Report to	Integrated Assurance Group
Meeting date	29 August 2024
Report Title	**(Learning from the Lives and Deaths of People with a Learning Disability) LeDeR annual report 2023-24**
Key question	How has LeDeR performed in the last year and what does it celebrate?
Sponsor	Allison Cannon: Chief Nursing Officer NHS Sussex.
Presenter	Allison Cannon: Chief Nursing Officer, NHS Sussex.
Authors	Edel Parsons: LeDeR senior reviewer and program lead.
Item number	3.2.1

Outcome/ action requested:

The Integrated Assurance Group (IAG) is asked:

- **Note** the content of the report.
- **Agree** that content of the report as fit for publication on the organisations public facing website as require by NHS England.

Executive summary:

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.

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).

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.

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 monitory ethnic community. LeDeR continues to gather information to support

improvements by understanding the intersectional needs of multiple protected characteristics.

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.

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.

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.

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 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.

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.

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.

The 'learning into action' section details our priorities for quality improvement in 2024/25.

Governance and engagement pathway to date:		
Org./Group/ Name	**Date**	**Outcome**
Alison Cannon	31/7/2024	Amendments made.

Naomi Ellis	22/7/2023	Amendments made
Joe Nhemachena	8/7/2024	Amendments made.

What happens next?
If agreed by IAG this report will go to Executive Committee for final sign off.

CONTENTS

1.0 Introduction

1.1 LeDeR set outs a structured way to review the lives and deaths of people with a Learning Disability and Autistic people, to identify the service developments needed to address the health inequalities that are leading to premature deaths. LeDeR in Sussex has been operational since 2017.

1.2 Since 2023 and in line with the LeDeR policy 2021 Sussex has a dedicated LeDeR team. The team has the equivalent of three full time Reviewers, a Senior Reviewer and a Project Support Officer. The team is multi-disciplinary with skills and expertise of Registered learning disability, and general Nurses, as well as a social worker and Best Interest's Assessors. They complete all of Sussex LeDeR Reviews and act as points of contact for local partner organisations.

1.3 LeDeR reviews are completed following the receipt of a notification of someone's death via the LeDeR Website: https://leder.nhs.co.uk.

1.4 LeDeR reviewers collect information from families, carers, providers, professionals, medical records and other relevant agencies and organisations in order to see where they can find areas of learning, opportunities to improve, and examples of good practice.

1.5 Once completed LeDeR reviews are shared with relevant stakeholders to agree learning and actions that will influence and drive forward service developments and improvements. Actions are followed up regularly with services and individuals by LeDeR reviewers and progress is tracked locally.

1.6 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.

1.7 LeDeR tells the stories of important people. People who lived with their families or other support services but 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.

2.0 Co-production

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

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

2.2 Undertaking a LeDeR review requires compassion and sensitivity. As reviewers we are privileged to hear the stories of so many incredible people. Positive relationships are required to influence system learning and practice. Sussex holds a strong value in the importance of doing justice to an important person's life recognising that LeDeR is likely to be the last words written about them.

2.3 Working with families and carers is the most rewarding part of undertaking reviews and we are grateful for their candour and often courage. We often receive feedback that talking about a loved one can be a helpful part of the grieving process with one bereaved mother saying "LeDeR was the full stop in my grief. "

2.4 "Living well for longer" is frequently discussed at all self-advocacy forums in Sussex including the West Sussex Autism board, Learning Disability Partnership Boards, the East Sussex Involvement Matters and Brighton and Hove 'SpeakOut'. Those with a learning disability were clear about not wanting to talk about death and dying and a shared journey has resulted in being able to have honest conversations about good health care and how to overcome barriers in accessing it.

2.5 It is those who may have experienced care throughout much of their lives often with the need to challenge stigma and face adversity that we thank the most. We are always reminded of their bravery. In last year's Spot the Difference film produced by the Staying Alive and Well group, there is an important reminder in that "if you get it right for people with a learning disability you get it right for everybody." Something LeDeR is helping us do in Sussex.

3.0 Governance arrangements in the Sussex system

3.1 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.

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

3.3 LeDeR governance group in Sussex also employs a lay member who is an expert by experience with considerable knowledge and expertise in the LeDeR program.

3.4 LeDeR separates its governance (business) and focused review panel sign off in Sussex. Focused panels are held fortnightly. Governance meetings are held quarterly. Both meetings have regularly reviewed terms of reference and have agreed quoracy.

3.5 All reviews are shared with the relevant stakeholders and followed up by reviewers for updates on progress against agreed actions. Here is some feedback received from a GP surgery after a completed review was shared with them.

> *Thank you for the report and comments, and we took the opportunity to discuss it at our Clinicians' meeting this week which involves all the GPs, nurses and HCAs……We reflected on the use of templates and frailty assessments, and whilst the templates are used regularly for reviews at the practice, they need to be used for home assessments too which we will do. We also noted the comments about the content of the LD review and will consider using the arm circumference for estimation of weight and also aim for better documentation of all aspects including constipation and epilepsy review.*
>
> *Thank you for your positive comments. This year we have changed our meetings with some of the community services to a more frequent and useful format which we are finding improves communication too."*

4.0 Ensuring compliance with policy and best practice

4.1 The LeDeR program in Sussex continues to be fully compliant with the 2021 national LeDeR policy. This policy is being reviewed nationally. Sussex welcomes this and will be part of this working group.

