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.**

---

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 or 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.

Contact Officer
LeDeR, NHS Sussex
Email: sxicb.leder@nhs.net

NHS
Sussex

Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR)

Sussex Annual Report 2024-25

Improving Lives Together

Contents

1 Introduction 3

2 Co-production 4

3 Governance arrangements in the Sussex system 5

4 Ensuring compliance with policy and best practice 6

5 Undertaking LeDeR for the death of autistic people in Sussex 7

6 Performance 9

7 Benchmarking 12

8 Analysis 13

9 Action from learning: system learning identified within completed LeDeR reviews 17

10 How did we do? Achievements against local priorities for delivery in 2024-25 25

11Our priorities for 2025-26 29

12 Conclusion 30

1 Introduction

1.1 LeDeR sets out a structured way to review the lives and deaths of people with a Learning Disability and Autistic people to share good practice and identify service improvements in order to promote living well for longer, ensuring the person, their family and their circle of support, are firmly at the centre of the work.

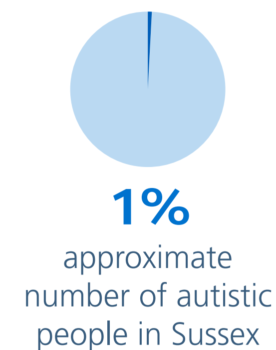
1.2 The LeDeR programme in Sussex is supported by a multidisciplinary team of reviewers who are registered learning disability and general nurses, and a social worker. Members of the team have additional skills in best interest assessing for the deprivation of liberty safeguards, autism support, patient safety and safeguarding adults.

1.3 The programme is supported by a collaboratively developed and robust standard operating procedure with terms of reference for strategic and operational meetings. This ensures NHS Sussex meets the requirements of the national LeDeR Policy 2021.

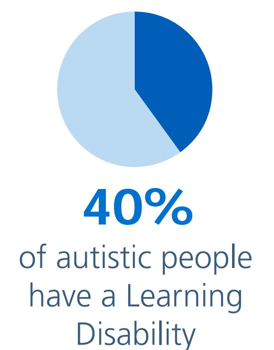
1.4 The total population of Sussex is approximately 1.8 million people. Based on a Learning Disability prevalence of approximately 2.16%, 41,730 people with Learning Disabilities are likely to live in Sussex. The prevalence of Autism is approximately 1% of the population and 40% of Autistic people will also have a Learning Disability; this means approximately 7,200 autistic people (without a learning disability) live in Sussex.

1.5 LeDeR enables us to tell the story of important people within our Sussex communities. We have included the stories of some of these people to illustrate our work and we thank these people. Their names have been changed.

41,730
people with a Learning Disability



1%
approximate number of autistic people in Sussex



40%
of autistic people have a Learning Disability

2 Co-production

2.1 LeDeR cannot operate in isolation and continues to acknowledge the contribution our partners make under the current system pressures. These include:

- GP surgeries
- People and their families
- NHS Trusts
- Local authority duty desks
- Registered managers and their staff
- Governance group members who all have large portfolios in senior roles
- Panel members including those with lived experience

Page 6

2.2 A LeDeR review is often the last words written about a person's life. Reviewers approach all reviews with compassion and sensitivity to develop rapport that often supports people in their loss, and to influence changes early in the process if helpful.

2.3 Working with families and carers is the most rewarding part of undertaking reviews and we are grateful for their candour and courage. Hearing the stories in LeDeR; both happy and sad, is a privilege.

2.4 When speaking with people with a learning disability, autistic people, their carers, families and service that support them, the message of "Living Well for Longer" is paramount. In all forums where we present our findings and service improvements the stark reality of inequalities that remain, are rightly pointed out. However, we are grateful to have the scope and capacity to be able to present the service improvement we drive, as a result of reviews undertaken in this report. LeDeR urges our stakeholders to develop their own service improvement plans as a result of reviews undertaken.

2.5 Most people with a learning disability have experienced care throughout much of their lives. For those that are autistic they may have had significant difficulties in accessing education and maintaining good mental health prior to their diagnosis. Almost all of these people will have experienced stigma and significant adversity and the subsequent trauma this causes. LeDeR is always reminded of their bravery.

3 Governance arrangements in the Sussex system

3.1 The Sussex LeDeR function has transferred from the Complex Commissioning arm of the NHS Sussex Integrated Care Board to the Chief Nursing Officer's remit. This was to enhance the clinical oversight of the programme and to bring it, along with the wider Learning Disability and Autism elements, to a single clinical management structure, that also oversees safeguarding.

3.2 The Sussex LeDeR Governance Group was established in 2021, in line with the Policy requirements, and is responsible for the governance and local implementation of the LeDeR programme.

3.3 Committed and consistent membership continues from the partner organisations in the Sussex integrated care system.

3.4 The LeDeR governance group in Sussex has benefited from a lay member who is an expert by experience with considerable knowledge and expertise in the LeDeR programme. This lay member left the programme at the end of this reporting period, and we pay particular thanks to them in this report.

3.5 Wider organisational governance routes include the Mental Health and Learning Disability Oversight Board, the Integrated Assurance Group, Quality and Patient Experience Committee and the NHS Sussex Board.

3.5 There are three Local Area Contacts, a national policy requirement, to support the work of the LeDeR programme by quality assuring reviews and chairing panels.

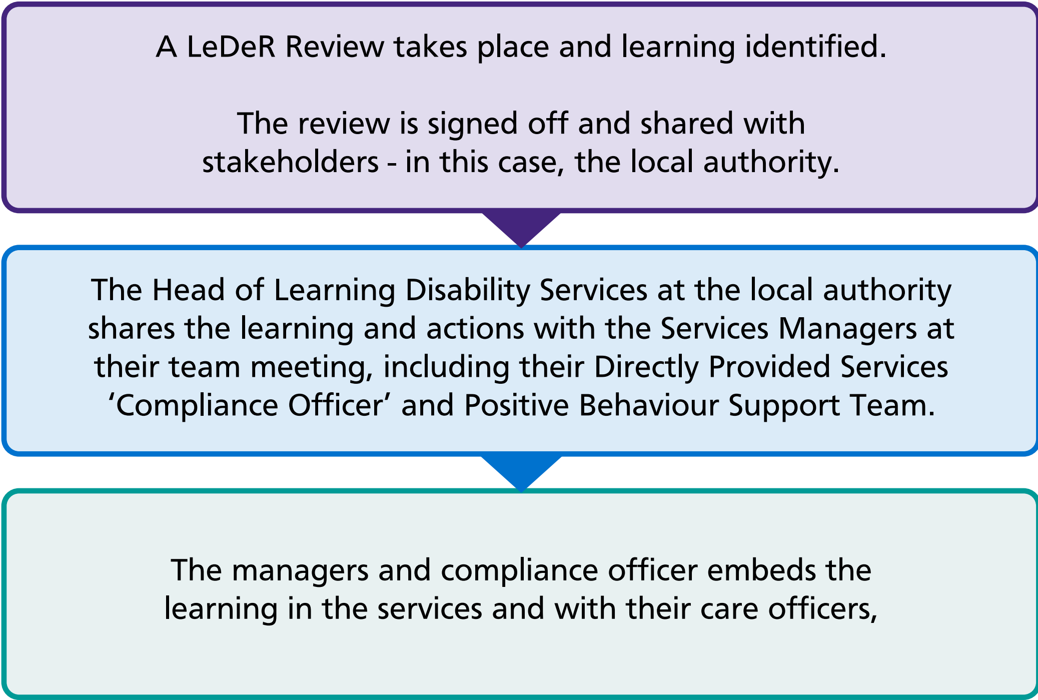
4 Ensuring compliance with policy and best practice

4.1 The LeDeR programme in Sussex continues to be fully compliant with the national LeDeR policy. The standard operating procedure is regularly reviewed and revised to ensure clear and up to date process and governance. This includes updating data protection impact assessments and data sharing arrangements with partners. Terms of reference have been agreed for the LeDeR governance group and focused review sign off panel, and these were reviewed and updated in September 2024.

