



Sept. 3, 2021

Dr. Rochelle P. Walensky
Director
Centers for Disease Control and Prevention

Dear Dr. Walensky:

The undersigned members and allies of the Consortium for Citizens with Disabilities (CCD) Rights Task Force write to request a meeting of disability organizations with the CDC to discuss the need for guidance concerning census reduction in congregate care facilities as part of infection control measures during a pandemic. We believe it is important to have a clear statement from the CDC concerning the importance of reducing the census of congregate care facilities during a pandemic. CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

In May, 2021, the CDC declined a request from national mental health organizations to highlight strategies to reduce the census in long-term care and correctional facilities as part of the CDC's guidance on COVID-19 infection control measures. We were surprised and dismayed that the CDC's response appeared to deny the importance of census reduction in long-term care facilities, stating:

Since residents within LTCFs may require 24/7 medical and personal care from healthcare personnel, CDC cannot recommend census reduction as part of the CDC infection prevention control (IPC) guidance or agency policy. LTCFs should follow CDC's current guidance recommending that LTCFs implement physical distancing measures. This recommendation is based on existing scientific data.

This statement reflects fundamental misunderstandings about modern disability service systems. The fact that a person is currently served in a long-term care facility does not, as the CDC’s statement implies, mean that the person is incapable of living in the community with appropriate services. Further, most individuals in long-term care facilities do not require round-the-clock care. Individuals with disabilities are routinely discharged from long-term care facilities into home and community-based settings. Many remain in these facilities simply because of the insufficient availability of community-based services and housing. As Alison Barkoff, Acting Administrator of the Administration on Community Living, observed, “[t]wenty-two years after the Supreme Court’s ruling, there are still far too many people who could – and want to – live in the community, but who are instead living in institutional settings because of a lack of access to the home and community-based services (HCBS) they need in order to do so.”¹

Indeed, it is national policy to promote community living for people with disabilities, including those with the most significant disabilities. The Americans with Disabilities Act’s “integration mandate” and the Supreme Court’s decision in *Olmstead v. L.C.* require states and local governments to administer services to people with disabilities in the most integrated setting appropriate. Tens of thousands of people with disabilities have transitioned from institutions to community settings as a result of *Olmstead* settlement agreements, including many entered between states and the U.S. Department of Justice. President Biden has committed, as part of his American Jobs Plan, to invest \$400 billion to ensure that hundreds of thousands of individuals with disabilities can gain access to home and community-based services.

The pandemic’s impact on the nation’s long-term care facilities highlighted that for the many individuals with disabilities who remain institutionalized even though they could live successfully in community settings, this is not only a civil rights issue. It was, and could again become, a matter of life and death.

COVID-19 ravaged America’s long-term care facilities. As of June 1, 2021, more than 184,000 residents and workers in nursing homes and other long-term care facilities had died of COVID-19.² While individuals in these facilities comprised less than 1% of the country’s population and accounted for only 4% of the country’s COVID-19 cases, they accounted for nearly one third of

¹ Alison Barkoff, *Unprecedented Opportunities to Achieve the Promise of Olmstead* (June 22, 2021), <https://acl.gov/news-and-events/acl-blog/Olmstead22>.

² *Nearly One-Third of U.S. Coronavirus Deaths are Linked to Nursing Homes*, New York Times, June 1, 2021, <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html>; Artis Curiskis et al., the COVID-19 Tracking Project, *What We Know—and What We Don’t Know—About the Impact of the Pandemic on Our Most Vulnerable Community*, Mar. 31, 2021, <https://covidtracking.com/analysis-updates/what-we-know-about-the-impact-of-the-pandemic-on-our-most-vulnerable-community>.

the country's COVID-19 deaths.³ Nearly one in twelve residents of these facilities died of COVID-19.⁴

While the number of deaths in long-term care facilities has declined dramatically following vaccination efforts, as COVID-19 rates have again surged across the country due to the delta variant, risks for individuals in long-term care facilities are re-emerging. New outbreaks have begun to occur in nursing facilities in a number of places, sometimes resulting in the deaths of fully vaccinated residents. For example, seven fully vaccinated residents died in an outbreak in an Indiana facility,⁵ four fully vaccinated residents died in an outbreak in a Colorado facility,⁶ three residents—one of whom was fully vaccinated—died in an outbreak started by an unvaccinated worker in a Kentucky facility,⁷ and several fully vaccinated residents died in outbreaks in Louisiana nursing facilities.⁸

Only about 60% of nursing home staff are vaccinated, and in some states less than half are vaccinated.⁹ In some facilities, staff vaccination rates remain in the single digits.¹⁰ We anticipate

³ *Nearly One-Third of U.S. Coronavirus Deaths are Linked to Nursing Homes*, *supra* note 1.

