

HEALTH AND WELLBEING BOARD

16 January 2024

LLR LEARNING FROM LIVES AND DEATHS: PEOPLE WITH A LEARNING DISABILITY AND AUTISTIC PEOPLE (LEDER)

Report of the Leicestershire Partnership NHS Trust

Strategic Aim:	Healthy and Well	
Exempt Information	No	
Cabinet Member(s) Responsible:	Councillor Diane Ellison, Portfolio Holder for Adults and Health Councillor Tim Smith, Portfolio Holder for Children and Families	
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Ward Councillors	N/A	

DECISION RECOMMENDATIONS

That the Committee:

1. Shares the annual report widely.
2. Promote the key learning points across all services.
3. Note the considerable disparity in life expectancy for people with a learning disability and autistic people.
4. Recognise that one third of deaths were potentially preventable.

1 PURPOSE OF THE REPORT

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

2 BACKGROUND

- 2.1 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.
- 2.2 The LeDeR programme aims are to:
- a) improve care for people with a learning disability (LD) and autistic people;
 - b) reduce health inequalities for people with a learning disability and autistic people;
and
 - c) prevent people with a learning disability and autistic people dying prematurely.
- 2.3 Within Leicestershire, Leicester and Rutland (LLR) a new team was established to solely focus on this programme. The leadership of the Learning Disability & Autism Programme is a joint programme with shared responsibility. Heather Pick, Assistant Director, Adults and Communities, Leicestershire County Council and David Williams, Director of Strategy and Partnerships, Leicestershire Partnership NHS Trust are joint Senior Responsible Officers (SROs) for this work.

3 THE 2022/23 LLR LEDE R REPORT

- 3.1 The report covers the financial year 2022/23 for Leicestershire, Leicester and Rutland.
- 3.2 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.
- 3.3 Of note within the report:
- a) A total of 83 deaths were notified to the LeDeR Programme during 2022/23.
 - b) The median age at death was 62.
 - c) This is over 20 years younger than the general population.
 - d) 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), there is very close working between LeDeR and CDOP
- 3.4 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.

4 LEARNING INTO ACTION

- 4.1 The aforementioned top ten learning into action points recommended across the LLR system from this year include:
 - 4.1.1 Report the deaths of those people autism (with or without a learning disability) to the LeDeR Programme.
 - 4.1.2 Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
 - 4.1.3 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.
 - 4.1.4 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.
 - 4.1.5 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.
 - 4.1.6 Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time.
 - 4.1.7 Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified.
 - 4.1.8 Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
 - 4.1.9 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.
 - 4.1.10 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.
- 4.2 A list of achievements in partner services in response to learning from LeDeR is given from page 37 in the LeDer Annual Report.

5 THE IMPACT OF THE COVID PANDEMIC ON ANNUAL HEALTH CHECKS:

- 5.1 People with a learning disability often have poorer physical and mental health than other people; this doesn't need to be the case. An annual health check can help people to stay well, prevent poor health and identify issues early and provide treatment.

- 5.2 Across LLR, Annual Health Checks attendance reduced during the COVID pandemic as many people did not want to attend in person. This trend was countrywide. As a result, GPs offered phone appointments to cover the main parts of the check. This was on the understanding that the physical parts of the check would be carried out later (e.g. weight, blood pressure etc.).
- 5.3 Despite the challenge of accessing GPs face to face during this period, there was an annual increase in the proportion of people accessing a check. This increased from 52% in 2018/19, to over 80% in 2022/23. We have been able to maintain this improvement trajectory and expect to exceed last year's figure.

6 APPENDICES

- 6.1 Appendix A - LeDeR Annual Report 2023/24
- 6.2 Appendix B – Presentation slides

A Large Print or Braille Version of this Report is available upon request – Contact 01572 722577.