Page 8

4.2 Here is an example of how a member of the Sussex governance group implements learning from LeDeR reviews.

An example of LeDeR learning through the system:



The Compliance Officer said:

"LeDeR have been instrumental in my work as a compliance officer. They've not only highlighted key areas for learning but also shared valuable health initiatives, these insights have helped me feed back into our directly provided services and support the promotion of initiatives that lead to better health outcomes for the people we support."

5 Undertaking LeDeR for the death of autistic people in Sussex

5.1 It is essential to understand the significant difference in undertaking reviews into the deaths of autistic people in Sussex who do not have a learning disability. This population may have achieved high levels of independence and attainment whilst experiencing barriers to health care due to a lack of understanding of needs such as sensory processing difficulties and the consequences of masking.

5.2 LeDeR recognises that the number of deaths of autistic people notified to the programme is likely to be lower than actual deaths of autistic people in Sussex. Findings from undertaking reviews into the death of autistic people have been shared to inform the Autism strategies in different stages of development and implementation in Sussex.

5.3 LeDeR is a member of the Pan Sussex working group hosted by public health for suicide prevention.

A person's story

David lived with his parents until he was 42. His learning disability was quite mild, and he had needs associated with his mental health and autism diagnosis. David loved music and played air guitar to his favourite tunes. He particularly loved anything to do with airplanes.

David had experienced phobias that restricted him going out and about in his community. When he moved into his home 10 years ago, he developed trusted relationships with staff. This eventually enabled him to go on overnight stays to watch planes at airports which he thoroughly enjoyed.

David also had a fear of medical procedures including blood tests and blood pressure. These had not been possible despite lots of reasonable adjustments. Sadly, at the age of 52 David had a large stroke that he could not recover from. But his care staff wanted him to come home and die in a familiar environment with people who loved him.

David's LeDeR was a focused review as his care was funded by an area outside of Sussex.

The discharge was well co-ordinated, and his care staff were supported by the end-of-life care hub.

LeDeR identified that David received regular reviews, and these were comprehensive and personalised and enabled coordinated support. This was from the funding authority's Mental health team.

His discharge from hospital was described as "excellent" and his treatment in hospital was respectful and dignified.

6 Performance

6.1 National Health Service England (NHSE), sets key performance indicators (KPI) of:

- **100% of all reviews to be completed within 6 months.**
- **35% of all reviews to be undertaken as focused reviews.**

6.2 The following were locally agreed priorities for focused reviews in 2024 - 2025:

- Where a woman has died of breast screening age and mammography is not recorded as being undertaken.
- Where a person has a BMI of over 30.
- Where there is a diagnosis of type 2 respiratory failure.
- Where a person is placed into Sussex from another area.
- Where epilepsy is contributory to the cause of death.
- Where there are concerns about care co-ordination or the threshold was met for safeguarding.
- Where constipation is contributory to the cause of death.
- Where a person is a care leaver.

6.3 The following are national priorities for focused review:

- When the person is autistic (without a learning disability).
- When the person is from a minority ethnic community.
- Where a family member requests a focused review.

6 Performance (cont.)

6.4 Focused reviews enable reviewers to detail the specific physical and mental health conditions a person experiences, as well as considering the commissioning of their care contact with other services such as substance use and housing. Actions are agreed by a panel of senior decision maker across stakeholders in Sussex including an expert by experience and care provider.

6.5 **LeDeR has achieved 68% of reviews completed within 6 months. LeDeR has exceeded the 35% KPI with 41% of reviews being undertaken as focused reviews at the end of this reporting period. Further benchmarking of performance is given in Section 7 below.**

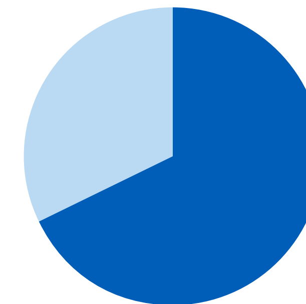
6.6 On audit it was found that 66% of 15 breeched reviews were signed off within 2 weeks of the 6-month target. We have therefore implemented an additional case load management tool to ensure that reviews are completed within 5 months.

6.7 Where reviews may not be completed within the required 6 months, risks are escalated and plans for completion devised.

6.8 LeDeR is not concluded until all statutory processes such as inquest or safeguarding enquiry have been undertaken. Where a statutory process is being undertaken LeDeR goes 'on hold' which stops the 6-month clock. After this, LeDeR will be completed within two months where possible. Regular audit of all reviews that are on hold is undertaken to ensure all reviews are appropriate to be on hold.

6.9 LeDeR tracks performance and collects data on high level themes for completed reviews. This is then segmented by provider. These themes are taken from both completed LeDeR initial and focused reviews.

6.10 On a quarterly basis LeDeR reports to Sussex system, Quality, Governance and Improvement Group (QGIG) and to the Integrated Assurance Group (IAG) and the Quality and Patient Experience Committee (QPEC).



68%
of reviews were completed within 6 months

Deidre

Deirdre was a 66 year old woman who lived in a care home. Deirdre grew up in the West Indies, she was a devout Christian who was described as a colourful and charismatic character often found knitting, dancing and gardening.

Deirdre had a history of serious mental illness, type 2 diabetes, abdominal swelling and constipation.

Deirdre hadn't attended cervical screening.

Deirdre often agreed with what people said and didn't 'make a fuss'.

Review Analysis

Deirdre hat numerous medical appointments and exploration of symptoms over two years, however she was diagnosed with a likely advanced malignancy with metastases (intraabdominal, ovarian and umbilical cancer) at a very late stage resulting in a terminal prognosis and palliative treatment pathway.

The review found that whilst there was lots of oversight and care for Deirdre, amongst other things there were issues around:

- Diagnostic overshadowing
- Recognition of deterioration
- Delayed diagnosis and missed opportunities in annual checks

Outcomes

The GP surgery was asked to complete a significant event review process using an intersectional lens. The care home manager and deputy attended 'Stop Look Care' training and implemented the toolkit in all homes.

We shared easy read information on diagnostic overshadowing, and this was discussed in the home's team meeting. The care home manager agreed to discuss screening needs for all residents with the GP on their next call. The care home contacted the health facilitation team about meeting their resident's health needs.

7 Benchmarking

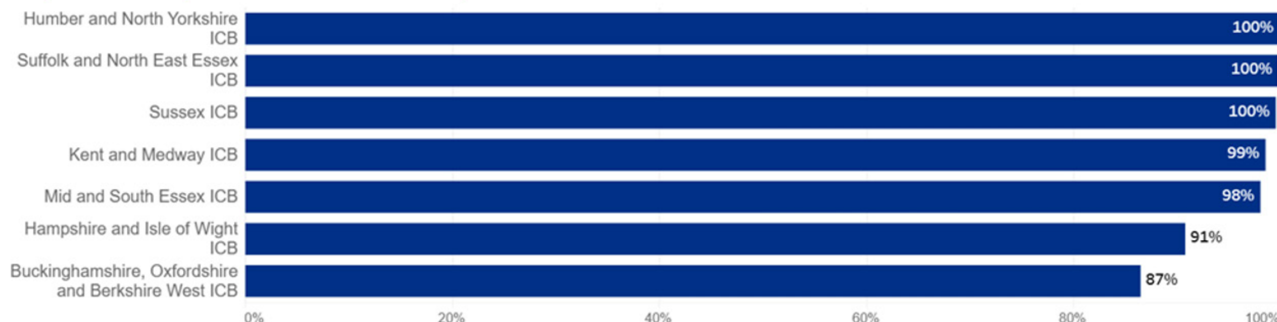
7.1 NHSE hosts the national LeDeR reporting dashboard. This shows relative performance with peers.

