## Comment

## beyond mortality risk. For instance, qualitative research should not place highlights the isolation, loneliness, and lost sense of self- to COVID-19 (and

Why are people with intellectual disabilities clinically

highlights the isolation, loneliness, and lost sense of selfworth experienced by people with intellectual disabilities during the COVID-19 pandemic.<sup>23</sup> Family members and caregivers were also put under immense strain.<sup>4</sup> A key question is why the impact of COVID-19 was greater for people with intellectual disabilities? More fundamentally, why was this group clinically vulnerable?

vulnerable to COVID-19?

In The Lancet Public Health, Maarten Cuypers and

colleagues<sup>1</sup> add to the growing literature showing that

people with intellectual disabilities were more likely to die

from COVID-19 during the first 2 years of the pandemic-

in this paper around five-times more likely. Putting these

figures into context, around 600 more people with

intellectual disabilities died in the Netherlands than would

be expected if they had the mortality rates of others in

the population. Cuypers and colleagues also showed

that this mortality gap existed before the pandemic,

and that non-COVID causes of death were elevated for

people with intellectual disabilities during the pandemic.

Other sources of data show that the adverse impact of

COVID-19 for people with intellectual disabilities went

First, we must consider the nature and cause of vulnerability. Some people with intellectual disabilities have a biological vulnerability to COVID-19. For instance, immune response dysfunction in people with Down syndrome is likely to contribute to their elevated risk of dying from COVID-19—in a study over a 30-times increased risk of death was found.5 Other individuals with intellectual disabilities might be at elevated risk of death from COVID-19 because of a high prevalence of other risk factors, such as obesity or diabetes.6 However, we must also recognise the discriminatory and exclusionary social structures that create clinical vulnerability in people with disabilities, particularly people with intellectual disabilities. Inaccessible health facilities and health information, removal of social care, a lack of protective measures in care homes, poorly trained health staff, and delayed vaccine prioritisation are all failings that made people with intellectual disabilities clinically vulnerable to COVID-19. People with intellectual disabilities were abandoned and forgotten in government responses to the pandemic across the world, particularly in the early stages.<sup>24</sup> They were made clinically vulnerable, in part, by neglect.

Sadly, this information is not new. For many years, there has been substantial evidence on health inequalities of people with intellectual disabilities because of structural, societal, and institutional failings, but governments have not adequately responded, entrenching clinical vulnerability.7 These failings include the social inequalities for people with disabilities, such as poor access to health care, education, and employment, poverty, and an increased risk of violence and abuse.8 These social inequalities further contribute to the clinical vulnerability of people with intellectual disabilities to health issues (including mental health problems). We should not place the burden of clinical vulnerability to COVID-19 (and wider morbidity and mortality) on individual people with intellectual disabilities, but on the failings of our societies, policies, and services.

As we move forward, there is hope and potential power in data, such as the study by Cuypers and colleagues,<sup>1</sup> to highlight and address health risks. Evidence showing that people with intellectual disabilities were more likely to die from COVID-19 allowed them to be prioritised for vaccination in many countries, including in the UK.9 As another example, the 2013 UK Confidential Inquiry showed that people with intellectual disabilities were dying 13-20 years earlier than their peers without disabilities, often because of health systems failure.<sup>10</sup> Consequently, the UK National Health Service introduced a range of services to close this gap, including mandatory training of health-care workers about intellectual disability, establishment of a learning disability register, invitation to routine health check-ups, and routine monitoring of the health gaps through the Learning Disability Mortality Review.<sup>11,12</sup> Although there is huge progress still to be made, we should take inspiration from these concrete examples of how evidence can be transformative. We need to put people with disabilities at the centre of health-care planning and delivery, so that inclusion in health care is not considered nice to have, but is entrenched as a priority and a right. We must not assume that these issues are too expensive or complex to address. There is a growing range of good practice,



Published Online April 16, 2023 https://doi.org/10.1016/ S2468-2667(23)00077-4 See Articles page e356 showing how we can create inclusive health systems, and how they are likely to be cost saving and work better for all.<sup>13,14</sup> In the words of the recently deceased Disability Rights activist Judy Heumann, "most things are possible when you assume problems can be solved".<sup>15</sup>

We declare no competing interests.

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- Cuypers M, Koks-Leensen MCJ, Schalk BWM, Bakker-van Gijssel EJ, Leusink GL, Naaldenberg J. All-cause and cause-specific mortality among people with and without intellectual disabilities during the COVID-19 pandemic in the Netherlands: a population-based cohort study. *Lancet Public Health* 2023; published online April 16. https://doi.org/10.1016/S2468-2667(23)00062-2.
- 2 Scherer N, Wiseman P, Watson N, et al. 'Do they ever think about people like us?': the experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic. *Crit Soc Policy* 2022; published online June 27. https://doi.org/10.1177/0261018322110914.
- 3 Voermans MAC, den Boer MC, Wilthagen T, Embregts PJCM. Long-term social restrictions and lack of work activities during the COVID-19 pandemic: impact on the daily lives of people with intellectual disabilities. Disabil Rehabil 2022; published online Nov 18. https://doi.org/10.1080/09 638288.2022.2147227.

- 4 Wormald A, McGlinchey E, D'Eath M, et al. Impact of COVID-19 pandemic on caregivers of people with an intellectual disability, in comparison to carers of those with other disabilities and with mental health issues: a multicountry study. Int J Environ Res Public Health 2023; **20:** 1–14.
- 5 Williamson EJ, McDonald HI, Bhaskaran K, et al. Risks of COVID-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. BMJ 2021; 374: n1592.
- 6 Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability—a systematic review. PLoS One 2021; 16: e0256294.
- 7 Emerson E, Baines S. Health inequalities & people with learning disabilities in the UK. Tizard Learn Disabil Rev 2011; 16: 42–48.
- 8 WHO. Global report on health equity for persons with disabilities. Geneva: World Health Oganization, 2022.
- 9 Public Health England. JCVI advises inviting people on Learning Disability Register for vaccine. Feb 24, 2021. https://www.gov.uk/government/news/ jcvi-advises-inviting-people-on-learning-disability-register-for-vaccine (accessed March 20, 2023).
- Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014; **383**: 889–95.
- 11 White A, Sheehan R, Ding J, et al. People with a learning disability and autistic people (LeDeR) report for 2021. London: King's College London, 2022.
- 12 NHS England. Learning from lives and deaths—people with a learning disability and autistic people (LeDeR): action from learning report 2021/22. London: NHS England, 2022.
- 13 WHO. Global report on health equity for persons with disabilities. Geneva: World Health Organization, 2022.
- 14 Missing Billion Initiative. Good practice compendium. https://www. themissingbillion.org/good-practices (accessed March 20, 2023).
- 15 Heumann J. Being Heumann: an unrepentant memoir of a disability activist. Boston: Beacon Press, 2020.