



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

SUBMITTED VIA REGULATIONS.GOV

October 23, 2020

Advisory Committee on Immunization Practices
Centers for Disease Control and Prevention
1600 Clifton Road, N.E. Mailstop A27
Atlanta, GA 30329

Re: CDC–2020–0100

Dear Committee Members:

Thank you for the opportunity to provide public comment for the October 2020 meeting of the Advisory Committee on Immunization Practices (ACIP) at the Centers for Disease Control and Prevention (CDC).

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.

Our detailed comments are below. In short, we urge the committee to:

1. Include all residents of congregate facilities in Phase 1 of allocation
2. Protect the civil rights of people with disabilities in allocation decisions
3. Ensure that the physical distribution and administration of the vaccine is accessible to people with disabilities.

In addition to our comments here, we have also developed principles for vaccine allocation.¹

In September, we submitted comments to the National Academies of Science, Engineering, Medicine Draft Framework for Equitable Allocation of Vaccine for the Novel Coronavirus.² We appreciated the National Academies' ad hoc committee's thoughtful approach and commitment to advancing health equity. In particular, we strongly supported many statements on the ad hoc committee's efforts to not base allocation on discriminatory measures and encouraged them to add disability to those statements. We also appreciated that the ad hoc committee's framework did not deprioritize people with disabilities or consider the lives of people with disabilities or chronic health conditions to be less worth saving.

¹ Consortium for Citizens with Disabilities. COVID-19 Vaccine Allocation Principles. October 2020. <http://c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf>

² Consortium for Citizens with Disabilities. Comment Letter on Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine. September 4, 2020. <http://c-c-d.org/fichiers/CCD-Vaccine-Allocation-Comments-9-4-20.pdf>

We understand that ACIP is likely to rely on the National Academies report to develop your vaccine allocation framework. While we proposed changes to the National Academies framework, specifically to include all people in congregate settings in Phase 1, we urge you to follow the example of the National Academies and strive to ensure that people with disabilities are protected in the allocation model. We also urge you to follow their model focusing first on prevention of severe morbidity and mortality, with a shift towards focusing on transmission for later phases. We specifically underline their first point supporting their phased approach “Death is an irreversible outcome.” (pg. S-6). While many groups have legitimate claims, and impact on the economy is a concern, we urge ACIP to prioritize those most at risk of severe morbidity and mortality due to the risk of loss of human life. Our detailed recommendations follow.

Including all People in Congregate Settings in Phase 1

The National Academies ad hoc committee recommended that older adults living in congregate or overcrowded settings be included in Phase 1b of allocation. Other people living in congregate settings, including homeless shelters; group homes; jails, prisons; and detention centers; and other such settings would be included in Phase 2. The National Academies framework does not mention other facilities, such as intermediate care facilities or psychiatric facilities.

CCD urged the committee to include more congregate settings in Phase 1. The committee’s own allocation criteria, as shown on Table 3-2, page 3-16 provide the exact same risk scores for older adults in congregate settings in Phase 1b as others in homeless shelters or group homes that it has included in Phase 2.

Based on materials from ACIP’s September 2020 meeting, it appears ACIP primarily discussed the staff of congregate facilities in Phase 1 allocation but did not discuss residents. The meeting slides also discuss people over age 65 and people with high risk medical conditions but without consideration of living situation. The risks to people living in congregate facilities is well documented, including in nursing facilities,³ group homes,⁴ jails and prisons,⁵ intermediate care facilities, psychiatric facilities, and other congregate settings. According to the Kaiser Family Foundation, while long-term care facilities account for 8% of total cases in the US, they account for 40% of total deaths.⁶ Living setting is a crucial factor when determining allocation, and consideration of congregate settings must include all congregate settings, not just nursing facilities. We strongly urge you to include all individuals living in such settings and staff in early phases of vaccination.

³ The New York Times. About 38% of U.S. Coronavirus Deaths Are Linked to Nursing Homes. Accessed October 20, 2020: <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html>

⁴ 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/>

⁵ Saloner B, Parish K, Ward JA, DiLaura G, Dolovich S. COVID-19 Cases and Deaths in Federal and State Prisons. JAMA. 2020;324(6):602–603. doi:10.1001/jama.2020.12528 <https://jamanetwork.com/journals/jama/fullarticle/2768249>

⁶ Kaiser Family Foundation. State Data and Policy Actions to Address Coronavirus. Accessed October 20, 2020: <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus/#long-term-care-cases-deaths>

ACIP further discussed how to prioritize people *within* phases if needed. ACIP includes people with high risk medical conditions in Phase 1. However, people with high risk medical conditions living in congregate settings are at much higher risk than those with the same conditions who are able to maintain distance from others and engage in other mitigation practices. The same applies for people over age 65. ACIP should prioritize people in congregate settings during the earliest phases of allocation, even within the focus on people with high risk conditions and those over age 65, due to their significant risk for severe morbidity and mortality.

