

Disability and COVID-19: who counts depends on who is counted

Recent publications have highlighted how people with disabilities could be at increased risk from COVID-19, and have made calls for a disability-inclusive pandemic response.^{1,2} However, little attention has been given to a crucial underlying factor that precludes movement towards addressing inequities: the scarcity of disability data. Without data, the impact of COVID-19 on people with disabilities remains unknown.

Early calls were made to publish COVID-19 data by other inequity strata including age, race, and sex.³ A key difference from disability is that these variables are more likely to be collected and are compulsory in some cases.⁴ Although progress still needs to be made in further improving data collection and addressing disparities by age, sex, and racial groups, the existence of collected data allows researchers and officials to provide accurate evidence of disparities, and form the basis for a data-driven pandemic response.

Surveillance is a fundamental pillar of public health. For people with disabilities, surveillance has been limited both before and during the pandemic. Current COVID-19 estimates among disabled people have primarily come from assisted living facilities, in which the disability status of residents is documented. However, these data represent only a fraction of the population with disabilities. Importantly, gaps in COVID-19 surveillance data affect more than just people with disabilities. Worldwide, more than 1 billion people have a disability.⁵ Without disability data, a large proportion of the high-risk population remains untracked and testing rates unknown. Inaccurate data creates unreliable risk estimates and could contribute to misguided

public health approaches and inappropriately allocated resources.

Collecting disability data is only the start. It needs to be followed by evidence-driven steps, to create an inclusive pandemic response and to be the foundation for equitable public health emergency planning. This approach would include a full review of the pandemic response to characterise current shortcomings and identify areas for improvement. Many of the previous calls for a disability-inclusive COVID-19 response have offered important ideas, but without data these good intentions will not move forward.

Who counts depends on who is counted. The disability data gap is more than just a surveillance oversight; social injustices exist that cannot be separated from this lack of information. The lack of data perpetuates the exclusion of disabled people from discussions of health equity and policies that are data driven. The profound global impact of COVID-19 presents a unique opportunity to create a new normal. Disability must finally be included as we move forward and towards creating a more equitable and healthier society. People with disabilities must be counted.

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