

Avoidable death in children and young people with intellectual disabilities in Scotland

Key Findings

- **Premature mortality was 12 times higher for children and young people with learning disabilities** compared to other children and young people, demonstrating that the health inequalities faced by people with learning disabilities are contributing to avoidable deaths in childhood and young adulthood.
- **For girls and young women, risk of death was 17 times higher**, than their peers without learning disabilities.
- **Treatable conditions contributed to many deaths** which could have been avoided through timely and effective quality healthcare intervention.
- **Some accidental deaths were potentially preventable.** Better health promotion or support to reduce accidents could have prevented some deaths.

Why is this study important?

In 2017, the Scottish Learning Disabilities Observatory published a systematic review on premature death and causes of death in people with intellectual disabilities. This study found that people with intellectual disabilities die an average of 20 years earlier often from avoidable causes^{1,2}. Young people are at a higher risk of premature death compared to the general population; and younger women and girls are at a particular increased risk compared to their peers without intellectual disabilities^{1,3}.

Following this review of existing research, the Scottish Learning Disabilities Observatory identified the need to quantify mortality rates amongst children and young people with intellectual disabilities compared to those in other children, and to identify major causes of death, particularly those which are potentially avoidable. The Office for National Statistics defines avoidable death as either amenable to timely and effective healthcare, preventable through public health action or both.

How was this cohort study developed?

Scotland's pupil census records were linked to the National Records of Scotland's death registry from 2008 up to 2015. Pupils who had additional support needs at school due to intellectual disabilities were identified and the mortality rates were compared to pupils without intellectual disabilities. The most common causes of death were investigated.

What were the avoidable conditions people died from?

- This study found that common causes of death in this group of children and young people included epilepsy, respiratory infection, aspirational pneumonia and digestive conditions like gastro-oesophageal reflux disease (GORD) or gastroenteritis.
- These are treatable, preventable or both.

The rate of neurological-related deaths was 77 times higher

- Epilepsy is a common neurological condition amongst people with intellectual disabilities and was a common cause of death amongst children and young people with intellectual disabilities in this study.
- Epilepsy can be more complex to diagnose in people with intellectual disabilities, who may need particular care and attention throughout treatment⁴⁻⁷.
- Epilepsy is manageable. With timely diagnosis and appropriate treatment, the risk of mortality reduces^{5,6}.
- Research evidence demonstrates the need to:
 - strengthen training and awareness around recognition to ensure timely diagnosis⁴.
 - provide equal access to pharmacological management compared to other people with epilepsy, including safely managing side effects⁷.
 - improve reasonable adjustments to investigations and referral procedures⁴.

The rate of respiratory-related deaths was 55 times higher

- Respiratory infections, especially from aspiration (food or liquid going down the wrong way) and influenza were major causes of death in children and young people with intellectual disabilities.
- Safety can be greatly improved by early diagnosis of dysphagia (swallowing problems) and improving access to postural care support for people who need it.
- Risk of dysphagia in people with intellectual disabilities is often affected by medical issues, fatigue, posture, oral health and motor disorders⁸.
- Speech and language therapists, physiotherapists and occupational therapists play a key role in implementing effective strategies to identify, manage and treat swallowing difficulties and can implement postural care support plans which can be followed by families and care givers.
- Flu is a major cause of death in people with intellectual disabilities who are more susceptible to its effects⁹.
- Protection against flu is a major priority of the Scottish Government. People of all ages (over 6 months) with at least one underlying clinical risk factor, such as intellectual disabilities, should be offered the annual flu vaccine by their GP. Vaccine uptake is considerably lower for this target group¹⁰. Additionally, from 2013, Scotland rolled out the paediatric influenza vaccination programme targeted at all healthy children aged 2-11 years, towards the end of this study period.
- A range of approaches to support people to get vaccinated and ensure that vaccinations are accessible. Frontline health and social care workers should be proactively encouraged to receive an annual flu vaccination.

Implications for policy and practice

- The wide range of avoidable causes of death identified in this study provides us with opportunities to take targeted action in both policy and practice development.
- Deaths from treatable conditions constitutes a failure to meet the fundamental human right to the highest attainable standard of health.
- These results draw attention to common health inequalities experienced by people with intellectual disabilities who have complex care needs, especially in epilepsy management and the prevention of respiratory infections, including from aspiration, and the flu.
- A major barrier to good health is from diagnostic 'overshadowing', where key health issues are overlooked and attributed to intellectual disabilities¹¹. Improved communication in healthcare settings and the implementation of reasonable adjustments to health and care practice is key to improving health and wellbeing.
- A rights-based approach to health is not solely the responsibility of healthcare services - it is also about ensuring that the underlying social determinants of health are addressed. We need to ensure children and young people with learning disabilities who have complex health needs, their families and carers get the multidisciplinary support they need and make our communities more inclusive.
- Premature mortality can be further reduced by integrating and improving health promotion policies within social care services to focus on prevention.