This page shows the closing position of LeDeR in Sussex against comparable systems, over a rolling period of 6 months.

Page 14

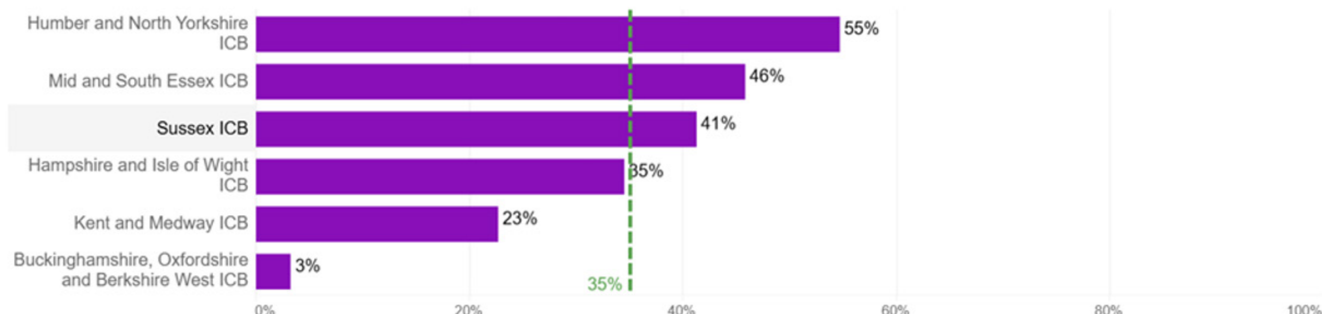
Proportion of eligible reviews that are completed

ICB breakdown - March 2025, All



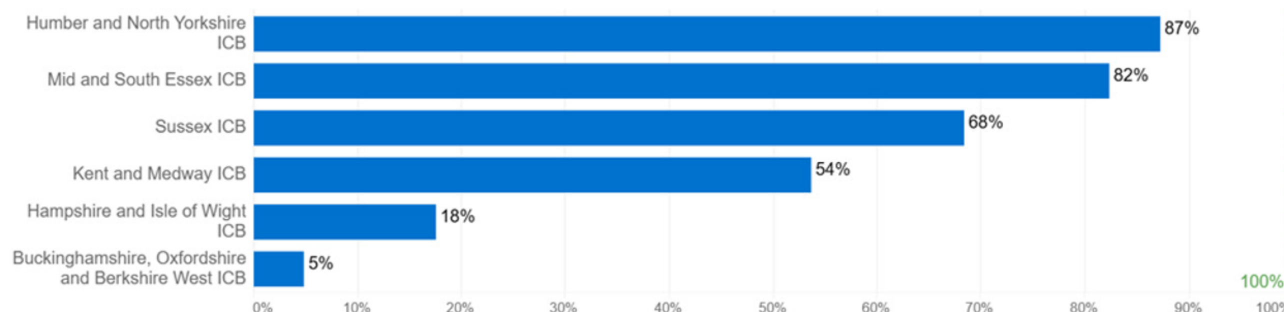
Proportion of completed reviews that were focused (6 month rolling period)

ICB breakdown - March 2025, All



Proportion of all reviews completed within 6 months of notification (6 months rolling period)

ICB breakdown - March 2025, All



8 Analysis

8.1 Equality impact

The purpose of the LeDeR programme is to reduce the health inequalities that people with a learning disability and autistic people experience, by attempting to understand the determinants that underpin them.

8.2 Four domains of analysis

The next part of this report focuses on the analysis of all the reviews received and completed in the reporting period.

These domains are:

- **Demographics of all notifications received: age, gender, ethnicity.**

- **The cause of death as recorded on the death certificate of completed reviews.**

- **Health conditions in order of prevalence and levels of multiple morbidities.**

- **Themes identified in the recommendations made in completed reviews.**

8 Analysis (cont.)

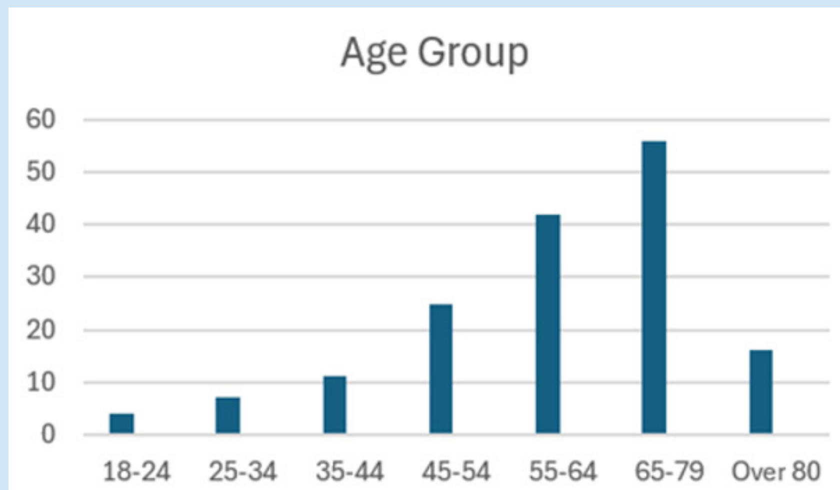
8.3 Age

158 deaths were notified to LeDeR during the reporting period.

This is an increase of 20 from the last reporting period and confirms a year-on-year increase in notifications received.

- The range of age of death was 19-91.
- The median age of death was 62.

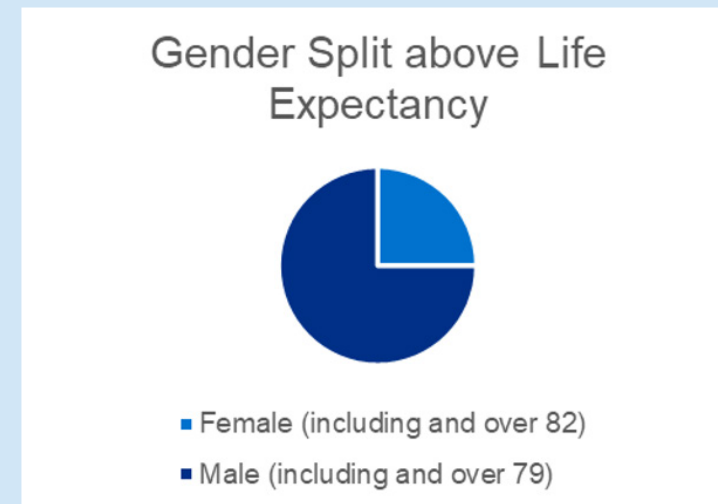
Page 16



8.4 Gender

- 77 females died in the reporting period.
- 79 males died in the reporting period.
- 2 autistic people who identified as non-binary died in this reporting period.

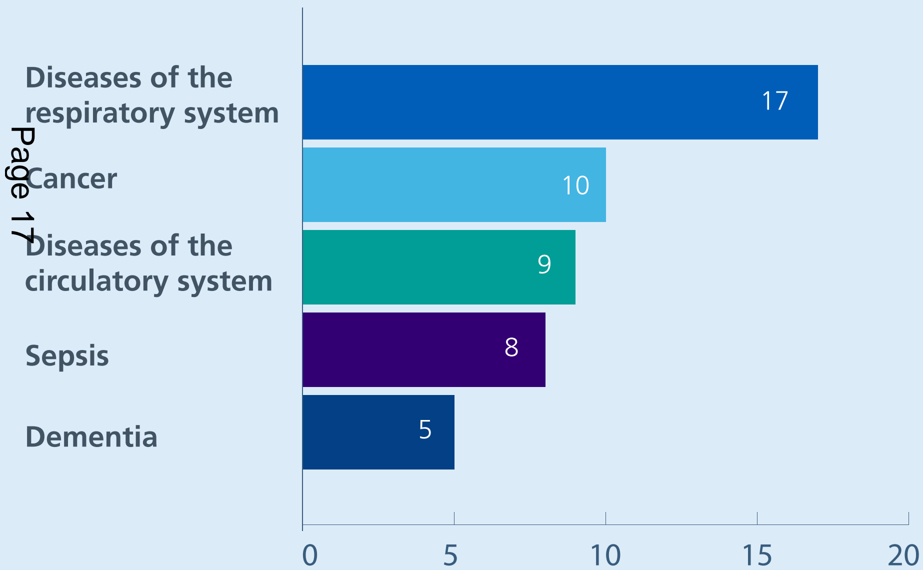
More people with a learning disability lived to their life expectancy and below shows the gender split of those with a learning disability who die in old age.



