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Joint Position Statement on Equity for People with Intellectual and Developmental Disabilities Regarding COVID-19 Vaccine Allocation and Safety

October 28, 2020 - Updated December 9, 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. The aim of this joint position statement is to address the risks facing people with IDD during the pandemic and to recommend how they should be included in vaccine allocation frameworks. The final provisions for vaccine allocation will ultimately be determined on a state level, and many different allocation frameworks exist. The following recommendations are intended to be broadly adaptable to state and national allocation frameworks.

Summary of Recommendations

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

- Individuals with intellectual and developmental disabilities who live in group homes or other community residential settings should be considered at equivalent risk to older adults who live in congregate settings and thus be included in equivalent phases of vaccine allocation.
- All direct support professionals (DSP), including group home staff, in care settings aiding persons with intellectual and developmental disabilities should be considered essential health care workers, and should be included in the appropriate phase of vaccine allocation.
- Given increased rates of serious illness and death from COVID-19 in people with intellectual and developmental disabilities, persons with this diagnosis or condition should be explicitly included in the list of high-risk diagnoses that are used to determine vaccine priority. Individuals with IDD as well as those who live with or provide their care must be included in the same phase of vaccine allocation, regardless of living setting.

Specific COVID-19 Risk Factors for People with IDD

There are an estimated 7.5 million Americans with IDD[i], 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[ii,iii,iv]. Complications from and death rates due to COVID-19 for people with IDD are disproportionately higher when compared to people without IDD.[v,vi] Mortality rates have been cited to be up to 15% in individuals with IDD[vii,viii,xi]. In individuals with Down syndrome specifically, there is an estimated four-fold increase in risk for COVID related hospitalization and ten-fold increase in COVID-19 related death[x]. 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 are more common in adults with IDD.[xi,xii] The Centers for Disease Control and Prevention (CDC) currently outlines the following as high risk diagnoses to be considered in vaccine allocation frameworks: cancer, chronic kidney disease, chronic obstructive pulmonary disease (COPD), immunocompromised state from solid organ transplant, obesity (BMI > 30), serious heart conditions (heart failure, coronary artery disease, cardiomyopathies), sickle cell disease, smoking, and type 2 diabetes. Many individuals with IDD will already be considered high risk based on one of the above listed diagnoses, as well as having a high risk for early-onset Alzheimer's disease in those with Down syndrome. However, the current list of high-risk diagnoses does not include intellectual or developmental disability, despite the disproportionately increased risks associated with people with IDD outlined above. We recommend that intellectual or developmental disability be explicitly included in the list of high-risk diagnoses in all vaccine frameworks.

Risk of Congregate Living Settings
There are approximately 600,000 adults with IDD living in community-based congregate settings such as group homes.[xiii] Many individuals with IDD also attend congregate day programs, many of which have already reopened. The Centers for Medicare and Medicaid Services (CMS) notes a significant proportion of COVID-19 deaths occurred in individuals living in long-term care facilities,[xiv] many of which represent congregate living. Data from 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 CDC database. [xv,xvi] 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.[xvii,xviii] Due to risk of exposure to staff who may test positive for COVID-19, individuals who live in group homes or other congregate residential settings should also be considered at equivalent risk to older adults who live in long-term care settings and thus be included in the first phase of vaccine allocation.

Direct Support Professionals
DSPs, the staff at residential and day services settings, continue to provide essential personal care and other support 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, like 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.[xix] All DSPs should be considered essential health care workers and should be appropriately included in the first phase of vaccine allocation.

Family and Household Members and Other Community Support Providers
Not all proposed frameworks currently account for care providers and family members of adults at high risk for severe illness and death from COVID-19. However, to minimize the risk of exposure and thus transmission, individuals and family members who live with and/or provide care for individuals with IDD should be prioritized as well. Specifically, they should be included in the same phase of vaccine allocation as the individual with whom they live with and for whom they provide care.

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 efforts fully in this regard. 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.[xx]

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 based on 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."[xxi]

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 and directives from OCR.

