ASAN
AUTISTIC SELF ADVOCACY NETWORK
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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

Autistic Self Advocacy Network Comments on Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine

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

The Autistic Self Advocacy Network[1] appreciates this opportunity to comment on the proposed framework[2] for equitable allocation of a future SARS CoV-2 (COVID-19) vaccine. We are the nation's leading self-advocacy organization by and for autistic people ourselves, and are dedicated to ensuring that the voices of autistic people and others with intellectual and developmental disabilities (I/DD) are heard in the policy discussions that impact our lives.

We appreciate the time and effort that the Committee has devoted to analyzing ethical vaccine allocation during this time of fear and uncertainty. Nonetheless, we are concerned that the resulting allocation scheme remains opaque on certain issues and does not adequately address the full range of people with disabilities who live in congregate settings. This includes people with disabilities, such as intellectual or developmental disabilities, that significantly affect health outcomes related to COVID-19.[3] Moreover, we are concerned that the Committee provided inadequate opportunity for the full public to review and comment on the framework.

The four-day public comment period allotted for the framework, as well as the 5,000 character limit in the "Your Comments" section of the comment submission form, are

[1] For more information on ASAN, you can visit our website at: http://www.autisticadvocacy.org.
[2] National Academies of Sciences, Engineering, and Medicine & Committee on Equitable Allocation of Vaccine for the Novel Coronavirus, Discussion Draft of the Preliminary Framework for Equitable Allocation of COVID-19 Vaccine (2020), *available at:* https://www.nap.edu/download/25914 [hereinafter "Discussion Draft"].
[3] John N. Constantino, Mustafa Sahin, Joseph Piven, Rylin Rodgers, & John Tshida, Letter to the Editor, *The Impact of COVID-19 on Individuals with Intellectual and Developmental Disabilities: Clinical and Scientific Priorities,* Am. J. Psychiatry, Aug. 28, 2020, at 12, *available at:* https://ajp.psychiatryonline.org/doi/10.1176/appi.ajp.2020.20060780,

inadequate to ensure adequate input from the public, especially stakeholders with disabilities.[4]

The Committee's lengthy 114-page discussion draft for the framework contains approximately 90 pages of substantive material (non-biographical and non-reference), which discusses the Committee's rationale for each component of the framework in great detail.[5] Very few individuals - outside of policy analysts and specialists - would be able to read and comprehend this material and produce relevant comments within the allotted four days. The Committee states repeatedly throughout the discussion draft that input from impacted stakeholders is critical to ensuring that the framework is fair, equitable, and transparent,[6] but the greatly abbreviated comment period makes it nearly impossible to get that input directly from impacted stakeholders. We therefore strongly recommend that the Committee extend their public comment period to 60 days.

Additional aspects of the discussion draft further reduce the number of clear and comprehensive comments that the Committee is likely to receive. The "Your Comments" section of the public comment submission form limits responses to a meager 5,000 characters.[7] Character limits greatly limit the degree of detail that may be included in comments and reduce the quality of stakeholder discussions of the framework. While there is an "Upload supporting file" section on the same form, many readers - particularly readers with cognitive disabilities - may assume that only "supporting files" such as journal articles could be uploaded there, rather than full comments.[8] The form is therefore inaccessible to many commenters with disabilities.

The discussion draft itself is also written using highly complex language that could not be understood by the majority of stakeholders, despite the Committee's stated commitment to a "clear articulation and explanation of the allocation criteria."[9] We recommend that the Committee create a plain language summary of the report's contents at minimum according to at least the plain language standards present in the Plain Writing Act of 2010, and if possible a summary at a 3rd-5th grade reading level.[10] The final report

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[4] National Academies of Sciences, Engineering, and Medicine, *Public Comment Form: Discussion Draft: Preliminary Framework for Equitable Allocation of COVID-19 Vaccine,* https://www.nap.edu/vaccine/ (last visited Sept. 3, 2020).
[5] Discussion Draft at 2-98.
[6] *See, e.g.,* Discussion Draft at 40-42.
[7] National Academies of Sciences, Engineering, and Medicine, *Public Comment Form: Discussion Draft: Preliminary Framework for Equitable Allocation of COVID-19 Vaccine,* https://www.nap.edu/vaccine/ (last visited Sept. 3, 2020).
[8] *Id.*
[9] Discussion Draft at 41.
[10] *Law and requirements,* Plainlanguage.gov, https://plainlanguage.gov/law/ (last visited Sept. 3, 2020).

should also be screen reader accessible and available in a wide variety of other alternative formats for people with disabilities, such as Braille or in a recorded video format. Additionally, the report should be made available in at least several major non-English languages spoken in the United States.

ASAN recommends that the Committee revise its allocation system to account for the high risk of morbidity and mortality faced by *all* people with disabilities in congregate settings.

Although the Committee's stated primary goal is to "maximize societal benefit by reducing morbidity and mortality caused by transmission of the novel coronavirus,"[11] the current allocation schema fails to adequately address risks to individuals who live in congregate settings. This may include people with disabilities living in nursing homes, assisted living facilities, group homes, psychiatric institutions, residential treatment centers, disability-specific intentional communities, and other such settings across the country.

