United States Senate

COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS

WASHINGTON, DC 20510–6300

October 14, 2020

The Honorable Seema Verma
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human
Services
200 Independence Avenue SW
Washington, DC 20201

Dear Administrator Verma,

Amid the ongoing COVID-19 pandemic, the Department of Health and Human Services (HHS) implemented critical new reporting requirements for nursing home facilities. But, a review of state-level data reporting reveals a substantial lack of data for congregate care settings for children and adults with mental illness, children and adults with disabilities, and older Americans.[1] Data collection within these facilities is critical to identifying these outbreaks in order to respond, save, and protect lives and urgently needs to be improved. The Centers for Medicare and Medicaid Services (CMS) has the responsibility and authority to expand current reporting requirement regulations beyond nursing homes to include other Medicaid-funded institutions and take immediate action in response to serious health and safety findings incorporating data collected by the Centers for Disease Control and Prevention (CDC) via the National Healthcare Safety Network (NHSN).[2] Given the importance of collecting this data as quickly as possible, we are requesting CMS issue guidance for mandatory comprehensive data collection and reporting on congregate care settings to better understand and address the impact of COVID-19 on people with disabilities and older Americans in these settings.

[1] HELP Committee Democratic staff conducted a review of all 50 states' and DC's coronavirus public data websites for reporting on congregate care settings and current guidance from federal health agencies to determine the type of settings included in COVID-19 reporting and the type of settings included in federal guidance. Complete methodology of the review conducted and aggregate data results are included in the Appendix.

[2] 42 CFR §441.304(g)
See, e.g., 42 C.F.R. § 482; 42 CFR 483.374;Centers for Medicare and Medicaid Services, "Quality, Safety & Oversight – General Information," CMS.gov, https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo; Centers for Medicare and Medicaid Services, State Operations Manual: Chapter 2 – The Certification Process, 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/CertificationandComplianc/ICFIID; 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, https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/QSO18-16-ICFIID; https://www.cdc.gov/nhsn/about-nhsn/index.html

Current public health guidance indicates a high spread of the virus in congregate living conditions and among high-risk populations.[3] A congregate care setting is any facility providing care for a voluntarily or involuntarily admitted patient or client that typically follows some form of licensing according to the type of facility and that may provide medical care, skilled nursing, and/or—as appropriate—food, housing, and direct care specific to the type of facility. These facilities typically serve children and adults with disabilities, children and adults with mental illness, and older Americans. Care is provided in one location where many people – often more than 10 – are located. Types of congregate care settings include long-term care facilities such as nursing homes, psychiatric hospitals, psychiatric residential treatment facilities, other mental health facilities, institutions for people with disabilities, assisted living facilities, day facilities for people with disabilities and aging adults, and group homes.[4] Definitions of these settings vary by state, largely due to states having regulatory oversight, specific licensure or certification requirements, and data collection protocols for many of these settings.

The Department of Health and Human Services has recommended that state regulators address outbreaks in nursing homes by imposing new reporting requirements, conducting inspections to ensure that infection controls and other procedures are in place, and providing facilities with PPE for staff. However, no new federal requirements have been implemented to help other congregate care settings improve their response to the pandemic, though they serve similar populations. As a result, people with disabilities, advocates, researchers, and the media have raised concerns that a parallel crisis has been playing out with far less scrutiny in other settings housing or caring for at risk populations, specifically in facilities providing care for people with disabilities.[5] For instance, although CDC has issued guidance on preventing and mitigating outbreaks in group homes, this guidance is purely voluntary. Similarly, while some congregate care settings may voluntarily report coronavirus cases to the federal government through the CDC's NHSN, they are not required to. This guidance differs from the guidance to nursing homes, which are required to comply with specific direction on standard formatting and frequency for reporting COVID-19 data to CDC.[6] The lack of federal guidance has left critical data on other congregate care settings out of reach to communities working to mitigate the pandemic.

