



## Commentary

## Prioritizing COVID-19 vaccinations for individuals with intellectual and developmental disabilities

Emily Hotez, PhD<sup>a</sup>, Peter J. Hotez, MD, PhD<sup>b</sup>, Kashia A. Rosenau, MA<sup>a</sup>,  
Alice A. Kuo, MD, PhD, MBA<sup>a,\*</sup>

<sup>a</sup> University of California, Los Angeles (UCLA) Department of Medicine, Los Angeles, CA USA

<sup>b</sup> Texas Children's Center for Vaccine Development, Departments of Pediatrics and Molecular Virology & Microbiology, National School of Tropical Medicine, Baylor College of Medicine, Houston TX USA

## ARTICLE INFO

## Article History:

Received 22 January 2021

Accepted 24 January 2021

Available online 5 February 2021

In December 2020, the Advisory Committee on Immunization Practices (ACIP) Coronavirus Disease 2019 (COVID-19) Vaccine Working Group issued recommendations for prioritizing and allocating vaccinations for the first available mRNA vaccines from Pfizer-BioNTech and Moderna [1]. Notably absent from the Phase 1 tiered guidelines are almost all individuals with intellectual and/or developmental disabilities (I/DD). This population comprises between 1 and 2% of the U.S. population and includes individuals with attention-deficit/hyperactivity disorder, autism spectrum disorder, blindness, cerebral palsy, moderate to profound hearing loss, learning disability, seizures, stuttering or stammering, and/or other developmental delays with or without intellectual impairment.

The exclusion of most I/DD diagnoses from the guidelines represents yet another barrier to health and well-being for this population that will have significant consequences. The I/DD population has historically grappled with fragmented access to primary and preventive care [2,3], social and medical stigma, and marginalization [4]. These barriers contribute to higher prevalence of co-occurring mental and physical health conditions and rates of mortality [5,6], particularly for racial and ethnic minorities, women, and individuals from low-income families [2,3]. Given these barriers and resulting health disparities, we can anticipate hurdles for vaccine dissemination and uptake among individuals with I/DD, making timely and strategic vaccination of this population even more critical.

The omission of most individuals with I/DDs from the guidelines presents a significant public-health concern. There is growing consensus that individuals with I/DDs are particularly susceptible to COVID-19, demonstrating more severe illness, greater risk of hospitalization, and almost twice the case fatality rates for individuals

aged 18–74 [7,8]. Individuals with I/DD have also disproportionately lost vital educational and health-care services and experienced employment layoffs and furloughs. Emerging evidence suggests that individuals with I/DDs may also struggle with adhering to social distancing guidelines [9]. Taken together, the evidence underscores that it is critical to vaccinate individuals with I/DD as soon as possible to prevent further disproportionate impacts on this population. Therefore, the Biden administration should move immediately to include individuals with I/DDs in the priority guidelines.

To be sure, ACIP recommended allocation of the first vaccines for healthcare providers and residents of long-term care facilities – including individuals with I/DD who reside in such settings – in Phase 1a. There is corresponding state discretion to determine priority status for individuals who reside in large institutions or smaller group homes that are not considered long-term care facilities [10]. But the guidelines exclude a significant swath of individuals with I/DD, including the approximately 70,000 who reside in large institutions or smaller group homes across the US [10]. This exclusion serves to accelerate the spread of the virus and affects not only those with I/DDs but also those who provide them direct support in these facilities, including professionals who have been noted to work multiple jobs and are disproportionately women of color [10]. And although the guidelines were properly revised on December 23, 2020, to include those with Down Syndrome, that revision does not account for I/DD conditions that are far more prevalent. For instance, approximately 1 in 1,200 children, teens, and adults are estimated to have Down Syndrome but the prevalence of autism spectrum disorder is currently 1 in 54 children and 1 in 45 adults. This is not to say that individuals with less frequently occurring I/DDs should not be prioritized – as certain diagnoses may be particularly susceptible – but to note that it is abundantly clear that the guidelines exclude a large proportion of at-risk individuals and those who care for them.

