



September 4, 2020

National Academies Sciences, Engineering, and Medicine
500 Fifth St. N.W.
Washington, D.C. 20001

Dear Committee on Equitable Allocation of Vaccine for the Novel Coronavirus:

Thank you for the opportunity to comment on the Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine. The American Association of People with Disabilities (AAPD) writes to express our strong recommendation to include individuals with disabilities and the array of direct care professionals – paid and unpaid – who serve them in the first phase allocation of COVID-19 vaccine. As a national cross-disability rights organization, AAPD advocates for full civil rights for the over 60 million Americans with disabilities by promoting equal opportunity, economic power, independent living, and political participation.

Prioritizing People with Disabilities in Vaccine Allocation, Especially those in Congregate Settings

People with disabilities face a particularly high risk of complications and death if exposed to COVID-19 and should be considered among priority populations due to myriad medical and social determinants that have resulted in a disproportionate negative impact from COVID-19. Many people with disabilities are at a higher risk of infection or severe illness because of underlying medical conditions. According to the CDC, adults with disabilities are three times more likely than adults without disabilities to have chronic conditions – such as heart disease, stroke, diabetes, underlying neurologic conditions or cancer – that increase the risk of severe illness from COVID-19.¹ An additional number of individuals with disabilities across the lifespan are at increased risk of infection due to limited mobility, understanding of health guidelines, and/or ability to communicate symptoms.

Further, while the committee does note the higher prevalence of certain comorbidities among some racial and ethnic minorities, it does not adequately consider the intersection of disability, age, and racial/ethnic minority status, including greater rates of disability among some racial and ethnic minorities, writ large. The severe outbreaks in institutional and congregate settings have meant an increase in exposure risk for many. Current conservative estimates of COVID-19 deaths of people in congregate settings number more than 70,000 as of August 20.² The

¹ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>

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<https://www.kff.org/coronavirus-covid-19/issue-brief/overlooked-and-undercounted-the-growing-impact-of-covid-19-on-assisted-living-facilities/>



committee underestimates this risk in its discussion draft and inappropriately separates congregate facilities into Phase 1 and Phase 2. The allocation framework focuses only on vaccinating older adults in congregate or overcrowded settings in Phase 1b despite the many people with disabilities who also live in long-term care facilities and other congregate settings who are at equal risk. Phase 2 only addresses people in homeless shelters or group homes and incarcerated or detained people or staff. The committee notes that those populations face “high risk of acquiring infection due to lack of choice in setting.” While that is certainly true, that same heightened risk of infection and death from COVID-19 exists across all institutional and congregate settings, including nursing homes, intermediate care facilities for people with intellectual and developmental disabilities, psychiatric hospitals, assisted living facilities, board and care homes, and other congregate settings, and the committee’s report should reflect that reality. The committee should include greater recognition of health disparities faced by people with disabilities, including disparities faced by people with disabilities during this pandemic in particular.

Protecting Against Discrimination in Vaccine Allocation

The draft framework includes very little discussion of disability or people with disabilities. The denial or removal of care from people with disabilities is a very real concern during this pandemic and in a vaccine allocation protocol. AAPD has advocated for equitable distribution of scarce resources during the pandemic, including for fair and non-discriminatory crisis standards of care in cases where need outstrips hospital capacity. Disability advocates have successfully challenged crisis standards of care that deny, deprioritize, or remove care from people with disabilities as violating federal civil rights laws. The disability community’s advocacy contributed to the US Department of Health and Human Services Office for Civil Rights (OCR) issuing a bulletin on Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19).³ It states that “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.” The vaccine allocation framework must comply with US civil rights law and directives from OCR. AAPD appreciates the framework’s recognition of an individual’s right to appeal the allocation of COVID-19 vaccine if done in a manner inconsistent with the framework’s equity principles. We recommend any decision in violation of civil rights laws and OCR directives is immediately overturned. We support the many statements on the committee’s efforts not to base allocation on illegal, discriminatory measures. Disability should be added to those statements.