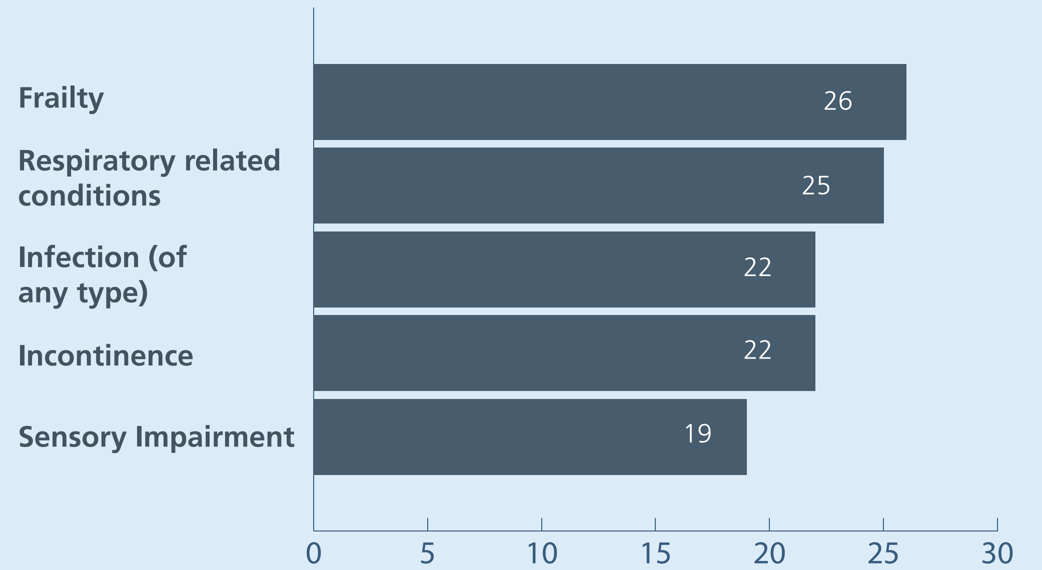
8 Analysis (cont.)

8.6 Cause of death

The top 5 causes of death in Sussex have remained consistent since reporting began in 2019.



Page 17



8 Analysis (cont.)

8.7 Recommendations made in completed reviews

163 reviews were signed off as completed in this reporting period with 63% undertaken as initial reviews. This increase in focused reviews was enabled by a change in process. The break down for the reasons focused reviews were undertaken are shown on this page (chart 2).

Sussex collects aggregated themes on the learning and actions in initial and focused reviews. The LeDeR platform groups actions by themes and below is the analysis of grouping of action by theme (chart 1).

Chart 1 **Themes**

Page 18

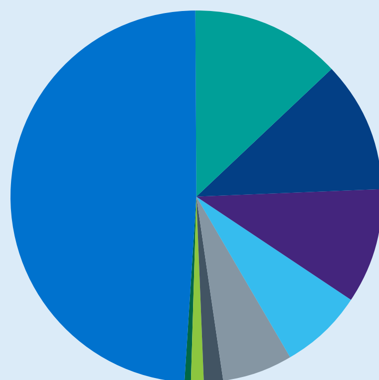
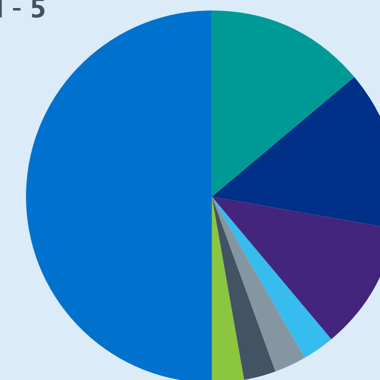


Chart 2 **Reason for focused review**



9 Action from learning: system learning identified within completed LeDeR reviews

9.1 Impact

Sussex has a long track record of developing and delivering service improvements across the health and social care system, some of which are detailed below. These service improvements would be unsuccessful without the collaboration of stakeholder including Voluntary, Community and Social Enterprise sector (VCSE) and people with a learning disability.

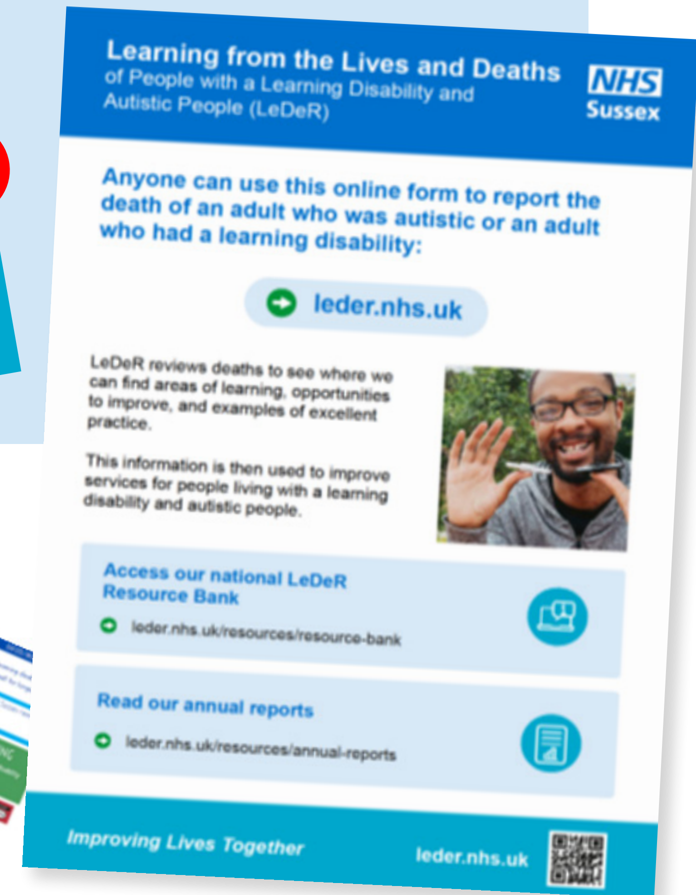
A National LeDeR report has yet to be published for 2024 but a Sussex LeDeR report was produced in full and easy read. The LeDeR team in Sussex created a briefing of these reports delivered and presented into:

- Sussex Integrated Care System (ICS) mental health, autism and learning disabilities board.
- Safeguarding adults' boards.
- Learning disability partnership boards.
- Sussex Health and Wellbeing boards.
- Chief nursing directorate meeting.
- Local authority social work teams.
- Shared lives carers teams.
- Autism partnership boards.
- Medical examiner services and teams.
- Adult social care provider forums.
- Self-advocacy groups.
- Suicide prevention boards.
- Sussex Safeguarding fortnight focusing on out of area placements.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

LeDeR also continues to create a quarterly newsletter which is published on the NHS Sussex and local authority websites here and distributed to a wide circulation list in Sussex.

LeDeR seeks to influence the system work force in understanding the barriers people with a learning disability and autistic people experience, in order to overcome them. 176 people or agencies are on the circulation list and a printable poster has been devised based on feedback received.



