

# Individuals With Intellectual and Developmental Disabilities Were Excluded From COVID-19 Vaccine Priority Guidelines

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Last week, my colleagues and I [authored a commentary in \*EClinicalMedicine\*](#), a clinical journal published by the Lancet, urging the Biden administration to amend the priority guidelines for COVID-19 vaccinations to include all people with intellectual and/or developmental disabilities (I/DD; [Hotez et al., 2021](#)).

*It is critical that the entire I/DD population gains access to priority vaccines. But it's also important that we consider why they were excluded in the first place.*

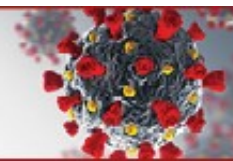
People with I/DD, including individuals with attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, learning disabilities, seizures, developmental delays, and/or intellectual impairment, comprise between 1% and 2% of the U.S. population. They are particularly susceptible to COVID-19, demonstrating more severe illness, greater risk of hospitalization, and almost twice the case fatality rates for individuals ages 18 to 74 ([Turk et al., 2020](#)). People with I/DD may experience difficulties following social distancing guidelines ([Embregts et al., 2020](#)) and often require in-person services from professionals who have been noted to work multiple jobs ([Contrera, 2021](#)). Despite that, the guidelines—from which states take their cue in administering vaccines—exclude the bulk of this

population. It is critical that the entire I/DD population gains access to priority vaccines. But it's also important that we consider why they were excluded in the first place.

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## **Disability stigma in health care**

Stigma—negative attitudes and beliefs based on distinguishing characteristics assumed to be disadvantageous—is at least partially to blame for the exclusion of people with I/DD from the COVID-19 vaccination guidelines ([Mayo Clinic Staff, 2017](#)). My experiences as both a developmental psychologist and the sibling of an autistic adult make plain that stigma against individuals with I/DD is rampant in health care. For starters, their interests are not adequately represented in health care policy, often because their needs and abilities are misunderstood and they are assumed to be different or separate from the general population ([Scior et al., 2016](#)). They are also excluded from research recruitment efforts and eligibility criteria. Indeed, a recent review of 300 randomized clinical trials published in high-impact medical journals found that people with I/DD were represented in only 2% of trials ([Feldman et al., 2014](#)). Exacerbating this is an undercurrent of implicit stigma, which is reflected in providers' use of negatively biased or exclusionary language.

For example, in focus groups, pediatric providers described working with their patients with I/DD as a “minefield” and referred to them as “those kids” ([Como et al., 2020](#)). Given that individuals with I/DD are well aware of these and other forms of stigma, they often conceal their I/DD status. Thus, a vicious cycle of stigma is at the root of their exclusion from the priority guidelines ([Ditchman et al., 2013](#)): Minimal research on this population, which is reluctant to self-identify, compounded by implicit bias and misinformation among health care professionals, resulted in insufficient data on their susceptibility to COVID-19 and a consequent unwillingness to include them in the priority guidelines.

Beyond this, stigma is directly and indirectly damaging to health. Stigma has been linked with heightened cardiovascular reactivity, exacerbated stress responses, increased substance use, and a host of other negative health outcomes ([Chaudoir et al., 2013](#); [Pascoe et al., 2009](#)). For individuals with I/DD, experiences of discrimination and concealment of disability status contribute to poorer health, including heightened stress and anxiety ([Botha & Frost, 2020](#); [Mitter et al., 2019](#); [Song et al., 2018](#); [Werner & Schulman, 2013](#)).

Further, negative attitudes about individuals with I/DD reduce the number of medical providers willing to provide those patients with care and compromise the quality of care that they receive ([Agaronnik et al., 2020](#); [Ditchman et al., 2013](#)). When primary care doctors view patients with I/DD as too “complicated” to treat, those patients must make appointments with specialists and miss out on important preventive care ([Burge et al., 2008](#)). Concealing a disability may also disqualify individuals with I/DD from receiving supports and services ([Ditchman et al., 2013](#)). We cannot begin to improve the health and well-being of individuals with I/DD without acknowledging the powerful role of stigma.

There are several steps we can take to address stigma against individuals with I/DD. To start, we need to better train health care professionals to work with individuals with I/DD ([Pelleboer-Gunnink et al., 2017](#)

; [Wilkinson et al., 2012](#)).

Currently, trainings exclusively focus on eliminating preexisting negative attitudes to enhance care. Effective programming must also promote neurodiversity, which conceptualizes disability as a valuable aspect of identity that does not require a cure ([Kapp et al., 2013](#)). In practice, this means that providers should utilize inclusive language that reflects patients' diverse needs and abilities, promote health and well-being rather than single out patients' limitations, and respond to the experiences and priorities of patients ([Baida & Ivanova, 2019](#)).

Training medical staff is not enough, however; stigma begins in childhood, and neurodiversity education should begin well before doctors become doctors ([Carter et al., 2016](#)). The field has witnessed the emergence of children's programming, such as *Realabilities*, a television show that emphasizes the strengths of children with I/DD ([Silton et al., 2016](#)). Continuing these efforts would ensure that the next generation is less subject to perpetuating stigma.

Lastly, there is a pressing need for a corresponding neurodiversity-focused approach to research. This requires collaborating with individuals with I/DD in research that involves them. With my team at UCLA, I co-lead the Autism Intervention Research Network on Physical Health. In developing the network, we prioritized the establishment of an Autistic Researchers Review Board—composed of autistic researchers who are both scientists and lived-experience experts—to guarantee that our research meets the needs of I/DD populations. Advancing these recommendations will go a long way toward eliminating the pervasive health care stigma that resulted in people with I/DD being excluded from the priority COVID-19 vaccination guidelines.

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