



PETITION

OF AMERICAN CIVIL LIBERTIES UNION, SERVICE EMPLOYEES INTERNATIONAL UNION, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, AUTISTIC SELF-ADVOCACY CENTER, DISABILITY RIGHTS EDUCATION AND DEFENSE FUND, NATIONAL COUNCIL ON INDEPENDENT LIVING, PARTNERSHIP FOR INCLUSIVE DISASTER STRATEGIES AND WORLD INSTITUTE ON DISABILITY

INTRODUCTION

Less than one-half of one percent of the U.S. population lives in a nursing home.¹ Yet, to date, according to data published by the U.S. Department for Health and Human Services (HHS), at least 29,497 residents and staff of nursing homes in the United States have died of the coronavirus²—27 percent of total deaths to date.³ Staff death rates exceed even those of staff working in federal prisons and meat packing facilities, based on the data that have been reported.⁴

¹ See National Center for Health Statistics, HHS, *Long-Term Care Providers and Services Users in the United States, 2015-2016* [hereinafter *Long-Term Care Statistics*], at 76 (Feb. 2019) (identifying 1,347,600 nursing home residents in the United States in 2016); *U.S. and World Population Clock*, U.S. Census (last visited June 22, 2020) (calculating United States population as of Dec. 31, 2016 was 324,070,652).

² CMS, *COVID-19 Nursing Home Data* [hereinafter *CMS Nursing Home Data*] (last updated June 18, 2020), <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg> (including data submitted as of week ending June 7, 2020).

³ *Coronavirus Disease 2019 (COVID-19) in the U.S.*, Centers for Disease Control and Prevention (last visited June 22, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html> (reporting daily death count, which was 109,192 as of June 7, 2020).

⁴ *Compare Employees on nonfarm payrolls by industry sector and selected industry detail*, U.S. Bureau of Labor Statistics (June 5, 2020), <https://www.bls.gov/news.release/empsit.t17.htm> (reporting 1,534,300 workers employed in nursing home facilities) and *CMS Nursing Home Data*, *supra* note 2 (data current as of June 18, 2020 showing 534 staff deaths, or a 0.036% staff death rate) *with COVID-19*

These numbers, while shocking, almost certainly understate the death toll in nursing homes.⁵ In at least 28 states, long-term care residents and staff account for 50 percent or more of total state deaths.⁶ Some states have reported a far higher share of deaths in long-term care facilities, including: Rhode Island (81 percent); Minnesota (77 percent); North Dakota (76 percent); Connecticut (73 percent); Pennsylvania (68 percent); and Delaware (64 percent).⁷

The data—to the extent they exist—are not much better in other congregate settings where people with disabilities live. Intermediate care facilities for people

Coronavirus, Federal Bureau of Prisons (last visited June 22, 2020), <https://www.bop.gov/coronavirus/> (reporting that as of June 22, 2020, of the approximately 36,000 Bureau of Prison staff members, there has been one death attributed to COVID-19, or a 0.0003% staff death rate); Jonathan W. Dyal, et al., *COVID-19 Among Workers in Meat and Poultry Processing Facilities—19 States, April 2020*, 69 *Morbidity and Mortality Weekly Report* 557–561 (May 8, 2020), <http://dx.doi.org/10.15585/mmwr.mm6918e3> (reporting that of approximately 130,000 meat packing workers, 20 COVID-related deaths were reported, or a 0.015% staff death rate).

⁵ For example, under the reporting guidelines adopted by the Centers for Medicare and Medicaid Services (CMS), nursing homes are not required to report deaths or cases that occurred before May 8, despite the fact that the first reported nursing home outbreaks occurred in February. The New York Times, Wall Street Journal, and Kaiser Family Foundation report significantly higher numbers of deaths in long-term care facilities—all reporting more than 50,000 deaths. See Kaiser Family Foundation, *State Reports of Long-Term Care Facility Cases and Deaths Related to COVID-19 (as of June 18, 2020)*, *State Data and Policy Actions to Address Coronavirus* [hereinafter *State Reports*] (last visited June 18, 2020) <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus> (reporting 50,185 deaths in long-term care facilities from 41 states); *Coronavirus in the U.S.: Latest Map and Case Count*, N.Y. Times (last visited June 20, 2020), <https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html> (reporting that more than 51,000 residents and employees nursing homes and other long-term care facilities have died, or 40 percent of the deaths in the United States); Jon Kamp & Anna Wilde Mathews, *As U.S. Nursing-Home Deaths Reach 50,000, States Ease Lockdowns*, Wall Street Journal (June 16, 2020) (reporting more than 51,000 Covid-19-associated deaths tied to long-term-care facilities, including nursing homes and assisted-living sites).

⁶ *State Reports*, *supra* note 5.

⁷ *Id.*

with developmental disabilities,⁸ group homes,⁹ and psychiatric facilities¹⁰ have also faced horrific COVID-19 outbreaks with widespread infections and deaths.

This is a human tragedy. And it is a tragedy that stems directly from decisions that HHS, and its agencies, the Centers for Medicare and Medicaid Services (CMS), Center for Clinical Standards and Quality (CCSQ), and the Centers for Disease Control and Prevention (CDC), have failed to protect the health and lives of residents and staff in these congregate settings. Collectively, HHS and these agencies delayed the effort to monitor the extent of the problem, significantly curtailed the inspection and enforcement program, waived basic patient and staff protections, and failed to issue clear, robust COVID-19 specific infection prevention and control directions for those facilities to follow. HHS has provided even less direction for other congregate facilities where people with disabilities live. CDC's and CMS's guidance for group homes for individuals with disabilities, intermediate care facilities for individuals with intellectual disabilities, and psychiatric facilities (collectively, "congregate settings for people with disabilities") is incomplete and equivocal. Since the COVID-19 crisis began, these agencies have left facilities without crucial direction in managing their COVID-19 response.

This tragedy is also a civil rights violation, landing disproportionately on people with disabilities, Black and Latinx people, and women. All nursing home

⁸ A state developmental center in Cook County, Illinois, has reported 220 cases and 6 deaths. Ill. Dep't of Human Servs., *COVID-19 Confirmed Positive Cases* (last updated June 19, 2020), <https://www.dhs.state.il.us/page.aspx?item=123651>. Another developmental disability center in Cook County has reported an additional 94 cases and 10 deaths. Jennifer Smith Richards & Jodi S. Cohen, *'Our Residents Are in Crisis': In State-Run Homes for Adults with Disabilities, COVID-19 Spread Quickly*, Chi. Trib. (May 22, 2020), <https://www.chicagotribune.com/coronavirus/ct-coronavirus-illinois-developmental-centers-20200522-phcgivbl3bbtvdzuaqjmmygjc4-story.html>.

⁹ In one group home in Oklahoma, four out of six residents were hospitalized for COVID-19. Clifton Adcock, *Pawnee County Group Home Residents Under Quarantine Following COVID-19 Death of Sheltered Workshop Employee*, Frontier (Mar. 27, 2020), <https://www.readfrontier.org/stories/pawnee-county-group-home-residents-under-quarantine-following-covid-19-death-of-sheltered-workshop-employee>.

¹⁰ St. Elizabeth's psychiatric hospital in Washington, D.C., has 202 confirmed cases and 14 deaths, including both residents and personnel. *Human Services Agency COVID-19 Case Data*, Government of the District of Columbia (June 22, 2020), <https://coronavirus.dc.gov/page/human-services-agency-covid-19-case-data>. Ancora psychiatric hospital in New Jersey, a state-run psychiatric hospital, has reported 89 cases amongst residents, 101 cases amongst staff, and 4 deaths of residents. *New Jersey COVID-19 Dashboard*, NJ Health (last updated June 22, 2020), https://www.nj.gov/health/cd/topics/covid2019_dashboard.shtml.

residents are people with disabilities; nearly seventy percent are women.¹¹ The grossly disproportionate deaths of people with disabilities in this pandemic are not inevitable, and not an accident. Despite the passage of the Rehabilitation Act,¹² despite the passage of the Americans with Disabilities Act,¹³ and despite the Supreme Court’s decision in *Olmstead v. L.C.*,¹⁴ our society continues its practice of warehousing people with disabilities and seniors in crowded, understaffed buildings,¹⁵ with poor resources and little oversight. These practices and these deaths arise not just from the pandemic, but from longstanding, entrenched attitudes that people with disabilities and seniors simply do not count as much as others.

Nursing homes with predominantly Black and Latinx residents have been twice as likely to be hit by COVID-19 as predominantly white nursing homes, even when controlling for factors such as the size of the home, the infection rate in the surrounding county, the population density in the neighborhood, the number of residents on Medicaid or Medicare, and the home’s government rating.¹⁶ Yet “[m]ore than 60 percent of nursing homes where at least a quarter of the residents are [B]lack or Latin[x] have reported at least one coronavirus case,” a rate double that where Black and Latinx people are less than 5 percent of the population.¹⁷ Black residents make up about 14 percent of nursing home residents, and Latinx residents make up about 5 percent.¹⁸

¹¹ See CMS, *Nursing Home Data Compendium 2015 Edition* [hereinafter *Nursing Home Compendium*] at 199 (2015), https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/nursinghomedatacompendium_508-2015.pdf; see also *Long-Term Care Statistics*, *supra* note 1, at 78 (reporting similar estimates for 2016 based in part on administrative records from CMS on nursing homes).

¹² 29 U.S.C. § 701 *et seq.*

¹³ 42 U.S.C. § 12101 *et seq.*

¹⁴ 527 U.S. 581 (1999).

¹⁵ See, e.g., Fangli Geng, David G. Stevenson, & David C. Grabowski, *Daily Nursing Home Staffing Levels Highly Variable, Often Below CMS Expectations*, 38 *Health Affairs* 1095, 1095, 1099 (2019) (finding that “the data suggest that a large proportion of nursing homes often have daily staffing below CMS’s case-mix-adjusted expected staffing levels” and “75 percent of nursing homes were almost never in compliance with what CMS expected their [registered nurse] staffing level to be, based on residents’ acuity”).

¹⁶ Robert Gebeloff et al., *The Striking Racial Divide in How Covid-19 Has Hit Nursing Homes*, *N.Y. Times* (May 21, 2020), <https://www.nytimes.com/article/coronavirus-nursing-homes-racial-disparity.html>.

