



CONSORTIUM FOR CITIZENS WITH DISABILITIES

COVID-19 Vaccine Allocation Principles October 2020

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 COVID-19 pandemic has required our health systems to prepare for and consider the implications of allocation of scarce medical resources in a number of contexts, and the same remains true regarding allocation of a potential coronavirus vaccine. Should a vaccine or multiple vaccines be approved either through the regular approval process or through emergency use authorization, there is not expected to be a sufficient supply to immediately conduct a widespread vaccination campaign. Therefore, it is of the utmost importance that any vaccine distribution plan or allocation framework be carefully considered. Any such plan should take into consideration the needs of people with disabilities and direct care workers across settings, ensure that both the information and the means of distribution are accessible, and comply with federal guidance and civil rights law. These principles may be updated as we learn more about the virus and about potential vaccines.

Ensure Compliance with Federal Civil Rights Laws and Guidance

Vaccine allocation must comply with US civil rights laws, including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, Title VI of the Civil Rights Act, and the Age Discrimination Act, and with federal guidance pertaining to COVID-19. Vaccine allocation prioritization also must comply with guidance¹ and recent resolutions of medical rationing complaints² from the Department of Health and Human Services Office for Civil Rights (OCR).

This means that, among other things, 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.

¹ Office for Civil Rights, US Department of Health and Human Services. BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). March 28, 2020. https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog.

² See comprehensive list of complaints against discriminatory protocols and OCR resolutions here: <https://www.centerforpublicrep.org/covid-19-medical-rationing>.

Use Non-Discriminatory Value Assessments in Vaccine Allocation Prioritization

While vaccine allocation may consider disability in certain instances, discussed above, a vaccine allocation framework should take care not to use discriminatory value assessments and cost-effectiveness measures that rely on Quality Adjusted Life Years (QALY), or similar measures, in the instances in which disability is considered. The QALY is a discriminatory measure based on the idea that disabled lives are less valuable than non-disabled lives and should not be used in vaccine allocation.

Prioritize 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-19,³ and the severe outbreaks in institutional and congregate settings have meant an increase in exposure risk for many. 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, and other congregate settings and vaccine allocation frameworks should reflect that.

In addition to individuals in congregate settings, individuals who receive home and community based services should receive priority for a vaccine when, as a result of disability or advanced age, 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 care workers who live outside the home. Individuals who provide those services should likewise be prioritized in vaccine allocation.

Address Health Disparities

Any vaccine allocation effort must work to effectively address health disparities. These disparities have always existed but have been exacerbated during the pandemic. This requires not only a commitment to address these disparities, but detail on how precisely they will be addressed. An appropriate framework must address the health disparities faced by people with disabilities,⁴ including disparities faced by people with disabilities during this pandemic in particular⁵ and consider the intersection of disability, age, gender, sexual orientation, race, ethnicity, and primary language, including greater rates of disability among some racial and ethnic minorities, writ large. In addition, given the history of racism in clinical trials and bias in healthcare delivery, some communities of color have developed a distrust of the healthcare system and may be reluctant to take the vaccine. Therefore, it is critical that the allocation, distribution, and administration plans be drafted in line with the National Standards for Culturally and

³ Landes S, Turk M, Formica M, McDonald K, Stevens J. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*. 2020 Jun 24: 100969.

doi: 10.1016/j.dhjo.2020.100969. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7311922>,
<https://ajp.psychiatryonline.org/doi/pdf/10.1176/appi.ajp.2020.20060780>.

⁴ See https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm?s_cid=mm6732a3_w.

⁵ <https://ajp.psychiatryonline.org/doi/10.1176/appi.ajp.2020.20060780>.

Linguistically Appropriate Services (CLAS) in Health and Health Care⁶ and the Blueprint for Advancing and Sustaining CLAS in Policy and Practice,⁷ as developed by the Office of Minority Health.

Ensure Disability and Language Access to Information

Public trust in the safety of any potential coronavirus vaccine is paramount if vaccine allocation efforts are to be effective. In order to build that trust and ensure the public understands the allocation process, all materials regarding the vaccination protocol 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, 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 non-English languages spoken in the US.

Ensure Accessibility of Vaccination Sites

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. Vaccine sites must also be 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.

Ensure All People Can Receive the Vaccine

All people in the United States should be eligible to receive any future coronavirus vaccine at the phase appropriate to their circumstances, regardless of legal status and without risking deportation or other legal action against them. To do any less would be detrimental to the efficacy of vaccination efforts. Furthermore, to ensure the efficacy of those efforts, not only should vaccination sites and information related to vaccination and to the allocation framework be accessible, but that information, particularly the eligibility criteria for different phases within vaccine allocation, must also be well-publicized. This may require reaching beyond the typical channels, to ensure that individuals who are members of underserved populations who meet the criteria to receive the vaccine within certain allocation phases are aware of their eligibility to receive the vaccine.

Signatories:

Allies for Independence
ALS Association
American Association on Health and Disability
American Network of Community Options and Resources
American Physical Therapy Association
Association of University Centers on Disabilities
Autism Society of America

⁶ <https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASStandards.pdf>.

⁷ <https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedCLASStandardsBlueprint.pdf>.

⁸ See, for example, https://www.disabilityrightsnebraska.org/file_download/01653280-73e0-4dfd-8deb-9acbb170216e.

Brain Injury Association of America
Center for Public Representation
Christopher & Dana Reeve Foundation
CommunicationFIRST
Disability Rights Education & Defense Fund
Easterseals
Epilepsy Foundation
Justice in Aging
Lutheran Services in America—Disability Network
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Respite Coalition
The Arc of the United States
United States International Council on Disabilities