Premature death in people with learning disabilities

A population-based cohort study in south west England reports that people with learning disabilities die roughly 16 years younger than the general population and are around twice as likely to die from causes preventable by good healthcare.

Overview: The term ‘learning disability’ refers to people who have:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence);
- a reduced ability to cope independently (impaired social functioning) and;
- a disability that started before adulthood, with a lasting effect on development (Department of Health 2001).

In 2012, an estimated 1.14 million people in England had learning disabilities, 908,000 of whom were adults aged 18 years or over (Improving Health and Lives: Learning Disabilities Observatory 2013).

People with learning disabilities are more likely to die prematurely than people in the general population (Tyrer et al. 2007). This group of people often has important comorbidities and associated polypharmacy (McCarron et al. 2013), which might contribute to the higher rate of premature death. However, other factors such as the environment, provision of care, and access to health and social care services are also likely to have a role.

Reports by the charity Mencap in 2004 (‘Treat me right’) and 2007 (‘Death by indifference’), and the Disability Rights Commission in 2006 (‘Equal Treatment’), highlighted that people with a learning disability often receive poor healthcare. In response, an independent inquiry into the premature deaths of people with learning disabilities was conducted (Michael 2008). This inquiry found evidence that people with learning disabilities are less likely to receive treatment for medical problems and many receive less effective treatment. It recommended that a time-limited confidential inquiry into premature deaths of people with learning disabilities should be set up ‘to provide evidence for clinical and professional staff on the extent of the problem and guidance on prevention’. An inquiry was subsequently commissioned by the Department of Health (the confidential inquiry into the premature deaths of people with intellectual disabilities).

Current advice: 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. Public sector bodies also have a duty to make reasonable adjustments to ensure that procedures and physical provisions do not put disabled people at a disadvantage. Such reasonable adjustments might include making sure that information on health and social care services is accessible to people with learning disabilities and giving people more time with doctors and nurses.

In 2011, the public sector equality duty became part of the Equality Act. This amendment requires public organisations to have due regard to the need to eliminate discrimination of people who are disabled, advance equality of opportunity, and foster good relations between people who are disabled and those who have no disability.
NICE guidance on patient experience in adult NHS services recommends that healthcare workers should ensure that factors such as physical or learning disabilities and difficulties with reading, understanding or speaking English are addressed so that patients are able to participate as fully as possible in consultations and care. NICE is currently preparing guidance on care of people with challenging behaviour and learning disabilities and on mental health problems in people with learning disabilities. Guidance is also being developed on transition from children’s to adult services for young people using health or social care services, which encompasses young people with learning disabilities.

New evidence: Heslop et al. (2014) reported the findings of the confidential inquiry into the premature deaths of people with intellectual disabilities. The inquiry examined the deaths of people with learning disabilities aged 4 years or older in 5 former primary care trusts in south west England. Data on deaths were collected from health, social care and voluntary services; community contacts; statutory agencies; GPs; prisons; and community groups, leaders and services. 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 1 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 health care, or both.

The analysis found that the median age at death of the 247 people with learning disabilities was 65 years (interquartile range [IQR] 54–76 years) for males and 63 years (IQR 54–75 years) for females. These median 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 that they reached agreement on were premature.

Among the 244 deaths of people with learning disabilities for whom data on cause of death were available (ICD-10 codes), 119 (49%) deaths 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 matched general population comparator cases from the same general practices found significant differences in the potential contributing factors surrounding the death. A greater proportion of people in the learning disabilities group had inadequate or inappropriate accommodation for their needs; family or paid carers who did not feel they were listened to; and problems in advanced care planning. For people in the learning disability group, there were also problems with those responsible for their care recognising the person’s needs and adjusting care when needs changed, and poor adherence to the Mental Capacity Act.

The authors warned that the links between contributing factors and deaths in people with learning disabilities may not be causal. In addition, the sample of people with learning disabilities who died was small and may not have included all deaths among people with learning disabilities in the study area.

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 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 but are certainly not limited to ensuring regular health checks are provided for people with learning disabilities (and to further reduce the age of eligibility for these checks) and ensuring that people with learning disabilities have access to information in formats they can most easily understand.” – Professor 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

Study sponsorship: Department of Health.

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