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.

This submission is a joint effort and collaboration by The American Network of Community Options and Resources (ANCOR), The National Association of State Directors of Developmental Disabilities Services (NASDDDS) and The American Academy of Developmental Medicine & Dentistry (AADMD).

The American Network of Community Options and Resources (ANCOR)is a national, nonprofit trade association representing more than 1,600 private community providers of services to people with disabilities. Our members provide long-term care to more than 600,000 people with intellectual and developmental disabilities across the country through Medicaid Home and Community Based Services. The providers who ensure their health and safety, do this largely unrecognized. They are among the unsung heroes that we hear about daily throughout the pandemic.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.

The American Academy of Developmental Medicine & Dentistry (AADMD) is a non-profit, membership organization of interdisciplinary health professionals — including primary physicians, medical specialists, dentists, optometrists, nurses and other clinicians — committed to improving the quality of healthcare for people with intellectual & developmental disabilities (IDD).

Concern with Limited Public Comment Period

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 4-day comment period. Comment periods of 30-60 days

are typical in federal policymaking. We appreciate the need to act quickly during this pandemic, but we hope that future comment periods will allow more time for 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 enough to gather meaningful public input or create the type of public trust necessary to recover from the pandemic. The final report should be open for public comment for at least 30 days.

IDD Specific Risk Factors for COVID-19

People with intellectual and developmental 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 focuses only on vaccinating older adults in congregate or overcrowded settings in Phase 1b despite the many people with disabilities who also live in long-term care facilities and other congregate settings and share similar medical risk factors.

Individuals with IDD spend a lot of time in group and congregate settings, significantly increasing the risk of transmission of COVID-19. There are 600,000 adults with IDD living in community based congregate settings such as group homes and host homes. Many individuals with IDD also attend congregate day programs, many of which have already reopened. Individuals who live in group homes or other congregate residential settings should be considered at equivalent risk to older adults who live in congregate settings and thus be included in phase one 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 include intellectual and developmental disability despite the increased risk outlined above. We recommend that intellectual and developmental disability be explicitly included in the list of high-risk diagnoses.

Referencing AADMD's white paper "COVID-19 Support Guidelines for Individuals with IDD During the Pandemic", there are an estimated 8 million Americans with intellectual and developmental disabilities (IDD), and it is well documented that people with IDD have long experienced structural health inequities, including social determinants of health, that put their health at far greater risk for poorer

outcomes from COVID-19. Complications from and death rates due to coronavirus disease 2019 (COVID-19) for people with intellectual and developmental disabilities (IDD) are disproportionately higher when compared to people without IDD (Turk, et al., 2020; Landes, et al., 2020). COVID-19-related fatality rates among people with IDD who have tested positive for COVID-19 are, in some states, more than three times the mortality rates among the general population who have tested positive for COVID-19. Extensive research has established the high rate of chronic morbidities and poorer health status common among people with IDD (Ervin, et al., 2014; Sullivan, et al., 2018; Anderson, et al.,2013). Therefore, individuals with IDD must be specifically considered and prioritized in the COVID vaccine allocation efforts.

Many of the risk factors that are associated with severe outcomes from COVID-19 infection, such as cardiovascular disease, diabetes and chronic lung disease (Stokes, et al., 2020; Centers for Disease Control and Prevention, 2020a), are common in adults with IDD. Thus, based on the current proposed allocation framework, many people with IDD would qualify for phase 1, with two high risk diagnoses. However, the current short list of high-risk diagnoses does not adequately address the risks facing individuals with IDD. Pneumonia and other respiratory complications are one of the most common causes of death in individuals with IDD. The vaccine allocation framework should also account for high risk pulmonary diagnoses including chronic or recurrent respiratory diseases from any cause, restrictive lung disease, and interstitial lung disease in the list of high-risk diagnoses outlined in phase 1b, beginning line 1374 in the current framework. Undoubtedly, people without IDD who also have these diagnoses are at much higher risk for morbidity and mortality related to COVID-19.

Direct Support Professionals (DSPs)

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."

DSPs provide a wide range of supports to individuals with IDD, including support with health-related tasks with exposures to aerosols and bodily fluids. Their occupation puts them at a greatly increased risk for exposure to COVID, similar to staff in nursing homes, although they have not been prioritized for PPE distribution, putting them at even greater risk.

Although Direct Support Professionals have been the forgotten faces of the 2020 Coronavirus Pandemic as they continue to arrive for work every day, ready to do everything they can to ensure the health and safety of people with intellectual and developmental disabilities and autism, they provide essential support that ensures all individuals with disabilities are—

(1) included as a valued part of their community;
(2) supported at home, at work, and in the communities of the United States; and
(3) empowered to live with the dignity that all people of the United States deserve.

Direct Support Professionals ensure that individuals with disabilities thrive through connections to their families, friends, and communities, thereby avoiding more costly institutional care. They've kept people healthy and safe, thereby avoiding unnecessary hospitalizations.
DSPs build close, respectful, and trusting relationships with individuals with disabilities and provide a broad range of individualized support, including—

(1) helping people to learn to make person-centered choices that lead to meaningful and productive lives;
(2) assisting with personal care, meal preparation, medication management, and other aspects of daily living;
(3) assisting with accessing the community and securing gainful employment;
(4) providing transportation to school, work, religious, and recreational activities;
(5) helping with general daily affairs, such as assisting with financial matters, medical appointments, and personal interests;
(6) transitioning from segregated settings or services to living robust lives in the communities of their choice;
(7) providing the first line of defense in keeping people with disabilities safe and healthy during the Coronavirus pandemic; and
(8) volunteering to quarantine with individuals served to reduce transmission of the virus.

We would respectfully ask the committee to clarify that group home staff (Direct Support Professionals) are included in Phase 1a of vaccine allocation, not Phase 2.

The Rights of People with Disabilities to Medical Care

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 concern during this pandemic and in a vaccine allocation protocol. We support the many statements on the committee's efforts to not base allocation on discriminatory measures. Disability (to include physical, intellectual and developmental) 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; and
- Page 45-46, lines 1020-121, which lists race/ethnicity, age, gender, and social status as variables for comprehensive data collection.

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).[1] 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. The vaccine allocation framework should comply with US civil rights law and directives from OCR.

The committee should include greater recognition of health disparities faced by people with disabilities,[1] including disparities faced by people with disabilities during this pandemic in particular.[2] While the committee does note the higher prevalence of certain comorbidities among some racial and ethnic minorities, it does not adequately consider the intersection of disability 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 Care and the Blueprint for Advancing and Sustaining CLAS in Policy and Practice,[4] as developed by the Office of Minority Health.

Access and Distribution

The report acknowledges that access considerations must be considered 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. We recognize that the committee does not control coverage policy.

Thank you again for the opportunity to comment. Please feel free to reach out to Shannon McCracken for any questions or follow up from the group at smccracken@ancor.org.

Sincerely,

Allen Wong, DDS,
EdD President
AADMD

Emily Johnson, MD
VP Policy
AADMD

Barbara Merrill
CEO, ANCOR

Shannon McCracken
VP Government Relations ANCOR

Mary Sowers
Executive Director, NASDDDS

Dan Berland
Director of Federal Policy, NASDD