

News release

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People with learning disabilities far more likely to die of preventable causes

- Death in childhood 12 times higher for people with learning disabilities
- Girls and young women with learning disabilities are at higher risk than males
- Adults with learning disabilities are twice as likely to die from preventable illness
- Common causes of death include preventable respiratory illnesses such as pneumonia and treatable conditions such as epilepsy

People with learning disabilities are at significantly increased risk of premature death compared to the rest of Scotland's population. Two new studies by the Scottish Learning Disabilities Observatory have found that children with learning disabilities are at least 12 times more likely than other children of the same age to die in childhood and that adults with learning disabilities are twice as likely to die from preventable illnesses. The research has found that many of these deaths were from illnesses that could be treated and highlights an urgent need for action to reduce unnecessary deaths.

The unique, large-scale study of mortality rates among children and young people, has, for the first time, quantified concerns that children with learning disabilities are at greater risk of dying prematurely. For girls with learning disabilities the risk is even greater. The study, which linked educational data and death records for children in Scotland*, also found that the most common causes of deaths in children with learning disabilities were different to those of other children. By investigating the causes of deaths in childhood and adolescence, this research shows that young people with learning disabilities are at greater risk of dying from treatable conditions.

The SLDO study of 961 adults in Scotland linking clinical data to death registrations found that preventable deaths were twice as high for adults with learning disabilities. The study, which looked at mortality rates and causes in adults with learning disabilities in community settings, found that complications related to respiratory illness were the most common underlying cause of mortality.

This stark inequality in mortality rates and causes of death in people with learning disabilities compared to the general population highlights an urgent need reduce premature deaths among children and adults with learning disabilities in Scotland.

Professor Craig Melville, Director of the Scottish Learning Disabilities Observatory, said: "These findings demonstrate that steps must be taken immediately to prevent unnecessary deaths of children and adults with learning disabilities. It is particularly shocking to find that people with learning disabilities are dying from causes that could be prevented or treated through targeted

training and guidance for carers and clinical staff and access to good quality health and care services. We are working with the Scottish Government, third sector agencies and health professionals to develop a multiagency response to these findings to tackle this inequality.”

Charlie McMillan, Chief Executive for the Scottish Commission on Learning Disability (SCLD) said: “These important findings from the Scottish Learning Disabilities Observatory remind us that the inequalities faced by people with learning disabilities in Scotland are of great public health concern. It is critical that the needs of people with learning disabilities are at the forefront of discussions to reform and renew national health policy and practice as we emerge from the current Covid-19 pandemic.”

The research was led by the Scottish Learning Disabilities Observatory, based in the Institute of Health and Wellbeing at the University of Glasgow. The Observatory is funded by the Scottish Government to help address the health inequalities experienced by people with learning disabilities through the provision of good quality evidence to support action.

Note to editors

* This study compared Scottish education data for 18, 278 children with learning disabilities with that of 777, 912 children without learning disabilities between 2008 and 2013. These records were linked to the death register up to 2015 to ascertain the number and causes of death for children included in the study.

A summary of the findings for each of the two studies together with the full articles related to these two studies can be read here: <https://bit.ly/2D5qTQH>

For more information about these studies contact Fiona Barlow, SLDO Communications Officer

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About the Scottish Learning Disabilities Observatory

The Scottish Government has funded the University of Glasgow to establish a Scottish Learning Disabilities Observatory that will support delivery of the goals of the national learning disabilities strategy. The Scottish Learning Disabilities Observatory was set up in 2015 to contribute to health improvement by providing information, data, and intelligence on the health and healthcare of people with learning disabilities and people with autism.

For more information about the Scottish Learning Disabilities Observatory see www.sldo.ac.uk