

Report to: East Sussex Health and Wellbeing Board

Date: 9 December 2025

By: Sussex learning from lives and deaths of people with a learning disability and autistic people (LeDeR), NHS Sussex

Title: Learning from the lives and death or people with a learning disability and autistic people (LeDeR) annual report 2024-25.

Purpose of Report: The report details the performance and progress of the LeDeR program 2024-25. This includes service improvement work undertaken across the Integrated Care System (ICS).

Recommendations:

East Sussex Health and Wellbeing Board is recommended to:

- 1. Note the publication of this report.**
 - 2. To help ensure system partners have a formal approach to utilising the learning from LeDeR to reduce the mortality gap for people with a learning disability and autistic people.**
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1. Background

- 1.1 This is the 6th annual report of the Sussex "Learning from the Lives and Deaths of People with a Learning Disability and Autistic People" (LeDeR) programme. LeDeR is identified as a priority in the [NHS Long Term Plan](#) and reviews a population of people in the [Core 20 plus 5 population](#)

2. Overview

- 2.1 We know that adults with a Learning Disability and Autistic people experience earlier deaths and more avoidable deaths than people in the general population
- 2.2 The median age of death of adults with a learning disability was 62.5 years old in the 2023 national annual report and 62 years old in the 2024/25 Sussex annual report. Since the introduction of LeDeR there has been an approximate 7 month increase of age at death, however there is still an approximate 20 year gap of age at death for someone with a learning disability compared to the general population. Adults with a learning disability and from a global majority background experience an even earlier age at death of between 42 and 53 years old.
- 2.3 Avoidable deaths for people with a learning disability have declined nationally since 2021, however the rate for adults with a learning disability who have died an avoidable death in 2023 is still nearly double the rate compared to the general population.
- 2.4 The most common causes of avoidable deaths for people with learning disabilities are influenza and pneumonia, cancers of the digestive tract and ischaemic heart disease.
- 2.5 Reviews for autistic people continue to be minimal with the number of notifications suggesting that only a minority of deaths of autistic adults are currently being reported to LeDeR, limiting data, insight and ability to act to improve health inequalities for autistic people.

3. Local Report

- 3.1 During the reporting period of 2024 to 2025, 158 deaths were notified to the programme, an increase of 20 notifications on the previous year. 123 reviews were completed; 45 of those reviews were for people living in East Sussex.
- 3.2 The most common cause of death in Sussex for someone with a learning disability was diseases of the respiratory system and most common health condition was frailty.
- 3.3 LeDeR completed just over a third of reviews as focused with a governance panel sign off process; the majority of those were due to the person being placed in Sussex from another authority. Thematic learning most often pertained to 'professional practice and the provision of care'.

4. Action from Learning

- 4.1 The 'Action from Learning' section of the annual report details when Tom Cahill, National Director for Learning Disability and Autism visited Sussex to meet those involved in service improvements as a result of LeDeR.
- 4.2 The details of the service improvements LeDeR has initiated across the ICS are reported on, including the newly published Learning Disability Stop Look Care booklet, work with the Sussex Prevention Board to develop resources to support people with a learning disability and autistic people to stop smoking, contributions to the Palliative and End of Life Care Ambitions in Sussex and LeDeR Roadshow Briefings across the region. All resources are on our website [Support for people with a learning disability](#).
- 4.3 The report details our achievements against our priorities for delivery in 2024 - 2025 and sets our priorities for 2025 - 2026.

5. Supporting Information

- 5.1 Learning from the lives and death of people with a learning disability and autistic people (LeDeR) annual report 2024-25 and easy read version: Appendix 1 & 2.

6. Conclusion and recommendations

- 6.1 LeDeR welcomes the interest of the Board and recommends that the East Sussex Health and Wellbeing Board notes the publication of the Sussex LeDeR annual report for 2024/25
- 6.2 LeDeR would request that the board help ensure system partners have a formal approach to utilising the learning from LeDeR reviews to reduce the mortality gap for those with a learning disability and autistic people.

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