The Committee notes, and we show in ASAN's COVID-19 tracker (which tracks resident cases and deaths in congregate facilities), that the death toll for people with disabilities in these settings is in the tens of thousands.[12] Nonetheless the Committee includes nursing home staff and other congregate setting workers among the individuals who should be vaccinated first in Phase 1a, while those actually *living* in congregate settings are either split between Phases 1b and Phase 2 or else are not included until Phase 3 or Phase 4.[13] In the discussion draft, the Committee notes that while 800 nursing home staff members have been reported as dying from COVID-19, more than 45,000 *residents* have died of complications related to COVID-19.[14] ASAN itself has witnessed that, within data recorded by the states on cases and deaths in long term care facilities, the deaths of residents far outnumber the deaths of staff members. We oppose an allocation framework that prioritizes staff over residents of congregate care facilities, particularly residents with significant additional risk factors.

The framework also appears to inappropriately place certain people in congregate settings, and those whose disabilities make self-isolation impossible, in Phase 3 or even 4, despite the elevated risk of acquiring infection. Although older adults in congregate settings (meaning those at or over 65) are included in Phase 1b as some of the earliest people to be vaccinated, no mention is made of *younger* adults, such as those with mental

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[11] Discussion Draft at 44.
[12] Discussion Draft at 59, 64; *COVID-19 Case Tracker,* Autistic Self Advocacy Network, https://autisticadvocacy.org/covid19/ (last visited Sept. 3, 2020).
[13] Discussion Draft at 58-61, 64-66, 71-76.
[14] Discussion Draft at 59-60.

health disabilities and developmental disabilities, who nonetheless live in nursing homes, assisted living facilities, and other locations listed under Phase 1b but who do not have two or more co-occurring conditions that tend to increase the risk of mortality from COVID-19.[15] Other people with disabilities in congregate settings would not be covered until Phase 2, which covers individuals living in group homes and homeless shelters, as well as individuals who have only *one* of the co-occurring conditions listed in this section.[16] Individuals with developmental disabilities living in nursing homes, DD centers, psychiatric facilities, or other similar congregate settings, who none of the listed co-occurring conditions, would paradoxically not be covered until Phase 3 (placing them alongside nail salon workers and nondisabled young adults)) or even Phase 4 (everyone else), despite their significantly elevated risk of exposure to COVID-19 and of mortality.[17] We recommend that, given the high risk of infection, this population be included in Phase 1b or, at the very least, alongside group home residents in Phase 2.

ASAN requests that the Committee clarify language in the discussion draft which does not clearly place some populations in one allocation phase or the other.

The discussion draft lacks clarity with respect to what constitutes a "congregate setting" and *which* co-occurring conditions, exactly, lead to a person's placement in a particular vaccine distribution phase. For example, in one part of the report, "group home staff" are considered to be among those working in a congregate setting and would be covered by Phase 1a.[18] However, on page 71, the staff of homeless shelters and group homes are considered part of Phase 2.[19] Similarly, the Committee lists "neurologic conditions" as among the disabilities which may lead to a person's placement in Phase 2, but does not define what a "neurologic condition" is. This phrase does not have one specific definition: it has been used to refer to conditions in the brain that are not developmental disabilities, but it is also used to refer to autism - a developmental disability.[20]

ASAN urges the Committee to define the terms it uses clearly and consistently so that individuals potentially impacted by its framework can easily determine when they

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[15] *Id.* at 62, 64-66, 71, 72-76.
[16] Discussion Draft at 71.
[17] *Id.* at 72-76.
[18] *Id.* at 58-59.
[19] *Id.* at 71.
[20] *What is a Neurologic Condition?* Child Neurology Foundation, https://www.childneurologyfoundation.org/patients-or-caregivers/living-neurological-condition/what-is-a-neurologic-disorder/ (last visited Sept. 3, 2020) (includes developmental disabilities and uses "neurological" as a synonym or extension, as seen above); *Neurological and Psychiatric Diseases and Conditions,* Brigham and Women's Hospital, https://www.brighamandwomens.org/neurosciences-center/neurological-and-psychiatric-diseases-and-conditions (last visited Sept. 3, 2020)(listed as "Neurologic Diseases and Conditions on Google; The definition does not include developmental disabilities).

could potentially receive the coronavirus vaccine. The Committee must remember that its framework, if utilized by decision-makers, could impact *whether and which individuals live or die from a deadly virus.* Without clarity, many stakeholders and their corresponding advocates or advocacy groups may be confused about which vaccination programs they qualify for, and health care providers may be uncertain about who to prioritize first.

ASAN recommends that the allocation system be revised to account for people with disabilities who live in the community and lack one of the prioritized co-occurring conditions, but nonetheless are at high risk of contracting the virus and of having severe outcomes due to their disabilities and living conditions.

