

Where can I find out more about the research discussed in this video on avoidable deaths among children and young people with learning disabilities?

You may wish to look at the study conducted by the SLDO in 2020, which is a national cohort study of children and young people with and without learning disabilities using data from Scotland's pupil census records linked to the National Records of Scotland's death register. This study identified 106 deaths (0.6%) from 18,278 children and young people who had learning disabilities. Premature mortality was 12 times higher for children and young people. More information and a link to the full study can be found below:

<https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/mortality-rates-for-children-and-young-people-with-learning-disabilities/>

Are adults with learning disabilities also at risk of avoidable respiratory deaths? If so, why is this video only about children and young people?

Yes, adults with learning disabilities do experience poorer health outcomes and higher rates of premature mortality compared to the general population. However, mortality rates for children and young people with learning disabilities are even higher compared to their peers, than is found for adults with learning disabilities. While this video is specifically based on children and young people, there are likely to be overlapping issues for adults and children. Yet, the needs of children with learning disabilities are also likely to be different in many ways to adults with learning disabilities. That is why we have focused on children and young people for this specific video.

To find out more about avoidable deaths in adults with learning disabilities, you may wish to read a recent SLDO study conducted in 2020 which found deaths were more than five times as common for adults with Down syndrome and twice as common for adults with learning disabilities without Down syndrome. The most common causes of death were dementia, then infections, for the adults with Down syndrome. The most common causes of death were breathing food or liquid into airways when trying to swallow/ breathing in vomit during heartburn/ choking, and lung infections, for the adults without Down syndrome. 29.8% of all the deaths could have been stopped by better care. More information and a link to the full study can be found below:

<https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/causes-and-rates-of-death-in-adults-with-learning-disabilities/>

Are there any other factors that may contribute to avoidable deaths in children and young people with learning disabilities not covered in this video?

This video is intended to highlight issues that we identified from research that we believe are linked to avoidable mortality in children and young people. However, it is extremely important for us to highlight that the topics for this video and the experts invited to participate were based on research findings of one specific project. While this study was the largest and most comprehensive study of its kind, we acknowledge that it is unlikely that all issues that contribute to avoidable deaths in children and young people will have been identified or covered in this video. Please see more details in our disclaimer.

Who is this video for?

We hope that this video will be a useful educational resource for health and social care providers who work alongside young people with learning disabilities. However, we also hope this video will provide relevant information to people with learning disabilities and carers or anyone else who is involved in the lives of children and young people with learning disabilities, in a professional or personal capacity.

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