



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

July 7, 2020

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

Re: Interim Final Rule – Nursing Home COVID-19 Reporting Requirements  
(CMS-5531-IFC)

Dear Secretary Azar,

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 Task Force write to implore HHS to include all institutional facilities that receive Medicaid funding, not just nursing homes, in its interim final rule on nursing home COVID-19 reporting requirements.

People with disabilities face a particularly high risk of contracting COVID-19 and of experiencing complications and death if exposed.<sup>1,2</sup> This risk has been elevated by the severe outbreaks in

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<sup>1</sup> A recent study showed that people with intellectual disabilities and autism die at rates that, in at least some states, are 2 to 2.5 times higher than the death rates among others who contract COVID-19. The study also showed that this population contracts the virus at a higher rate. Joseph Shapiro, "COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities," *National Public Radio* (June 9, 2020; 5:00 AM), <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>.

<sup>2</sup> People with intellectual and developmental disabilities (IDD) experience a higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Margaret Turk, Scott Landes, Margaret Formica, and Katherine Goss, "Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis,"

institutions for people with disabilities, including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs) and psychiatric hospitals, across the country.<sup>3</sup> Widespread COVID-19 infections in these institutions have continued in recent weeks<sup>4</sup> and likely will increase in frequency and severity as states experience a second wave of the virus or surges in cases following premature reopening. Residents in all institutional settings – not just nursing homes – are at serious risk during the COVID-19 crisis, and regulations to promote resident safety must address all institutions if we hope to effectively mitigate the outbreaks residents in these settings face. We raised this concern in an April 21, 2020 letter to CMS in response to the announcement of the “New Nursing Homes COVID-19 Transparency Effort,” which led to the promulgation of the regulations about which we are commenting in this letter.<sup>5</sup>

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*Disability and Health Journal* (May 24, 2020),

<https://www.sciencedirect.com/science/article/pii/S1936657420300674>.

<sup>3</sup> See, e.g., Zak Koeske, “Illinois National Guard activated for COVID-19 response at Park Forest developmental center with more than 100 cases,” *The Chicago Tribune* (Apr. 17, 2020), <https://www.chicagotribune.com/suburbs/daily-southtown/ct-sta-illinois-national-guard-ludeman-center-st-0419-20200417-evmpvn4bfbegtia2njinmdbf54-story.html>; Kevin Rothstein, “Nearly half of developmentally disabled at state home infected with coronavirus,” *WCVB* (Apr. 17, 2020), <https://www.wcvb.com/article/nearly-half-of-developmentally-disabled-at-state-home-in-massachusetts-infected-with-coronavirus/32178605>; Kit Ramgopal, “Coronavirus in a psychiatric hospital: 'It's the worst of all worlds'” *NBC News* (Apr. 17, 2020), <https://www.nbcnews.com/health/mental-health/coronavirus-psychiatric-hospital-it-s-worst-all-worlds-n1184266?fbclid=IwAR2499y-eUjZaumicyvZdBqzbYDdwUWp0xBXXpQvpmex-dNru0TYNp9fi70>; Justin Wm. Moyer, Fenit Nirappil, and Alyssa Fowers, “Most St. Elizabeths patients under quarantine after four coronavirus deaths,” *The Washington Post* (Apr. 15, 2020), [https://www.washingtonpost.com/local/most-st-elizabeths-patients-under-quarantine-after-four-coronavirus-deaths/2020/04/15/37aec03e-7e6a-11ea-8de7-9fdff6d5d83e\\_story.html](https://www.washingtonpost.com/local/most-st-elizabeths-patients-under-quarantine-after-four-coronavirus-deaths/2020/04/15/37aec03e-7e6a-11ea-8de7-9fdff6d5d83e_story.html); 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=IwAR3EwXDlBGLYRTAflzAUc5uvmTkWJicH3EKFCY0axCudg1EmF3vi0hHxotc>; Russ Crespolini, “COVID-19 Deaths, Infections Keep Rising In NJ Psych Facilities,” *Patch* (May 12, 2020), <https://patch.com/new-jersey/parsippany/covid-19-deaths-infections-keep-rising-nj-psych-facilities>.