Moreover, a review of state-level data and current guidance from federal health agencies revealed states are not disaggregating data for these congregate care settings nor do these other settings have explicit requirements for federal data reporting from their respective federal

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[3] https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html; https://www.cms.gov/files/document/qso-20-26-nh.pdf

[4] https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/facility-based-care

[5] https://www.propublica.org/article/more-than-1-in-5-illinoisans-living-in-state-homes-for-adults-with-disabilities-have-tested-positive-for-the-coronavirus; https://www.sciencedirect.com/science/article/pii/S1936657420300674#!;%20https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili; https://www.cdc.gov/coronavirus/2019-ncov/community/group-homes.html

[6] Standard formatting and frequency for reporting data includes residents or staff with suspected or confirmed COVID-19, residents with severe respiratory infection resulting in hospitalization or death, or ≥ 3 residents or staff with new-onset respiratory symptoms within 72 hours of each other; https://www.govinfo.gov/content/pkg/FR-2020-05-08/pdf/2020-09608.pdf; https://www.cms.gov/files/document/qso-20-26-nh.pdf; https://www.cdc.gov/nhsn/pdfs/covid19/ltcf/cms-covid19-req-508.pdf

agency.[7] The review of the 39 states' reporting data demonstrates that data from rehabilitation facilities (8 states), psychiatric hospitals (2 states), mental health facilities (2 states), institutions for people with disabilities (9 states), group homes (7 states), and day facilities for people with disabilities (1 state) are significantly underreported. Data from nursing homes (30 states), long-term care facilities (27 states), and assisted living facilities (26 states) are more consistently reported across states. There are varying state definitions of long-term care facilities, which makes it unclear whether data reported includes nursing homes, assisted living facilities, or other long-term care facilities. While the data indicate that most states are reporting long-term care facilities and assisted living facilities cases and deaths, they are not reporting COVID-19 cases and fatalities in these facilities directly to the federal government. Recognizing that CMS's oversight over nursing homes varies from other Medicaid-participating institutions and providers, that does not preclude CMS from collecting data from states on care provided in congregate care settings, including psychiatric hospitals, Psychiatric Residential Treatment Facilities, and Intermediate Care Facilities.

From the review of guidance from federal agencies, the data reported from states matches the emphasis placed on nursing homes, long-term care facilities, and assisted living facilities rather than other congregate care settings. There are only two guidance documents on group homes, compared to 25 guidance documents on nursing homes, long-term care facilities, or assisted living facilities.[8]

As the COVID-19 pandemic unfolds, it is also critical that CMS collect and report data regarding testing, infection, and mortality rates, in order to fully understand how the virus is affecting communities of color.[9] The review of the 39 states' reporting data on congregate care settings indicates a significant lack of disaggregation of data on race and ethnicity, sex, sexual orientation, and gender identity (7 states).[10] While data has indicated COVID-19 is disproportionally impacting people of color, without cross tabulation on disability, we do not know the impact on people of color with disabilities.[11]

Despite the high risk of contracting COVID-19 for older Americans, children and adults with mental illness, and children and adults with disabilities living in or receiving services in congregate care settings, there are huge gaps in federal reporting requirements for these facilities. As a result, federal government officials, public health experts, and the public have no comprehensive information on COVID-19 occurrence and fatality rates in various congregate care settings—all while residents continue to face a significant public health threat. The collection of this information is critical to support surveillance of COVID-19 locally and nationally, monitor trends in infection rates, and inform public health policies and actions. Thus, in order to understand the scope and severity of the pandemic within congregate care settings,

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[7] See Appendix
[8] See Appendix
[9] Gross, C. P., Essien, U. R., Pasha, S., Gross, J. R., Wang, S., & Nunez-Smith, M. (2020). Racial and Ethnic Disparities in Population Level Covid-19 Mortality. *Journal of General Internal Medicine*. doi:10.1101/2020.05.07.20094250
[10] See Appendix
[11] According to CMS, Black Americans enrolled in Medicare were hospitalized with the disease at rates nearly four times higher than their white counterparts; https://www.cms.gov/newsroom/press-releases/trump-administration-issues-call-action-based-new-data-detailing-covid-19-impacts-medicare

providers' COVID-19 data should be regularly reported to the federal government, and that this data be made public. To safeguard the health and welfare of people with disabilities, people with mental illness, and older Americans, we request the following action by October 30:

1. Use your authority to expand the reporting requirement regulations intended to protect the health and safety of nursing home residents to residents in other Medicaid-participating institutions, including psychiatric hospitals, Psychiatric Residential Treatment Facilities, and Intermediate Care Facilities.[12] Where CMS cannot extend its regulatory authority directly to providers of long-term care, use CMS's regulatory authority to impose standardized, comprehensive COVID-19 reporting requirements on states to collect data across different types of congregate care settings in which providers participate in Medicaid.

