CONSORTIUM FOR CITIZENS WITH DISABILITIES

September 9, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

Dear Mr. Severino,

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, write to provide input regarding allocation of a potential coronavirus vaccine. We provided comments regarding the Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine that was released for public comment last week by the National Academies' Committee on Equitable Allocation of Vaccine for the Novel Coronavirus.[1] We are separately writing you because we believe that the Office for Civil Rights (OCR) plays a critical role in ensuring that any guidance from the federal government about vaccine distribution ensures fair and equal access for people with disabilities and older adults and complies with federal non-discrimination laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, and the Age Discrimination Act.

Protecting People with Disabilities in Allocation

Denying or deprioritizing people with disabilities in receiving care is a very real concern[2] during this pandemic,[3] and the same concerns apply to the potential for discrimination in vaccine allocation protocols. This is particularly true for people of color with disabilities and older adults of color facing much worse infection rates, hospitalizations, and deaths due to COVID-19.[4] OCR itself has recognized the discrimination that people with disabilities and older adults have faced in accessing care during this pandemic in guidance and in resolutions with several states across the nation regarding crisis standards

[1] In those comments we noted the strong concerns we had with the abbreviated period for public comment given to the discussion draft and the issues that raised in terms of ensuring meaningful public input, transparency, and accessibility and we would encourage OCR in its own efforts to respond rapidly to the pandemic to take those concerns into consideration.
[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.cms.gov/files/document/medicare-covid-19-data-snapshot-fact-sheet.pdf

of care and other policies. A vaccine allocation framework must comply with OCR's bulletin issued on March 28, 2020 on Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19),[5] which 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."

Vaccine allocation must comply with US civil rights laws, including the ADA, Section 504, Section 1557, and the Age Discrimination Act, and directives from OCR. We ask OCR to be clear that any vaccine allocation prioritization cannot be based on illegal, discriminatory measures and to describe when disability and age can and cannot be considered. Consistent with OCR's guidance mentioned above and recent resolutions of medical rationing complaints, disability status and age should not be used to deny or deprioritize people for a vaccine, such as categorically excluding people with certain disabilities or functional impairments or prioritizing people based on projections of long-term survivability. However, disability and age can and should be considered – based on the best available objective medical evidence and data -- in evaluating the level of risk, transmission, and severity of outcome for these populations when identifying high risk populations to prioritize for vaccination. In addition, it is also paramount that actual vaccination distribution be transparent and include mandatory data collection about key demographics and intersectionality between those demographics including disability status, age, race, and residential setting.

Prioritization of Residents and Staff in All Long Term Services and Supports (LTSS) Settings

People with disabilities face a particularly high risk of complications and death if exposed to COVID-19,[6] and the severe outbreaks in institutional and congregate settings have meant an increase in exposure risk for many. While much of the attention in the media has been focused on nursing homes, this is true across all congregate settings and includes both older adults within those settings and younger people with disabilities who also live in those settings. An allocation framework should be based on evidence-based analysis of the risks, including risks to residents and staff in congregate settings. We believe this evidence would show that an allocation framework should not differentiate between the type of congregate setting or a particular group of residents or staff within a congregate setting in allocation of a potential vaccine. 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, jails, prisons, homeless shelters and other congregate settings, and the COVID-19 outbreaks those facilities have faced will remain rampant if all residents and staff are not prioritized in vaccine allocation.

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

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

[6] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7311922, https://ajp.psychiatryonline.org/doi/pdf/10.1176/appi.ajp.2020.20060780.

contact with one or more staff members who live outside the home. Staff who provide those services should likewise be prioritized in vaccine allocation.

Access, Distribution, and Public Trust Concerns

Guidance from the federal government on vaccine allocation should also address access considerations, including along factors of disability status and age. We have encouraged a "no wrong door" approach to vaccination. The vaccine should be available at all regular sources of care, through public health agencies, and at non-traditional sites of care which may be needed to reach underserved populations that face disparities in access to care, as OCR addressed in its recent guidance regarding Title VI and its application to the COVID-19 pandemic.[7] This will require significant collaboration with community health centers and other community-based groups. This will also require OCR monitoring and oversight that vaccine sites are accessible to people with disabilities. This includes, for example, that vaccinations cannot only be offered at facility-based or "drive-up only," sites, as has occurred with some states' testing programs.[8] Instead, states must make reasonable modifications, such as establishing mobile vaccination programs or providing no-cost transportation, to ensure that vaccinations are accessible to people with disabilities who do not drive or are in settings that do not provide transportation.

In addition, it is critical to the efficacy of a potential vaccine that the public trust in its safety and understand the allocation process. To this end, OCR should ensure that materials regarding the vaccination protocol 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, providing the information in plain language, in screen-reader accessible formats, in other alternative formats needed by people with disabilities, including graphic format that is understandable by people who may not be able to read, and in the major non-English languages spoken in the US.

We appreciate the opportunity to provide our input on this topic 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, to Rachel Patterson at rpatterson@efa.org or Erin Shea at eshea@cpr-us.org.

Sincerely,

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[7] https://www.hhs.gov/sites/default/files/title-vi-bulletin.pdf
[8] See, for example, https://www.disabilityrightsnebraska.org/file_download/01653280-73e0-4dfd-8deb-9acbb170216e.

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