9 Action from learning: system learning identified within completed LeDeR reviews

9.2 Outcomes

Some of the highlights of the year include:

On 24 June, Tom Cahill, National Director for Learning Disability and Autism visited Sussex to meet those across the ICS involved in service improvements as a result of LeDeR. This visit had been initiated by Sussex presenting their work at a national health inequalities event. Tom said this about his visit:

"I came away feeling both inspired and excited by the work you are doing and the potential there to make such a difference to the local population".

Tom's visit featured in the NHSE Mental Health, Learning Disability and Autism Bulletin with this picture, of our colleagues who developed our cardiovascular disease prevention and management resources.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

On 15 October, Sussex hosted Clive Parry, England Director for the Association for Real Change (ARC), who had co-chaired the initial event with Tom. He reflected that he was unaware of LeDeR influencing other ICS's in the same way and particularly saw the benefit of Stop Look Care (a tool developed to identify deterioration and adapted for use in care settings for those with a learning disability) to adult social care. This was subsequently presented by Sussex at an ARC national registered managers event.

Page 22

▸STOP ▸LOOK ▸CARE

Four teams in Sussex continued to deliver this 90-minute virtual training sessions on a rota basis. Hard copies of the booklet have been produced with a plan for distribution developed.

Numbers of people trained in Stop Look Care for those with a learning disability:

- **2022-23 (3 sessions) -** 263
- **2023-24 (4 sessions)-** 575
- **2024-25 (4 sessions) -** 595

There are already 4 identified dates for this training in 25/26 and booking has commenced.

The Sussex LeDeR team delivered a two-hour workshop at the Safeguarding Fortnight event in November 2024 titled 'LeDeR: Supporting your Work in Safeguarding Adults'.

The workshop focused on the prevention principle of safeguarding adults and utilising resources developed because of LeDeR reviews, such as Stop Look Care and our Cardiovascular Disease Prevention and Management (CVDPM) films, in addition to national resources such as the Clive Treacy Checklist (tools for supporting the safety of people with a learning disability and autistic people with epilepsy).

Break out room sessions focused on the learning gleaned from focused reviews completed for those people that died and were placed from authorities outside of the Sussex area. LeDeR had learned that services may not understand the risks in placing people away from family advocates and networks, where referral pathways for additional support may not be known and the oversight from a person's funding authority is limited. Adults may not come to the attention of the hosting authority until they have experienced, or are at risk of experiencing, abuse or neglect.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

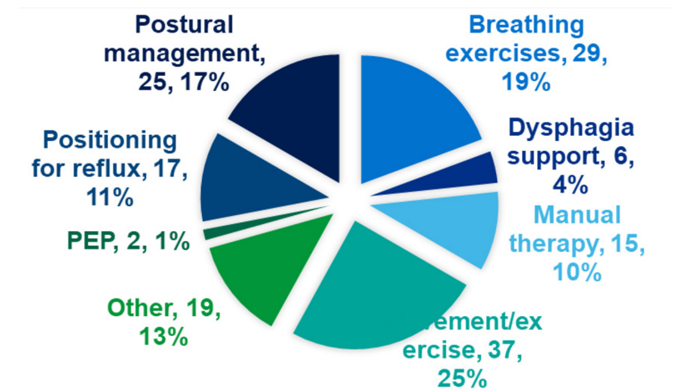
There was good attendance at the workshop from across Sussex, including VCSE, primary care, local authorities and district and borough workers. Over 70 people attended, and feedback included:

"The faciliator was really knowledgeable and passionate about the topic of service improvement. The inclusion of people with learning disabilities in resources helped to reinforce the importance of the programme and the ethos of the programme. I learned lots of valuable information."

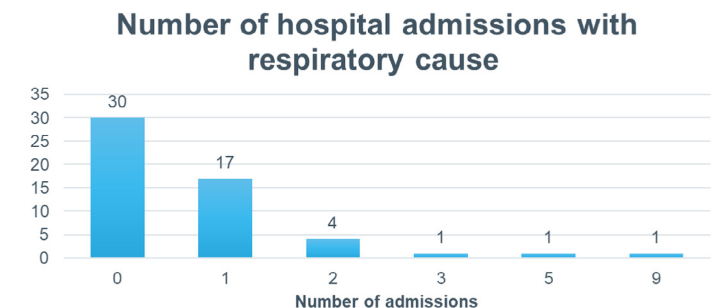
"My role has some strategic elements through training and policy development. I will certainly be using information from this course when I train others around organisational harm and neglect."

We asked the group for one or more new things learned from this training, presented here as a word cloud:

Extensive work continues with the community learning disability physiotherapy teams on their respiratory pathway, for those usually with profound and multiple learning disability, who are at the highest risk of premature mortality due to pneumonia. Below details the interventions and reduction in hospital admission. Of the 59 referred into the service, two followed the pathway into secondary respiratory services. Baseline scores in respiratory assessment determined intervention.



The interventions were then able to evidence better outcomes particularly regarding hospital admission avoidance as below:



9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

Last year, money was secured from the Sussex prevention board to develop resources to support people with a learning disability and autistic people to stop smoking. This was due to LeDeR identifying that whilst records stated, “smoking cessation advice offered”, referrals for onward support were not seen and cessation rates were nil unless a person became too ill to smoke.

Utilising a tobacco dependency service (TDS) that was already established within an NHS Trust, a project plan was developed to:

- Undertake focus groups with both adults with a learning disability and autistic adults to inform adjustments into the service.
- Co-deliver training to skill TDS advisors.
- Provided training to specialist staff supporting those with a learning disability
- In the importance of onward referrals and available support.
- Co-produce a set of accessible resources including films with branding similar to that of previously produced cardiovascular disease prevention and management resources.
- Co-deliver training to universal prevention services providing tobacco dependency services, including public health, social prescribing and community pharmacies.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

The TDS developed a set of standards on good engagement based on what they heard. Approximately 70 people joined an online training event co-delivered by people with a learning disability.

Here are some of the feedback comments received:

"An action I'll take from this training is to me more aware of the environment we're in - sensory requirement."

"Loved the fact that the training also comprised of people sharing their experiences which made things so much more useful to understand."

"Excellent training. Informative and lovely to meet Expert by experience."

"Going forwards I'll be more mindful of barriers and find ways to ask about reasonable adjustments."

This work has been shared at the Sussex ICS Prevention Board and all resources are available online with the agreement that providers can add their own logos as needed. Local health facilitation teams have also worked with their public health TDS to ensure that the resources are made available.

9 Action from learning: system learning identified within completed LeDeR reviews (cont.)

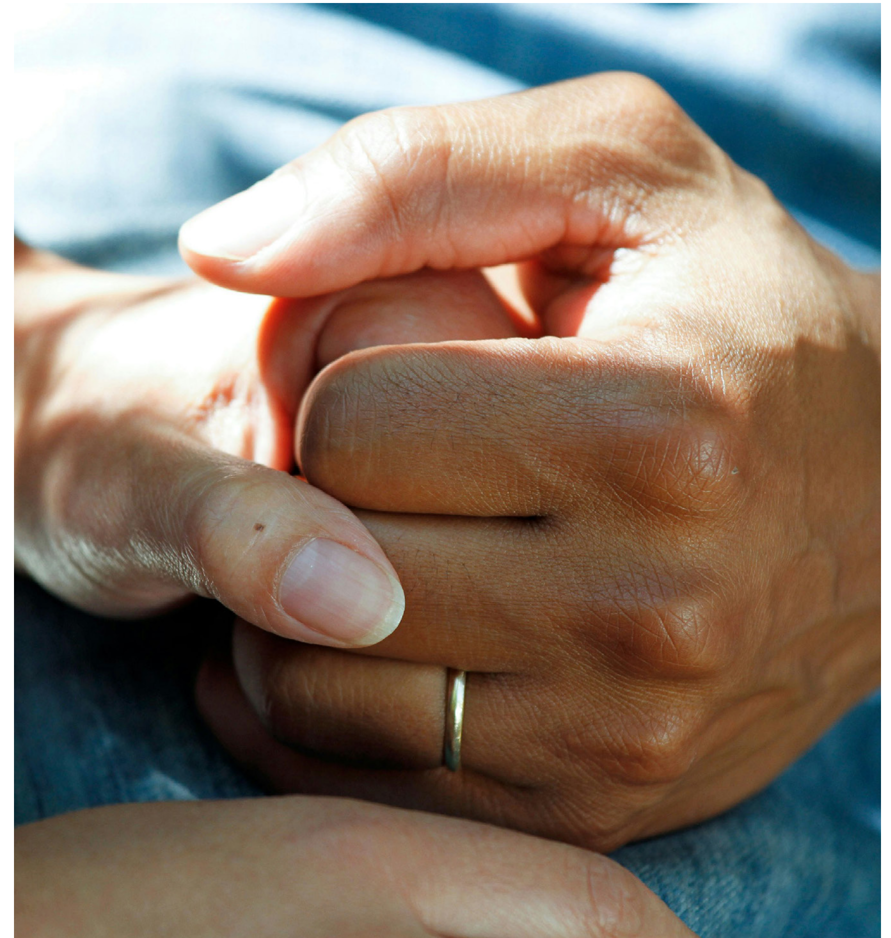
LeDeR is an active member of the Sussex Palliative and End of Life oversight group and has contributed to the submission to NHSE of the Palliative and End of Life care ambitions for people in Sussex.