<sup>4</sup> See, e.g., Jordan Howington, “Arkansas’s Largest State-Run Intermediate Care Facility Confirms 92 Active COVID-19 Cases,” *THV11* (June 26, 2020), <https://www.thv11.com/article/news/health/coronavirus/arkansas-largest-state-ran-intermediate-care-facility-confirms-92-active-covid-19-cases/91-5648f7c9-180d-4e3a-a573-e2156cf7237e>; Mary Sell, “3 COVID-19 deaths at mental health hospital in Tuscaloosa,” *Alabama Daily News* (June 4, 2020), <https://www.wbrc.com/2020/06/04/covid-deaths-mental-health-hospital/>.

<sup>5</sup> Letter from Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, Seema Verma, and Robert Redfield (April 21, 2020), <http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-institutional-and-congregate-care-and-COVID19-final.pdf>. We also raised this same concern in other letters to CMS and in testimony submitted to Congress. See Letter from Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, Seema Verma, and Robert Redfield (May 5, 2020), <http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-COVID19-and-CMS-nursing-home-safety-initiative-5-5.20-to-CMS.pdf>; Letter from Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs to the House Ways and Means Committee (June 25, 2020), <http://www.c-c-d.org/fichiers/CCD-LTSS-Statement-for-House-Ways-and-Means-Nursing-Home-Hearing-6-25-20.pdf>.

As CMS itself emphasizes in the preamble to the new regulations, tracking data on infection and death rates as well as providing notice to residents and their families or representatives about confirmed or suspected COVID-19 cases, are essential to supporting the health and safety of residents of institutional settings.<sup>6</sup> It is therefore appalling that the only source currently tracking 50-state data on infection and death rates in all institutional settings – not just nursing homes – is a small non-profit, the Autistic Self Advocacy Network (ASAN),<sup>7</sup> which is compiling data largely from media reports to fill major gaps in data reported directly by states or the federal government.<sup>8</sup> Addressing a crisis of the magnitude of COVID-19 demands accurate, consistent, and official collection of data from all states on all institutional settings that receive Medicaid funding, not just nursing homes. CMS has the responsibility and authority to expand the reporting requirement regulations intended to protect the health and safety of nursing home residents to residents in other Medicaid-funded institutions given CMS' similar regulatory oversight role over non-nursing home institutions like psychiatric hospitals and Intermediate Care Facilities.<sup>9</sup> Therefore, we urge CMS to expand the new nursing home reporting requirements to all Medicaid-funded institutions.

In addition, we endorse the comments submitted by the American Association on Health and Disability and the National Consumer Voice for Quality Long-Term Care, particularly their recommended changes about required demographic data collection, analysis and public reporting.

We appreciate the efforts the Department has taken during the COVID-19 pandemic. We urge you to act quickly to protect the lives of ALL people with disabilities and older adults residing in institutional settings, who are at serious risk during this crisis. If you have any questions, feel free to contact Alison Barkoff ([abarkoff@cpr-us.org](mailto:abarkoff@cpr-us.org)).

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<sup>6</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, 85 Fed. Reg. 27,550, 27,601 (May 8, 2020).

<sup>7</sup> Autistic Self Advocacy Network, *COVID-19 Case Tracker* (accessed June 30, 2020), <https://autisticadvocacy.org/covid19/#info>.

<sup>8</sup> *Id.*

<sup>9</sup> See, e.g., 42 C.F.R. § 482; Centers for Medicare and Medicaid Services, "Quality, Safety & Oversight – General Information," CMS.gov, <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo> (accessed June 30, 2020); Centers for Medicare and Medicaid Services, *State Operations Manual: Chapter 2 – The Certification Process*, (Jan. 17, 2020), <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107c02.pdf>; Centers for Medicare and Medicaid Services, "Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)," CMS.gov, <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/ICFIID> (accessed June 30, 2020); Centers for Medicare and Medicaid Services, QSO-18-16-ICF/IID, *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Survey Protocol State Operations Manual (SOM) Appendix J Revised*, (Apr. 6, 2018), <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/QSO18-16-ICFIID>.

Sincerely,

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