Relevant initiatives in Scotland

Preventing premature mortality demands action across policy, practice and professional areas. The specific needs of children and young people with intellectual disabilities needs to be integrated into national initiatives to improve the prevention, identification and treatment of common causes of death. Current strategies in Scotland that can contribute to improvement include:

Epilepsy:

1. SIGN guidelines on Epilepsy in Children and Young People will be published in 2020
2. Epilepsy is a priority area for action in the NHS HIS *Excellence in Care* strategy
3. Scottish Epilepsy Improvement Programme includes a learning disabilities representative
4. Scottish Paediatric Epilepsy Network (SPEN) care pathways will be updated by November 2020

Other causes of death:

1. Scottish Patient Safety Programme guidance on paediatric sepsis identifies children with complex neurodisabilities at higher risk of sepsis
2. Scottish Government is developing a 10-year Child and Adolescent Health and Wellbeing Action Plan
3. NHS Education Scotland DVD and Learner's handbook, "Making Dysphagia Advice easier to Swallow"
4. "Postural care: A guide to 24-hour postural management for family carers"— resource by PAMIS
5. The National Postural Care Strategy, funded by NHS Education for Scotland, is due 2020.
6. Learning Disabilities is a priority for action in the NHS HIS *Excellence in Care* strategy
7. International Dysphagia Diet Standardisation Initiative (IDDSI) framework launched by NHS HIS in April 2019
8. Disabled Children and Young People (Transitions)(Scotland) Bill

Next steps

- The Scottish Learning Disabilities Observatory will work collaboratively with the Scottish Government's Learning Disability Policy team and policy makers across health and social care to highlight the needs of children and young people with intellectual disabilities
- Primary care plays a vital role in prevention, early detection and intervention of treatable diseases, management of long-term health conditions, the promotion of accessible healthcare information, as well as increasing follow-up of health appointments¹¹. The Observatory will collaborate with primary care to highlight the needs of people with intellectual disabilities.
- We will work together with healthcare professionals in clinical practice, and across specialties to highlight concern over amenable conditions such as epilepsy and respiratory illness, and to identify routes to reducing premature mortality from these conditions.
- We will also work collaboratively with social care providers, families and people with intellectual disabilities, to improve recognition and early detection of important health issues and build understanding of risk factors to secondary health problems.
- The Observatory will engage with the public through national and social media to promote understanding of the health and societal challenges faced by children and young people with intellectual disabilities in Scotland and disseminate important information about their health needs.

Contact: SLDO-info@glasgow.ac.uk

The full article: <https://bit.ly/3f4eHwA>



Acknowledgements

This study was funded by a Medical Research Council Mental Health Data Pathfinder Award and the Scottish Government via the Scottish Learning Disabilities Observatory.

Appendix 1. References

1. O'Leary et al. Early death and causes of death of people with intellectual disabilities: A systematic review. *J Appl Res Intellect Disabil* 2018a;31(3):325–342. doi: 10.1111/jar.12417.
2. O'Leary et al. Early death and causes of death of people with Down syndrome a systematic review. *J Appl Res Intellect Disabil* 2018b;31(5):687-708. doi: 10.1111/jar.12446
3. Bourke et al. Twenty-Five Year Survival of Children with Intellectual Disability in Western Australia. *J Pediatr* 2017;188:232-239.e2. doi: 10.1016/j.jpeds.2017.06.008
4. Kerr M et al. Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *J Intellect Disabil Res.* 2009;53(8):687-94. doi: 10.1111/j.1365-2788.2009.01182.x
5. Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2018. (SIGN publication no. 143). Available from: https://www.sign.ac.uk/assets/sign143_2018.pdf
6. National Institute for Health and Care Excellence. Epilepsies: diagnosis and management [Internet]. [London]: NICE; 2019 (Clinical guideline [CG137r]). Available from: <https://www.nice.org.uk/guidance/cg137>
7. Jackson et al. Pharmacological interventions for epilepsy in people with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005399. doi: 10.1002/14651858.CD005399.pub3
8. Wright et al. Dysphagia. Guideline for the identification and management of swallowing difficulties in adults with learning disability. Working Party Guidelines 2018.

9. Heslop et al. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014;383(9920):889-895 doi: 10.1016/S0140-6736(13)62026-7
10. Health Protection Scotland: Influenza. Website available at: <https://www.hps.scot.nhs.uk/a-to-z-of-topics/influenza/>
11. Truesdale et al. 2017. People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Update Report