Public Health England

Protecting and improving the nation's health

Health inequalities: Mortality

Introduction

Mortality (whether assessed through life expectancy, median age at death, or other indicators) is a widely used indicator of health, both for general populations and for sub-groups within populations. Increasing information is becoming available concerning the mortality of people with learning disabilities, both in England and internationally.

Mortality statistics for people with learning disabilities

A recent systematic review of international literature found that the age at death of people with learning disabilities remains up to 20 years younger than that of the general population[1]. Based on data from around half of GP practices in England, in 2017-18 females with learning disabilities had a life expectancy 18 years lower than females without learning disabilities (65 years compared to 83 years) and males with learning disabilities had a life expectancy 14 years lower than males without learning disabilities (66 years compared to 80 years)[2].

The English Learning Disabilities Mortality Review (LeDeR) programme which is reviewing all deaths of people with learning disabilities aged 4 years and over reported a median age at death of 60 years for males and 59 years for females[3].

For some groups of people with learning disabilities life expectancy has shown marked increases[4 5]. For example, the life expectancy of people with Down syndrome increased from 9 years in 1929 to 49 in 1997[6].

Risk factors

Life expectancy for males and females with learning disabilities is very similar, although there is a gender disparity in the general population with females having a longer life expectancy than males. Standardised mortality rates (SMRs) show a greater inequality for women than men with learning disabilities compared to their general population peers, although the reasons for this are currently unclear[1].

People with learning disabilities have increased age-specific mortality rates across all ages when compared to the general population[7 8 9 10 11 12]. Data from Sheffield suggest that there was a sustained reduction in age-standardised mortality rates and a sustained increase in life expectancy for people with learning disabilities over the 33-year period 1980-2012[5]. However, these changes were extremely similar to those observed in the general population of England and Wales, and there was little evidence of any closing of the gap in age-standardised mortality rates or life expectancy between people with learning disabilities and the general population[5].

Age at death is lower for people with more severe learning disabilities and for people with epilepsy, genetic syndromes and functional impairments[1]. All-cause mortality rates among people with moderate to severe learning disabilities remain 3 times higher than in the general population, with mortality being particularly high for people with more severe disabilities, young adults, women, people with epilepsy and people with Down syndrome and other genetic causes of learning disability[7 13 14].

Healthcare and preventable mortality

One issue is the extent to which the higher mortality rates among people with learning disabilities reflect an excess of preventable or premature deaths[15 16]. For example, potentially preventable causes of death that are relatively common and affect most groups of people with learning disabilities include aspiration pneumonia and other respiratory diseases, seizures, and cardiovascular disease[8 17].

A recent investigation into the causes and circumstances of 244 deaths of people with learning disabilities in England concluded that:

- 42% were premature in that specific adverse events were identified in the pathway leading to death that if prevented would probably have allowed the person to live for at least another year
- 28% were ‘amenable’ in that current knowledge would suggest that all or most deaths from that cause could have been avoided through the provision of good quality health care[18]
- rates of premature and amenable deaths were substantially higher for people with learning disabilities than those in a matched general population sample[18]

Improved health care, including anticipatory care such as health checks, and initiatives that address the behaviours and health risks that are most relevant for people with learning disabilities, are required to begin to address the inequalities in mortality for people with learning disabilities[1].

Social determinants

There are clear socio-economic gradients for life expectancy in the general population in England[19]. Research in the UK and internationally has established that people with learning disabilities experience socio-economic disadvantage to other groups, linked to health inequalities[16], but research evidence linking these socio-economic inequalities to mortality in the population of people with learning disabilities is currently not robust.

Resources

University of Bristol The Learning Disabilities Mortality Review (LeDeR) includes information about mortality, easy read materials and links to organisations and resources.

References

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