



**HEALTH OVERVIEW AND SCRUTINY COMMITTEE:**  
**31 AUGUST 2022**

**LEARNING FROM DEATHS OF PEOPLE WITH LEARNING  
DISABILITY AND AUTISTIC PEOPLE REVIEW PROGRAMME  
ANNUAL REPORT**

**REPORT OF THE JOINT SENIOR RESPONSIBLE OFFICERS  
FOR THE LEDER WORK (Heather Pick, LCC & David Williams,  
LPT)**

**Purpose of the Report**

1. The purpose of this report is to update the Committee on progress and achievement within the Leicester, Leicestershire and Rutland (LLR) LeDeR (Learning from lives and deaths of people with learning disability and autistic people) programme in 2021/22.

**Policy Framework and Previous Decisions**

2. The report does not implicate any change to current policy or plans. We ask the committee to receive the report, as provided to stakeholders.

**Background**

3. LeDeR is a national service improvement programme directed by NHS England and Improvement, managed in LLR by the Integrated Care Board for the Integrated Care System. Originating from the Transforming Care work carried out by the former CCGs in partnership with LLR Health and Social Care Services, the programme reviews the lives and deaths of people with a learning disability or autism, or both, to extract and disseminate learning into action.
4. The two main aims of the programme are
  - To support improvements in the quality of health and social care service delivery for people with learning disabilities and people with autism;
  - To help reduce premature mortality and health inequalities for people with learning disabilities and people with autism.
5. Learning from reviews is taken through a Governance Panel to formulate SMART actions which advise and enable services to make improvements.

This in turn increases quality of life and care for people and helps prevent premature death.

6. There are two types of review:
7. **Focused** (in-depth): it is expected that approximately 35% will be of this type. Focused reviews are automatically given for automatically for and death of a person
  - With autism only (no learning disability);
  - From an ethnic minority;
  - Who had mental health restrictions in the last 5 years of life;
  - If family request a focused review.

Additionally, focused review is allocated locally if a priority analysis area in LLR, e.g. respiratory or COVID deaths. LLR is currently running at 45% focused.

8. **Initial** (light-touch) for all other cases.
9. Learning from reviews in year has resulted in actions for LLR services including Primary Care, Secondary Care and Community Care.
10. Primary care is asked to
  - Read the weekly e-newsletter that is sent to all GP practices, it now includes a Learning Disability section, with all the key information;
  - Designate a Clinical Lead GP for Learning Disabilities in every Practice. Support and advice for this person is available from ICB Clinical Leads for LD;
  - Ensure individuals are included on the LD QOF Register\* this is the gatekeeper to being invited to LD AHC, awareness of reasonable adjustments, safeguarding and referrals to secondary care;
  - Instigate RESPECT forms when the person is well enough to ensure their wishes are heard, in primary healthcare. People with a LD, their family and carers should be supported to understand about RESPECT forms and they differ from a DNACPR;
  - Ensure use of regular appropriate Mental Capacity Act Assessment;
  - Promote hospital passports for people with LD and to promote at consultation/LD AHC\*;
  - Increase knowledge and awareness of the “Adult not brought to appointment; Y2de1” (Was not brought) read code and safeguarding policy, especially for GP Receptionist teams;

<https://vimeo.com/392944939>

11. The ICB is working on:

- Wheelchair scales; update the GP Annual Health Check and LD Newsletter with guidance on accessing them.
- Improving and simplifying the AHC template;
- Clarifying the blood-letting pathway, designating a Co-Ordinator and will share this with Primary Care.

12. Secondary Care is asked to:

- Effectively plan, identify and consider people at the end of their life through timely commencement of End of Life care pathway;
- Communicate with and remind Care Providers they are welcome to support people with a learning disability in hospital and advocate for them;
- Review process of community follow up after discharge, e.g. CLDT discharge coordinator in LPT could feed into LPT long term plan;
- Establish and communicate as early as possible, the funding required when someone with an LD goes into hospital;
- Establish early dialogue with family and carers so their needs are taken into account when giving information;
- Use of regular appropriate MCA Assessment;
- Promote use of Hospital Passport;
- SALT to consider leading a REFLUX campaign for people with LD in partnership with LeDeR team;
- Where a hospital has been informed that a person has a LD, this is to be communicated to other staff early. Any information about the person/resources to also be circulated amongst staff supporting the patient at admission.
- Inform Acute Liaison Nurses immediately of any hospital admission of a person with LD and give ALN contact details for family and carers.
- Pursue wider training for other staff around supporting a patient with LD in an acute setting, so the ALNs are not pressurised with the support required to be provided.

13. Community Care is asked to

- Support people to live where they choose and enable them to make decisions in a timely manner. *Funding should not be a barrier.*
- Ensure that all care providers have access to current, wider learning disability services and know who to contact.
- Ensure all care providers clearly understand when a RESPECT form is to be instigated by all everyone including people with a learning disability, family, carers, health and social care staff.
- Use of regular appropriate MCA Assessment

- Promote training and education around the use of tools to help staff recognise the deteriorating patient.
- Ensure care providers are appropriately risk assessed and safeguarding is assured
- Ensure that when sourcing residential care placements that an individual's culture, language, preferences and communication needs are taken into account.
- Put steps into place to ensure that these needs can be met at all times by the identified care provider.

### **Engagement**

14. Every review of a death includes involvement of any family and carers of the person who died. They are informed in writing of the review, invited to contribute to the review itself, request a focused review if this is not already set, and receive a copy of the final submitted review. The review is carried out whether the family participate or not, in line with national policy.

### **Resource Implications**

15. There are no resource implications.

### **Timetable for Decisions**

16. No decisions are required.

### **Conclusions**

17. The report is submitted for information. It shows progress made against the two main aims of the LeDeR Programme, notably in reducing premature deaths of people with learning disability and/or autism.

In the two previous years (2018/19 and 2019/20), the median age at death for people with a learning disability was 59 years. This report shows an improvement in median age at death to 64 years in 2021/22.

Additionally, more children and young people reached the age at which they transition into adult services.

### **Background papers**

Presentation slides from Health Overview and Scrutiny Committee meeting on 5 September 2018:

<https://politics.leics.gov.uk/documents/s140050/LEDER%20Information%20pack.pdf>

**Circulation under the Local Issues Alert Procedure**

18. None

**Equality and Human Rights Implications**

19. There are no equality or human rights implications arising from the recommendations in this report. The LeDeR programme supports and advises on actions to improve services for people and so influences positive change for people with learning disability and/or autism.

**Appendices**

20. Appendix A - LLR LeDeR Annual Report 2021/22  
Appendix B - Summary presentation of the annual report

**Officer to Contact**

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