



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 8, 2021

Dr. Robinsue Frohboese
Acting Director, Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 2021

Dear Dr. Frohboese,

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 write to provide input regarding allocation and accessibility of the coronavirus vaccines authorized for emergency use.

The co-chairs of the CCD Health, Rights, and Long-Term Services and Supports wrote to OCR regarding allocation initially last September. As the vaccine rollout continues and people with disabilities of all ages continue to be left out in some states, we share urgent additional concerns. The Office for Civil Rights (OCR) plays a critical role to ensure that federal guidance on vaccine distribution and administration complies with federal non-discrimination laws, including the Civil Rights Act of 1964, the Americans with Disabilities Act (ADA), Section 504 and Section 508 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, and the Age Discrimination Act. This helps guarantee fair and equitable vaccine access for persons with disabilities of all ages.

We have been closely monitoring the vaccine rollout across the country and how it is impacting the disability community. In this letter, we focus on accessibility and prioritization of the vaccine roll out. We recognize and thank the Administration for its recent announcement that it will invest millions of dollars in the aging and disability networks to help people with disabilities get the vaccine and call on them to work with us to ensure proper implementation that addresses our concerns outlined below.

Accessibility

We are very concerned by continued reports on lack of accessibility of vaccination information, registration, and sites. For example, WebAIM, a nonprofit web accessibility organization, found accessibility issues on nearly all of the 94 state COVID vaccine websites it reviewed. Its January nationwide review included pages with general vaccine information, lists of vaccine providers and registration forms.¹ Even the CDC's own Vaccine Administration Management System remains inaccessible for blind users.

¹ <https://khn.org/news/article/covid-vaccine-websites-violate-disability-laws-create-inequity-for-the-blind/>
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We have also heard anecdotal reports of inaccessibility across all phases of the vaccination process, including: limited access to information and registration for people without reliable internet access; lengthy phone wait times; sites with no accessible transportation options; drive-up only vaccination sites; long lines with standing required; no clear way to request accommodations; and appointments being confirmed with only a few hours' notice. Many in our community need at least a day or two to make personal care attendant/direct support worker and transportation arrangements just to make it to their appointment.

The Administration must take further action to ensure that states make vaccination protocols, appointment systems, and related materials accessible to all members of the public, including people with disabilities and those with limited English proficiency. Information accessibility includes, but is not limited to, providing information about vaccine safety, vaccination procedures, and follow-up care and appointments in plain language, American Sign Language, Braille, screen-reader accessible formats, and other alternative formats needed by people with disabilities, including graphic format understandable for those with low literacy, as well as in the top 15 non-English languages spoken in the state.

Individuals should be able to express interest in a vaccine and schedule a vaccine appointment through multiple modalities. Registration accessibility could be achieved through an accessible survey form where residents can indicate their interest in receiving the vaccine and state their preferences of how to be contacted when an appointment becomes available (by phone, email, or other method.) This survey should also be available via telephone.

To achieve vaccination site accessibility, states must make reasonable modifications to ensure that vaccinations are accessible to people with disabilities who do not drive or who are in settings that do not provide transportation. Solutions could include establishing mobile vaccination programs, establishing options and services for "house call vaccinations" for individuals who cannot leave their home, or providing no-cost transportation. Further, for individuals who can drive or get a ride to facility-based vaccination sites but cannot access them due to their disability, the facility should administer the vaccine to the individuals in their vehicles as a reasonable accommodation.

Community Based Organizations (CBOs) including disability and aging advocacy organizations play a crucial role supporting older adults and people with disabilities. These organizations, as trusted messengers, provide vital information and assistance to the community. Managed care and HCBS providers also support populations that immediately need access to the COVID-19 vaccine. State and local governments should adequately fund and collaborate with these organizations to disseminate information and help older adults and people with disabilities schedule and access their vaccines.

Prioritization

We recognize that the landscape of vaccine eligibility and distribution is rapidly changing. We had been very concerned that some states abandoned risk-based eligibility in favor of age-only allocation. This left out younger people with disabilities who have certain high risk medical conditions, family caregivers and frontline essential workers. Then, the President's recent announcement to direct all states to make all people aged 16 and over eligible for vaccination by May 1 changed the nature of the problem: shifting from overly narrow prioritization criteria or age-based approaches that left out many people with disabilities to overly broad universal eligibility that forces people with disabilities to compete for vaccine slots on inaccessible playing fields. A complete opening up of vaccination without eliminating the specific barriers that confront people with disabilities will still result in unequal access. People with disabilities and high-risk conditions are at a great disadvantage as they

compete for still limited appointment slots. Without immediate federal action to overcome the accessibility shortcomings present in nearly all states, people with disabilities who *should* have been near the front of the vaccination line may well end up near the end. Some may become infected as they wait. For these reasons, as long as vaccine supply is still limited in any state or region of the country, federal leadership is urgently needed to ensure active prioritization of and outreach to people with disabilities and high-risk conditions to ensure they can access vaccine appointment registration systems and sites.

For states that have not yet made all adults eligible, the federal government should provide further guidance to make it easier for people with disabilities and high-risk conditions to access vaccinations. First, we urge clarification on the prioritization categories put out by the federal Advisory Committee on Immunization Practices (ACIP) and their interaction with the latest HHS recommendations to prioritize age and people with disabilities and high-risk conditions. Some states have been using the CDC list of high-risk conditions as an exclusive list, as if no other high-risk conditions exist, despite CDC and ACIP making it clear that is not the case. We recommend that the federal government continue to update the CDC list as new evidence becomes available.