2. The Administration is already collecting Medicare and Dual-Enrolled claims data to monitor and track the impact on people with disabilities and older Americans.[13] We request you to cross-tabulate this data to know and report the impact of COVID-19 on people of color with disabilities. Additionally, the Administration's reporting of this claims data on discharge status omits the following: rehabilitation facilities, inpatient rehabilitation facilities, psychiatric hospitals, psychiatric residential treatment facilities, other mental health facilities, institutions for people with disabilities, and group homes.[14] We request you include these as options in your methodology to disaggregate data in order to identify and respond to trends.

3. Through the Section 1915(c) Waiver Appendix K, some state Medicaid programs amended their oversight provisions to include tracking COVID-19 cases among waiver enrollees and modified incident reporting requirements to account for emergency circumstances. [15] For unplanned hospitalizations, serious injuries—such as contracting COVID-19—and deaths classified as critical incidents, we request you take immediate action in response to serious health and safety findings in settings where home and community based services (HCBS) are provided for all states, using authorities under 42 CFR §441.304(g).[16] Critical incidents occurring under HCBS

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[12] See, e.g., 42 C.F.R. § 482; 42 CFR 483.374; Centers for Medicare and Medicaid Services, "Quality, Safety & Oversight – General Information," CMS.gov, https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo; Centers for Medicare and Medicaid Services, State Operations Manual: Chapter 2 – The Certification Process, 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/CertificationandComplianc/ICFIID; 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, https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/QSO18-16-ICFIID

[13] https://www.cms.gov/files/document/medicare-covid-19-data-snapshot-fact-sheet.pdf

[14] https://www.cms.gov/files/document/medicare-covid-19-data-snapshot-methodology.pdf

[15] https://aahd.us/wp-content/uploads/2020/04/NHeLP_Trends-in-Appendix-K-Approvals.pdf

[16] https://www.govregs.com/regulations/expand/title42_chapterIV_part441_subpartG_section441.301#title42_chapterIV_part441_subpartG_section441.304

waiver programs require a major level of review and are to be reported to a State agency's critical event or incident reporting system.[17]

4. Expand the recently released Interim Final Rule, CMS-3401-IFC, "Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency related to Long-Term Care (LTC) Facility Testing Requirements and Revised COVID19 Focused Survey Tool" released on August 25, 2020 to include all congregate care settings as defined here.[18]

Sincerely,

PATTY MURRAY
Ranking Member, Senate Committee on Health, Education, Labor & Pensions

/s/Margaret Wood Hassan

MARGARET WOOD HASSAN
United States Senator

/s/Elizabeth Warren

ELIZABETH WARREN
United States Senator

[17] See HCBS waiver, Appendix G-1, Participant Safeguards: Response to Critical Events or Incidents
[18] https://www.cms.gov/files/document/covid-ifc-3-8-25-20.pdf

Appendix

HELP Committee Democratic Staff State-Level Congregate Care Data Review

From June 1 – July 31, 2020, HELP Committee Democratic staff conducted a review of state-level data reporting on congregate care settings and current guidance from federal health agencies. Methodology of the review conducted and aggregate data results are included.