LeDeR is also a member of the Learning Disability Palliative Care Link Group, established due to learning from a LeDeR review, and in this period our contributions included:

- LeDeR provided a briefing on the annual report.
- LeDeR presented on grief and bereavement for people with a learning disability.
- LeDeR presented on the importance of Life Story Work
- LeDeR increased the membership and reach of the group.
- LeDeR circulated and shared learning from the group.

Page 26

LeDeR has undertaken subsequent reviews where plaudits have been made regarding palliative and end of life care due to learning and relationships developed in this group.



10 How did we do? Achievements against local priorities for delivery in 2024-25

"LeDeR has identified that women with a learning disability continue to die of breast cancer when they are of screening age but have not attended for the mammogram. We are working with the Surrey, Sussex and Frimley cancer alliance to deliver training across primary care to reduce the barriers to mammography for woman who have a learning disability or are autistic."

- Focused reviews have been undertaken for women of screening age who have not received mammography to better understand the barriers. Health facilitators in Sussex are members of the newly established Inequality Group as part of the Surrey and Sussex Screening and Immunisation team who share learning on the barriers to this screening process.
- Sussex has met with a service in Somerset which is specifically commissioned to increase the uptake of screening for those with a learning disability and has shared this learning with our system.
- The Sussex provider collaborative has 'closing the mortality gap and health inequalities for people with a learning disability and/or mental health disorder' in their list of four priorities. LeDeR has met with the director in order that mammography is included in this priority.

"LeDeR continues to identify a gap in understanding of the health inequalities autistic people in Sussex experience. We will work hard to undertake LeDeR as soon as possible to ensure we have better information to make service improvements."

- Sussex awaits the outcome of NHSE pilots expected by April 2026, in combined learning disability, serious mental illness and autism annual health checks in order to mobilise this learning. With regards to mental health, NHS Sussex is undertaking a transformation plan to increase the resource of their post diagnosis support which has shown to reduce admissions to a mental health hospital setting and to considerably decrease the length of hospital stays if admitted.
- In relation to suicide prevention, LeDeR has shared case studies into autism partnership boards and suicide prevention boards. The specialist mental health provider has co-developed and delivered a presentation at a national event called Neurodivergence and Suicide Prevention. NHS Sussex has established the Lived Experience Advisory Group to inform their transformation programmes.

10 How did we do? Achievements against local priorities for delivery in 2024-25 (cont.)

LeDeR has identified that a lack of structured education and support is provided to people with a learning disability and autistic people who are obese and/or have type two diabetes or non-diabetic hyperglycaemia. LeDeR will support work already underway in the mapping and improvement of these services by informing Integrated Care Board (ICB) colleagues of the barriers identified in reviews.

- LeDeR will work with stakeholders to increase the use of continuous glucose monitoring in line with NICE guidance. Health facilitators in Sussex are members of the Health Inequities Group established as part of the Surrey and Sussex Screening and Immunisation team where this information is shared.
- ‘D2day’, is an initiative across Sussex to better understand the barriers that result in Type 2 Diabetes being diagnosed before 40, when outcomes are known to be poorer. LeDeR has flagged an increased risk of those with a learning disability who are on psychotropic medication or have specific chromosomal disorders. LeDeR has provided case studies and support on how to adjust education to be inclusive of those with a learning disability. LeDeR has shared guidance regarding the use of continuous glucose monitoring (CGM) for those on insulin, and has seen their use and trial in reviews.

Sepsis continues to result in many deaths of those with a learning disability or who are autistic. We will work jointly with NHS Sussex and other ICS stakeholders to deliver training to those supporting people with a learning disability or who are autistic in identifying sepsis.

- LeDeR has facilitated the co-development and delivery of a webinar on the prevention of sepsis in people with a learning disability. Targeted at the adult social care workforce the training was co-developed with health facilitation teams, a nurse with over 10 years working in the emergency department now working with adults with a learning disability, a registered nurse: learning disabilities who is the registered manager of a supported living provider and a registered manager of a residential home for those with profound and multiple learning disabilities.
- The webinar was attended by over 100 people and was well received. The edited version of the webinar is available on you tube and the Sussex ICS website.

10 How did we do? Achievements against local priorities for delivery in 2024-25 (cont.)

"LeDeR will develop and implement a communication plan to promote the use of the Victoria and Stuart toolkit to support advance care planning for those with a learning disability."

- This toolkit on advanced care planning, has been circulated widely via the developed communication plan. It has been included in the LeDeR newsletter, the hospice link forum and in training for Stop Look Care. It has also been presented at the Sussex ICS Palliative and End of Life Oversight Group. Sussex looks forward to an evaluation of its use and benefit at a national conference later in the year. LeDeR has also influenced the submission to NHSE of the ICS's Palliative Care Ambitions in order that the needs of those with a learning disability, based on learning from LeDeR, are represented.

"LeDeR will increase its reach and influence through active engagement into our minority ethnic communities with the support of ICB colleagues. This will enable LeDeR to understand the intersectional barriers experienced and ensure notifications are in line with the demographics of Sussex in order to result in culturally informed service improvements."

- Dying Matters week 2025 adopted the theme "The Culture Of Dying Matters". This saw the launch of the 'Respecting Faith and Culture in End-of-life Care Handbook'. LeDeR supported the development of this resource to ensure that it included the needs of those with a learning disability from our minority communities who may be approaching the end of their lives. Learning from LeDeR reviews on the inequalities that people with a learning disability from a minority ethnic background experience, was detailed in Dying Matters Week, alongside the launch of this handbook.

A Case Study - Janet

Janet was born with tuberous sclerosis and had a severe learning disability and epilepsy. She lived at a residential home and was described as happy and full of life.

In March 2021, Janet's carers noticed a distortion of her breast, which then returned to normal.

In June 2022, a further lump was found and following a biopsy, breast cancer was confirmed. Janet had surgery and hormone therapy.

In November 2022, Janet's breast cancer returned with widespread metastases.

Janet collapsed at home and died, at the age of 66, a few months later, on the day the hospice was due to visit her to plan her end-of-life care.

Background

In 2010, Janet attended a "disabled screening clinic" and was deemed not suitable for mammogram due to non-cooperation.

In 2012, Janet attended for a mammogram, but it was not completed. A breast screening disclaimer was completed.

In November 2020, a breast care letter was sent to the surgery but was returned.

In January 2022, the care provider asked the family to sign a disclaimer regarding withdrawal from mammography screening, stating it was unfair to continue when it causes upset.

