



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

September 4, 2020

Committee on Equitable Allocation of Vaccine for the Novel Coronavirus
National Academies of Sciences, Engineering, and Medicine
500 5th St NW
Washington, DC 20001

Committee Members:

Thank you for the opportunity to comment on the Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine.

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. We, the co-chairs of the CCD Health, Long Term Services and Supports, and Rights Task Forces, appreciate the opportunity to comment on this important framework.

Concerns with Public Comment Period and Accessibility of Information

We recognize the challenge of this project, and the need for both speed and flexibility during the response to this pandemic. We must note, however, that we are very concerned about the short comment period. Despite statements in the report about the importance of hearing from the public, the committee only provided an extremely short less than four day comment period on a report of more than 100 pages. We appreciate the need to act quickly during this pandemic, but we urge you to extend the comment period in order to ensure meaningful public input.

The framework makes many references to the need for transparency (pg. 41-42) and importance of hearing from the public (pg. 3). We strongly agree with the need for transparency and need for public trust in a vaccine and vaccine allocation framework. However, an 84-hour comment period is far from sufficient to gather meaningful public input or create the type of public trust necessary to recover from the pandemic. While the committee has indicated that it will accept comments after the official comment period closes, there is no guarantee that those comments will be considered as carefully as the comments received during the public comment period, which are part of the public record. Furthermore, neither the extremely short public comment period nor the option to submit comments after that period has ended have been widely publicized, meaning that many stakeholders are likely unaware that this discussion draft even exists and is open for comment, making this highly abbreviated public comment period even less likely to be effective.

In order to ensure public trust in this vaccine allocation framework, the final report should be open for public comment long enough to ensure meaningful public input, and HHS should widely publicize the request for comment on this matter of critical importance to the health and lives of Americans.

In addition, the report makes many references to the importance of public trust in the allocation framework (see especially pg. 42, lines 917-920). To achieve these aims, the final report must be accessible to all members of the public, including to people with disabilities and with limited English proficiency. This includes, but is not limited to, information available in plain language, screen-reader accessibility, availability in other alternative formats needed by people with disabilities, and versions in the major non-English languages spoken in the US. The framework should also be available in graphic format that is understandable by people who may not be able to read.

People Who Live or Work in Congregate Settings Should Receive Priority in Allocation of a Vaccine

People with disabilities face a particularly high risk of complications and death if exposed to COVID-19,¹ and the severe outbreaks in institutional and congregate settings have meant an increase in exposure risk for many, as the committee has recognized in its discussion draft. The committee's proposal does not adequately address that risk, and inappropriately separates congregate facilities into Phase 1 and Phase 2. The committee notes the impact of COVID on long-term care facilities on page 64, lines 1436-1440, stating that, "A significant proportion of COVID-19 deaths occurred in individuals living in long-term care facilities (CMS, 2020a). Data from Canada and other countries, as well as investigative reporting in the United States, suggests that the percentage of COVID-19 deaths in long-term care facilities may be higher than indicated by CDC's database." However, the allocation framework appears to focus only on vaccinating older adults in congregate or overcrowded settings in Phase 1b despite the many younger people with disabilities who also live in long-term care facilities and other congregate settings who are at similar 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 does refer to group homes and homeless shelters as "congregate settings" on page 55, line 1213 of the discussion draft, and we would encourage the committee to be clear and ensure that all residents and staff in all congregate settings are treated similarly and included in the same phase of vaccine allocation.

Some of the individuals left out of those priority categories in Phase 1b and Phase 2 may still receive the vaccine under the committee's framework during Phase 1b and Phase 2 of vaccine allocation if they have a significantly higher risk or moderate risk due to comorbid conditions (defined by the report as having two or more comorbid conditions or one comorbid condition, respectively). However, that list of comorbid conditions (see page 62, lines 1379-1382 and page 69 lines 1578-1585) does not reflect

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7311922>,
<https://ajp.psychiatryonline.org/doi/pdf/10.1176/appi.ajp.2020.20060780>.

disability status and is not broad enough to include all people with disabilities in congregate settings left out of those priority categories.

We recommend that all older adults and people with disabilities in congregate settings (including homeless shelters, jails, and prisons) be included in Phase 1b. However, if that recommendation would provide too large of a population size for Phase 1b, we would recommend dividing Phase 2 into priority levels a and b as well and ensuring that all people in congregate settings of any kind be included in Phase 2a.

