Scottish Learning Disabilities Observatory

Avoidable death in adults with learning disabilities in Scotland

Key Findings

- **Young adults (25-34yrs) with learning disabilities are 6 times more likely to die prematurely compared to adults in the general population. For adults of all ages, the mortality risk is 3 times higher**. These findings demonstrate significant health inequalities faced by people with learning disabilities, which is particularly pronounced in young adulthood.
- **Young adults (25-34 yrs) with learning disabilities are 9 times more likely to die of treatable health conditions.**
- **Adults 25+ with learning disabilities are dying, on average, 15 years younger than adults without learning disabilities.** Women with learning disabilities and those residing in areas with lower levels of deprivation are disproportionately affected by increased risk of premature death.
- **Down syndrome was the most commonly recorded underlying cause of death for adults with learning disabilities** indicating prevailing uncertainty in relation to underlying causes of death in people with learning disabilities and an urgent need to review the way deaths are recorded for people with learning disabilities.

Why is this study important?

In 2017, the Scottish Learning Disabilities Observatory published a systematic review examining premature death and its causes in people with learning disabilities. The study revealed that individuals with learning disabilities died, on average, 20 years earlier than the general population, with many of these deaths attributable to avoidable causes.[1,2]

Avoidable mortality is an under-researched area for adults with learning disabilities. Its definition includes preventable mortality (deaths which are preventable through public health interventions, for example, deaths from infectious diseases that can be prevented by vaccination, or alcohol or drug related deaths), and treatable (previously

known as ‘amenable’) mortality (deaths amenable to timely and effective healthcare, for example, deaths due to epilepsy, diabetes, or respiratory infections) while some causes of death can be both preventable and treatable.[3,4]

Recent studies that have reported on avoidable deaths suggest that up to 40% of deaths of adults with learning disabilities may be avoidable, compared to 28% of deaths in the general adult population.[5-8] Following the review of existing studies on avoidable mortality in the population with learning disabilities, the Scottish Learning Disabilities Observatory identified the need to quantify rates of avoidable deaths in adults with learning disabilities, compared to adults in the general population without learning disabilities, and to identify major causes of death, particularly those which are avoidable.

How we conducted the study

Scotland’s Census 2011 records were linked to the National Records of Scotland Statutory Register of Deaths database from 2011 up to 2019. Adults aged 25 and over who self- or proxy reported having learning disabilities in Scotland’s Census in 2011 were identified and the mortality rates were compared to adults of the same age without learning disabilities. The rates and most common causes of death were investigated.

Causes of Mortality in adults with learning disabilities compared to adults in the general population

In our study, adults with learning disabilities were:

- **Nearly 8 times more likely to die from neurological-related conditions (e.g., due to epilepsy)**
- **5 times more likely to die from diseases of the genitourinary system (e.g., diseases of the urinary system or kidneys)**
- **Nearly 4 times more likely to die from respiratory-related deaths (e.g., due to pneumonia)**

What were the avoidable conditions people died from?

Adults with learning disabilities: The most commonly recorded underlying causes of death and all contributing factors in death, which are avoidable, were: **acute myocardial infarction, epilepsy and pneumonia.**

General population of adults without learning disabilities: The most commonly recorded avoidable underlying causes of death were ischaemic heart diseases, cancer of bronchus and lung, and chronic obstructive pulmonary disease. For all contributing factors in death, chronic ischemic heart disease, pneumonia and other chronic obstructive pulmonary disease were most commonly recorded as avoidable causes of death. These conditions are treatable, preventable or both.

Recording of Down syndrome as a cause of death

Our study has shown that recording of Down syndrome as a cause of death in adults with learning disabilities is still common among attending medical practitioners in Scotland. Down syndrome was recorded as a top underlying cause of death and second most commonly recorded contributing factor in death in adults with learning disabilities. This suggests that there may still exist prevailing uncertainty in relation to underlying causes of death in people with learning disabilities and that there is continued conflation of disability and health among medical practitioners responsible for recording causes of death in Scotland.[9] It is, therefore, crucial that we better understand how individual health conditions impact on the health and mortality of adults with learning disabilities.

Recommendations

- Research and clinical focus must be directed towards the management of epilepsy and pneumonia, which are two of leading causes of death in this population.
- Our findings on mortality caused by cardiovascular diseases and cancers in adults with learning disabilities highlight the need for public health interventions

aimed at circulatory diseases and cancer screening with appropriate adaptation and tailoring for this population.

- Clinical and health training initiatives should be introduced across all age groups and all neighbourhoods, given that our findings suggest that mortality risk is highest in the most affluent areas for adults with learning disabilities.
- There is an urgent need to ensure that causes of death in Scotland are recorded appropriately to provide an accurate measure and understanding of mortality for people with learning disabilities.

Next Steps

- The Scottish Learning Disabilities Observatory will continue to collaborate with the study's co-authors, which include the Scottish Commission for People with Learning Disabilities and Public Health Scotland as well as with the Scottish Government's Learning Disability Policy Team and policy makers across health and social care to highlight the needs of adults with learning disabilities in Scotland.
- We will work with relevant bodies to review the way that causes of death are recorded for people with learning disabilities in Scotland.

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