

Report to: East Sussex Health and Wellbeing Board

Date: 10 December 2024

By: Edel Parsons, Senior reviewer and program lead: 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 2023-24.

Purpose of Report: The report details the performance and progress of the LeDeR program 2023-24. This includes service improvement work undertaken across the Integrated Care System (ICS) as a result of reviews undertaken.

Recommendations:

East Sussex Health and Wellbeing Board is recommended to:

- 1. Note the publication of this report.**
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1. Background

1.1 This is the 5th annual report of the Sussex "Learning from the Lives and Deaths of People with a Learning Disability" (LeDeR) programme. It draws on system work with incredible families, services, and professionals, including those who are autistic or who have a learning disability over the last year. We extend our sincere thanks and appreciation to everyone who has supported this work and been involved with the LeDeR programme.

1.2 All previous reports (including accessible versions) can be found on the NHS Sussex website, and via this link: [Support for people with a learning disability - Sussex Health & Care \(ics.nhs.uk\)](https://www.nhs.uk/healthcare/learning-disability-support).

1.3 Identified as a priority in the [NHS Long term plan](#), we know that people with a Learning Disability and Autistic people die considerably younger than the general population. The median age of deaths of those over 18 is reported as 63 in the 2022 national annual report and 61 in the 2021-23 Sussex annual report. This is because of difficulties accessing services and often not receiving the same quality of care as people without a learning disability or who are not autistic.

1.4 If you are from an ethnic minority community this is younger. This reporting period saw the publication of the NHS Race and Health Observatory report [We deserve better: Ethnic Minorities with a Learning Disability and Access to Healthcare](#). This report identifies a life expectancy of only 34 if you have a learning disability and are from a minority ethnic community. LeDeR continues to gather information to support improvements by understanding the intersectional needs of multiple protected characteristics.

1.5 LeDeR aims to improve care for people with a learning disability 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 from early deaths.

1.6 This report details the progress of the LeDeR programme in Sussex between 1 April 2023 and 31 March 2024. It outlines work undertaken to understand the lives of people who have died. It also details the important service improvement work that is undertaken as a result.

1.7 During this reporting period a total of 138 notifications of deaths have been made to the Sussex LeDeR Team. This is an increase of 13 from last year although it is worth noting that the deaths of autistic people were only included in quarter 4 of last years' report. The median age of death of someone with a Learning Disability in Sussex has increased to 65.

1.8 Similarly to last year, diseases of the respiratory system were the most common cause of death of someone with a Learning Disability in Sussex in 2023-2024. Frailty features are recorded on the second highest number of medical certificates of cause of death, which reflects that more people are living over 65 than before. Only one person in Sussex with a learning disability had COVID recorded on their medical certificate as cause of death this year.

1.9 The work of LeDeR continues to inform the Integrated Care System approach to reducing health inequalities. The work of the Learning Disability and Autism Health Inequality (LDA HI) Project Board continues and has matured, drawing national recognition as good practice.

1.10 At a time of significant and increasing challenge for the health and social care sector LeDeR continues to identify person centred and compassionate care. We are grateful to those working across our health and care system in Sussex.

1.11 The 'learning into action' section of the annual report details our priorities for quality improvement in 2024/25.

2. Supporting Information

2.1 The LeDeR annual report is published in full and easy read versions copies of which are contained in Appendix 1 and Appendix 2 of this report.

3. Conclusion and reasons for recommendations

3.1 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 2023/24.

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