¹⁷ *Id.*

¹⁸ *Nursing Home Compendium*, *supra* note 11, at 179.

The workforce serving our nursing homes and other congregate settings for people with disabilities are disproportionately women of color. Eighty-two percent of aides in long-term care facilities are women;¹⁹ nearly one third of aides are Black;²⁰ 16 percent are Latinx;²¹ 23 percent are immigrants.²² Aides in these facilities help to bathe, dress, and feed residents. This work does not allow for social distancing. Staff are paid so little,²³ or given so few hours, that many have to work multiple jobs, thus increasing the risk of contracting and spreading the virus. And many staff have insufficient paid sick leave to cover quarantine—or no paid sick leave at all—forcing them to choose between their health and much-needed income.²⁴

HHS did not prioritize providing personal protective equipment (PPE) for staff in nursing homes and other congregate settings for people with disabilities.²⁵

¹⁹ Sarah True, et al., *COVID-19 and Workers at Risk: Examining the Long-Term Care Workforce*, Kaiser Family Foundation (Apr. 23, 2020), <https://www.kff.org/medicaid/issue-brief/covid-19-and-workers-at-risk-examining-the-long-term-care-workforce/>.

²⁰ *Id.*

²¹ *Id.*

²² Leah Zallman et al., *Care for America's Elderly and Disabled People Relies on Immigrant Labor*, 38 *Health Affairs* 919, 923 (2019), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05514>.

²³ As of 2018, more than 30% of aides and personal care workers made less than \$15,000 per year; sixty-eight percent made less than \$30,000. Sarah True, et al., *COVID-19 and Workers at Risk: Examining the Long-Term Care Workforce*, Kaiser Family Foundation (Apr. 23, 2020), <https://www.kff.org/medicaid/issue-brief/covid-19-and-workers-at-risk-examining-the-long-term-care-workforce/>.

²⁴ In an online survey conducted by The Service Employees International Union (SEIU) from May 20–June 7, 2020, of 2,397 nursing home workers living in the U.S., 64% of respondents stated they had no paid sick leave provided by their employer. See *SEIU COVID-19 Nursing Home Survey Report* (June 2020), <https://seiufacultyforward.wufoo.com/reports/seiu-covid19-nursing-home-survey-report-0620>. This lack of paid sick time was not remedied by the Families First Coronavirus Response Act's (FFCRA) emergency leave provisions. Despite the law's ostensible provision of emergency paid sick leave to workers most in need, the law also allowed employers of certain "healthcare providers" to simply opt-out of providing paid leave to their staff, even where it was needed to allow workers to self-quarantine after actual or suspected exposure to a person with COVID-19. The U.S. Department of Labor's rule implementing the FFCRA's paid leave provisions specifically allowed nursing home facility employers to opt-out of the law's paid leave requirements for *all staff* of nursing homes. See 85 Fed. Reg. 19326 (Apr. 1, 2020), codified at 29 C.F.R. Part 826.

²⁵ Jordan Rau, *Nursing Homes Run Short Of COVID-19 Protective Gear As Federal*

Nor did it issue clear or sufficient PPE requirements, despite the manifest importance of PPE for the health and safety of both staff and residents. Nor did HHS prioritize testing for either residents or staff. These policy choices have had particularly dire and deadly consequences for staff as well as for the family and community members to whom they return each day.

These human and civil rights violations lie at the feet of HHS. HHS has abdicated its responsibilities in at least four ways that have unnecessarily magnified the death toll for people who live in nursing homes and other congregate settings for people with disabilities:

- **Hiding the scope of the problem.** Until just this last month, HHS did not require that nursing homes report COVID-19 deaths or infections in nursing homes to the federal government. Nor did it require that nursing homes report to residents and their families that there were infections in a facility. Those requirements, which went into effect on May 8, 2020, came only after public outcry at nursing home deaths. Even now, CMS does not require reporting of deaths prior to May 8, 2020.²⁶ HHS still does not require reporting in psychiatric facilities, in intermediate care facilities for individuals with intellectual disabilities, or in group homes. HHS still does not require reporting of race, ethnicity, sex, primary language, disability status, and age of those who have perished. And in nursing homes, HHS also suspended reporting of staffing levels—which it admits is critical to patient care.²⁷

Response Falters, NPR (June 11, 2020), <https://www.npr.org/sections/health-shots/2020/06/11/875335588/nursing-homes-run-short-of-covid-19-protective-gear-as-federal-response-falters>; Peter Whoriskey et al., *Hundreds of Nursing Homes Ran Short on Staff, Protective Gear as More Than 30,000 Residents Died During Pandemic*, Wash. Post (June 4, 2020), <https://www.washingtonpost.com/business/2020/06/04/nursing-homes-coronavirus-deaths/>; see also CDC, *Strategies to Optimize the Supply of PPE and Equipment* (last reviewed May 18, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/hcp/ppe-strategy/index.html>.

²⁶ There is some ambiguity as to the dates for which nursing homes are required to report deaths. The interim final rule with comment period (“IFC”) which established the reporting requirements states that the “reporting requirements are applicable on the effective date of this” interim final rule with comment period,” which was on May 8, 2020, 85 Fed. Reg. 27550-01. However, the IFC also “require[s] facilities to electronically report information about COVID-19 in a standardized format specified by the Secretary,” *id.*, and the standardized form instructs nursing homes to “include counts since May 1, 2020.” see CDC, *Instructions for Completion of the COVID-19 Long-term Care Facility (LTCF): Resident Impact and Facility Capacity Form* (CDC 57.144) (May 2020), <https://www.cdc.gov/nhsn/pdfs/covid19/lctf/57.144-toi-508.pdf>.

²⁷ CMS, *Staffing Data Submission Payroll Based Journal (PBJ)* [hereinafter *PBJ*] (last

- **Creating the tinderbox and letting it burn.** Before COVID-19, HHS knew that many nursing homes did not have proper infection control procedures. It knew that nursing homes were understaffed. It knew that staff were not properly trained. When COVID-19 surfaced in this country, HHS knew nursing homes were ill-prepared to manage the crisis. But in response to the pandemic, HHS eased inspections, lifted reporting requirements, waived training requirements, and failed to prioritize PPE and testing.
- **Failing to reduce crowding in nursing homes and other congregate settings for people with disabilities,** both before the COVID-19 pandemic, and once the pandemic hit. The Supreme Court’s *Olmstead* decision created an obligation to reduce the institutionalization of people with disabilities. CMS has Home and Community Based Service programs to expand and support community living. Yet, HHS did little to advance this mandate. In the face of COVID-19, HHS should have recognized the dangers in these congregate settings; it should have recognized that a lower census would make social distancing possible. But HHS has taken little action to divert people from entering nursing homes or other congregate settings for people with disabilities or to increase appropriate discharges from such settings for those residents who wish to move to the community.
- **Issuing incomplete, inconsistent, and confusing guidance,** that, in its omissions and directives, responds more to the needs of nursing home owners than nursing home residents and staff. For example, HHS instructs nursing homes to admit residents without testing for COVID-19, but does not require these new admissions to be separated from others – criteria that keep up the population of the home at the expense of the health and well-being of the residents. The guidance to other congregate settings for people with disabilities is even more threadbare. For example, CDC tells group home administrators that they “may want to consider screening residents, workers, and essential volunteers for signs and symptoms of COVID-19.”²⁸

This week marks the twenty-first anniversary of *Olmstead v. L.C.*, the landmark Supreme Court decision for the disability rights community. In this decision, the United States Supreme Court recognized that “unjustified institutional

updated June 5, 2020), <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Staffing-Data-Submission-PBJ>.

²⁸ CDC, *Guidance for Group Homes for Individuals with Disabilities* [hereinafter *Guidance for Group Homes*] (last reviewed May 27, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/community/group-homes.html>.

isolation of persons with disabilities is a form of discrimination;” that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment;” and that such confinement “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”²⁹

If COVID-19 has done nothing else, it has demonstrated the danger of congregate settings, and the deadly consequences of our ongoing unwarranted assumptions that people with disabilities are unworthy of our resources and attention.

Consistent with HHS’s mandate to save lives and protect people from health threats today, the American Civil Liberties Union (ACLU), Service Employees International Union (SEIU), American Association of People with Disabilities (AAPD), Autistic Self-Advocacy Center (ASAN), Disability Rights Education and Defense Fund (DREDF), National Council on Independent Living (NCIL), Partnership for Inclusive Disaster Strategies, and World Institute on Disability (WID) petition HHS and its agencies CMS, CCSQ, and CDC, to take swift, clear, and essential action to correct the flaws in their approach to the COVID-19 emergency and to modify their previously issued directives to save the lives of people living and working in nursing homes and other congregate settings for people with disabilities. The need for this action is urgent to address the current rise of COVID-19 cases in some states and to prepare before the next wave of COVID-19 sweeps through the nation’s nursing homes, intermediate care facilities for people with developmental disabilities, group homes, and psychiatric facilities.

BACKGROUND

1. HHS’s, CMS’s, CCSQ’s, and CDC’s Obligations to People with Disabilities

HHS’s mission is “to enhance the health and well-being of all Americans, by providing for effective health and human services.”³⁰ CMS aims to “strengthen and modernize the Nation’s health care system [and] to provide access to high quality care and improved health at lower costs.”³¹ CCSQ “[s]erves as the focal point for all

²⁹ *Olmstead*, 527 U.S. at 600–01.

³⁰ HHS, *Introduction: About HHS* (Feb. 28, 2018), <https://www.hhs.gov/about/strategic-plan/introduction/index.html#:~:text=Mission%20Statement,public%20health%2C%20and%20social%20services>.

³¹ *Centers for Medicare and Medicaid Services*, USA.gov (last visited June 20, 2020), <https://www.usa.gov/federal-agencies/centers-for-medicare-and-medicaid->

quality, clinical, medical science issues, survey and certification, and policies for CMS' programs.”³² The CDC's mandate is to “save lives and protect people from health threats.”³³ Pursuant to these missions, HHS is charged with protecting the more than 1.3 million people who live in the approximately 15,640 nursing homes in the United States³⁴ and the people who live in other congregate settings for people with disabilities, certified by Medicaid, Medicare, or both.

HHS and its agencies have two overarching obligations to those in nursing homes and other congregate settings for people with disabilities. HHS is obligated to support the deinstitutionalization of people with disabilities in these facilities. And HHS has specific statutory obligations to protect the health of those who remain in these institutions, including nursing homes.