⁴ *What We Know—and What We Don't Know—About the Impact of the Pandemic on Our Most Vulnerable Community*, *supra* note 1.

⁵ CDC Probes Deaths in Immunized Patients in Nursing Homes, U.S. News & World Report (July 21, 2021), <https://www.usnews.com/news/world/articles/2021-07-21/cdc-probes-deaths-in-immunized-patients-in-nursing-homes>.

⁶ *Id.*

⁷ Deborah Yetter, *Kentucky nursing home with deadly COVID-19 variant outbreak identified as Rowan facility*, Louisville Courier Journal (May 4, 2021), https://www.courier-journal.com/story/news/local/2021/05/04/kentucky-nursing-home-deadly-covid-19-variant-outbreak-morehead-site/4935105001/?utm_source=emailcampaign299&utm_medium=phpList&utm_content=HTMLemail&utm_campaign=Institutionalization+is+a+Public+Health+Crisis.

⁸ Faimon A. Roberts III, *Three Louisiana nursing home deaths reported as COVID cases nearly triple among residents*, The Times Picayune (updated July 29, 2021), https://www.nola.com/news/coronavirus/article_2ee08b96-efd8-11eb-be57-df826b89794f.html.

⁹ Matt Richtel and Reed Abelson, *Nursing Homes Confront New Covid Outbreaks Amid Calls for Staff Vaccination Mandates*, New York Times (updated Aug. 10, 2021), <https://www.nytimes.com/2021/08/04/health/nursing-homes-vaccine-delta-covid.html>.

¹⁰ Robert McCoppin, *COVID-19 vaccination rate in single digits for workers at some Illinois nursing homes. Owners would support statewide mandate*, Chicago Tribune (Aug. 13, 2021), <https://www.chicagotribune.com/coronavirus/ct-covid-illinois-nursing-homes-vaccine-mandate-20210813-idwv6x6vo5dvvis6rulqr6yssy-story.html>.

that staff vaccinations will rise once CMS has issued its announced emergency regulation to require staff vaccinations in Medicare/Medicaid participating nursing homes, but that rule will apply only to nursing facilities and not to other long-term care facilities. Moreover, we anticipate significant compliance concerns.

Accordingly, we urge the CDC to revisit its decision not to include any recommendation concerning long-term care facility census reduction as an infection control measure in its guidance. While the CDC's guidance recommends that facilities "implement aggressive social distancing measures (remaining at least 6 feet apart from others),"¹¹ such measures would not be possible in most long-term care facilities without significant census reduction. Residents share rooms and bathrooms. Beds are often less than six feet apart. Residents eat together in common dining rooms, frequently without the possibility of social distancing. Residents have little choice but to share elevators, particularly when meals are served, and medications are dispensed, at particular times.

If the CDC believes that specific recommendations about how to accomplish census reduction and accelerate discharges fall outside of its expertise, it should, at a minimum, work with other agencies such as ACL, CMS, FEMA, and HUD to provide guidance on these issues and/or direct individuals to information from those agencies.

We would like to meet with you concerning this urgent matter.

Sincerely,

The Arc of the United States

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Center for Public Representation

Civil Rights Education and Enforcement Center

CommunicationFIRST

Disability Independence Group

Disability Rights Education and Defense Fund

¹¹ CDC, *Preparing for COVID-19 in Nursing Homes*, updated Nov. 20, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html>.

Disability Rights International

Epilepsy Foundation

Justice in Aging

National Association of Councils on Developmental Disabilities

National Association for Rights Protection and Advocacy

National Disability Rights Network (NDRN)

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

TASH

United Spinal Association

World Institute on Disability

Alabama Disabilities Advocacy Program

Arizona Center for Disability Law

Arizona Center for Law in the Public Interest

Disabilities Law Project of Community Legal Aid Society, Inc. (DE)

Disability Law Center of Alaska

Disability Law Center, Inc. of Massachusetts

Disability Law Center (Utah)

disAbility Law Center of Virginia

Disability Law Colorado

Disability Rights Arkansas

Disability Rights California

Disability Rights Center of Kansas

Disability Rights Florida
Disability Rights Iowa
Disability Rights Maine
Disability Rights Maryland
Disability Rights Michigan
Disability Rights Nebraska
Disability Rights New Jersey
Disability Rights New York
Disability Rights North Carolina
Disability Rights South Dakota
Disability Rights Tennessee
Disability Rights Texas
Disability Rights Washington
Georgia Advocacy Office
Indiana Disability Rights
Kentucky Protection and Advocacy Division
Missouri Protection and Advocacy Services
Nevada Disability Advocacy and Law Center
North Dakota Protection and Advocacy Project
Oklahoma Disability Law Center, Inc.
Public Justice Center (MD)