



LLR LeDeR Annual Report Summary 2025

**LeDeR – Learning from Lives and Deaths of autistic
people and those with a learning disability**

For consideration by:
Adult Social Care Scrutiny Commission

Date: 23 April 2026

Lead director: Kate Galoppi

Useful information

- Ward(s) All
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1. Purpose of report

- 1.1. This cover report accompanies a slide deck which will be presented at the ASC scrutiny commission meeting on 23 April 2026.
- 1.2. The purpose is to ensure our Adult Social Care Scrutiny Commission are fully briefed and sighted on the findings of our LLR LeDeR programme and their work to date to learn and prevent premature deaths of people with a learning disability and autistic people in our area. The summary offers a sense of both the system planning requirements for NHS services and support and those provided by local authority (particularly in relation to our care and support providers).
- 1.3. Whilst the report is mainly focussed on LeDeR which is an 18+ improvement programme, it includes a sense of the initiatives being undertaken to support the child death overview process (CDOP) for children and young people with a learning disability.
- 1.4. This report is for information only.

2 Report Summary

- 1.1. This cover report and the accompanying presentation provide the background to Leicester, Leicestershire and Rutland's LeDeR programme, which includes a review of deaths in 24/25. This is set against the national context and includes important statements garnered from the findings of those reviews and how that is supporting system planning for this year and beyond.
- 1.2. A key plank of our LeDeR work supports learning into action which will help ensure people with a learning disability or who are autistic do not die prematurely from avoidable (preventable or treatable) death in LLR.

3. Recommendations

- 1.1. ASC Scrutiny Commission are invited to:
 - Note and make any comments.

2. Supporting information

- 2.1. This cover report and accompanying presentation presents an important summary from the deaths of people with a learning disability or those who are autistic in 2024/25 in Leicester, Leicestershire and Rutland.
- 2.2. LeDeR (Learning from Lives and Deaths - People with a Learning Disability and Autistic People) is an NHS-funded service improvement programme in England. It reviews the care of people with learning disabilities and autistic people aged 18+

who have died, aiming to improve services, reduce health inequalities, and prevent premature mortality.

- 2.3. The focus is on learning from lives and deaths to identify good practice and areas for improvement, rather than investigation, complaints, or attributing blame.
- 2.4. When a person with a learning disability, or an autistic person dies, a notification is made, and a review is conducted (often involving families) to understand their care and identify any lessons that might be learned from their death.
- 2.5. Operating in LLR since 2016/17, the lives and deaths of people with a learning disability, and from January 2022, autistic people, have been reviewed with the findings presented in the LeDeR annual reports. The local LeDeR team focuses on turning reviews into learning and action to enhance local health and social care services. Led locally by the Leicestershire Partnership NHS Trust, the programme involves partnerships with people, our ICB, hospital trust and all three local authorities.
- 2.6. Key findings from 90 deaths notified to LeDeR in 24/25 include key statistics about their age, ethnicity and diagnosis. This tells us that people with a learning disability are still dying at a younger age compared to those in the general population. However, the median age at death decreases even more for those with a severe or profound LD and for those from ethnic groups when compared to white adults with a LD.
- 2.7. This tells us that health inequality due to ethnicity, or for those more complex is still a real area of concern and whilst avoidable deaths are declining – the rate for those who died up to 2023 is still double the rate of the general population.
- 2.8. In terms of the causes of deaths – respiratory (40%) remains the leading cause of death for people with a LD in LLR, followed by cardiac (16%) and cancer (11%).
- 2.9. Key and important statements from the report suggest that the application of the mental capacity act remains a concern for people with LD as does cancer screening – the low uptake of screening opportunities means most people included in the review had a stage 4 diagnosis (the most advanced stage of their cancer).
- 2.10. For autistic people whilst notifications remain low (337 notifications which resulted in the completion of 127 reviews between 2021-23), the leading cause of death for those people who died was recorded as suicide, misadventure or accidental death (31.5%) followed by circulatory system (20.2%) and cancer (14.5%). More than half of those reviewed had a diagnosis of depression.
- 2.11. The report identifies some important and essential opportunities for system planning and for learning to be implemented that reduce levels of inequality through access and understanding (ensuring reasonable adjustments are considered and) are put in place.
- 2.12. The report also points to some specific learning needed to support our autistic population in LLR including the importance of post diagnostic support, support for health and wellbeing including mental health, complemented by annual autism health checks with their GP.
- 2.13. This report is for information only.

4. Financial, Legal, and other implications

Financial implications

There are no direct financial implications arising from this report.

Mohammed Irfan
Head of Finance, Leicester City Council
Date: 13 April 2026

Legal implications

The report is for noting. Generally, any ongoing activities which includes commissioning services, or otherwise payment to third parties, early engagement and advice should be sought from Procurement and Legal Services to ensure that any such arrangements comply with the Procurement Act as well as the Authority's own Contract Procedure Rules.

Mannah Begum, Principal Solicitor, Commercial & Contracts Legal Services
Date: 13 April 2026

Climate Change Emergency implications

There are no direct climate change implications arising from this report.

Phil Ball, Sustainability Officer, Ext 372246
13th April 2026

Equalities implications

The Council must comply with the Public Sector Equality Duty (PSED) (Equality Act 2010) by paying due regard, when carrying out their functions, to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations between people who share a 'protected characteristic' and those who do not.

In doing so, the council must consider the possible impact on those who are likely to be affected by the recommendation and their protected characteristics. Protected groups under the Equality Act 2010 are age, disability, gender re-assignment, pregnancy/maternity, marriage and civil partnership, race, religion or belief, sex, and sexual orientation.

The LLR LeDeR Annual Report Summary highlights health inequalities affecting several protected groups:

People with learning disabilities have much shorter life expectancies and higher rates of avoidable deaths than others. Those with severe or profound learning disabilities

are most affected. People from ethnic minority backgrounds tend to die younger than White people, with gaps of almost 20 years between some groups.

Most autistic adults in the review were male, and a significant number died through suicide or accidents. High levels of depression and anxiety were also recorded.

The report shows barriers to fair healthcare access, including inconsistent use of the Mental Capacity Act and lower participation in cancer screening.

Although the report is for noting, the System Planning for 2025/26 will help address these inequalities. Key actions include the use of the Reasonable Adjustment Digital Flag, plans to improve access to health services, and local reviews using an intersectional approach. These measures will help advance equality of opportunity and reduce health inequalities across LLR

Equalities Officer, Surinder Singh, Ext 37 4148
Dated 13 April 2026