Under federal law, nursing homes that participate in Medicare and Medicaid must meet certain specified requirements.³⁵ These standards include requirements that nursing facilities “establish and maintain an infection control program designed . . . to help prevent the transmission of disease and infection.”³⁶ CMS monitors compliance with the nursing home standards, including infection control, with an inspection survey protocol that sets the criteria by which state agencies assess compliance with the federal quality standards.³⁷ Nursing homes that fail to meet federal quality standards can be cited with a deficiency, with possible penalties ranging from civil money penalties, to denial of Medicaid or Medicare payment, to termination from the Medicaid or Medicare program.³⁸ CMS also surveys intermediate care facilities for individuals with intellectual disabilities³⁹

services#:~:text=The%20CMS%20seeks%20to%20strengthen,improved%20health%20at%20lower%20costs.

³² CMS, *Center for Clinical Standards and Quality* (last modified June 1, 2020), https://www.cms.gov/About-CMS/Agency-Information/CMSLeadership/Office_CCSQ.

³³ CDC, *Mission, Role and Pledge* (May 13, 2019), <https://www.cdc.gov/about/organization/mission.htm#:~:text=As%20the%20nation's%20health%20protection,and%20responds%20when%20these%20arise>.

³⁴ See *Long-Term Care Statistics*, *supra* note 1, at 6, 78; *Nursing Home Compendium*, *supra* note 11, at 1-2, 12.

³⁵ 42 U.S.C. § 1395i-3; 42 U.S.C. § 1396r; 42 C.F.R. § 483.1.

³⁶ 42 U.S.C. § 1395i-3(d)(3); 42 U.S.C. § 1396r(d)(3)(A).

³⁷ 42 U.S.C. § 1395i-3(g); 42 U.S.C. § 1396r(g); 42 C.F.R. § 488.305; 42 U.S.C. § 1395i-3(g)(2)(A)(ii)(I); 42 U.S.C. § 1396r(g)(2)(A)(ii)(I).

³⁸ 42 U.S.C. §§ 1395i (h)(2)(B), 1396r(h)(2)(A); 42 C.F.R. § 488.406.

³⁹ *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)*, CMS (last modified Nov. 22, 2016), <https://www.cms.gov/Medicare/Provider-Enrollment->

and psychiatric facilities.⁴⁰

2. The Risk COVID-19 Presents to People with Disabilities in Nursing Homes and Other Congregate Settings

On January 21, 2020, the United States reported its first case of COVID-19, a novel and extremely contagious respiratory disease causing severe illness and death, particularly among elderly populations.⁴¹ By January 30, the World Health Organization Director General declared that the COVID-19 outbreak constitutes a Public Health Emergency of International Concern and, one day later, HHS declared a national public health emergency to respond to COVID-19.⁴² The virus is known to spread “primarily through droplets of saliva or discharge from the nose when a person coughs or sneezes.”⁴³ Infected individuals may transmit the virus to others even if they are asymptomatic, making it impossible to avoid the virus’s spread solely by isolating individuals who are coughing, feverish, or experiencing other COVID-19 symptoms.⁴⁴

and-Certification/CertificationandCompliance/ICFIID.

⁴⁰ *Psychiatric Residential Treatment Facilities*, CMS (last modified Nov. 30, 2016), <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/PRTF>.

⁴¹ Anita Patel and Daniel B. Jernigan, *Initial Public Health Response and Interim Clinical Guidance for the 2019 Novel Coronavirus Outbreak — United States, December 31, 2019-February 4, 2020*, 59 *CDC Morbidity and Mortality Weekly Report* 140 (Feb. 7, 2020), <https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6905e1-H.pdf>.

⁴² *Id.*

⁴³ World Health Organization, *Coronavirus - Overview*, https://www.who.int/health-topics/coronavirus#tab=tab_1 (last visited June 21, 2020).

⁴⁴ See Melissa M. Arons *et al.*, *Presymptomatic SARS-CoV-2 Infections and Transmission in a Skilled Nursing Facility*, 382 *N. Eng. J. Med.* 2081, 2081 (2020), <https://doi.org/10.1056/NEJMoa2008457> (studying the spread of SARS-CoV-2 in a skilled nursing facility and finding that more than half the residents who tested positive were asymptomatic at the time of testing); U.C. Davis Health, *COVID-19 FAQs for Health Professionals* (last updated June 1, 2020), <https://health.ucdavis.edu/coronavirus/resources/covid-19-faqs-for-health-professionals.html> (“According to the CDC, 35% of all people with COVID-19 are asymptomatic. However, those individuals are still as infectious as people with symptoms.”); CDC, *COVID-19 Pandemic Planning Scenarios* (last reviewed May 20, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/hcp/planning-scenarios.html>; Xi He *et al.*, *Temporal Dynamics in Viral Shedding and Transmissibility Of COVID-19*, 26 *Nature Medicine* 672–675, 672 (2020) (showing that 44 percent of people in a study sample were infected by individuals who were pre-symptomatic).

Core guidance issued by the CDC to prevent the spread of COVID-19 was simple: (i) basic infection prevention strategies, including thorough and regular handwashing—already a deficiency in nursing homes before COVID-19⁴⁵—and donning of PPE for medical staff; (ii) strategies to prevent community spread, including reducing personal interactions, using masks, and engaging in social distancing—difficult in facilities where two or more people share a room and bathroom with staff moving frequently between rooms; and (iii) infection control measures once COVID-19 was present, including increased screening and testing, contact tracing, and implementation of quarantine and medical isolation protocols.

Social distancing and medical isolation, in particular, were recommended for those at greatest risk. That includes virtually all residents of nursing homes, by virtue of their age or health conditions. An estimated 85 percent of those living in nursing homes are over the age of 65, with most between 75 to 95 years old.⁴⁶ In addition, most nursing home residents have preexisting health conditions that put them at higher risk from serious complications and death from COVID-19. About three-quarters have high blood pressure or hypertension, and nearly 40 percent have heart disease.⁴⁷ Because of this, “the health and safety of the nation’s 1.4 million nursing home residents—who are often in frail health and living in close proximity to one another—has been a particular concern.”⁴⁸ And while the data are limited, that which are available suggest that case fatality rates in intermediate care facilities for people with developmental disabilities, group homes, and psychiatric facilities are also far higher than for the general population, evidencing the urgent need for government action.⁴⁹

⁴⁵ See Government Accountability Office, *Infection Control Deficiencies Were Widespread and Persistent in Nursing Homes Prior to COVID-19 Pandemic* [hereinafter *GAO Infection Control Deficiencies*], GAO-20-576R, at 4 (May 20, 2020), <https://www.gao.gov/assets/710/707069.pdf> (finding, in an audit of CMS data between 2013 and 2017, that “most nursing homes had infection control deficiencies prior to the covid-19 pandemic; half of these homes had persistent problems” including “where nursing home staff did not regularly use proper hand hygiene or failed to implement preventive measures during an infectious disease outbreak, such as isolating sick residents and using masks and other personal protective equipment to control the spread of infection. Many of these practices can be critical to preventing the spread of infectious diseases, including COVID-19.”).

⁴⁶ *Nursing Home Compendium*, *supra* note 11, at 181.

⁴⁷ *Long-term Care Statistics*, *supra* note 1, at 78.

⁴⁸ *GAO Infection Control Deficiencies*, *supra* note 45.

⁴⁹ See, e.g., Joseph Shapiro, *COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities*, NPR, (June 9, 2020), <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili> (analyzing data from Pennsylvania and finding 801

HHS, AND ITS AGENCIES CMS, CCSQ, AND CDC, MUST IMMEDIATELY RESCIND OR MODIFY THEIR PRIOR AGENCY ACTION IN ORDER TO PROTECT RESIDENTS AND STAFF OF CONGREGATE SETTINGS FOR PEOPLE WITH DISABILITIES

Petitioners request that HHS, and its agencies, CMS, CCSQ, and CDC, confront the crisis in nursing homes and other congregate settings for people with disabilities by (i) requiring true transparency and accountability; (ii) reducing the census in facilities by diverting admissions and transitioning people to community living; and (iii) protecting the residents and staff who remain.⁵⁰

I. REQUIRE TRANSPARENCY AND ACCOUNTABILITY

a. Mandate Reporting of All Deaths from the COVID-19 Pandemic

More than four months after HHS declared a national public health emergency, and nearly two months after President Trump declared the pandemic an emergency, HHS did not require nursing homes to report to the federal government the number of residents and staff who have been infected with or who have died from COVID-19.⁵¹ HHS delayed even requiring notification to residents and their families regarding COVID-19 infections and deaths inside nursing homes for this same time period.⁵² Only in May did HHS issue an interim final rule with comment period (“IFC”) requiring data collection and reporting.⁵³

confirmed cases and 113 deaths among people with intellectual disabilities and autism monitored by the state, for a case fatality rate of 14% and of the people receiving services from the NY office for people with DDs, 2,289 have tested positive for COVID-19 and 368 have died, for a case fatality rate of 16%.); Ill. Dep’t of Human Servs., COVID-19 Confirmed Positive Cases (last updated June 19, 2020), <https://www.dhs.state.il.us/page.aspx?item=123651> (showing about 23% of the residents of the state’s 7 state-run developmental centers have contracted COVID-19).

⁵⁰ The term “residents” is used to refer to all people living in nursing homes or other congregate settings for people with disabilities.

⁵¹ *Compare Letter from President Donald J. Trump on Emergency Determination Under the Stafford Act*, White House Statements & Releases (Mar. 13, 2020), <https://www.whitehouse.gov/briefings-statements/letter-president-donald-j-trump-emergency-determination-stafford-act/> with 85 Fed. Reg. 27550 (May 8, 2020).

⁵² 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. 27550 (May 8, 2020).

⁵³ *Id.*

The IFC that requires data reporting was not only late in coming, but also incomplete. It does not require reporting of infections or deaths prior to May 8—critical months when COVID-19 resulted in a devastating number of deaths in many nursing homes, indeed months when the devastation was the worst to date. And HHS and its agencies have still not required *any* reporting of COVID-19 infections and deaths in other congregate settings for people with disabilities, such as group homes, psychiatric facilities, and intermediate care facilities for people with developmental disabilities.