Equally important, people with disabilities who receive long-term services and supports (LTSS) and who cannot quarantine or socially distance from those who assist them with activities of daily living should be prioritized for vaccination.² In 2018, 14 million adults with disabilities and other conditions aged 18 and over in the United States needed assistance with essential everyday activities like bathing, dressing, and food shopping. About 90 percent of these persons lived in the community and most received some or all of the assistance they required from a spouse, family member or another person on an unpaid basis.³ Even though the vast majority of states have prioritized individuals who receive LTSS in nursing home settings, those same states have tended to ignore individuals who receive LTSS in home and community-based settings, irrespective of the fact that most of these individuals have multiple health conditions and some have an equivalent “nursing home level” of LTSS need.

People with significant disabilities are also at greater risk due to implicit bias among physicians⁴ and the potential for being subjected to the discriminatory denial or delay of COVID-19 treatment during periods of medical rationing, a concept which the Office for Civil Rights is aware and has been engaged with the disability community and other stakeholders. All states should follow the lead of those states which permit medical providers to use their discretion to designate additional individuals as high-risk, whether the risk arises from a physiological health condition or from other circumstances that exist because of the presence of disability.⁵

As of March 27, 2021, at least 49 states, as well as Washington, D.C., are now allowing some younger adults with certain medical conditions to receive vaccines.⁶ However, the conditions given higher priority differ significantly from state to state, and even county to county. Further, many states require a person to prove they have a medical condition, although at least 16 states (plus DC) do not.⁷ In states still prioritizing for medical conditions,

² <https://dredf.org/wp-content/uploads/2021/02/Vaccination-priority-for-HCBS-recipients-02-11-2021.pdf>

³ <https://www.aarp.org/content/dam/aarp/ppi/2019/08/long-term-services-and-supports.doi.10.26419-2Fppi.00079.001.pdf>

⁴ <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452>

⁵ Amy Harmon and Danielle Ivory, *How America’s Vaccine System Makes People with Health Problems Fight for a Place in Line*, (updated Mar. 27, 2021), <https://www.nytimes.com/2021/03/09/us/covid-vaccine-eligible-preexisting-conditions.html?action=click&module=RelatedLinks&pgtype=Article>.

⁶ New York Times, *Who is Eligible for a Vaccine by Age*, <https://www.nytimes.com/interactive/2020/us/covid-19-vaccine-doses.html#eligibility> (Last visited Mar. 30, 2021).

⁷ Amy Harmon and Danielle Ivory, *How America’s Vaccine System Makes People with Health Problems Fight for a Place in Line*, (updated Mar. 27, 2021), <https://www.nytimes.com/2021/03/09/us/covid-vaccine-eligible-preexisting-conditions.html?action=click&module=RelatedLinks&pgtype=Article>.

the federal government should encourage states to eliminate verification requirements, which will reduce barriers for people with disabilities to get vaccinated, particularly among the most marginalized groups.

Alongside the urgent vaccination efforts, the CDC and the FDA should implement real-time technical assistance (TA) to states and local authorities/vaccine entities regarding the federal government's gathering, review and synthesis of research of people with disabilities and high-risk conditions. This data can inform ongoing COVID activities, help to counter the issue of vaccine hesitancy across a diverse set of populations and also help prepare the nation for the next pandemic. TA could focus on analyzing all information available from public and private sources to determine the vaccination rates and the ongoing risks of COVID morbidity and mortality among people with disabilities across a range of ages, income levels, race, ethnicity and other risk factors. All entities that receive federal financial assistance, from State Medicaid services to nursing homes to small group homes to vaccination entities, could include granular questions about disabilities (to be voluntarily collected from people with disabilities or their authorized support personnel) in their vaccine data collection. Researchers could be incentivized to analyze and evaluate how COVID-19 has affected all people with disabilities across a range of settings and states in terms of infection, hospitalization, treatment and ICU admittance rates, death rates, and vaccination rates.

CCD would like to thank you for listening to our concerns regarding accessibility and prioritization in vaccine distribution. We appreciate the opportunity to provide this information, look forward to continuing the dialogue with you and thank you for your continued efforts to support the disability community throughout this pandemic. Please do not hesitate to reach out for questions or follow up with Rachel Patterson at rpatterson@efa.org or Alexandra Bennewith at abennewith@unitedspinal.org.

Sincerely,

ALS Association

American Academy of Physical Medicine and Rehabilitation

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Council of the Blind

American Network for Community Options and Resources (ANCOR)

American Occupational Therapy Association (AOTA)

American Therapeutic Recreation Association

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Autistic Self Advocacy Network

Brain Injury Association of America

Center for Public Representation

Christopher and Dana Reeve Foundation

CommunicationFIRST

Council of Administrators of Special Education

Disability Rights Education and Defense Fund (DREDF)

Easterseals

Epilepsy Foundation

Family Voices

Justice in Aging

Lakeshore Foundation

Lupus Foundation of America
Lutheran Services in America - Disability Network
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Council on Independent Living
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Health Law Program
Spina Bifida Association
The Arc
United Spinal Association
World Institute on Disability

CC:

White House COVID-19 Equity Task Force
White House Domestic Policy Council
Centers for Disease Control and Prevention
Centers for Disease Control and Prevention COVID-19 Emergency Response
Food and Drug Administration, Office of Stakeholder Engagement
Health and Human Services
Health and Human Services' Administration for Community Living
National Council on Disability
National Institute of Allergy and Infectious Diseases
National Institute on Disability, Independent Living, and Rehabilitation Research

and

Association of State and Territorial Health Officials
National Association of County and City Health Officials