Guidance Review

Methodology

In conducting a review of current guidance from federal health agencies, Committee Democratic staff read, analyzed, and collected data from the following agencies: CDC, FEMA, CMS, ACL, HHC, SAMSHA, and VA. Data collected included: Setting, Audience, Content Type, and Content Specifics. Below includes data collected for each category:

Setting	Group Homes, Day Settings, Nursing Homes, Assistive Living Facilities, Skilled Nursing Facilities, Long-term Care Facilities, General – No setting Specified, Psychiatric Facilities/Hospitals, Psychiatric Residential Treatment Facilities, ICF-IDD, VA Community Providers, VA Health Care Network
Audience	Families, Caregivers, Older Americans, People with Disabilities, Facility Staff, Residents, Medicaid/Medicare Certified Facilities/Nursing Homes, State Administrators,
Content Type	Guidance, Checklist, Factsheet, Survey Activities, Toolkit, FAW, Letter, Worksheet, Resources/Recommendations, Response Plan
Content Specifics	CDC Everyday Prevention Protocols, Clean and disinfect home protocol, Medication and supply stock up, Use of PPE, Laundry work clothes, Crisis plan, Care Plan , Communication Plan, Restrict Visitors, Check workers and residents for fevers and symptoms, Limit activities within the facility, Designated IPC staff, Case data reported to NHSN LTCF, Educate Residents, Healthcare Personnel, and Visitors, Testing Plan, Designated Space and plan for Care and Monitor of Residents with COVID, Admission/Readmission plan, Reopening Procedures, Restrictions on Communal Rooms, Dedicated/Limited staff on unit, Telehealth

Results

From the review of guidance from the federal government (CDC, CMS, etc.), the data reported shows an emphasis on nursing homes, long term care facilities, and assisted living facilities rather than other categories of congregate care settings.

Documents Reviewed

Agency	Number Reviewed
CDC	14
FEMA	2
CMS	17
ACL	1

Guidance Per Setting

Type of Facility	Number of Documents
Group Homes	2
Day Settings	1
Nursing Homes	21
Assistive Living	3

HHS	2
SAMHSA	1
VA	2

Skilled Nursing	2
Long-term Care	5
Psychiatric Facilities/Hospitals	2
Psychiatric Residential Treatment Facilities	1
ICF-IDD	1
VA Community Providers	1
VA Health Care Network	1
General – No setting Specified	6

State-Level Reporting Review

Methodology

In conducting a review of state-level reporting on congregate care settings, Committee Democratic staff read, analyzed, and collected data from all 50 states and the District of Columbia (D.C.). States' coronavirus public data websites were used to collect congregate care facility data being reported. Websites were compiled into an excel spreadsheet and states were tracked on the various indicators below. Data collected included: Congregate Care Setting, Definition of Congregate Care, Resident/Staff, Disaggregation, and Timing. Below includes data collected for each category:

Setting	Nursing Homes, Long-Term Care Facilities, Assisted Living Facilities, Rehabilitation Facilities, Psychiatric Hospitals, Mental Health Facilities, Institutions for People with Disabilities, Group Homes, VA Hospitals/Facilities, Day Facilities for People with Disabilities
Definition	Long-term Care Facilities including or not the above settings
Resident/Staff	Data collected on Resident, Staff, or Both
Disaggregation	Data disaggregated by Race, Income, Disability, LGBTQIA+, Ethnicity, or Age
Timing	Point-in-time Testing or Continuous

Results

Of a review of all 50 States and D.C., 10 states did not report any data on any congregate care settings. There are varying definitions of congregate care and of long-term care facilities (whether that includes nursing homes and assisted living facilities or not).

Type of Facility	**Number of States Reporting**
Nursing Homes	30
Long Term Care Facilities	27
Assisted Living	26

Rehabilitation Facilities	8
Psychiatric Hospitals	2
Mental Health Facilities	2
Institutions for PWD	9
Group Homes	7
VA hospitals/ facilities	1
Day Facility for PWD	1
Data not available or website down during review	12
Reporting on more than one facility type	30
Reporting on only one facility type	9

Additionally, seven states disaggregate data on some combination of race, income, disability, LGBTQIA+, etc. and 29 states collected data on residents and staff. There is a variance of whether this data is combined and reported as one or disaggregated. Of the 35 states that detailed the type of testing they provide to residents and staff, 31 provide continuous, on-going testing. Four states provide point-in-time testing for the data collection efforts.

Data Includes Residents, Staff or Both

Inclusion	Number of States
Residents	6
Staff	0
Both	29
Other	16

Continuous vs. Point in Time Testing

Type of Testing	Number of States
Continuous, on- going Testing	31
Point in Time Testing	4
Did not report or did not specify	16