The exclusion of individuals with I/DD from the priority guidelines stems, in part, from a continued inattention to this population in research studies. Specifically, national population health data for individuals with I/DD is incomplete and strategies to improve vaccination rates in individuals with I/DD are under-explored. Additionally, the vast majority of research has not been informed by the perspectives, experiences, and priorities of individuals with I/DD and their families. These research gaps are particularly critical to fill

\* Corresponding author.

E-mail addresses: [ehotez@mednet.ucla.edu](mailto:ehotez@mednet.ucla.edu) (E. Hotez), [hotez@bcm.edu](mailto:hotez@bcm.edu) (P.J. Hotez), [rosenau@mednet.ucla.edu](mailto:rosenau@mednet.ucla.edu) (K.A. Rosenau), [Akuo@mednet.ucla.edu](mailto:Akuo@mednet.ucla.edu) (A.A. Kuo).

during the pandemic in order to identify strategies to increase vaccination rates and understand host immunological responses to vaccinations for this population.

We propose the following to address the pressing needs of the I/DD community during the COVID-19 pandemic. First, all individuals with I/DDs should be prioritized for vaccinations. This requires a broadening of current Phase 1 prioritizations. Of course, merely amending the guidelines will not be sufficient to address the health disparities, exacerbated by COVID-19, that individuals with I/DDs face. Thus, there is a concomitant need to develop a public-health infrastructure that will promote access to vaccinations. These investments should support awareness and education regarding vaccination availability and protocols to ensure that individuals with I/DD are able to benefit from the priority guidelines. As an example, ACIP should provide clear guidance to individuals and families on their website and all public materials. Further, I/DD populations should expressly be integrated into state vaccination guidelines. State guidelines should consistently include those in group homes or other institutions, as well as their direct support professionals, and make procedures understandable and easy to navigate. Finally, researchers and funders should prioritize studies that will promote the health and well-being of individuals with I/DDs during the pandemic. We urge the new Biden administration and community of policymakers to accept these recommendations and commit to a social-justice oriented agenda that will ameliorate health disparities for individuals with I/DDs.

#### Declaration of Competing Interest

The authors do not have any financial and personal relationships directly or indirectly related to the submitted work.

#### References

- [1] Dooling K. The Advisory committee on immunization practices' updated interim recommendation for allocation of COVID-19 vaccine—United States, December 2020. *MMWR Morb Mortal Wkly Rep* 2020:69.
- [2] Zerbo O, Qian Y, Ray T, et al. Health care service utilization and cost among adults with autism spectrum disorders in a US integrated health care system. *Autism Adulthood* 2018;1(1):27–36. doi: 10.1089/aut.2018.0004.
- [3] Magaña S, Parish S, Morales MA, Li H, Fujiura G. Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellect Dev Disabil* 2016;54(3):161–72.
- [4] Nicolaidis C, Raymaker DM, Ashkenazy E, et al. Respect the way I need to communicate with you": healthcare experiences of adults on the autism spectrum. *Autism* 2015;19(7):824–31.
- [5] Haverkamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J* 2015;8(2):165–72. doi: 10.1016/j.dhjo.2014.11.002.
- [6] Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health* 2020;10(1):20–34. doi: 10.1177/2156869318804297.
- [7] Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disabil Health J* 2020;13(4):100969.
- [8] Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: triNetX analysis. *Disabil Health J* 2020:100942 Published online.
- [9] Embregts PJ, van den Bogaard KJ, Frielink N, Voermans MA, Thalen M, Jahoda A. A thematic analysis into the experiences of people with a mild intellectual disability during the COVID-19 lockdown period. *Int J Dev Disabil* 2020:1–5 Published online.
- [10] Contrera J. People with disabilities desperately need the vaccine. But states disagree on when they'll get it. *Washington Post* 2021 <https://www.washingtonpost.com/dc-md-va/2021/01/13/disabled-coronavirus-vaccine-states/> Accessed January 14.