As a result, Janet was removed from the breast screening programme without appropriate application of the Mental Capacity Act 2005 (MCA).

Learning

The application of the Mental Capacity Act (MCA) is a legal requirement for all those involved in the care of a person who may not be able to provide consent.

- Principle 2 – Capacity must be maximised using reasonable adjusted information and experiences.
- Principle 4 – Decisions made about a person who is unable to consent must be made in their best interest under the MCA.
- Principle 5 – Any best interest decision made must be of the less restrictive means.

Service improvement

- As a result of the LeDeR process, the review was shared with all services undertaking mammography screening to be used as a case study regarding the application of the Mental Capacity Act (MCA) and reasonable adjustments.
- The case and learning were presented to 153 nationwide healthcare professionals working within a Breast Cancer Screening setting during the Surrey and Sussex Cancer Alliance Breast Cancer Education webinar by LeDeR.
- A film was commissioned on applying the MCA to cancer screening programmes.
- Resources regarding cancer screening and follow-up appointments were shared across provider forums.
- Cancer screening programmes were asked to consider reviewing those who have been 'opted out'.

Page 30

11 Our priorities for 2025-26

1. To ensure that 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 mental illness. That these are shared in the quarter 4 LeDeR governance group.

2. To increase the number of notifications of the deaths of Autistic people to the LeDeR programme to ensure an accurate picture of this population in Sussex. This will be demonstrated in next year's annual report.

3. To seek assurance via the Mental Health, Learning Disability and Autism Transformation Programme regarding the care of autistic people in community and inpatient mental health.

4. To ensure that learning from LeDeR is included in the commissioning, and de-commissioning of all NHS services in Sussex and included in health inequalities impact assessments, by linking to this report on the NHS insight bank when published.

5. LeDeR will develop and implement accessible information to support improved hydration as part of the Hydrate to Feel Great initiative by the end of quarter 3.

6. LeDeR will work with prevention and dental services to ensure accessible resources are available to promote better oral health in those with a learning disability and autistic people.

12 Conclusion

This report demonstrates that health inequalities for people with a learning disability and autistic people remain. LeDeR commits to continue striving to reduce these inequalities.

People with a learning disability and autistic people, their families and their carers all tell us that they want to live for a long as possible, and as well as possible.

In hearing the stories of the lives of incredible people in Sussex, LeDeR is committed to informing service improvements across the whole health and care system.

This report serves to highlight the need for all health and care services to be aware of inequalities that are consistently reported and the times when things go well in order that they are shared and replicated.

We all have a duty under the Equality Act to ensure services are accessible but it is the barriers to these services that results in inequalities. LeDeR hopes that this report is of use to all services when considering how they meet the needs of those with a learning disability or who are autistic, as they are legally required to do so.

Finally:

Julie had down's syndrome and was very frail due to her Dementia. LeDeR found that she had been cared for by her stepmother who also had Dementia. Their needs were not seen holistically or well understood by Julie's carers. Julie died in hospital when she would have preferred to die at home with those who cared about her. Julie's sister wanted LeDeR to know that her sister was insightful and emotionally articulate. Prior to developing Dementia, she was a talented poet. She wrote this poem in her 50's in memory of her father's birthplace, that she visited as a child.

The distant hills are calling.

They are far away.

I can't remember where they are.

Yes I do now.

Blue sky.

The rolling hills are soft and green and gentle.

I know where they are…..on the moors where I love to be.

They are calling me to come to the place where I belong.

In the distance, the soft wind is blowing.

I'm the only one there, only me.

I love the sounds.

I am free and the gentle wind is blowing my hair.

It's just nice to be out there.

I look around.

What a sight!

I walk about or run, I just love to be free.

I see the hills in the distance, soft and gentle.

I sit down.

I hear something or is it calling?

I don't remember.

I lie there still.

I think I must be in a dream, only I am not in a dream.

I was still there.

I wake up, I am still in a dream.

I hear voices, the Northern accent.

Soft Lancashire voices, they have a sense of humour which I like.

I listen quietly.

I thought I heard someone I know.

It was Molly!

She recognises me.

She said, "Come on, we'll go home, lass, and have a mug of tea and cake."

Good old Lancashire.

They do make good cakes and a good mug of tea.

The cobble streets.

All you see are lots of houses in a row.

They are back to back, but I am not too sure where the shops are.

Some have the loos at the bottom of the garden.

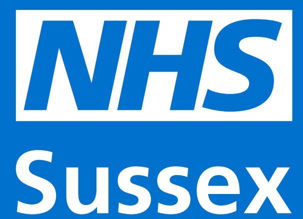
They cook a lot of meals.

The coal fire. The kettle is on.

The damp cold air outside.

Good old Lancashire.

Thank you for taking the time to read this report.



LeDeR 2024 - 2025 NHS Sussex Report

Learning from the Lives and Deaths of People with a Learning Disability and Autistic People

An easy read guide

made with photosymbols®

Brighton & Hove Independent Advocacy SPEAK OUT

NHS Sussex

What is LeDeR?

LeDeR is the name for the programme that Learns from the Lives and Deaths of People with a Learning Disability and Autistic People.

It finds out why people with a learning disability or autistic people have died. It does this to make improvements for future.

This report is about people with learning disabilities and autistic people who died in Sussex from April 2024 until April 2025.

Why is this important?

We believe everyone has the right to good health. Getting the care you need is very important.

Unfortunately, people with learning disabilities and autistic people are more likely to have health problems.They die at a younger age than other people.

Working together

People with learning disabilities, autistic people, families and carers know most about the care they need. We listen and learn from them carefully.

The LeDeR programme also works with other organisations in the health service - GP surgeries, NHS trusts, the Council, care home managers, and experts by experience.

How we work

The LeDeR programme in Sussex reports to the NHS Sussex Integrated Care Board. We follow the national LeDeR policy on how we should work.

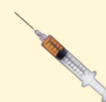
One person on our board is an expert by experience who knows a lot about LeDeR. They left this year, so we wanted to say a big thank you to them in this report.

We work with health services in Sussex to share the learning from our reviews, so that they can learn and make improvements.

An example of really good healthcare

We did a focused review of a man called David.

David loved music and watching airplanes.



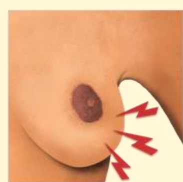
He didn't like medical procedures.

David had lived at home with his parents until he was 42. He had phobias that stopped him going out, but when he moved into his new home he built good relationships with the staff that helped him to start to go out more.

Sadly, David had a large stroke that he could not recover from at the age of 52. But his care staff wanted him to come home and die in a familiar place with loved ones. Everyone worked together to make this happen.

An example of unequal healthcare

We did a focused review of a woman called Janet. She was described as being happy and full of life. In 2021 Janet's carers noticed her breast looked strange, but it then returned back to normal again.



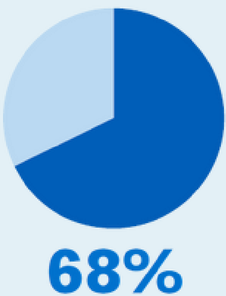
In 2022 they found a lump and found out Janet had breast cancer. She had surgery and treatment. But a little later on in 2022, the breast cancer returned and spread throughout her body.

Janet later collapsed at her home and died at age 66.

Janet had been seen as not suitable for a mamogram to screen for breast cancer in 2010 because she did not cooperate. We found that Janet had been removed from breast screening programme in the wrong way.

Are we working well and meeting our targets?

We have national targets for how quickly we review the death of someone, and what things we should look at in each review.

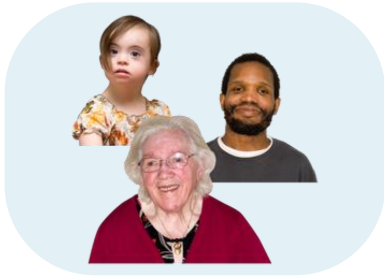


We are meant to complete all reviews within 6 months of the person dying. This year, we completed nearly 7 out of 10 of our reviews within that 6 month deadline.

