A confidential inquiry found that people with learning disabilities were three times more likely than the general population to die from causes that could have been prevented by high-quality healthcare.

Premature death in people with learning disabilities

In this article...

- People with learning disabilities are more likely to die prematurely from causes that were avoidable through good care
- Commentary on “institutional discrimination”

People with learning disabilities are more likely to die prematurely than the general population and are less likely to receive effective treatment for medical problems.

The Equality Act 2010 states that public sector bodies, such as health and social care organisations, must not discriminate against people with disabilities, including those with mental impairments or any impairment that has a substantial and long-term effect on their ability to carry out normal day-to-day activities.

New evidence

Heslop et al (2014) reported the findings of a confidential inquiry into the premature deaths of people with intellectual disabilities. The inquiry examined the deaths of people with learning disabilities aged four years or older in five former primary care trusts in south west England.

A local review panel designated a death as premature if it was more likely than not that the person would have continued to live for at least one more year without a specific event that formed part of the pathway that led to death. Deaths could also be categorised as “avoidable” if they could have been prevented by public health interventions, avoided through good-quality healthcare, or both.

The analysis found that the median age at death of the 247 people with learning disabilities was 65 years for males and 63 years for females. These ages were 13 years younger than the median age at death in the male general population of England and Wales (78 years) and 20 years younger than in the female general population (83 years).

The panel decided that 100 (42%) of the 238 deaths on which they reached agreement were premature. Among the 244 deaths of people with learning disabilities for whom data on cause of death were available, 119 (49%) were categorised as avoidable, almost double the rate in the general population (24%).

A total of 21% of deaths among people with learning disabilities were designated as preventable by public health interventions — the same rate (21%) as in the general population. However, 37% of deaths in people with learning disabilities could have been avoided with good-quality healthcare, compared with 13% of deaths in the general population.

A comparison between 58 people with learning disabilities and 58 general population comparator cases from the same general practices found significant differences in the potential contributing factors surrounding the death. A greater proportion of the people with learning disabilities had inadequate or inappropriate accommodation for their needs; family or paid carers who felt they were not listened to; and problems in advanced care planning.

There were also problems with those responsible for their care recognising their needs and adjusting care when needs changed, as well as poor adherence to the Mental Capacity Act.

BOX 1. COMMENTARY

This paper provides the first reasonably robust estimates of the extent to which the premature mortality of people with learning disabilities in England results from what Mencap has described as institutional discrimination in our health and social care system.

People with learning disabilities were twice as likely as the general population to have had deaths that were avoidable, and nearly three times more likely to have had deaths that could have been avoided by the provision of good-quality healthcare. There is a strong moral imperative to redress this injustice.

In addition, healthcare commissioners and providers also have a clear legal responsibility under the Equality Act 2010 to introduce “reasonable adjustments” to take account of the specific needs and situation of people with learning disabilities.

These adjustments could include ensuring regular health checks are provided for people with learning disabilities and that people with learning disabilities have access to information in formats they can most easily understand.

Eric Emerson, emeritus professor of disability and health research, Centre for Disability Research, Lancaster University and professor of disability population health, University of Sydney, Australia

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Helen Jaques is a medical writer in Evidence Information Services, National Institute for Health and Care Excellence

Reference