Syracuse University
Aging Studies Institute

December 2, 2020

Centers for Disease Control and Prevention
Advisory Committee on Immunization Practices (ACIP)

Dear ACIP members:

We write to **advocate for the prioritization of people with intellectual and developmental disabilities (IDD) in the allocation of the COVID-19 vaccine**. We expressed concern[1] early in the pandemic that this population would experience disproportionate burdens of the disease due to:

1) higher prevalence of underlying medical conditions that can increase the severity of COVID-19 outcomes;[2,3]
2) a disproportionate percentage of the population residing in congregate settings;[4]
3) inaccessible health communications about COVID-19 and mitigation strategies;[5,6]
4) historic and continuing status as a vulnerable, and often marginalized, health disparities population.[7,8]

These concerns were on target. Our first study of a large sample of people with and without IDD with a COVID-19 diagnosis confirmed higher prevalence of underlying conditions among those with IDD at all ages, and a higher case-fatality rate for people with IDD at ages 0-17 and 18-74.[9] Our second study on congregate settings revealed that in New York State, people with IDD living in group homes had a case rate 4x higher, and case-fatality rate 1.9x higher than for the state overall.[10] Studies currently in progress demonstrate that the higher case rate for those living in congregate settings is likely associated with number of residents per facility, but the higher case-fatality rate is likely due the higher prevalence of pre-existing conditions, these trends are consistent for this population across the US.[11,12]

Just distribution of vaccines requires prioritization decisions to consider highest medical need, social marginalization, and overall health-related harm or outcomes.[13] The **evidence is clear that people with IDD are experiencing disproportionate severe COVID-19 outcomes and this population should be taken into account as the ACIP determines the allocation of COVID-19 vaccination**. We concur with the recommendation from the National Academies of Sciences, Engineering and Medicine that people with IDD residing in congregate settings, as well as the staff that provide their care, should receive priority in the vaccination strategy.[14] However, we are concerned that limiting prioritization only to people with IDD who reside in congregate settings – rather than the entire IDD population – may be short-sighted. Due to the higher prevalence of co-occurring medical conditions that can increase COVID-19 severity, the extent of likely exposure due to challenges in keeping social distancing and needs for direct support, and status as a vulnerable health population, **we ask that the committee consider prioritizing all people with IDD for the COVID-19 vaccine**.

Respectfully,

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References

1. Landes SD, Stevens JD, Turk MA. *COVID-19 and pneumonia: Increased risk for individuals with intellectual and developmental disabilities during the pandemic.* Syracuse, NY: Lerner Center for Public Health Promotion, Syracuse University; April 27 2020.
2. Landes SD, Stevens JD, Turk MA. Cause of Death in Adults with Down Syndrome in the US. *Disability and Health Journal.* 2020;13(4):1-9.
3. Landes SD, Stevens JD, Turk MA. Cause of death in adults with intellectual disability in the United States. *Journal of Intellectual Disability Research.* 2020;65(1):49-59.
4. Braddock D, Hemp R, Rizzolo MC, Tanis ES, Haffer L, Wu J. *The State of the States in developmental disabilities: Emerging from the Great Recession.* Washington, DC: American Association on Intellectual and Developmental Disabilities; 2015.
5. Sabatello M, Blankmayer-Burke T, McDonald KE, Applebaum P. Disability, Ethics and Health Care in the COVID-19 Pandemic. *American Journal of Public Health.* Accepted.
6. Sabatello M, Landes SD, McDonald KE. People With Disabilities in COVID-19: Fixing Our Priorities. *The American Journal of Bioethics.* 2020;20(7):187-190.
7. Spong CY, Bianchi DW. Improving Public Health Requires Inclusion of Underrepresented Populations in Research. *JAMA.* 2018;319(4):337-338.
8. Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities.* 2014;27(5):431-446.
9. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal.* 2020;13(3):1-4.
10. 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. *Disability and Health Journal.* 2020;13(4):1-5.
11. Landes SD, Turk MA, Ervin DA. Case-fatality rates for people with intellectual and develomental disabilities in 11 US states. In progress.
12. Landes SD, Turk MA, Wong AWWA. COVID-19 Outcomes among People with Intellectual and Developmental Disability in California: The Importance of Type of Residence and Skilled Nursing Care Needs *Disability and Health Journal.* Under review.
13. Williams JH, Dawson A. Prioritising access to pandemic influenza vaccine: a review of the ethics literature. *BMC Medical Ethics.* 2020;21(1):40.
14. National Academies of Sciences E, Medicine. *Framework for Equitable Allocation of COVID-19 Vaccine.* Washington, DC: The National Academies Press; 2020.