In addition to individuals in congregate settings, individuals who receive services at home should receive priority for a vaccine when, as a result of disability, they are unable to effectively distance from others outside their household. This includes individuals who receive personal care services that require close contact with one or more staff members who live outside the home.

The committee's allocation framework also inappropriately places some congregate setting staff in Phase 1a while placing others in Phase 2 and is unclear regarding the vaccine priority level for staff in certain congregate settings. While on page 59, lines 1277, the committee includes "group home staff" in its discussion of high risk workers in health care facilities who would receive the vaccine in Phase 1a, on page 71, lines 1617-1618, the committee says people in homeless shelters or group homes who would receive the vaccine in Phase 2 include "people who live in homeless shelters or group homes for individuals with physical or mental disabilities or in recovery, as well as staff of these facilities." We would respectfully ask the committee to clarify that group home staff are included in Phase 1a of vaccine allocation, not Phase 2, and as above, we recommend that staff in all congregate settings (including homeless shelters, jails, and prisons) be included in the same phase of vaccine allocation. We also support that homecare workers and other caregivers for people with disabilities living in the community are included in this initial high priority phase.

Protecting People with Disabilities in 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 concern² during this pandemic³ and in a vaccine allocation protocol. Many of our organizations have been advocating 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. We have successfully challenged crisis standards of care that deny, deprioritize, or remove care from people with disabilities as violating federal civil rights laws.

On March 28, 2020, the US Department of Health and Human Services Office for Civil Rights (OCR) issued a bulletin on Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19).⁴ It stated 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

² <https://ncd.gov/publications/2019/bioethics-report-series>

³ <https://files.asprtracie.hhs.gov/documents/crisis-standards-of-care-and-civil-rights-laws-covid-19.pdf>

⁴ https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog

treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

Since OCR issued the bulletin in March it has resolved complaints in Alabama, Tennessee, Pennsylvania, Utah, and Connecticut regarding the illegal exclusion of certain people with disabilities and older adults from access to life-saving treatment, reasonable accommodations to hospital visitation policies, accessibility of information on treatment, and other protocols.⁵

The vaccine allocation framework must comply with US civil rights law and directives from OCR. We appreciate the framework’s recognition of an individual’s right to appeal the allocation of vaccine if done in a matter inconsistent with the framework’s equity principles. We recommend any decision in violation of civil rights laws and OCR directives is immediately overturned in any appeals process. 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. Specifically, disability should be added to:

- Page 36, line 760, which describes how the allocation “excludes rationing based on religion, race, ethnicity, national origin, etc.”;
- Page 39, line 845, which explains that age is not a criterion for allocation except as a predictor for heightened risk, transmission, or severity of outcome; and
- Page 45-46, lines 1020-121, which lists race/ethnicity, age, gender, and social status as variables for comprehensive data collection.

Health Disparities

We strongly support 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.

However, the allocation framework seems to lack detail on how these disparities will be directly addressed beyond discussion of application of CDC’s Social Vulnerability Index. The committee should be sure to seek out and receive input from racial justice and health equity advocates on the details of this plan. The committee should also get tribal input on the details of the planned allocation to tribal communities via the Indian Health Services, including any additional funding needs to ensure prompt access to the vaccine. The short length of the comment period, as discussed above, makes it less likely the committee will hear from these groups.

The committee should include greater recognition of health disparities faced by people with disabilities,⁶ including disparities faced by people with disabilities during this pandemic in particular.⁷ While the committee does note the higher prevalence of certain comorbidities among some racial and ethnic

⁵ See comprehensive list of complaints against discriminatory protocols and OCR resolutions here:

<https://www.centerforpublicrep.org/covid-19-medical-rationing/>

⁶ See <https://www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html>, and

https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm?s_cid=mm6732a3_w

⁷ <https://ajp.psychiatryonline.org/doi/10.1176/appi.ajp.2020.20060780>

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 framework should be drafted in line with the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care⁸ and the Blueprint for Advancing and Sustaining CLAS in Policy and Practice,⁹ as developed by the Office of Minority Health.

Access and Distribution

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.

Thank you again for the opportunity to comment. Please do not hesitate to reach out for questions or follow up, to Rachel Patterson at rpatterson@efa.org or Erin Shea at eshea@cpr-us.org.

Sincerely,

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⁸ <https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASStandards.pdf>

⁹ <https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedCLASStandardsBlueprint.pdf>

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