbers of tests and rates of testing for COVID-19 of people with disabilities and staff in nursing homes, psychiatric facilities, facilities for people with intellectual and developmental disabilities, board and care homes, group homes, and other congregate facilities for people with disabilities, as well as for people with disabilities in supported housing and other community settings.
- Numbers of people with disabilities and staff testing positive for COVID-19 and rates of positive tests in each of these settings.
- Numbers of COVID-19 related hospitalizations of people with disabilities and staff in each of these settings.
- Numbers of COVID-19 related deaths and death rates among people with disabilities and staff in each of these settings.
- Numbers of people who have recovered from COVID-19 and recovery rates among people with disabilities and staff in each of these settings.
- Numbers of people with disabilities who have been transferred from community settings to institutional settings as a result of COVID-19.
- Numbers of people with disabilities who have been discharged from institutions as a result of COVID-19.
- Analysis of the data to identify trends and factors such as facility type, disability type, location or geographical area, or other factors that correlate with rates of testing, positive cases, or outcomes.

The Paycheck Protection and Health Care Enhancement Act that Congress just passed requires HHS to report on the number of positive diagnoses, hospitalizations, and deaths resulting from COVID-19, disaggregated nationally by race, ethnicity, age, sex, geographic region, and “other relevant factors.” We believe it is critical that disability be included as one of those “relevant factors” and we urge you to include it. We also urge you to collect and report on the additional data identified above.

We appreciate your prompt attention to this urgent matter.



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