Of all of our reviews, at least 3 out of every 10 should be ‘focused reviews’, meaning they look at more detail than the other reviews. This year, 4 out of every 10 of our reviews were ‘focused’ reviews.

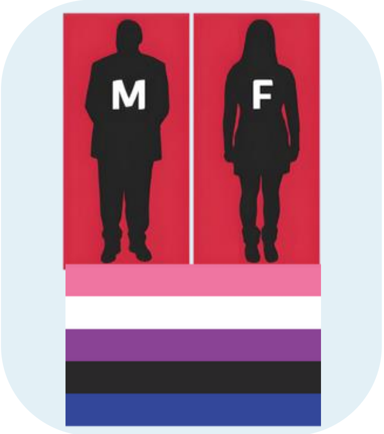
The facts for 2024 - 2025

We were told about **158 deaths.** This is 20 more deaths than we were told about last year. This doesn’t have to mean more people are dying, just that more people are learning to tell us about deaths so we can review them.



Age

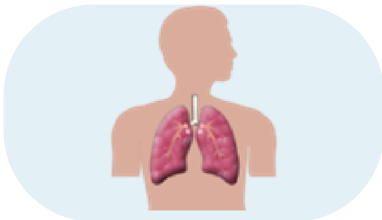
- Age of death ranged between 19 - 91.
- Many people died in their early 60s.



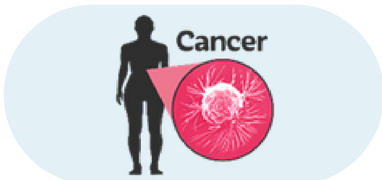
Gender

- 77 females died
- 79 males died
- 2 autistic people who were ‘non-binary’ died. Non-binary means they don’t see themselves as male or female.

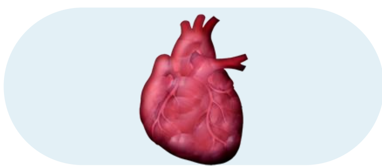
Main causes of death



Respiratory diseases - Diseases of the lungs and breathing systems.



Cancer - this is when the cells in your body go wrong and start to make you sick.



Diseases of the heart and blood systems

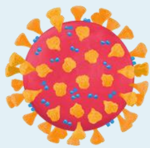
Sepsis - Sepsis is when your body fights too hard against an infection and damages itself.

Dementia - a disease of the brain that stops it from working properly.

Most common health issues

Frailty - Frailty is when your body becomes weak due to age or health condition. It makes it harder to recover when you become ill.

Respiratory conditions - Issues with the lungs and breathing systems.



Infection - any type, like a UTI or a virus.

Incontinence - Incontinence is when you cannot control your bladder, so that pee can leak out when you don't want it to.

Sensory impairment - This means that one of your senses does not work well or at all. For example, trouble seeing or hearing.

What we have been doing

Our LeDeR programme works hard to learn from the reviews and make changes to health services as a result. We do this by working with others, including charities and people with learning disabilities.

We tell people about our learning and service improvements through talks and newsletters.

The ‘Stop Look Care’ tool and training

We worked with our Health Facilitation colleagues to create a tool for staff in care homes to use to spot if anybody is getting really unwell.

595 people were trained this year on how to ‘Stop Look Care’. There are 4 more trainings booked in for 2025 and 2026.

We have shown care staff other resources they can use, like the Cardiovascular (or Heart Health) films we helped to make last year, and epilepsy resources.

Support to stop smoking

Continuing a plan we started last year, we worked with a Stopping Smoking service to improve these services for people with learning disabilities and autistic people.

We helped to create easy read resources to help people stop smoking. We sent these out to other areas of the country so that they can use the resources too.

We helped to train 70 different healthcare staff about stop smoking resources and how they could improve their services for people with learning disabilities too.

Planning for the end of life

We have been working with the 'Sussex Palliative and End of Life Oversight' group and the 'Learning Disability Palliative Care Link Group'.

Palliative care is the care and treatment for people living with serious or longterm illness to make them more comfortable.

Did we achieve our goals for last year?

We had 6 goals, or priorities, from last year's report. In this section we will track what we have been doing to achieve each one.

Breast cancer

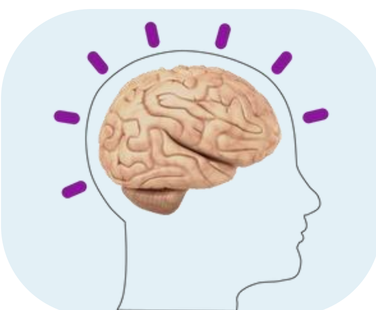
We wanted to learn more about women with a learning disability who died from breast cancer, especially if they could have had screening to catch the cancer earlier.

We did 'focused' reviews into these deaths to work out what the main issues are stopping women from using breast cancer screening.

We have helped start a new group of healthcare professionals to work together to address the issue in Surrey and Sussex.

We met with a breast cancer screening service in Somerset that is for people with learning disabilities to learn from them. We have shared this with the services in Sussex.

Health inequalities for Autistic people



We wanted to focus on the health inequalities that autistic people face in Sussex around their physical and mental health, neurodivergence support and suicide prevention.

We are still waiting on a trial of doing annual health checks for autistic people.

We are focusing on helping people after a mental health diagnosis. This should reduce mental health hospital admissions or make stays shorter.

We are working with local suicide prevention and autism partnership boards. The local specialist mental health provider delivered a national presentation on Neurodivergence and Suicide Prevention.

Obesity and diabetes

We are working with different healthcare staff to tell more people with learning disabilities learn about 'continuous glucose monitoring', which is a device that lets diabetics check their sugar levels without pricking their finger.

We have been working with a Sussex programme that is trying to understand why some people are getting Type 2 diabetes before they are 40, beacuse we know getting it early makes the disease more deadly.

We helped them understand what happens for people with learning disabilities, and how to make their resources accessible for them.

Sepsis

Sepsis is when your body fights too hard against an infection and damges itself. It is one of the main causes of death for people.

We have helped to train over 100 people on how to prevent people with a learning disability from dying of sepsis. This was mainly adult social care staff.

Planning to die how you would like to

We have been sharing a toolkit that was developed to help people with learning disabilities plan for the end of life. It is called ‘The Victoria and Stuart Project’.

We have also been working with healthcare staff in Palliative Care and End of Life Care to make sure they understand what people with learning disabilities need.

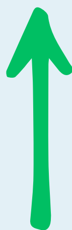
Supporting people from ethnic minorities

We know that we don't understand as much we would like to about people with learning disability for minority ethnic communities. We want to improve this.

We helped to make sure that a new resource called 'Respecting Faith and Culture in End-of-Life Care Handbook' included the needs of people with learning disabilities too.

What we are going to focus on over the next year

We will make sure that healthcare providers have a formal system to learn from LeDeR reviews to stop people from dying earlier.



We will work to hear from more autistic people who should be entitled to a proper review of their death.

We will look into the community and hospital mental health care for autistic people.

We will make sure LeDeR learning is used to help make the decisions about which NHS services are funded or not funded.

We will make accessible information about how to drink enough and stay hydrated.

We will work with dental care services to make sure there is accessible information about having healthy teeth and gums.

To finish

This report shows that people with learning disabilities and autistic people still face health inequalities. We need to do better.

One of the people who died was Julie. Julie had to die in hospital, even though she would have preferred to die in her home. Her sister wanted to share Julie's talent for poetry. Here is a piece of a poem she wrote.

The distant hills are calling.
They are far away.
I can't remember where they are.
Yes I do now.
Blue sky.
The rolling hills are soft and green and gentle.
I know where they are.....on the moors where I love to be.
They are calling me to come to the place where I belong.