Access and Distribution
Access must be considered in an allocation framework, including considerations of disability status and age. We urge 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 also encourage reasonable modifications to "drive-up only" sites or other testing facilities, such as establishing mobile vaccination programs or providing no-cost transportation, to ensure that vaccinations are accessible to people with IDD whose family members do not drive or reside in settings that do not provide transportation. Additionally, the vaccine protocol and accompanying information must be accessible to people with IDD in plain language, in screen-reader accessible formats, in alternative formats needed by people with IDD, including graphic format that is understandable by people who may not be able to read, and in non-English languages spoken in the US.

Autonomy and Choice
Regardless of diagnosis or level of intellectual functioning, no individual should be mandated to receive a vaccine. All vaccines should be given on a voluntary basis as determined by the individual or their legal decision maker. Assent should be obtained for any individual who is not their own legal decision maker. The risks and benefits of the vaccine, as well as consequences of not receiving the vaccine, should be appropriately discussed.

Communications with State Health Authorities
We recognize that state health authorities, whose responsibility is to oversee the distribution and allocations of vaccines and manage inoculation protocols and procedures, are wrestling with many challenges during this difficult time. We further recognize and call upon state developmental disabilities agencies and other relevant state bodies to liaise and consult with state health authorities and the service provider community and advocacy organizations on the selection and prioritization of at-risk groups within the population of persons with IDD and assure the equitable distribution and allocation of vaccines so as to mitigate continued contact infections and prevent spread of the COVID-19 virus within home and other settings where persons with IDD reside.

The Evolving COVID-19 Landscape
Vaccine allocation parameters should be constantly reviewed and updated as the knowledge regarding COVID-19, safety and efficacy of vaccines, and high-risk populations changes. We acknowledge that provisions for the distribution and accessing the COVID-19 vaccine are constantly changing and subject to the vagaries of state policies and procedures. Please check back periodically to the site where you accessed this statement for any updates and changes in recommendations.

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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).

American Association on Intellectual and Developmental Disabilities (AAIDD) is the oldest and largest interdisciplinary society of professionals concerned with intellectual and developmental disabilities. AAIDD was founded in 1876 to address questions relating to the causes, conditions, and understanding of intellectual and developmental disabilities and to develop best practices in education and services. The major functions of AAIDD are to support its members' professional activities; publish cutting edge research and materials that inform policy and practice; develop and implement educational opportunities for professionals, policy makers, and others; and engage in activities that promote progressive public policy.

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.

Developmental Disabilities Nurses Association 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 **Global Down Syndrome Foundation (GLOBAL)** is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome. GLOBAL has donated more than $32 million to establish the first Down syndrome research institute supporting over 400 scientists and over 2,000 patients with Down syndrome from 28 states and 10 countries. Working closely with Congress and the National Institutes of Health, GLOBAL is the lead advocacy organization in the U.S. for Down syndrome research and care. GLOBAL has a membership of over 150 Down syndrome organizations worldwide, and is part of a network of Affiliates – the Crnic Institute for Down Syndrome, the Sie Center for Down Syndrome, and the University of Colorado Alzheimer's and Cognition Center – all on the Anschutz Medical Campus.

The **LuMind IDSC Foundation** is a national non-profit organization for people with Down syndrome that accelerates research to increase availability of therapeutic, diagnostic, and medical care options and empowers the largest online community of individuals with Down syndrome and their families with education, resources, connections, and support. We envision a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential.

The vision of the **National Alliance for Direct Support Professionals (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.

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.

National Task Group on Intellectual Disabilities and Dementia Practices is a nonprofit organization whose purpose is to advocate for appropriate services for adults with intellectual disability affected by dementia, as well as provide information and education related to dementia and its impact on persons with intellectual disability to caregivers, providers of services, and governmental and non-governmental bodies.

The Arc of the United States is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities (I/DD) and serving them and their families. We work tirelessly to uphold our vision that every individual and family living with I/DD in the United States has access to the information, advocacy, and skills they need to support their full inclusion and participation in the community throughout their lifetimes.

The National Disability Rights Network (NDRN) works in Washington, DC on behalf of the Protection and Advocacy Systems (P&As) and Client Assistance Programs (CAPs), the nation's largest providers of legal advocacy services for people with disabilities. NDRN promotes the network's capacity, ensures that P&As/CAPs remain strong and effective by providing training and technical assistance, and advocates for laws protecting the civil and human rights of all people with disabilities.

The National Down Syndrome Congress (NDSC) is the country's oldest national non-profit, non-partisan organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. The NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.