



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

November 2, 2020

Administrator Seema Verma
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments on Interim Final Rule CMS-3401-IFC

Dear Administrator Verma,

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 in response to CMS' interim final rule (IFR) regarding COVID-19 testing and enforcement of reporting requirements for long term care facilities (LTCs). We ask CMS to include all congregate long-term care settings that receive Medicaid funding, not just nursing homes, in this interim final rule's requirements.

People with disabilities and older adults face a particularly high risk of contracting COVID-19 and of experiencing complications and death if exposed.^{1,2} This risk has been elevated by the

¹ 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>.

severe outbreaks in institutional and congregate settings across the country. Given the surge currently being seen in COVID-19 cases and hospitalizations, the dangers faced in institutional and congregate settings is unlikely to end any time soon, and may increase in frequency and severity. While the media and public have understandably focused on the outbreaks and deaths in nursing homes, people with disabilities and older adults face increased risks in all institutional and congregate settings, which we have previously addressed.³ None of these institutional and congregate settings have been immune to the COVID-19 crisis and regulations to promote safety must address all of them, not only nursing homes, if we hope to effectively mitigate the outbreaks these settings face.

CMS itself recognizes this. The agency notes that in the background of the IFR that high-risk populations identified by the CDC include:

“Residents 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.”⁴

CMS elaborates on this later in the IFR, noting that because of the “congregate nature of LTC facilities and the high-risk nature of the population served, LTC facilities are at greater risk of COVID–19 outbreaks as well as higher rates of incidence, morbidity, and mortality.”⁵ Furthermore, in justifying its testing requirements, CMS states that “we believe there exists a need to strengthen the requirements for LTC facilities to better protect residents, members of a

² 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,” *Disability and Health Journal* epub ahead of print (May 24, 2020), <https://www.sciencedirect.com/science/article/pii/S1936657420300674>.

³ Letter from Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar (July 7, 2020), <http://www.c-c-d.org/fichiers/Nursing-Home-Reg-Comments-final-7-7-20.pdf>; Letter from Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs to Alex Azar, Seema Verma, and Robert Redfield (Apr. 21, 2020), <http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-institutional-and-congregate-care-and-COVID19-final.pdf>.

⁴ Medicare and Medicaid Programs, Clinical Laboratory Improvement Amendments, and Patient Protection and Affordable Care Act: Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency, 85 Fed. Reg. 54820, 54821 (Sept. 2, 2020).

⁵ *Id.* at 54851.

high-risk population. . . . [A] strong infection control program is critical to protect the health and safety of both residents and healthcare personnel of LTC facilities.”⁶

We appreciate the agency’s recognition of this reality. However, we are troubled that the testing requirements⁷ and enforcement of reporting requirements⁸ laid out in the IFR do not explicitly include all of the LTC facilities identified in the background of the IFR. The risks CMS identified and the need for strong infection control exist across all congregate settings. Addressing a crisis of the magnitude of COVID-19 will require accurate, consistent, and official collection of data from all states on all congregate settings that receive Medicaid funding, not just nursing homes, as well as testing for residents and staff in all of those settings. The ability to enforce reporting requirements is critical to the success of those reporting efforts. CMS has the responsibility to ensure that regulations intended to protect the health and safety of people living in congregate settings don’t leave out residents in settings other than nursing homes, especially given CMS’ regulatory oversight role over non-nursing home institutions like psychiatric hospitals and Intermediate Care Facilities.⁹

Finally, we would like to address the discussion of quality adjusted life years (QALYs) in the IFR.¹⁰ While we understand the need for cost estimates regarding efforts to curb the spread of COVID-19, we encourage CMS not to use cost effectiveness measures that rely on QALYs or other similar measures. QALYs rely on the discriminatory assumption that the lives of people with disabilities and older adults are less valuable than their non-disabled and/or younger counterparts and should not be relied on in determining the value of interventions related to COVID-19.¹¹

We appreciate the efforts CMS 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 congregate

⁶ *Id.*

⁷ *Id.*

⁸ *Id.* at 54823.

⁹ See, e.g., 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); 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).

¹⁰ Medicare and Medicaid Programs, Clinical Laboratory Improvement Amendments, and Patient Protection and Affordable Care Act: Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency, 85 Fed. Reg. 54820, 54865 (Sept. 2, 2020).

¹¹ See, e.g. National Council on Disability, Quality-Adjusted Life Years and the Devaluation of Life with Disability (Nov. 6, 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf (accessed Nov. 2, 2020).

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,

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