



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

October 19, 2021

The Honorable Dr. Rochelle Walensky
Director, Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear Director Walensky,

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The undersigned members of the CCD Health Task Force and allies are writing to ask for more guidance and outreach on vaccine boosters and additional doses for people with disabilities and chronic conditions.

The CCD Health Task Force has been engaged in the vaccine allocation and distribution process for over a year now. In September of 2020, we submitted [comments](#) to the National Academies of Medicine's preliminary vaccine allocation framework urging, among other issues, prioritization of people who live and work in congregate settings as well as a broad definition of those settings. In October of 2020 we issued [principles](#) for vaccine allocation and [wrote](#) to the Advisory Committee on Immunization Practices (ACIP), similarly urging the inclusion of people in all congregate settings in early phases of allocation. We have also worked on [civil rights protections](#) for people with disabilities in vaccine allocation, distribution, and administration, including [accessibility of information](#).

We appreciate the steadfast work of CDC and the ACIP to implement a data-driven process and ensure as many people as possible in the US are vaccinated, especially CDC's work with the Administration for Community Living to reach residents of congregate facilities. Unfortunately, as recent CDC research shows, the vaccination rate among non-institutionalized people with disabilities is lower despite this population having less vaccine hesitancy than people without disabilities. People who reported comorbidities or fair/poor mental health were even less likely to be vaccinated.¹ These findings highlight the need for more targeted efforts to make vaccination, and information about the vaccine, accessible to address inequities. However, recent recommendations from CDC regarding additional doses and

¹ Ryerson AB, Rice CE, Hung M, et al. Disparities in COVID-19 Vaccination Status, Intent, and Perceived Access for Noninstitutionalized Adults, by Disability Status — National Immunization Survey Adult COVID Module, United States, May 30–June 26, 2021. MMWR Morb Mortal Wkly Rep 2021;70:1365–1371. DOI: <http://dx.doi.org/10.15585/mmwr.mm7039a2external icon>.

booster doses has been confusing to people with disabilities, and we write today to ask for more detailed, accessible guidance and outreach for people with disabilities and chronic conditions. Specifically, we are asking for:

1. Additional outreach from CDC to people with compromised immune systems on the need for an additional dose of Pfizer or Moderna;
and
2. More detailed guidance and education on the conditions for which people are recommended to get a booster dose of Pfizer; and
3. Further publicizing and encouraging states to adopt a broad definition of congregate settings to be included in the recommendation for residents and workers to get a booster dose.

Additional Doses for People with Compromised Immune Systems

On August 13, 2020, CDC recommended that people with moderately to severely compromised immune systems receive a third dose in addition to their primary series of the Pfizer or Moderna vaccine. However, the timing of this announcement coincided closely with the August 18, 2020 White House [announcement](#) of booster doses for all people and all three vaccines. Later in September, CDC released recommendations regarding booster doses for Pfizer only. This has created significant confusion among the public.

We are concerned that people with compromised immune systems who received two doses of the Moderna shot may erroneously believe they are not eligible for an additional dose because they think that only Pfizer recipients are currently eligible for another dose. The media coverage of boosters significantly overshadowed the coverage of additional doses for people with compromised immune systems. We urge CDC to conduct outreach and education specific to people with immunocompromising conditions urging them to get a third dose if their primary series was from Moderna. CDC should emphasize that additional doses are not limited to those with [conditions listed on the CDC website](#), but also includes other conditions with similar impacts on the immune system.

To date, no discussion of additional doses has included those who received the Johnson & Johnson vaccine. We are encouraged that the FDA is discussing authorization of boosters of both Johnson & Johnson and Moderna. However, we are concerned that the lack of discussion of additional doses of Johnson & Johnson may cause further confusion for people with compromised immune systems about whether and when they are eligible for a second dose or booster. Therefore, we urge CDC to work with FDA to collect the necessary data to make clear recommendations for all people who received the Johnson & Johnson vaccine, including and especially for people with compromised immune systems and other disabilities and chronic conditions. Clarity will be critically important if recommendations for who should receive a booster (or additional dose) of the Johnson & Johnson vaccine are different than recommendations for the Pfizer or Moderna vaccine recipients.

High Risk Conditions

The current CDC webpage on boosters includes the age-based recommendations for those with underlying medical conditions and links to CDC's [main page](#) on conditions that place a person at higher risk. We appreciate that CDC has recognized that this is not an exhaustive list of medical conditions that place a person at higher risk and states so on the page. Less common conditions may not have the

available data or research funding necessary to determine inclusion on the list but may still put a person at higher risk. We urge CDC to include this in its communications to the public. We also urge CDC to collect data on COVID-19 and lower incidence conditions so that people with these conditions and their physicians can make evidence-based decisions about booster doses.

Long-Term Care Settings

The CDC boosters website states that residents of and workers in long-term care settings should get a Pfizer booster shot but does not include a definition of to which settings this applies. We recommend clarifying whether this applies to people who provide and receive care in the home. CCD has long advocated for a [broad definition of congregate and institutional settings](#) to include any place with congregate living and reduced ability to conduct social and physical distancing. We appreciate that the CDC [website](#) on boosters includes broad examples of settings, including health care settings, schools, correctional facilities, and homeless shelters. Residents of these and similar settings are often less empowered to seek vaccine doses on their own and may be constrained by guardianship or the warden or superintendent of the prison where they reside. We also appreciate that CDC's website now links to an ACL page describing a broad definition of long-term care settings. We recommend urging states and others responsible for vaccine administration to include broad definitions of congregate settings in booster administration. We also urge CDC to continue to collect data on COVID-19 infection and transmission in a broad array of congregate settings so further recommendations can be made based on that data, as well as conduct research on the risks for people who provide and receive care in the home and include them in future guidance.

Thank you for your time and attention. For more information, please contact Rachel Patterson, Senior Director of Government Relations & Advocacy for the Epilepsy Foundation at rpatterson@efa.org and Natalie Kean, Senior Staff Attorney for Justice in Aging at nkean@justiceinaging.org.

Sincerely,

ALS Association
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Council of the Blind
American Foundation for the Blind
American Physical Therapy Association
APHA Disability Section
Association of University Centers on Disabilities (AUCD)
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Medicare Advocacy
Center for Public Representation
CommunicationFIRST
Cure SMA
Disability Rights Education and Defense Fund (DREDF)

Easterseals
Epilepsy Foundation
Family Voices
Justice in Aging
Lakeshore Foundation
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Council on Independent Living
National Disability Rights Network (NDRN)
National Down Syndrome Society
National Health Law Program
Spina Bifida Association
TASH
The Arc of the United States
United Spinal Association