Prioritizing Direct Support Workers in Vaccine Allocation

³ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>



AAPD is concerned that the proposed framework’s specific language of “health professionals who are involved in direct patient care” (p. 54, 1177) will exclude the caregivers and direct that serve individuals with disabilities from phase one vaccination allocations. Already an underfunded and poorly respected profession prior to the COVID-19 pandemic, the exclusion of direct support professionals (DSPs) from state and local definitions of “healthcare workforce” has resulted in the lack of access to adequate healthcare, personal protective equipment, and resources have only further burdened these workers placed their lives and the lives of the individuals they serve at risk. AAPD believes it is imperative to health equity and mitigation efforts to include the following language within the definition of “‘frontline’ health workers” (p.54, 1177): “direct service professionals and trained caregivers of individuals with disabilities in congregate care and healthcare settings.” Inclusion of caregivers and DSPs, both those who work in congregate settings and those who work in community based settings, within the definition of frontline health workers reinforces CDC recommendations for DSPs, which indicate that there should be access to PPE when providing services for people with disabilities.⁴

Ensuring Accessibility of Vaccine Distribution

AAPD strongly supports the committee’s efforts to recognize and address the disparities in health outcomes among racial and ethnic minorities in the allocation framework. We also support the committee’s assertion that all people in the United States should be eligible to receive the vaccine at the phase appropriate to their circumstances, regardless of legal status and without risking deportation or other legal action against them. AAPD recommends that the framework not tie any state-issued identification requirements to the receipt of the vaccines, as people with disabilities are less likely to have an up-to-date state-issued ID.⁵ This disparity also extends to older adults⁶, those living in poverty, and communities of color⁷-- communities that are also highly vulnerable to the coronavirus. The report acknowledges that access considerations must be taken into account in an allocation framework, including along factors of disability status and age. However, no details are provided beyond that recognition. We encourage a “no wrong door” approach to vaccination. The vaccine should be available at all regular sources of care, through public health agencies, and non-traditional sites of care which may be needed to reach underserved populations. This will require significant collaboration with community health centers and other community-based groups. All information about the vaccine and its distribution must be available in accessible formats and in multiple languages, including American Sign Language.

⁴ <https://www.cdc.gov/coronavirus/2019-ncov/hcp/direct-service-providers.html>

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<https://smlr.rutgers.edu/sites/default/files/images/Disability%20and%20voting%20survey%20report%20for%202012%20elections.pdf>

⁶ <https://www.aging.senate.gov/imo/media/doc/Voting%20Rights%20Report.pdf>

⁷ https://www.brennancenter.org/sites/default/files/2019-08/Report_Challenge_of_Obtaining_Voter_ID.pdf



Concurrent Disasters and Vaccine Distribution

At the writing of these comments, in addition to the existing COVID-19 disaster declarations in all 50 states, there were nine active Federal disaster declarations ranging from hurricanes to wildfires, flooding to mudslides. Concurrent disasters during the pandemic pose great threats to further surges of virus spread as communities may be forced to break social distancing requirements and utilize mass care congregate shelters in response to danger or damage caused by a disaster. Disasters further limit access to services and supports that people with disabilities may use to maintain their health and increase an individual's vulnerability. The framework for vaccine allocation must recognize the reality and regularity of extreme weather and other human made disasters. AAPD recommends that the framework prioritize communities where an active disaster declaration exists vaccine distributions should be considered amongst the life-sustaining mass care and emergency assistance services that state, local, tribal or territorial agencies provide.

In sum, AAPD urges the National Academies to include individuals with disabilities and the care professionals who serve them in the first phase allocation of COVID-19 vaccine. We further urge the National Academies to make vaccine distribution processes and materials accessible to all. It is both an ethical imperative to support this vulnerable population and a practical measure to mitigate the spread of the novel coronavirus.

Thank you for your consideration of these comments. Please do not hesitate to reach out if you have any questions.

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