



American Association on Health & Disability

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AAHD - Dedicated to better health for people with disabilities through health promotion and wellness



LAKESHORE

July 5, 2020

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-5531-IFC
P.O. Box 8010
Baltimore, Maryland 21244

Re: 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 CMS-5531-IFC

AAHD & Lakeshore Areas of Comment Focus: Disability Status and Related Demographic Data Collection, Analysis, and Public Reporting

Submitted electronically: <http://www.regulations.gov>

Dear Administrator Verma:

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on proposed nursing home quality in relation to COVID-19.

Our emphasis here is disability status and related demographic data collection, analysis, and public reporting. We also endorse the National Consumer Voice for Quality Long Term Care submitted comments on other topics; they are listed at the end of our comments.

The American Association on Health and Disability (AAHD) (www.aahd.us) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

Disability Status and Related Demographic Data Collection, Analysis, and Public Reporting

AAHD and Lakeshore Foundation support the collection of COVID-19 data in nursing facilities, and all Medicaid and Medicare funded congregate facilities, and appreciates the time and effort that CMS has spent crafting this rule. The new Interim Final Rule requiring nursing facilities to report COVID-19 data under §483.80 Infection Control. The data will permit facilities, and local, state, and national officials to monitor the spread of COVID-19, identify the best interventions, and determine where resources and assistance are needed. In addition, it will allow nursing home residents, their representatives and families, staff, and the public to know the status of COVID-19 in any Medicare and/or Medicaid funded facility. Residents and staff need to have this information because it directly impacts the place where they live or work. The data also enables both current and prospective residents and families to make informed decisions regarding their options for care.

§483.80 (g)(1) COVID-19 Reporting

AAHD and Lakeshore appreciate that CMS is requiring mandatory reporting on a standardized format so the data will be uniform and easy to compare from facility to facility. However, to get a more in-depth, comprehensive understanding of the extent and impact of COVID-19 on nursing home residents, we urge CMS to require that the following also be reported for residents and staff:

• **Race, ethnicity, sex, age, disability status, primary language, sexual orientation, gender identity, socio-economic status, urban/rural locations.**

Demographic characteristics are associated with disparities in COVID-19 infections and deaths. Tracking demographic data for those who have been infected or hospitalized, or who have recovered or died from COVID-19 helps identify groups that may have a higher likelihood of getting sick and experiencing severe illness from COVID-19 as the pandemic progresses. It can help state, tribal and local agencies, health systems, hospitals, and health care providers invest in and direct resources to provide access to testing, health care, and social services for diverse

populations with different needs. Finally, it can help policymakers prioritize and distribute resources based on anticipated need. Reports of hospitalization age and **disability discrimination** in care have been made during the pandemic. The Consortium for Citizens with Disabilities (CCD) has worked closely with the HHS OCR to correct and prevent these situations. AAHD and Lakeshore also endorse the Consumer Voice recommendation for CMS clarity in the definition of “suspected” cases.

Recommendation:

Revise (g)(1)(i)-(ii) as follows:

- (i) Suspected **infections of COVID-19, defined as any resident or staff with signs and symptoms suggestive of COVID-19 as described by CDC’s guidance**, and confirmed COVID-19 infections among residents and staff, including residents previously treated for COVID-19;
- (ii) **Recovered COVID-19 cases among residents and staff;**
- (iii) **Hospitalizations of residents and staff;**
- (iv) Total deaths **including deaths occurring at the hospital or other outside location** and COVID-19 deaths among residents and staff;
- (v) **For (i) (ii) (iii) and (iv) aggregate data for race, ethnicity, sex, age, gender, disability status, primary language, sexual orientation, gender identity, socio-economic status, and urban/rural locations must also be reported.**

§483.80 (g)(2) Providing Information to the CDC and Posting Publicly

AAHD and Lakeshore join Consumer Voice strongly supports the public posting of COVID-related data. Because we are in the midst of a public health emergency, and this data can change so rapidly, we urge CMS to require daily, rather than weekly, reporting as well as posting. CDC itself recommends daily reporting; its NHSN instructions state: ... “daily reporting will provide the timeliest data to assist with COVID-19 emergency response efforts....”

§483.80 (g)(7) Reporting Requirements for Other Settings

AAHD, Lakeshore, the Consortium for Citizens with Disabilities, and many disability and aging advocates join Consumer Voice strongly supporting expanding the reporting requirements to other institutional and congregate settings. People with disabilities and older adults in these facilities are at serious risk related to COVID-19. As noted in a letter from the Consortium of Citizens with Disabilities (CCD), there have been similar outbreaks and deaths in congregate facilities serving persons with ID/DD. Press reports and beginning peer-reviewed professional research journals have begun documenting this situation.

We join the Consumer Voice and other advocates, such as CCD, in urging CMS to extend the nursing home data requirements to all Medicaid and Medicare congregate and institutional settings. 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 facilities.

Other Issue Areas

We also endorse the National Consumer Voice for Quality Long Term Care submitted comments on other topics; specifically those on:

1. Personal Protective Equipment
2. Hand Hygiene
3. Access To Testing
4. Staffing Shortages
5. Informing Residents, Their Representatives, and Their Families
6. Informing the General Public
7. Penalty for Failure To Report

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at clarkeross10@comcast.net.

Sincerely,



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Member, National Quality Forum (NQF) workgroup on Medicaid adult measures (December 2017-present), Medicaid-CHIP Scorecard Committee (October 2018-present) and Measure Sets and Measurement Systems TEP (June 2019-present). Member, National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid (July 2012-July 2017) and NQF population health task force (2013-2014) <http://www.qualityforum.org/> and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (<http://www.c-c-d.org/>). 2017 member, NQF MAP workgroup on Medicaid adult measures. 2016-2017 NQF duals workgroup liaison to the NQF clinician workgroup. 2015-2016 and 2014-2015 NQF duals workgroup liaison to the NQF PAC/LTC workgroup. Member, NQF Medicare Star Ratings Technical Expert Panel (June-November 2019). AAHD Representative to the CMS-AHIP-NQF Core Quality Measures Collaborative (2019-present). Member, ONC (Office of the National Coordinator for Health Information Technology) Health IT Policy Committee, Consumer Workgroup, March 2013-November 2015; Consumer Task Force, November 2015-April 2016. (<http://www.healthit.gov/policy-researchers-implementers/federal-advisory-committees-facas/consumer-empowerment-workgroup>). Member, SAMHSA Wellness Campaign National Steering Committee – January 2011-September 2014. (<http://promoteacceptance.samhsa.gov/10by10/>).

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