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Director
Centers for Disease Control and Prevention
Atlanta, Georgia

Karen Remley, MD, MBA, MPH, FAAP

Director
National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Atlanta, Georgia

Nancy Messonnier, MD

Director
National Center for Immunization and Respiratory Diseases (NCIRD)
Atlanta, Georgia

Dear Dr. Walensky, Dr. Remley, and Dr. Messonnier,

Our collective organizations sincerely appreciate the tireless and selfless work from everyone at the Centers for Disease Control and Prevention during the ongoing worldwide novel coronavirus disease 2019 (COVID-19) derived health crisis. Our organizations share the commitment of ensuring that vaccine allocation frameworks are designed to protect the most vulnerable and prioritize those persons at highest risk of death from COVID-19. Research continues to show that individuals with intellectual and developmental disabilities (IDD) are at high risk of hospitalization and death from COVID-19 and are being overlooked in vaccination allocation frameworks. While some states have made all people with IDD a part of Phase 1 vaccination priority groups, others have not. Our collective organizations urge the Centers for Disease Control and Prevention to amend its vaccination guidelines to also include people with IDD living in other than group residential facilities as Phase 1B vaccination priority (including those living with family or on their own).

In the initial phase of vaccine allocation, many high-risk individuals have already been offered the opportunity to be vaccinated, including older adults, persons living in congregate settings, and staff at care facilities. Fortunately, most if not all state vaccination frameworks have included individuals with IDD who live in congregate settings and care staff (direct support professionals - DSPs) in this phase. Such individuals with IDD who live in congregate settings and DSPs should be offered vaccination opportunities as soon as possible -- if they have not been already. 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

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may be higher than indicated by the CDC database.^{1,2}

Individuals with IDD are at significantly higher risk compared to the general population, regardless of their living situation. Complications from and death rates due to COVID-19 for people with IDD are disproportionately higher when compared to people without IDD.^{3,4} Mortality rates have been cited to be up to 15% in individuals with IDD.^{5,6,7} Further, there is an estimated four-fold increase in risk for COVID related hospitalization and ten-fold increase in COVID-19 related death in individuals with Down syndrome specifically. In addition, those adults with IDD and specifically with Down syndrome and diagnosed with dementia have also shown increased morbidity and mortality.⁹ Thus, we believe that at-risk individuals with IDD must be prioritized explicitly along with other high-risk diagnoses.

Currently, there is significant variability in how individuals with IDD are prioritized in vaccine allocation frameworks. We ask that the Centers for Disease Control and Prevention provide a centralized framework for vaccine allocation with clear guidelines regarding risk that includes adults with IDD. After frontline healthcare workers (including DSPs), individuals should be prioritized for vaccination based on risk of severe complication or death from COVID-19 rather than solely on occupation or location of residence in order to protect the most vulnerable, including those with IDD.

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¹ Bondy H. 39% of Covid-19 deaths have occurred in nursing homes — many could have been prevented: report. [December 8, 2020]. NBC News. <https://www.nbcnews.com/health/your-value/feature/39-covid-19-deaths-have-occurred-nursing-homes-many-could-ncna1250374>

² Burton JK, Baybe G, Evans C, Garbe F, Gorman D, Honhold, N et al. Evolution and effects of COVID-19 outbreaks in care homes: a population analysis in 189 care homes in one geographical region of the UK. *The Lancet-Health Longevity*, 1(1), E21-E31, October 1, 2020. [https://www.thelancet.com/journals/lanhl/article/PIIS2666-7568\(20\)30012-X/fulltext](https://www.thelancet.com/journals/lanhl/article/PIIS2666-7568(20)30012-X/fulltext)

³ Cuypers M, Schalk BWM, Koks-Leensen MCJ, Nägele ME, Bakker-van Gijssel EJ, Naaldenberg J, & Leusink GL. Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 2020, 64(7), 482-488.

⁴ Spreat, S., Cox, R., & Davis, M. COVID-19 case & mortality report – intellectual or developmental disabilities. New York Alliance for Inclusion and Innovation, 2020. https://www.ancor.org/sites/default/files/covid-19_case_and_mortality_report.pdf

⁵ 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*, 2020, 1-5.

⁶ 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, 100942.

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. *Disability and Health Journal*, 2020, 100969.

⁸ Clift AC, Coupland CAC, Keogh RH, Hemingway H, Hippisley-Cox J. COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults. *Annals of Internal Medicine*, 2020, 21 October 2020: Letters.

⁹ Hüls, A., Costa, A.C.S., Dierssen, M., Asaad Baksh, R., Bargagna, S., Baumer, N.T., Brandão, A.C., Carfi, A., Carmo-Iragui, M., Chicoine, B.A., Ghosh, S., Lakhnpaul, M., Manso, C., Mayer, M-A., del Carmen Ortega, M., Real de Asua, D., Rebillat, A-S., Russell, L.A., Sgandurra, G., Valentini, D., Sherman, S.L., & Strydom, A.

An international survey on the impact of COVID-19 in individuals with Down syndrome medRxiv, November 5, 2020. <https://doi.org/10.1101/2020.11.03.20225359>

¹⁰ COVID-19 Vaccines. Commonwealth of Pennsylvania. <https://www.health.pa.gov/topics/disease/coronavirus/Vaccine/Pages/Vaccine.aspx>



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The framework from the commonwealth of Pennsylvania provides an example of prioritization largely based on risk of death and explicitly includes Down syndrome as a high-risk condition.¹⁰ We are encouraged by the CDC's classifying Down syndrome as a high-risk condition and suggest that this type of framework be used, although should include all IDD diagnoses in a high risk category. Specifically, we recommend that all at-risk adults with IDD be prioritized in phase 1B of the CDC vaccine phased allocation.

We appreciate your ongoing work on behalf of our nation and careful consideration of all individuals with intellectual and developmental disabilities.

Sincerely,

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