

# **LLR LeDeR Annual Report 2022/23**

Public Health and Health Integration Scrutiny Commission

Date of meeting: 12/12/2023

Lead director/officer: David Williams,  
Director of Strategy and Partnerships  
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## Useful information

- Ward(s) affected: All LLR
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- Report version number: V.001

### 1. Summary

**This report provides a summary to the LLR LeDeR Annual Report 2022/23 and offers key actions from learning for all partners.**

### 2. Recommendation(s) to scrutiny:

Public Health and Health Integration Scrutiny Commission are invited to:

- Share the annual report widely.
- Promote the key learning points across all services, noting a whole LLR system response is required.
- Note the considerable disparity in life expectancy for people with a learning disability and autistic people.
- Recognise that one third of deaths were potentially preventable.

### 3. Detailed report

#### 3.1: Background:

The 'Learning From Lives and Deaths of People with a Learning Disability and Autistic People' (LeDeR) Programme was launched in 2016/17. Since being established, 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, where action from learning has been captured.

The LeDeR programme aims are to:

- ✓ improve care for people with a learning disability (LD) and autistic people;
- ✓ reduce health inequalities for people with a learning disability and autistic people; and
- ✓ prevent people with a learning disability and autistic people dying prematurely.

Within Leicestershire, Leicester and Rutland (LLR) a new team was established to solely focus on this programme.

#### 3.2: The 2022/23 LLR LeDeR report:

The report covers the financial year 2023/23 for Leicestershire, Leicester and Rutland.

This is the first time a LeDeR report has included reviews for autistic people. Quality of care was also measured for the first time in this report. This was measured using six themes set out nationally, and further examined by sub-themes. The report also focuses on preventative healthcare; an area which the LLR LeDeR programme team have actively been involved with in supporting the learning into action part of the report.

Of note within the report:

- A total of 83 deaths were notified to the LeDeR Programme during 2022/23.
- The median age at death was 62.
- This is over 20 years younger than the general population.
- From 1 July 2023, any deaths of people under 18 years of age, reviews are no longer carried out by LeDeR, but by the Child Deaths Overview Panel only (CDOP).

The report is supplemented by top ten learning into action points. These are followed by plans for the forthcoming year, with appendices containing more detail in relation to various sections of the report.

### 3.3: Learning into Action:

The aforementioned top ten learning into action points recommended across the LLR system from this year include:

1. Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
3. There is an emerging theme around the widespread misuse of the Mental Capacity Act. All services should review their practices to ensure compliance with this important legislation.
4. The practice of estimating someone's weight is a significant risk for people. People should be weighed using appropriate weighing equipment and the weight should be recorded accurately.
5. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with learning disabilities as physical health and nursing care needs increase particularly towards the end of their life.
6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.
7. Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.
8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. The changing of pathway at discharge to LD MDT is imperative.

10. There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy, which is not always accessed appropriately. Intervention by these teams does not guarantee successful outcomes but the availability should be widely known.

A list of achievements in partner services in response to learning from LeDeR is given from page 37 in the report.