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Less Worthy Lives? We Must Prioritize People with Intellectual and Developmental Disabilities in COVID-19 Vaccine Allocation

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We expressed concern¹ early in the COVID-19 pandemic that people with intellectual and developmental disabilities would disproportionately experience the health burdens of COVID-19 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 people with intellectual and developmental disabilities living in group home residences:4
- 3) communications about COVID-19 prevention and treatment advice that is not accessible to people with disability;5,6
- 4) historic and ongoing status as a vulnerable, and often marginalized, health disparities population.^{7,8}

Unfortunately, these concerns were on target. Our first study included a large sample of people with and without intellectual and developmental disabilities who had been diagnosed with COVID-19 and confirmed a higher prevalence of underlying conditions among those with intellectual and developmental disabilities at all ages. It also indicated a higher case-fatality rate for people with intellectual and developmental disabilities at ages up to age 74.9 Our second study on group residential settings revealed that in New York State, people with intellectual and developmental disabilities living in group homes had a case rate 4 times higher, and case-fatality rate 1.9 times higher than the overall state population. ¹⁰ A more recent study demonstrated that the higher case rate for those living in congregate settings (group homes and health care facilities) is likely associated with the number of residents per facility. However, the higher case-fatality rate is likely due to the higher prevalence of pre-existing conditions. ¹¹ Finally, a study in progress documents that these trends are consistent for people with intellectual and developmental disabilities across the U.S.¹²

Vaccination priorities reveal our values

Just distribution of vaccines requires prioritization decisions that consider medical need, social marginalization, and overall health-related harm and benefits.¹³ The evidence is clear that people with intellectual and developmental disabilities experience disproportionately severe COVID-19 outcomes and should be prioritized in the allocation of COVID-19 vaccines. Vaccine allocation decisions will speak volumes about whether we do—or do not—value the lives of people with intellectual and developmental disabilities. We concur with the recommendation from the National Academies of Sciences, Engineering and Medicine that people with intellectual and developmental disabilities residing in congregate settings, as well as their care staff, should receive priority in vaccination distribution.¹⁴ However, we are concerned that limiting prioritization only to those who reside in congregate settings, rather than the entire intellectual

and developmental disabilities population, may be short-sighted. This vulnerable group experiences greater prevalence of pre-existing conditions that can exacerbate the severity of COVID-19. They also often need direct, not socially-distanced, support. Thus, it is imperative to prioritize all people with intellectual and developmental disabilities for timely access to the COVID-19 vaccine. Caring for those with the greatest need is a moral responsibility. Whether, and how, we prioritize people with intellectual and developmental disabilities in COVID-19 vaccine allocation will reveal the extent to which we value this group within our society.

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