Failure to require comprehensive data conceals from the public the full scope of the problem, and thwarts attempts to assess the risk of entering or remaining in a particular facility. In other words, the IFC, as currently drafted, obscures the failure of the Administration to protect people with disabilities and seniors, as well as the people who care for them.

The data are also incomplete because HHS does not mandate reporting of demographic information, as required by 42 U.S.C. § 300kk, which stipulates that “any federally conducted or supported health care or public health program, activity or survey collects and reports, to the extent practicable . . . data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants.” As HHS has recognized, “Data improvement efforts enhance the ability of the public health and healthcare systems to identify and track disparities in health and health care, understand their correlates and consequences, and facilitate greater accountability for reducing them.”⁵⁴ As discussed above, the limited demographic data available indicate that there are significant health disparities in nursing homes and other congregate settings based on disability and race. Collecting this information is critical for transparency and policy-making purposes. Given that studies have shown age is a significant factor in the risk of COVID-19,⁵⁵ HHS should add age to the demographic information that it collects.

Additionally, HHS must increase transparency by requiring facilities to

⁵⁴ HHS, *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status* (Oct. 31, 2011), <https://aspe.hhs.gov/pdf-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>.

⁵⁵ Janko Nikolich-Zugich et al., *SARS-CoV-2 and COVID-19 in Older Adults: What We May Expect Regarding Pathogenesis, Immune Responses, and Outcomes*, 42 *Geroscience* 505, 508 (2020) (“Older adults are more susceptible to COVID-19 and are at significantly increased risk for morbidity and mortality.”); Zunyou Wu & Jennifer M. McGoogan, *Characteristics of and Important Lessons From the Coronavirus Disease 2019 (COVID-19) Outbreak in China: Summary of a Report of 72 314 Cases From the Chinese Center for Disease Control and Prevention*, 323 *JAMA* 1239–1242 (2020), (showing higher fatality rate in patients aged 70 or older).

report the number of discharges and evictions (or involuntary discharges) with other weekly data. This is essential to permit investigations to assess if nursing homes and other congregate settings for people with disabilities are appropriately reducing the census and to ensure that facilities are not evicting or involuntarily discharging residents to medically unsafe locations, a practice now emerging given CMS's increased reimbursement rate for people with COVID-19.⁵⁶

While CMS has recognized that monetary penalties are necessary to ensure nursing homes comply with the reporting requirements, the penalties imposed are inadequate—if a facility does not report by the fourth week after the IFC reporting requirements went into effect, “CMS will impose a per day (PD) CMP [civil monetary penalty] of \$1,000 for *one day* for the failure to report that *week* For each subsequent week that the facility fails to submit the required report, the noncompliance will result in an additional *one-day* PD CMP imposed at an amount increased by \$500.”⁵⁷ Not only is such a small penalty unlikely to incentivize a change in behavior, by assessing the CMP only once a week, rather than per day as CMS is authorized to do,⁵⁸ CMS has removed *any* incentive for facilities to report until the seventh day. Residents, staff, their families, and communities do not have days and weeks to spare before gaining access to this vital information.

Requested Actions:

HHS should modify the IFC to:

- (1) Require that all nursing homes and other congregate settings for people

⁵⁶ Jessica Silver-Greenberg & Amy Julia Harris, *They Just Dumped Him Like Trash: Nursing Homes Evict Vulnerable Residents*, N.Y. Times (June 21, 2020), <https://www.nytimes.com/2020/06/21/business/nursing-homes-evictions-discharges-coronavirus.html> (reporting that according to 22 watchdogs in 16 states, as well as dozens of elder-care lawyers, social workers and former nursing home executives, nursing homes are “are kicking out old and disabled residents—among the people most susceptible to the coronavirus —and shunting them into homeless shelters, rundown motels and other unsafe facilities.”); *id.* (“The New York Times contacted more than 80 state-funded nursing-home ombudsmen in 46 states for a tally of involuntary discharges during the pandemic at facilities they monitor. Twenty-six ombudsmen, from 18 states, provided figures to The Times: a total of more than 6,400 discharges, many to homeless shelters.”).

⁵⁷ CMS, *Interim Final Rule Updating Requirements for Notification of Confirmed and Suspected COVID-19 Cases Among Residents and Staff in Nursing Homes* [hereinafter *Updated Notification Requirements*] at 5 (May 6, 2020), <https://www.cms.gov/files/document/qso-20-29-nh.pdf>.

⁵⁸ See 42 C.F.R. § 488.430(a) (“CMS or the State may impose a civil money penalty for either the number of days a facility is not in substantial compliance with one or more participation requirements or for each instance that a facility is not in substantial compliance, regardless of whether or not the deficiencies constitute immediate jeopardy.”).

with disabilities that receive Medicaid or Medicare report:

- (a) Data required by the reporting module for national reporting of COVID-19 cases for nursing homes;
 - (b) All deaths (resident and staff) related to COVID-19 since January 1, 2020, including deaths of residents that occurred in hospitals or outside of the facility after the resident was transferred for medical care;
 - (c) All deaths (resident and staff), for any reason, since January 1, 2020;
 - (d) All discharges and evictions (or involuntary discharges).
- (2) Include demographic data (race, ethnicity, sex, primary language, disability status, and age) for infections, deaths, discharges, and evictions as part of the reporting module.
 - (3) Require that all data collected be made publicly available.
 - (4) Revise the fines for failure to report data required by the IFC to (i) accrue daily and to (ii) the maximum fines allowed under federal law.

b. Restore Reporting of All Staffing Levels

On March 30, CMS issued a blanket waiver of the timeline requirements for nursing homes to report their staffing data through the Payroll-Based Journal (PBJ) system.⁵⁹ CMS waived the reporting requirement, even though “CMS has long identified staffing as one of the vital components of a nursing home’s ability to provide quality care” and the payroll-based journal system was adopted to enable ready reporting.⁶⁰ As a result of the waiver, nursing homes have not been required to submit any data for this year. Yet these data are essential for the health and safety of residents.⁶¹

⁵⁹ CMS, *COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers* [hereinafter *CMS Blanket Waivers*] (last updated June 12, 2020) (“CMS is waiving 42 CFR 483.70(q) to provide relief to long-term care facilities on the requirements for submitting staffing data through the Payroll-Based Journal system.”).

⁶⁰ *PBJ*, *supra* note 27.

⁶¹ In addition, when reported, these data provide important information to potential residents and families choosing a nursing homes, through the CMS’s Five-Star Quality Rating System and through CMS’ Nursing Home Compare website. *Id.*; see Geng *et al.*,

Requested Action:

CMS should immediately rescind the waiver of the PBJ reporting requirements and require all facilities to report current staffing levels, as well as staffing levels for the time period of the waiver.

c. Rescind and Modify the Inspection Survey Protocol

CMS “is responsible for ensuring . . . nursing homes nationwide meet federal quality standards to participate in the Medicare and Medicaid programs.”⁶² Generally, CMS (through CCSQ) requires that a state survey agency inspect each nursing home once per year and conduct investigations in response to complaints and facility-reported incidents.⁶³ If a surveyor “determines that a nursing home violated a federal standard . . . a nursing home receives a deficiency code specific to that standard.”⁶⁴ Deficiencies are categorized by scope and severity.⁶⁵

The standard survey promulgated by CCSQ includes an assessment of a nursing home’s compliance with federal infection prevention and control standards as well as protections against abuse and neglect among other factors.⁶⁶ CMS also conducts standard surveys of intermediate care facilities for individuals with intellectual disabilities.⁶⁷

On March 4, 2020, CMS “suspend[ed] non-emergency inspections across the country” for both nursing homes and intermediate care facilities for individuals with intellectual disabilities.⁶⁸ On March 20, CMS and CCSQ issued a revised

supra note 15, at 1096 (“Reflecting the potential value of the PBJ data, CMS began using them as the source for staffing information in Nursing Home Compare and the Five-Star Quality Rating System in April 2018”); *see, e.g.*, Maggie Flynn, *COVID-19 Upended Star Rating Calculations for Nursing Homes—But Nothing is ‘Frozen,’* Skilled Nursing News (May 6, 2020), <https://www.skillednursingnews.com/2020/05/covid-19-upended-star-rating-calculations-for-nursing-homes-but-nothing-is-frozen/>.

⁶² *GAO Infection Control Deficiencies*, *supra* note 45, at 1.

⁶³ *Id.* at 1.

⁶⁴ *Id.*

⁶⁵ *Id.*

⁶⁶ *GAO Infection Control Deficiencies*, *supra* note 45, at 1; *see* 42 C.F.R. § 483.80(a)(1)-(4).

⁶⁷ CMS, *Prioritization of Survey Activities* [hereinafter *Prioritization of Survey Activities*], QSO-20-20-All (Mar. 20, 2020), <https://www.cms.gov/files/document/qso-20-20-allpdf.pdf>.

⁶⁸ CMS, *Suspension of Survey Activities* [hereinafter *Suspension of Survey Activities*], QSO-

survey limited to targeted infection control⁶⁹ and directed that “[i]f surveyors identify potential situations that may constitute immediate jeopardy during these focused surveys, they will investigate them. Otherwise, surveyors should not” investigate.⁷⁰ Additionally, CMS and CCSQ directed that state survey agencies *only* conduct “surveys related to complaints and facility-reported incidents . . . that are triaged at the Immediate Jeopardy . . . level.”⁷¹ On May 8th, CMS and CCSQ updated the survey instrument (referred to as QSO-20-29). Unlike the earlier guidance on surveys, the May 8th updated survey instrument does *not* discuss intermediate care facilities for individuals with intellectual disabilities.⁷² Most recently, CMS announced new standards related to inspections.⁷³ Those standards set a deadline for completion of infection control surveys, provided for enhanced enforcement of infection control deficiencies, and expanded survey activities.

This regime poses several issues of great import to the health and lives of residents and staff of nursing homes.

First, CMS and CCSQ have belatedly set a deadline for completion of the focused infection control surveys, on June 1st, five months after the emergency was declared and after tens of thousands of deaths in nursing homes. CCSQ finally announced, the deadline to complete the first infection control surveys will be July 31, nearly seven months after the emergency was declared. The response of CMS and CCSQ lacks recognition of the threat residents and staff of congregate settings face.

