Joint Position Statement on COVID-19 Vaccine Allocation and Safety

October 28, 2020

The development of a safe, effective vaccine is a critical component of the global response to the coronavirus disease 2019 (COVID-19) pandemic. Vaccine distribution and allocation must be done in a safe and equitable manner, and individuals with intellectual and developmental disabilities (IDD) must be explicitly addressed in any framework for vaccine allocation. This joint position statement addresses the risks facing people with IDD during the pandemic and recommends how they should be included in the vaccine allocation framework. Commentary is based on Framework for Equitable Allocation of COVID-19 Vaccine, published by the National Academy of Sciences, Engineering, and Medicine.

Summary of Recommendations:

The organizations party to this Position Statement, as named herein, recommend the following be included in the vaccine allocation framework:

1. IDD should be explicitly included in the list of high-risk diagnoses that are used to determine if an individual is included in phase 1b (2 high risk diagnoses required) or phase 2 (1 high risk diagnosis required).
2. Include additional pulmonary comorbidities in the list of high risk diagnoses: chronic or recurrent respiratory diseases from any cause, restrictive lung disease, and interstitial lung disease
3. 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.
4. All direct support professionals (DSP), including group home staff should be considered essential health care workers and should be included in Phase 1a of vaccine allocation, not Phase 2.

Specific COVID-19 Risk Factors for People with IDD

There are an estimated 8 million Americans with IDD, and it is well documented that people with IDD have long experienced structural health inequities, including adverse social determinants of health, that put their health at far greater risk for poorer outcomes from COVID-19 (Ervin, et al., 2014; Sullivan, et al., 2018; Anderson, et al., 2013). Complications from and death rates due to COVID-19 for people with 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, two and three times the mortality rates among the general population who have tested positive for COVID-19. Therefore, individuals with IDD must be specifically considered and prioritized in the COVID-19 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 more common in adults with IDD. The current proposed vaccine allocation framework does account for increased risk due to chronic conditions, including cancer, chronic kidney disease, COPD, immunocompromised state from solid organ transplant, obesity (BMI>20), serious heart conditions (heart failure, coronary artery disease, cardiomyopathies), sickle cell disease, and type 2 diabetes. Additionally, pneumonia and other respiratory complications are among 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. People without IDD who also have these diagnoses are at much higher risk for morbidity and mortality related to COVID-19.

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Individuals with certain high risk diagnoses would be vaccinated in Phase 1b and Phase 2 of vaccine allocation if they have a significantly higher risk or moderate risk due to specific comorbid conditions (defined by the report as having two or more comorbid conditions or one comorbid condition, respectively). However, the current list of high-risk diagnoses does not include IDD despite the disproportionately increased risks associated with people with IDD outlined above. We recommend that IDD be explicitly included in the list of high-risk diagnoses.

Risk of Congregate Living Settings

There are approximately 600,000 adults with IDD living in community-based congregate settings such as group homes. Many individuals with IDD also attend congregate day programs, many of which have already reopened. The Centers for Medicare and Medicaid Services notes a significant proportion of COVID-19 deaths occurred in individuals living in long-term care facilities (Centers for Medicare and Medicaid Services, 2020), many of which represent congregate living. Data from Canada and other countries, as well as investigative reporting in the United States, suggest that the percentage of COVID-19 deaths in long-term care facilities may be higher than indicated by the Centers for Disease Control and Prevention (CDC) database." However, the allocation framework focuses only on vaccinating older adults in congregate or overcrowded settings in Phase 1b, despite the many people with IDD who also live in long-term care facilities and other congregate settings and share similar medical risk factors. 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.

Direct Support Professionals

DSPs continue to provide essential supports to ensure the health and safety of people with IDD, including support with health-related tasks that elevate exposure to aerosols and bodily fluids. Their occupation puts them at a greatly increased risk for exposure to COVID-19, similar to staff in nursing homes, although they have not been prioritized for personal protective equipment (PPE), diagnostic testing or other infection control resources, putting them at even greater risk.All DSPsshould be considered essential health care workers and should be included in Phase 1a of vaccine allocation, not Phase 2.

The Rights of People with IDD to Medical Care

The draft framework does explicitly acknowledge the importance of avoiding discrimination in allocation efforts, and we support the committee's efforts to not base allocation on discriminatory measures. However, the draft framework includes very little discussion of people with IDD. The denial or removal of care from people with IDD is a very real concern during this pandemic and in a vaccine allocation protocol.

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). It 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" (2020).

Since its issuance, OCR 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

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and directives from OCR.

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.

Vaccine Safety

A safe and effective COVID-19 vaccine is a critical tool in combating the pandemic and has the potential to benefit the lives of countless people with IDD. Although we advocate that individuals with IDD and DSPs be prioritized in vaccine allocation frameworks, we only advocate for this once safety and efficacy has been determined based on adequate clinical trials and prevailing science.
The proposed vaccine allocation framework makes many references to the need for transparency and importance of hearing from the public. We strongly agree with the need for transparency and need for public trust in a vaccine and vaccine allocation framework.

References

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United States Department of Health and Human Services Office for Civil Rights. Bulletin on Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). Washington, DC: OCR, 2020. URL: https://www.justice.gov/file/1263421/download

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 National Alliance for Direct Support Professionals (NADSP)
The vision of NADSP is a world with a highly qualified and professional direct support workforce that partners with, supports, and empowers people with disabilities to lead a life of their choosing. NADSP works to elevate the status of direct support professionals by improving practice standards, promoting system reform, and advancing their knowledge, skills and values, through certification, credentialing, training, professional development, and accreditation services.

The Developmental Disabilities Nurses Association (DDNA) is a 501(c)(3) nursing specialty organization committed to advocacy, education and support for nurses who provide services to persons with developmental disabilities. Our goal is to foster the growth of nursing knowledge and expertise about optimal care of persons with DD through improving the care services and quality of life. DDNA believes that DD nurses are the experts in this specialty area of nursing.

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).

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