Many individuals with disabilities, rather than living in congregate settings, receive home and community-based services (HCBS) and other long term services and supports (LTSS) through state-funded Medicaid waiver programs, such as Section 1915(c) and others.[21] Although some of these individuals have two or more co-occurring medical conditions that would lead to their vaccination during Phase 1b, or one co-occurring medical condition which would lead to their vaccination during Phase 2, others may have conditions or disabilities which would lead to them only being vaccinated during Phase 3 or Phase 4, which mostly covers the general population.

These individuals may nonetheless be at a higher risk of contracting COVID-19 than people in the general population. Individuals receiving HCBS are often in unavoidable and very close contact with other people, such as home health aides and other supporters. LTSS services such as those provided under HCBS waivers can involve a person helping another with daily living tasks, transportation, home health care, and doing household chores - all of which are tasks that can involve sustained intimate physical contact between the person and their supporter.[22] People with disabilities who use LTSS and their staff may be unable to access or use PPE. This may include ventilator users, people with significant developmental disabilities, people who need assistance with eating and bathing, and people who have home health aides present in the house while they sleep. LTSS users may have multiple aides throughout the course of the day and those aides themselves often support multiple people in different households, including people with significant medical risk factors. As a result, LTSS users and their staff are at a high risk not only of contracting the virus but also of transmitting it to others. ASAN therefore recommends that individuals

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[21] *See, e.g., Home & Community-based Services,* Centers for Medicare and Medicaid Services, https://www.medicaid.gov/medicaid/home-community-based-services/index.html (last visited Sept. 3, 2020).

[22] Erica L. Reaves and MaryBeth Musumeci, *Medicaid and Long Term Services and Supports: A Primer,* Kaiser Family Foundation (Dec. 15, 2015), https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/.

receiving Medicaid-funded HCBS be included within at least Phase 1b or Phase 2, with other individuals with disabilities receiving these services in congregate settings.

The Committee should ensure that people with disabilities do not experience discrimination in vaccine allocation decisions.

ASAN appreciates the Committee's commitment to avoid discrimination on the basis of protected characteristics or immigration status, as well as its commitment to ensuring that the framework does not add to or duplicate existing health disparities.[23] We recommend that disability be referenced and added to this commitment wherever possible. We additionally recommend that the Committee consult with advocates and stakeholders from the civil rights community and immigrant communities when refining its framework.

ASAN is among those organizations who have been significantly concerned about previous triage and rationing policies related to COVID-19 that have discriminated on the basis of disability with no medical basis for such discrimination. For example in July 2020, the Autistic Self Advocacy Network collaborated with multiple disability and civil rights organizations to file a joint complaint with the U.S. Department of Health and Human Services.[24] Our complaint alleged that Arizona and Texas' crisis of care plans denied certain categories of people with disabilities lifesaving treatment on the basis of disability, failed to modify no-visitor policies to avoid discrimination, and failed to prohibit treatment decisions based on discriminatory assessments of future care an individual may require.[25] We have also historically been involved in protesting decisions made on the basis of uninformed, prejudiced ideas about the "worth" of disabled lives, such as those made by utilizing quality-adjusted life years or in organ transplant discrimination.[26]

We therefore urge the Committee to adopt an explicit statement that vaccine allocation decisions, like allocation decisions regarding therapies, should not "exclude people based on age, disability, religion, race or ethnicity, national origin, gender, sexual orientation, or perceived quality of life or comorbid conditions."[27]

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[23] *See* Discussion Draft at 36, 39, 45-46 (concerning non-discrimination on the basis of disability); Discussion Draft at 67, 79 (concerning immigration and the fact that immigrants should nonetheless not be denied the vaccine on the basis of their legal status, whether undocumented or not).

[24] *COVID-19 Hotspots Arizona and Texas Crisis Standard of Care Plans Challenged by State and National Groups in Federal Complaints,* Autistic Self Advocacy Network (July 22, 2020), https://autisticadvocacy.org/2020/07/covid-19-hotspots-crisis-standard-of-care-plans-challenged-by-state-and-national-groups/.

[25] *Id.*

[26] *See Bioethics and Disability Report Series,* National Council on Disability (2019), https://ncd.gov/publications/2019/bioethics-report-series.

[27] *See* Discussion Draft at 19 (discussing allocation of therapies for hospitalized patients).

ASAN additionally recommends that the Committee contact and consult with national and local civil rights organizations with respect to health disparities and other forms of discrimination and how these concerns relate to COVID-19 vaccination. It may be necessary for the Committee to consider and collaborate with civil rights organizations and disability rights organizations simultaneously, as disability may be intersectional with another protected status or multiple statuses, such as race, ethnicity, gender, or sexual orientation.

ASAN reiterates its interest in a fair, equitable distribution of the novel coronavirus vaccine that truly considers the many kinds of individuals with disabilities there are and their risks of contracting COVID-19. For more information on ASAN's positions with respect to the equitable allocation of the coronavirus vaccine, please contact Sam Crane, our Legal Director, at scrane@autisticadvocacy.org.