Moreover, prior to the COVID-19 outbreak, CMS data show that 82 percent of surveyed nursing homes had an infection prevention and control deficiency cited in one or more years from 2013 to 2017.⁷⁴ Since the COVID-19 outbreak, analysis of CMS’s data from the 5,724 targeted infection control surveys found that only 2.83

20-12-All (Mar. 4, 2020), <https://www.cms.gov/files/document/qso-20-12-all.pdf>.

⁶⁹ *Prioritization of Survey Activities*, *supra* note 67.

⁷⁰ CMS, *Nursing Home Five Star Quality Rating System Updates, Nursing Home Staff Counts, and Frequently Asked Questions* [hereinafter *Five Star Quality Rating System Updates*], QSO-20-28-NH (Apr. 24, 2020) (emphasis added); *see also* CMS, *Prioritization of Survey Activities*, *supra* note 67.

⁷¹ *Suspension of Survey Activities*, *supra* note 68.

⁷² *See Updated Notification Requirements*, *supra* note 57.

⁷³ CMS, *COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes* [hereinafter *COVID-19 Survey Activities*], QSO-20-31-All, at 4-5 (June 1, 2020).

⁷⁴ *GAO Infection Control Deficiencies*, *supra* note 45, at 4.

percent of nursing homes had any infection control deficiency.⁷⁵ Against the backdrop of widespread infection control failure, the 29,497 COVID-19-related deaths and 178,667 known or suspected infections in these facilities, this infection deficiency rate is simply not credible.

Surveys are a useful intervention only if they are effective at identifying the problem and lead to the corrective measures necessary to save lives. The inspection instrument is insufficient to capture what needs to be assessed if residents and staff are to be protected in the age of COVID-19. More specifically, CMS/CCSQ COVID-19 Focused Survey for Nursing Homes currently in use⁷⁶ fails to assess whether the institution is complying with CDC guidance in the following ways:

1. **Testing:** The survey inquires only about what the protocol is and how many people have been tested. It does not assess whether the institution is conducting facility-wide testing and whether it is engaged in periodic retesting.
2. **Mask use:** The survey seeks information only about whether staff wear masks “based on availability” or “as supply allows.” It also only inquires whether residents wear facemasks when “there is a case in the facility.” It does not inquire whether staff are required to use facemasks as a universal precaution.
3. **Medical isolation:** The survey inquires whether individuals with suspected COVID-19 are isolated if a private room is “available.” The survey should inquire whether suspected COVID-19 cases are medically isolated, full stop. Additionally, there is no survey question confirming that patients exposed to COVID-19 are medically isolated until their COVID-19 status is known.

⁷⁵ CMS, *Nursing Home COVID-19 Data and Inspections Results Available on Nursing Home Compare* (June 4, 2020), <https://www.cms.gov/newsroom/press-releases/nursing-home-covid-19-data-and-inspections-results-available-nursing-home-compare> (excel file titled “Deficiencies—March 4 to April 29 2020” available to download at <https://www.cms.gov/files/zip/nursing-home-infection-control-surveys.zip>) (providing data for surveys conducted between March 4 and April 29, 2020). As of June 12, CMS reports that 10,414 nursing homes have been surveyed, but data for surveys beyond April 29, 2020 are not available. *Id.* (excel title titled “Onsite Nursing Home Surveys March 1 – June 12 2020”); see Center for Medicare Advocacy, *Special Report – Nursing Homes Cited with Infection Control Deficiencies During the Pandemic: Poor Results In Health Inspections, Low Staffing Levels*, at 1 (June 17, 2020), <https://medicareadvocacy.org/star-ratings-for-nursing-homes-cited-during-pandemic/> (analyzing CMS’s data and finding only 163 infection control deficiencies found in 162 facilities out of the 5,724 facilities that were surveyed and for which data is available).

⁷⁶ *Updated Notification Requirements*, *supra* note 57, at 11–21.

4. **Dedicated Staffing:** The survey does not confirm that staff for patients known to have COVID-19 only work with known cases. Additionally, it does not confirm that staff who care for residents who are suspected of having COVID-19 or whose COVID-19 status is unknown are dedicated exclusively to those patients.
5. **PPE:** The survey instrument states that institutions will not be cited for failure to provide PPE, such as gowns, N95 respirators, and surgical masks, “if they are having difficulty obtaining these supplies for reasons outside of their control.” Inspectors should note and cite facilities if they are not providing PPE to staff.
6. **Disinfection:** The survey does not inquire whether a facility has increased routine disinfection of all surfaces.
7. **Staff lounges or eating areas:** The survey does not inquire whether social distancing or mask use is required in staff lounges and eating areas.

The revised criteria set out by CMS for inspection and enforcement allow too many nursing homes to ignore infection control problems.

Second, the current inspection does not require the identification of a Root Cause Analysis whenever there is an infection control deficiency.

Third, the COVID-19 Focused Survey for Nursing Homes removes *any* obligation on inspectors to inspect all facilities for other types of harm that residents are vulnerable to, including abuse, neglect, and other serious problems in facilities. Originally, the standard surveys were suspended for three weeks.⁷⁷ They have yet to be fully reinstated. The failure to assess this harm is all the more critical now, when nursing homes are short on staff and closed to almost all outsiders, including families. If HHS is to fulfill its job to protect health and safety, the surveys should include an assessment of whether any of the deficiencies that result in abuse, neglect, or exploitation are present.

CMS’s recent announcement—permitting states to expand beyond the focused infection control survey—does not remedy this problem.⁷⁸ Expanded surveys remain limited and may start only when a state has entered Phase 3 of the Nursing Home Reopening Guidance, or at a state’s discretion.⁷⁹

⁷⁷ *Suspension of Survey Activities*, *supra* note 68.

⁷⁸ *Five Star Quality Rating System Updates*, *supra* note 70.

⁷⁹ CMS, *Nursing Home Reopening Recommendations for State and Local Officials*, QSO-20-30-NH (May 18, 2020), <https://www.cms.gov/files/document/qso-20-30-nh.pdf>.

Requested Actions:

CMS and CCSQ should:

- (1) Rescind and modify the QSO-20-29-NH to:
 - (a) Include infection prevention and control standards in the inspection survey protocol consistent with the above noted inadequacies;
 - (b) Include for all facilities the “standard” inspection survey elements that assess abuse, neglect, and exploitation; and
 - (c) Require the survey for all congregate settings for people with disabilities that are subject to CMS oversight and inspection.
- (2) Rescind and modify its guidance of June 1 to require a Root Cause Analysis, and notification of the State Long-Term Care Ombudspeople, for every deficiency associated with Infection Control requirements.
- (3) Given the suspension of the “Standard” survey, respond to all complaints and facility-reported incidents at the “actual harm” as well as “immediate jeopardy” level.

II. REDUCE THE CENSUS IN CONGREGATE SETTINGS

HHS, and its agencies, have completely failed to wield the many policy and funding tools at their disposal to ensure that residents of nursing homes and other congregate settings for people with disabilities have alternative and safer places to stay and receive care. Despite HHS’s legal obligation to support independent living wherever and whenever possible,⁸⁰ and despite the existence of programs such as Home and Community Based Services,⁸¹ HHS has failed to direct, support, or encourage states and nursing homes and other congregate settings for people with disabilities to safely and appropriately reduce their nursing home population.⁸²

⁸⁰ *Olmstead v. L.C.*, 527 U.S. 581 (1999); Section 504 of the Rehabilitation Act, 29 U.S.C. § 794.

⁸¹ *Home & Community Based Services*, Medicaid.gov <https://www.medicaid.gov/medicaid/home-community-based-services/index.html> (last visited June 22, 2020).

⁸² The CDC has required such consideration in correctional and detention facilities. See CDC, *Interim Guidance on Management of Coronavirus Disease 2019 (COVID-19) in Correctional and Detention Facilities* (reviewed May 7, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/community/correction-detention/guidance->

Despite the alarming death rates in the homes, the inability of many facilities to comply with basic prevention and inspection measures (social distancing, regular testing, PPE), staffing shortages, and preexisting deficiencies in infection control compliance—HHS has taken more steps to support nursing home operators than to support nursing home residents. Indeed, since the onset of the pandemic, CMS has waived the one program that is intended to divert people with disabilities from nursing homes, the PASSR program (Pre-Admission Screening and Annual Resident Review).⁸³ Pursuant to their obligations under Section 504 of the Rehabilitation Act, the agencies must take all steps to reduce the population of nursing homes and other congregate settings for people with disabilities, in a framework that prioritizes the health and safety of residents and staff.

Requested Actions:

- (1) CMS should immediately rescind the waiver of the PASRR program.
- (2) As part of the IFC, HHS and CMS should require that no congregate setting for people with disabilities should accept new residents who have not been through diversion assessment and planning and make clear that, at least during the pendency of this pandemic, if an appropriate housing option other than a congregate facility is available, and the resident consents, that housing options should be the first choice for placement.
- (3) In conjunction with the IFC, and in furtherance of taking all appropriate steps to reduce the census for those residents who wish to move to the community, HHS and CMS should:
 - (a) Issue guidance setting forth for states all options available to support alternatives to nursing homes and other congregate settings for people with disabilities, including programs to pay family members for support; waivers for Home and Community Based Services; Community First Choice waivers; and innovative and effective alternatives to hospitalization, such as “Hospital at Home” programs,⁸⁴ emergency personal assistance registries, and cohorting in alternative housing while transitioning to the

correctional-detention.html (requiring facilities to “[e]xplore strategies to prevent overcrowding of correctional and detention facilities during a community outbreak”).

⁸³ *CMS Blanket Waivers*, *supra* note 59, at 16.

⁸⁴ Sarah Klein, “*Hospital at Home*” Programs Improve Outcomes, Lower Costs But Face Resistance from Providers and Payers, The Commonwealth Fund (last visited June 22, 2020), <https://www.commonwealthfund.org/publications/newsletter-article/hospital-home-programs-improve-outcomes-lower-costs-face-resistance>.

community.⁸⁵

- (b) Issue guidance to states affirmatively confirming family members may serve as paid support workers within both agency-managed and self-directed service programs and reminding states of the availability of Appendix K waivers to permit payment to family members.
- (c) Commit in writing to provide states with at least 90 days' notice prior to expiration of Appendix K waivers to provide states with sufficient time to make permanent those changes first allowed in Appendix K and state plan amendments due to the public health emergency.
- (d) Issue guidance to states directing them to grant immediate access to Independent Living Center staff, Aging and Disability Center Ombudspeople, Protection and Advocacy staff, and others with expertise in transitioning people from institutions to the community, so that they may speak directly to all residents in congregate facilities, either in-person (with appropriate PPE provided) or via the internet, to introduce an offer of assistance for relocating and an assessment of each person's desire to move to a safer location, either temporarily or with the option to make a permanent transition to the community.
- (e) Exercise their authority to issue 1915(c) waivers,⁸⁶ 1915(i) and

⁸⁵ Silvia Yee, DREDF Policy Recommendations for Reducing COVID-19 Nursing Home Deaths Through Innovative HCBS (May 21, 2020) <https://dredf.org/2020/06/04/dredf-policy-recommendations-for-reducing-covid-19-nursing-home-deaths-through-innovative-hcbs/>.