Outside of congregate settings, however, it is also important that ACIP consider the degree to which people are able to engage in mitigation practices. 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.

It may be that there are enough vaccine supplies to provide for all people over age 65 and with high risk medication conditions in phase 1. However, if this is not the case, we urge ACIP to take setting into account and prioritize people living or receiving services in congregate settings and those who receive home and community-based services who are unable to engage in mitigation practices such as distancing from others outside of their household.

Finally, we appreciate ACIP's analysis of racial and ethnic breakdown of essential workers and support efforts to use this data to promote health equity in vaccine allocation. Direct care staff, both in congregate settings and in home and community-based settings are disproportionately women of color.⁷ We support efforts to vaccinate staff and residents or recipients of home and community-based services simultaneously.

Protecting People with Disabilities in Allocation

The denial or removal of care from people with disabilities and older adults is a very real concern⁸ during this pandemic⁹ and in a vaccine allocation protocol. Many of our organizations have been advocating for equitable distribution of scarce resources during the pandemic, especially crisis standards of care in cases where need outstrips hospital capacity. In several states, crisis standards of care have explicitly outlined the ways in which people with certain disabilities and/or advanced age would be denied care, or have care removed, in a crisis situation.

⁷ Scales K. It's Time to Care: A Detailed Profile of America's Direct Care Workforce. PHI.

<https://phinational.org/caringforthefuture/itstimetocare/>

⁸ National Council on Disability. Bioethics and Disability Report Series.

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

⁹ Assistant Secretary of Planning and Response, US Department of Health and Human Services. Crisis Standards of Care and Civil Rights Laws. <https://files.asprtracie.hhs.gov/documents/crisis-standards-of-care-and-civil-rights-laws-covid-19.pdf>

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).¹⁰ 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 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 from access to life-saving treatment, reasonable accommodations to hospital visitation policies, accessibility of information on treatment, and other protocols.¹¹ The vaccine allocation framework should comply with US civil rights laws and directives from OCR.

Ensuring Accessibility of Distribution and Administration

In addition to protecting people with disabilities in allocation decisions, we also urge ACIP to promote a distribution plan that is accessible to people with disabilities. On September 9, we wrote to Roger Severino, Director of the Office for Civil Rights at the US Department of Health and Human Services outlining key civil rights concerns in vaccine allocation and distribution.¹²

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 at non-traditional sites of care which may be needed to reach underserved populations that face disparities in access to care.¹³ This will require significant collaboration with community health centers and other community-based groups. We urge ACIP and CDC to include these considerations in plans and communications to state and local governments and the public. For example, vaccinations cannot only be offered at facility-based or “drive-up only,” sites, as has occurred with some states’ testing programs.¹⁴ 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 and older adults 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, CDC must 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

¹⁰ 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_OasYiXi91XW4rnAKW8kxcog

¹¹ See comprehensive list of complaints against discriminatory protocols and OCR resolutions here: <https://www.centerforpublicrep.org/covid-19-medical-rationing/>

¹² Consortium for Citizens with Disabilities. Letter to the Office for Civil Rights, US Department of Health and Human Services. September 9, 2020. <http://c-c-d.org/fichiers/CCD-OCR-Vaccine-Allocation-Letter-9-9-20.pdf>
¹³ <https://www.hhs.gov/sites/default/files/title-vi-bulletin.pdf>

¹⁴ See, for example, https://www.disabilityrightsnebraska.org/file_download/01653280-73e0-4dfd-8deb-9acbb170216e.

disabilities, including graphic format that is understandable by people who may not be able to read, and in the top 15 non-English languages spoken in each state.

Finally, we must note that we have heard hesitancy among some who might otherwise be among the first to receive a vaccine if they do not have trust in the FDA process or believe a vaccine has been rushed to market. To ensure compliance with vaccine recommendations, ACIP should engage with community partners to provide targeted outreach and education to high-risk groups explaining the development, allocation, efficacy, and risks associated with a COVID-19 vaccine. ACIP should serve as a crucial check point for public trust when it makes its recommendations.

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,

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
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Public Representation
Christopher & Dana Reeve Foundation
CommunicationFIRST
Cure SMA
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 Spinal Association
United States International Council on Disabilities