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Covid 19: People with learning disabilities are highly vulnerable

They must be prioritised, and protected

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The covid-19 pandemic has had a devastating effect on people with learning disabilities across the world. The linked paper by the OpenSAFELY collaborative led by Williamson and colleagues (doi:10.1136/bmj.n1592) makes an important contribution to the evidence on how the pandemic has affected this vulnerable group.¹ The findings that people with learning disabilities with covid-19 were five times more likely to be admitted to hospital and eight times more likely to die supports the findings of other studies.²⁻⁴ People with learning disabilities are extremely vulnerable to the effects of SARS-CoV-2 infection.

The NHS Long Term Plan in 2019 acknowledged the inequalities and prioritised annual health checks and influenza vaccination (through targets in primary care in England) to help reduce morbidity.⁵ Before the pandemic, clinicians in learning disability services and families were well aware of the high prevalence of comorbid disorders⁶ and unacceptably high mortality rates⁷ affecting people with learning disabilities. On average, people with learning disabilities die more than 20 years younger than the general population.⁸

With the arrival of covid-19, families and specialist services knew people with learning disabilities were particularly vulnerable but were uncertain how to protect them. While the focus was on older adults, whose mortality rates shocked the nation, a hidden calamity was also taking place among people with learning disabilities. Data from Public Health England in 2020 show that mortality rates in this group were up to three times higher than that of the general population.⁴

People with learning disabilities often need care from a young age and might require lifelong support. The services that support this diverse group with a range of health and care needs are also varied. People with learning disabilities might live in community settings (in supported living arrangements or residential care) or live with their families with support. Some people share accommodation, and support workers or personal assistants might work across settings with several different individuals.

In line with their human rights and with government policy, individuals with learning disabilities should enjoy and participate in the same activities as all citizens. Reasonable adjustments should be made to ensure that information about the pandemic and risk of infection are accessible, and that practical support is provided to protect people and manage risks.

Prejudice

Worrying attitudes and prejudices about the value of the lives of people with learning disabilities have

surfaced during the pandemic. Use of DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders for people with life threatening infections resulted in fear and outrage among the families of people with learning disabilities, friends, advocates, and those providing support.⁹ The clear implication was that the value of a person's life would be based on age and degree of cognitive impairment, returning to a time when disability was openly stigmatised. Self-advocates and families campaigned strenuously to overturn blanket decisions that were not based on an individual's best interests.

The covid-19 vaccination programme also disadvantaged people with learning disabilities, prioritising people according to age rather than severity of comorbid disorders.¹⁰ BBC presenter Jo Wiley for example, reported how she and her parents were offered vaccines before her sister, who had a severe learning disability.^{11 12}

Initially, young people with other high risk conditions were more likely to be offered vaccination than peers of the same age with learning disabilities, and this was only overturned after calls from self-advocates and families.

We must work much harder to reduce the health inequalities exposed and amplified by the pandemic—including further training of all health and care staff about the needs of people with learning disabilities and the health inequalities they face.

Mechanisms already in place also need to work more effectively and efficiently. The new OpenSAFELY study highlights that learning disability registers in general practice are incomplete, limiting the reach of the vaccination programme. Greater efforts to update and maintain accurate registers are required so that all eligible individuals can benefit.

The specialist role of learning disability doctors should be developed to provide holistic, specialised, and tailored healthcare and support to people with learning disabilities in both primary and secondary healthcare settings¹³. In addition to direct care, specialist clinicians would provide support, expertise, and guidance to other healthcare professionals to improve the care of people with learning disabilities across all services in the NHS.

Before the next pandemic, investment in research is essential, to help us understand the risks faced by people with learning disabilities and how best to protect them from the high risks of hospital admission and death from covid-19 identified by Williamson and colleagues. People with learning disabilities have the same rights as everyone else, including the right to good health and to be safe from harm.

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