⁸⁶ CMS has the statutory authority to support states in provision of Home & Community Based Services. As the federal Medicaid website states, "Within broad Federal guidelines, States can develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting." *Home & Community-Based Services 1915(c)*, Medicaid.gov, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> (last visited June 21, 2020). These are known as 1915(c) waivers. See *State Waivers List*, Medicaid.gov, https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html?f%5B0%5D=waiver_authority_facet%3A1571&search_api_fulltext=&items_per_page=10&f%5B0%5D=waiver_authority_facet%3A1571&page=4#content#content#content (last visited June 21, 2020). According to the website:

"States can offer a variety of unlimited services under an HCBS Waiver program. Programs

1915(j) programs,⁸⁷ waivers through Appendix K,⁸⁸ and state plan amendments (SPAs).

- (f) Provide incentives to states to redesign their Medicaid programs to expand Home and Community Based Services and other community-based services and supports with the goal of reducing the population of nursing homes and congregate settings by 50 percent.

III. PROTECT RESIDENTS AND STAFF

a. Test or Isolate New Admissions

Both the CDC and CMS instruct nursing homes to admit residents whose COVID-19 status is unknown—without first requiring either testing or 14 days of medical isolation. In other words, HHS does not require the most basic infection prevention steps be taken before admitting someone to a nursing home—a setting populated by individuals exceptionally vulnerable to serious health risk and death from contracting COVID-19. Specifically, CDC guidance provides that “[t]esting

can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose ‘other’ types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.”

States can and do ask for HCBS waivers for a variety of populations, including but not limited to those who would otherwise be at risk of being in a nursing home.

⁸⁷ Notably, the HCBS waiver programs permit states to support self-directed personal assistance services. *Self-Directed Personal Assistant Services 1915(j)*, Medicaid.gov, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/self-directed-personal-assistant-services-1915-j/index.html> (last visited June 21, 2020) (“At the States option, people enrolled in 1915(j) can: [among other things,] [h]ire legally liable relatives (such as parents or spouses) [and] [p]urchase goods, supports, services, or supplies that increase their independence or substitute for human help (to the extent they'd otherwise have to pay for human help”).

⁸⁸ *Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers*, Medicaid.gov, <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html> (last visited June 21, 2020). (The authority of CMS to grant state requests for amendment to approved 1915(c) waivers using Appendix K “includes actions that states can take under the existing Section 1915(c) home and community-based waiver authority in order to respond to an emergency.”).

should not be required prior to transfer of a resident from an acute-care facility to a nursing home.”⁸⁹ Similarly, CMS has directed that “[p]atients hospitalized for non-COVID-19-related illnesses whose COVID-19 status is not known can be transferred to a nursing home *without* testing.”⁹⁰ CDC and CMS provide no guidance on how other congregate settings for people with disabilities should manage new admissions during the pandemic.

Testing or medical isolation of new admissions is essential, given the nature of COVID-19 which can spread from infected people who are asymptomatic.

Requested Actions:

CMS and CDC should rescind and modify their guidance to make clear that:

- (1) Before new people are admitted to any congregate setting for people with disabilities, they should be tested for COVID-19; and
- (2) Pending two negative tests at least 72 hours apart, people who are new admissions should be kept in medical isolation.⁹¹

b. Require Facility-Wide Testing

Facility-wide testing for COVID-19 is essential to stem the staggering numbers of deaths in nursing homes. Universal testing is not only important for

⁸⁹ CDC, *Responding to Coronavirus (COVID-19) in Nursing Homes* [hereinafter *CDC Responding in Nursing Homes Guidance*] (reviewed Apr. 30, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-homes-responding.html>.

⁹⁰ *Five Star Quality Rating System Updates*, *supra* note 70, at 2 (emphasis added); *see also id.* (“We note that on April 2, 2020 CMS released ‘COVID-19 Long-Term Care Facility Guidance’ which stated that, ‘patients and residents who enter facilities should be screened for COVID-19 through testing, if available.’ This language is meant to highlight that a test-based strategy is preferred when making decisions about discontinuing Transmission-Based Precautions for residents with COVID-19, but it is not a requirement to test residents prior to admission.”).

⁹¹ *See, e.g., Costa et al. v. Barzon et al.*, D.D.C. No. 19-CV-3185 ECF No. 81-1 (May 11, 2020) at 2 (report of court appointed amici) & No. 83 (May 11, 2020); Yafang Li et al., *Stability issues of RT-PCR testing of SARS-CoV-2 for hospitalized patients clinically diagnosed with COVID-19*, 92 J. MED. VIROL. 903–908 (2020) (finding a high false negative rate of real-time reverse-transcriptase polymerase chain reaction testing for SARS-CoV-2 - of the 348 patients who initially tested negative, 60 (17.2 percent) came to test positive with subsequent tests); Yicheng Fang et al., *Sensitivity of Chest CT for COVID-19: Comparison to RT-PCR*, RADIOLOGY (2020) (finding that RT-PCR tests only have a sensitivity of 71 percent).

containment, but also for ensuring high-quality care for infected residents. Early detection can help reduce the risk of death and improve health outcomes for residents and staff.⁹² Early detection can also reduce the risk of transmission, whether to residents, staff, or families.

CDC and CMS have been too vague on this critical point. CDC has stated that facilities should “[p]erform initial testing of all residents and HCP [health care professionals], along with weekly testing thereafter, as part of the recommended reopening process.”⁹³ That is a step in the right direction. But the time frame for when nursing homes must conduct baseline testing is not clear, and testing should not be linked to reopening but to the need to prevent and contain infection in these settings. And CDC’s guidance is undermined by CMS’s position that CMS is not requiring testing in nursing homes.⁹⁴

CDC and CMS provide even less guidance to other congregate settings for people with disabilities. They have issued no guidance even suggesting, let alone requiring, testing in these facilities. For group homes, CDC provides only that administrators “*may want to consider screening residents, workers, and essential volunteers for signs and symptoms of COVID-19.*”⁹⁵ Guidance on psychiatric facilities and intermediate care facilities for individuals with intellectual disabilities suggests only that “[f]acilities should consider frequent monitoring for potential symptoms of respiratory infection as needed throughout the day.”⁹⁶ There is no

⁹² Daniel K. Goyal et al., *Early Intervention Likely Improves Mortality in COVID-19 Infection*, 20 *Clinical Med.* 248 (2020), <https://www.rcpjournals.org/content/clinmedicine/20/3/248> (presenting evidence that late identification of illness is associated with increased mortality); Qin Sun et al., *Lower Mortality of COVID-19 by Early Recognition and Intervention: Experience from Jiangsu Province*, 10 *Annals of Intensive Care* Article 33 (2020), <https://annalsofintensivecare.springeropen.com/articles/10.1186/s13613-020-00650-2> (highlighting that early detection and intervention are key to reducing COVID-19 mortality, given that there is no treatment for the virus. In particular, showing that the Jiangsu Province was able to lower its mortality rate through vigilant early monitoring and intervention).

⁹³ CDC, *Testing Guidelines for Nursing Homes* (last updated June 13, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-homes-testing.html>; see also CDC, *Preparing for COVID-19 in Nursing Homes* [hereinafter *Preparing for COVID-19*] (June 19, 2020).

⁹⁴ CMS, *Nursing Home Reopening Recommendations Frequently Asked Questions*, at 2–3 (May 18, 2020), <https://www.cms.gov/files/document/covid-nursing-home-reopening-recommendation-faqs.pdf>

⁹⁵ *Guidance for Group Homes*, *supra* note 28 (emphasis added).

⁹⁶ CMS, *Guidance for Infection Control and Prevention of Coronavirus Disease 2019*

timeframe and no requirement of concrete direction. Such an infection control strategy based on symptom screening alone is inadequate and contrary to the scientific evidence showing that COVID-19 is transmitted by people who are asymptomatic but infected.⁹⁷ Indeed, individuals are most contagious 1-2 days *before* becoming symptomatic.⁹⁸ This possibility of asymptomatic transmission is especially problematic where there is no mandate to isolate individuals with unknown COVID-19 status.

Facility-wide testing is the most effective way to mitigate the spread of infection once the virus is present in a facility⁹⁹ or once it is widespread in a community, and given the high rates of people infected without symptoms, the only way to know if COVID-19 is in a facility is to conduct universal testing.

The effectiveness of other infection control measures also depends on a successful, facility-wide implementation of testing. For example, facility-wide testing allows “appropriate isolation of infected residents so that they can be cared for and quarantine of exposed residents to minimize the [risk of] spread.”¹⁰⁰

Such testing is also important to the residents’ quality of life in the facility; for example, testing could permit non-infected residents to resume some group activities.¹⁰¹ Those known to be positive could also be cohorted. Both these

(COVID-19) in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs) and Psychiatric Residential Treatment Facilities (PRTFs) (Mar. 30, 2020), <https://www.cms.gov/files/document/qso-20-23-icf-iid-prtf.pdf>.

⁹⁷ See Arons, *supra* note 44.

⁹⁸ Xi He, *supra* note 44, at 672 (“[I]nfectiousness started from 2.3 days . . . before symptom onset and peaked at .7 days.”).

⁹⁹ See, e.g., Amy V. Dora, et al., *Universal and Serial Laboratory Testing for SARS-CoV-2 at a Long-Term Care Skilled Nursing Facility for Veterans — Los Angeles, California, 2020*, 69 *Morb Mortal Wkly Rep (MMWR)* 651 (2020), <https://www.cdc.gov/mmwr/volumes/69/wr/mm6921e1.htm> (last visited June 15, 2020); Innokentiy Bakaev, Tammy Retalic & Helen Chen, *Universal Testing-Based Response to COVID-19 Outbreak by a Long-Term Care and Post-Acute Care Facility*, *J. of the Am. Geriatrics Soc’y* (2020), <https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.16653> (last visited Jun 15, 2020) (writing about the effectiveness of universal testing at Hebrew Rehabilitation Center, a 723 bed organization that provides long-term care and rehabilitation services and primarily serves the elderly).

¹⁰⁰ See Monica Gandhi, Deborah S. Yokoe & Diane V. Havlir, *Asymptomatic Transmission, the Achilles’ Heel of Current Strategies to Control Covid-19*, 382 *N. Engl. J. Med.* 2158, 2159 (2020).

¹⁰¹ *Id.*

measures could help combat the mental health consequences of isolation.¹⁰² Given that residents of congregate care facilities are largely unable to maintain their regular social contact with family members during this time, allowing for safe participation in group activities is all the more important for residents' mental health.¹⁰³

Requested Actions:

- (1) CDC should rescind and modify its guidance to require that nursing homes and other congregate settings for people with disabilities conduct a facility-wide testing baseline, and clarify that such testing must begin immediately and be completed by a certain date, with all new employees and residents tested before coming to the facility. HHS and CMS should modify the IFC to require and pay for the same.
- (2) CMS should modify its grant program rules (including the payment terms and conditions recipients must sign) to Coronavirus Aid, Relief and Economic Security (CARES) Act funding to require that states and facilities prioritize COVID-19 testing for staff and residents in nursing homes and other congregate care facilities for people with disabilities.¹⁰⁴

c. Require Facilities to Implement Medical Isolation and Cohorting Practices to Contain Viral Spread

Along with universal testing, medical isolation and cohorting have been demonstrated to be critical measures to interrupt the transmission of COVID-19 in congregate care settings. The CDC nursing home guidance is, however, equivocal, inconsistent, and imprecise about the need to isolate those with known COVID-19 from others and to medically isolate those suspected to have COVID-19, who have been exposed, or whose status is unknown. The guidance as to psychiatric hospitals, group homes, and intermediate care facilities for people with developmental disabilities are either nonexistent or similarly lacking.

¹⁰² Marla Berg-Weger & J. E. Morley, *Loneliness and Social Isolation in Older Adults During the Covid-19 Pandemic: Implications for Gerontological Social Work*, 24 J. Nutr. Health Aging 456, 456 (2020) (“[N]early one-third of older adults experience loneliness and/or social isolation and a subset (5%) report[] often or always feeling lonely.”); Anne Madden & Brendan Leen, *Evidence summary: What is the impact of the coronavirus pandemic on the mental health of elderly nursing home residents?* [v1.0], Health Service Executive (2020), <https://www.lenus.ie/handle/10147/627785> (last visited Jun 15, 2020).

¹⁰³ Berg-Weger & Morley, *supra* note 102, at 457.

¹⁰⁴ Coronavirus Aid, Relief, and Economic Security Act, Pub. L. 116-136, 134 Stat 281, 560 (2020); *see, e.g., COVID-19 Survey Activities, supra* note 73.

Cohorting of Known Cases: The *Responding to Coronavirus (COVID-19) in Nursing Homes* guidance is not sufficiently directive about the need to isolate those known to have COVID-19 from others, and to ensure separate staffing for these residents. The guidance provides that, “[i]deally the [cohorting] unit should be physically separated from other rooms or units housing residents without confirmed COVID-19”; that health care professionals working in the cohort unit should “ideally have a restroom, break room, and work area that are separate from HCP working in other areas of the facility”); that the “COVID-19 care unit could be a separate floor, wing, or cluster of rooms;” and that the facility could “[t]o the extent possible, restrict access of ancillary personnel . . . to the unit.”¹⁰⁵ The guidance thus does not mandate that those with COVID-19, or those caring for them, be separated from others, despite the known contagion.

Guidance governing healthcare settings, however, suggests that residents with known COVID-19 cases should be placed in a private room,¹⁰⁶ introducing confusion. Individuals with known COVID-19 can, however, be cohorted, provided the cohort is separate from those with an unknown or negative status. Cohorting, rather than complete separation, eases social isolation.

Guidance to facilities must make clear that individuals known to have COVID-19 should be separated from all those with a different status, be it those with suspected COVID-19, those who have been exposed, or those who are known negative.

Isolation of Suspected Cases: The *Preparing for COVID-19 in Nursing Homes* guidance states: “Residents with known or suspected COVID-19 do not need to be placed into an airborne infection isolation room (AIIR) but *should ideally* be placed in a private room with their own bathroom.”¹⁰⁷ Elsewhere, the *Preparing for COVID-19 in Nursing Homes* guidance states that “[r]esidents in the facility who develop symptoms consistent with COVID-19 *could* be moved to a single room pending results of SARS-CoV-2 testing.”¹⁰⁸ The *Responding to Coronavirus (COVID-19) in Nursing Homes* guidance is similarly not directive about the need to isolate residents suspected of having COVID-19 from all other residents until their status is determined. Rather, it states, “Place the resident in a single room *if*

¹⁰⁵ *CDC Responding in Nursing Homes Guidance*, *supra* note 89.

¹⁰⁶ *Preparing for COVID-19*, *supra* note 93 (“Residents with known or suspected COVID-19 . . . *should ideally* be placed in a private room with their own bathroom.”) (emphasis added).

¹⁰⁷ *Id.* (emphasis added).

¹⁰⁸ *Id.* (emphasis added).

possible pending results of SARS-CoV-2 testing.”¹⁰⁹

But the guidance is even more confusing than suggested above. Suspected cases are presumably those where the resident has symptoms. As to symptomatic residents, the *Nursing Home Guidance* states that “if cohorting symptomatic residents, care should be taken to ensure infection prevention and control interventions are in place to decrease the risk of cross-transmission.”¹¹⁰ The *Infection Prevention and Control Assessment Tool for Nursing Homes Preparing for COVID-19*, on the other hand, seems to suggest that facilities should isolate, rather than cohort, untested symptomatic residents, stating that “[i]f they [residents] have a fever (temperature of 100.0 F or higher) or symptoms, they should be restricted to their room and put into appropriate Transmission-Based Precautions.”¹¹¹ But restricting a resident to their room is not isolation, given that most nursing home residents share a room. And the *Preparing for COVID-19 in Nursing Homes Guidance* suggests yet another approach—isolation—stating that “[r]esidents in the facility who develop symptoms consistent with COVID-19 *could* be moved to a single room pending results of SARS-CoV-2 testing.”¹¹²

In other words, the guidance for nursing homes both suggests that cohorting suspected cases is an option and that it is not appropriate. It further suggests that isolation of suspected cases is desirable, or perhaps required.

Guidance for other congregate settings for people with disabilities is similarly ambiguous. For example, the CDC guidance addressing group homes provides only that “[r]esidents with COVID-19 symptoms, their roommates, and close contacts should self-isolate, limiting their use of shared spaces as much as possible.”¹¹³

CDC must direct facilities to take action that will avert spread: Isolate those with suspected COVID-19, until such time as they are known to be positive, and can join the known COVID-19 cohort, or negative, and can return to the broader population.

Unknown Status: There is similar ambiguity in the CDC’s guidance for housing residents whose status is unknown. The guidance in *Create a Plan for*

¹⁰⁹ *CDC Responding in Nursing Homes Guidance*, *supra* note 89 (emphasis added).

¹¹⁰ *Id.*

¹¹¹ CDC, *Infection Prevention and Control Assessment Tool for Nursing Homes Preparing for COVID-19* (May 8, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/hcp/assessment-tool-for-nursing-homes.html>.

¹¹² *Preparing for COVID-19*, *supra* note 93 (emphasis added).

¹¹³ *Guidance for Group Homes*, *supra* note 28.

Managing New Admissions and Readmissions Whose COVID-19 Status is Unknown states that “[o]ptions include placement [of the resident] in a single person room or in a separate observation area so the resident can be monitored for evidence of COVID-19.”¹¹⁴ This guidance creates the risk that asymptomatic COVID-19 positive individuals could be housed with uninfected residents. This type of asymptomatic transmission has been identified as the “Achilles’ heel of current strategies to control COVID-19”¹¹⁵ and shown to be a particularly acute problem in nursing homes, specifically.¹¹⁶ CDC must direct that those of unknown status be medically isolated until their status is known.

Exposed Individuals: The CDC guidance is also insufficiently directive regarding the need to medically isolate individuals who have been exposed to known or suspected cases. The *Preparing for COVID-19 in Nursing Homes* guidance states, “As roommates of residents with COVID-19 might already be exposed, it is generally not recommended to place them with another roommate until 14 days after exposure.” While the *Responding to Coronavirus* guidance is more emphatic, it still does not clearly provide that exposed individuals should be isolated: “[R]oommates of residents with COVID-19 should be considered exposed and potentially infected and, if at all possible, should not share rooms with other residents unless they remain asymptomatic and/or have tested negative . . . 14 days after their last exposure.” This language is notably less clear and direct than the comparable *Correctional and Detention Facilities* guidance: “Incarcerated/detained persons who are close contacts of a confirmed or suspected COVID-19 case . . . should be placed under quarantine for 14 days . . . Facilities should make every possible effort to quarantine close contacts of COVID-19 cases individually.” CDC guidance should make clear as to all congregate settings for people with disabilities that exposed individuals should be isolated until their status is known.

Requested Actions:

- (1) CDC should rescind and modify its guidance to provide clear direction that for all nursing homes and other congregate settings for people with disabilities:
 - (a) Facilities must have separate physical spaces for (1) residents

¹¹⁴ *Preparing for COVID-19*, *supra* note 93 (emphasis added).

¹¹⁵ Gandhi *et al.*, *supra* note 100, at 2159.

¹¹⁶ Kendra Quicke *et al.*, *Longitudinal Surveillance for SARS-CoV-2 RNA Among Asymptomatic Staff in Five Colorado Skilled Nursing Facilities: Epidemiologic, Virologic and Sequence Analysis.*, medRxiv (June 8, 2020), <https://www.medrxiv.org/content/10.1101/2020.06.08.20125989v1>.

confirmed to have COVID-19, and (2) residents confirmed not to have COVID-19;

- (b) Facilities must medically and individually isolate all residents whose COVID-19 status is unknown (i.e., they are suspected of having COVID-19, have been exposed to COVID-19, or they simply haven't been tested) until their status is known; and
 - (c) For residents whose status is unknown, before they can be released from medical isolation, they must have 2 negative tests at least 72 hours apart or complete a quarantine period.
- (2) CDC and CMS should modify guidance to provide clear direction that staff for each type of unit must be exclusively dedicated to that type of unit to minimize the risk of cross-contamination. For staff working with individuals whose status is unknown (including suspected), CDC and CMS should require use of N95 masks and separate, sufficiently protective PPE for interactions with each patient.
- (3) CMS must direct that, where facilities do not have physical capacity to separate residents appropriately, the facility must work with state authorities to arrange sufficient housing outside the facility to meet these standards.

d. Require a Full-time, Qualified and Trained Infection Preventionist

CDC's recent guidance provides only that "[f]acilities should assign at least one individual with training in [infection prevention and control (IPC)] to provide on-site management of their COVID-19 prevention and response activities because of the breadth of activities for which an IPC program is responsible, including developing IPC policies and procedures, performing infection surveillance, providing competency-based training of HCP, and auditing adherence to recommended IPC practices."¹¹⁷ This instruction leaves unclear whether that individual must be the "infection preventionist" that existing regulations require every facility to have on staff.¹¹⁸

This distinction is more than semantic: An "infection preventionist" is

¹¹⁷ *Preparing for COVID-19, supra* note 93.

¹¹⁸ See 42 C.F.R. § 483.80(b) ("The facility . . . must designate one or more individual(s) as the infection preventionist(s) (IPs) who are responsible for the facility's [infection prevention and control program].").

required by regulation to have specific qualifications. Specifically, the infection preventionist must: “(1) [h]ave primary professional training in nursing, medical technology, microbiology, epidemiology, or other related field; (2) [b]e qualified by education, training, experience or certification; (3) [w]ork at least part-time at the facility; and (4) [h]ave completed specialized training in infection prevention and control.”¹¹⁹

CDC’s initial guidance notably failed to mention a facility’s obligation to have a specially trained infection preventionist on staff at all, or to provide any specific direction to a facility that assesses what the infection preventionist should be implementing during the pandemic.

This combination of the failure to reference the existing infection preventionist regulation and the ambiguous discussion of infection prevention protocol leaves facilities with incomplete and confusing directions. Infection control protocols are of utmost importance at this time.

Requested Actions:

- (1) The CDC should modify its guidance to explicitly state that the person in charge of the infection protocol pursuant to *Preparing for COVID-19 in Nursing Homes* guidance should be the infection preventionist as defined by 42 C.F.R. § 483.80(b).
- (2) The CDC should further modify its guidance to direct that the infection preventionist should be full time for the duration of the pandemic.

e. Restore Training Requirements for Staff

In response to the COVID-19 pandemic and anticipated need for more healthcare staff in nursing homes, CMS has waived a number of training and evaluation requirements. At least two of these waivers are inconsistent with HHS’s directive to protect the public health.

First, CMS waived most of 42 C.F.R. § 483.35(d), which sets out requirements for individuals working as nurse aides for longer than four months in a skilled nursing facility or nursing facility, including training and certification

¹¹⁹ *Id.* at § 483.80(b)(1)-(4). In addition, the “individual designated as the IP, or at least one of the individuals if there is more than one IP, must be a member of the facility’s quality assessment and assurance committee and report to the committee on the [infection prevention and control program] on a regular basis.” *Id.* at § 483.80(c).

requirements.¹²⁰

Second, CMS has postponed the deadline for nursing assistants to complete their annual in-service training, as required by 42 C.F.R. § 483.95, until the end of the first full quarter after the public health emergency concludes.¹²¹

Third, the length of training time required for paid feeding assistants has been shortened to allow for training to be a minimum of one hour, instead of eight hours, through modification of the requirements in 42 C.F.R. § 483.60(h)(1)(i) and 42 C.F.R. § 483.160(a).¹²²

Requested Action:

CMS should immediately revoke these waivers and reinstate training requirements for staff. The training should be expanded to include infection control protocols specific to COVID-19.

f. Require the use of sufficiently protective PPE

On March 10, 2020, CMS issued guidance on the use of industrial respirators by health care personnel. CMS stated that health care workers involved in the care of residents with known or suspected COVID-19 may use surgical facemasks rather than the more protective N95 respirator mask in light of supply chain problems.¹²³ Since that time a multitude of studies have concluded that N95 respirator masks are far superior to surgical masks in protecting essential workers from COVID-19.¹²⁴ CMS has, however, provided no updated guidance or other requirement for

¹²⁰ CMS, *Long Term Care Facilities (Skilled Nursing Facilities and/or Nursing Facilities): CMS Flexibilities to Fight COVID-19* [hereinafter *CMS Flexibilities*] at 10 (May 15, 2020), available at <https://www.cms.gov/files/document/covid-long-term-care-facilities.pdf> (June 12, 2020), <https://www.cms.gov/files/document/covid-long-term-care-facilities.pdf>; see also *CMS Blanket Waivers*, *supra* note 59, at 17.

¹²¹ *CMS Flexibilities*, *supra* note 120, at 3.

¹²² *Id.* at 11.

¹²³ CMS, *Guidance for use of Certain Industrial Respirators by Health Care Personnel*, QSO-20-17-ALL (Mar. 10, 2020), <https://www.cms.gov/files/document/qso-20-17-all.pdf> (“Based on local and regional situational analysis of PPE supplies, *facemasks are an acceptable temporary alternative* when the supply chain of respirators cannot meet the demand. During this time, available respirators should be prioritized for procedures that are likely to generate respiratory aerosols, which would pose the highest exposure risk to Health Care Providers.” (emphasis added)).

¹²⁴ Derek K. Chu *et al.*, *Physical Distancing, Face Masks, and Eye Protection to Prevent Person-to-Person Transmission of SARS-CoV-2 and COVID-19: A Systematic Review and*

the use of N95 masks by staff in nursing homes or other congregate settings for people with disabilities.

Requested Action:

CMS should rescind and modify its guidance to require the use of N95 masks by staff in all nursing homes and other congregate settings for people with disabilities who have any exposure to residents with known or suspected COVID-19, or whose COVID-19 status is unknown.

g. Using Appropriated Funds To Incentivize Facilities To Provide Paid Sick Leave And Hazard Pay To Workers

Evidence shows that once COVID-19 enters a congregate facility it puts both residents and staff at mortal risk; minimizing the risk of COVID-19 entering a facility is a matter of life and death. An important way to minimize the chance of COVID-19 is for the people coming into and out of nursing homes—the staff—to minimize their own risk of exposure and cross contamination. Although the CDC has suggested that nursing homes “[i]mplement sick leave policies that are non-punitive, flexible, and consistent with public health policies that support HCP to stay home when ill,”¹²⁵ more is required given the stakes.

To address the devastation ravaging nursing homes, HHS should condition the distribution of any funds from the Public Health and Social Services Emergency

Meta-Analysis, The Lancet (June 1, 2020), [https://doi.org/10.1016/S0140-6736\(20\)31142-9](https://doi.org/10.1016/S0140-6736(20)31142-9) (An “analysis of 172 studies confirms what scientists have said for months: N95 and other respirator masks are far superior to surgical or cloth masks in protecting essential medical workers against the coronavirus.”); *see also* Apoorva Mandavilli, *Medical Workers Should Use Respirator Masks, Not Surgical Masks*, N.Y. Times (June 1, 2020), <https://www.nytimes.com/2020/06/01/health/masks-surgical-N95-coronavirus.html?referringSource=articleShare> (It is “clear that the W.H.O. and the Centers for Disease Control and Prevention should recommend that essential workers like nurses and emergency responders wear N95 masks, not just surgical masks, experts said.”).

¹²⁵ *Preparing for COVID-19*, *supra* note 93.

Fund¹²⁶ to facilities to support staff to prevent spread.¹²⁷

Requested Action:

CMS should modify its grant and disbursement rules (including the payment terms and conditions recipients must sign) to require facilities receiving funds from the Public Health and Social Services Emergency Fund to (i) provide a minimum of two weeks paid sick leave (ii) provide a minimum of two weeks paid sick leave for workers, (iii) provide sufficient hours and pay that its staff only need to work at one facility, (iv) adopt measures to ensure workers cannot be fired if they call in sick or must stay home due to COVID-19, and (v) provide hazard pay to frontline caregivers at risk of exposure for COVID-19.

CONCLUSION

The nation currently confronts a human and civil rights crisis in nursing homes, group homes, psychiatric hospitals, and intermediate care facilities for people with developmental disabilities. While known cases of COVID-19 are dropping in some states, they are increasing in others. Public health experts have widely warned there will be a second wave of infection in the fall, or possibly an extended first wave as re-opening leads to reduced social distancing and precautions.

HHS must act, and it must act urgently if it is to hold true to its mission to enhance the health and well-being of all Americans.

¹²⁶ Through the CARES Act and subsequent legislation, Congress appropriated \$175 billion for the Public Health and Social Services Emergency Fund, which is overseen by HHS. This money has been allocated “to prevent, prepare for, and respond to coronavirus, domestically or internationally, for necessary expenses to reimburse, through grants or other mechanisms, eligible health care providers for health care related expenses or lost revenues that are attributable to coronavirus,” including nursing homes and other congregate care facilities. Coronavirus Aid, Relief, and Economic Security Act, Pub. L. 116-136, 134 Stat 281, 560 (2020). Congress appropriated these funds for “medical supplies and equipment including personal protective equipment and testing supplies, increased workforce and trainings, emergency operation centers, and surge capacity for diagnostic, serologic, or other COVID-19 tests, or related supplies” amongst other uses. *Id.*; see HHS, *CARES Act Provider Relief Fund* (last updated June 17, 2020), <https://www.hhs.gov/coronavirus/cares-act-provider-relief-fund/index.html>.

¹²⁷ See, e.g., *COVID-19 Survey Activities*, *supra* note 73 (“[I]ntitiating a performance-based funding requirement tied to the Coronavirus Aid, Relief and Economic Security (CARES) Act supplemental grants for State Survey Agencies.”).

Absent action within three weeks, we will view the Department and its components as having rejected the requests in this petition and will proceed accordingly.

Sincerely,

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