4.2 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 partners. Terms of reference have been agreed for LeDeR governance group and focused panel.

4.3 LeDeR team members also work to agreed 'portfolios. This has enabled the development of trusted relationships with system partners such as our medical examiner colleagues and Local Authorities. This influences not just the engagement with LeDeR but the drive to improve services.

4.4 A service improvement project looking to improve cardiovascular disease prevention and management has had a poster submitted to a national health inequalities conference. Two submissions have been made for Health Service Journal awards.

5.0 The inclusion of autistic people in LeDeR in Sussex

5.1 Information has been provided to autistic people and system partners to ensure notifications are made to LeDeR when an autistic person dies.

5.2 The broad findings of completed reviews have been discussed at Autism Partnership boards and our specialist mental health trust is engaged at senior level in the development of service improvements.

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

5.4 Sussex has received 11 notifications for the deaths of an autistic person in this reporting period. Only three reviews have been completed due the high number of statutory processes underway which require LeDeR to go 'on hold'. In line with national guidance LeDeR is placed on hold for reasons explored in the performance section of this report.

5.5 Details of these three reviews will not be included in this report due to the risk of identifiable information. This does not preclude service improvement work in suicide prevention due to already known causes of death.

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 24 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.

6.0 Performance

6.1 Sussex works hard to achieve the LeDeR key performance indicators (KPIs) set by NHSE.

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

6.2 Sussex has set an internal target for completion of reviews within four months of notification to ensure any delays in completion or panel sign off for focused reviews is mitigated.

6.3 All notifications where a statutory process is undertaken are placed on hold until it is it concluded. After this LeDeR will be completed within two months where possible.

In Sussex we have a high number of reviews on hold and whilst not a KPI these are regularly reviewed in order that all holds are appropriate.

6.4 Sussex LeDeR are involved with one safeguarding adults review (SAR) that is in progress. This is being undertaken by another area due to the person moving just before they died but there is NHS Sussex representation on the SAR panel.

6.5 LeDeR collects data on high level themes which can be segmented by provider. These themes are taken from the LeDeR focused reviews, but initial review themes are captured in the same way.

6.6 Performance data is reported to the ICB senior leadership team on a weekly basis. Outcomes and service improvements are also reported. A project management slide is reported monthly for inclusion in the ICS Learning disability, mental health, and autism board. On a quarterly basis LeDeR reports to Sussex system, Quality, governance and improvement group (QGIG) and to the Integrated Assurance Group and Patient Experience Committee.

6.7 This annual report is produced, which is presented at executive board level in the ICB and joint committees across Sussex. The 3 Sussex Health and Wellbeing Boards and Safeguarding Adult Boards also receive the report for discussion and an agreed version including in accessible formats is published on the NHS Sussex website.

6.8 The information contained in this report is then used to develop a briefing which is shared across the system including an accessible version.

6.9 This case study illustrates how LeDeR drives change through performance.

Tapan	Background	Thematic Learning	LeDeR Review Learning	Service Improvement
Tapan lived in Sussex all his life with his mum who was his main carer. Tapan was an Asian British man who was Hindu and loved his family, food and Jacuzzis. Tapan had profound and multiple learning disabilities, Cerebral Palsy, Epilepsy, Dysphagia needs and a history of Sepsis and Pneumonias.	A lot of Tapan's health oversight came from his GP, community nursing and learning disability specialisms. Tapan also had long hospital admissions in the last 5 years of his life. Tapan was 53 years old when he died in hospital of multi-organ failure and community acquired pneumonia.	LeDeR has learned that using frailty care pathways for people with profound and multiple learning disabilities can be beneficial to their care planning. This isn't always identified in primary care due to frailty being associated with age rather than multi-morbidities.	Tapan's LeDeR Review identified some very good health practice as well as recognising that a frailty assessment might have resulted in earlier interventions for Vitamin D deficiencies, family carer signposting and use of the gold standards framework for advance care planning.	As a result of the LeDeR process the GP surgery for Tapan reflected on the use of templates and frailty assessments for patients with a learning disability especially when doing home visits for people who live with family carers and improvements in documentation for annual health checks and multi-morbidities.

6.10 Benchmarking

Comparative performance ICB data is now available via the NHSE LeDeR internal reporting dashboard.

- Sussex ICB completed 100% of eligible reviews compared with 95% nationally.
- Sussex is in the top 10 ICBs for completion of all reviews in 6 months.
- Sussex undertakes 35% of reviews as focused compared to 32% nationally.

The national LeDeR report was published in November 2023. Sussex had the same median age of death of 61as reported in the national report.

The median age of death had increased from 61 to 65 in Sussex.

In this reporting year 41 or 31% of notifications received were for people who lived until 65-79 compared to 22 or 19% last year.

A person's story.

Ruth was our longest living person with a learning disability in Sussex. Ruth spent a lot of her life in a long stay hospital, she then lived at a care home for over two decades and died in 2023 at the incredible age of 98 years old. Ruth's carers were like her family, they told us how mischievous she was, that her favourite thing was fish and chips and that she was loved. Ruth died at home with the people who cared for her by her side. Her life is remembered and celebrated by us all.

7.0 Equality

7.1 Equality Impact

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

7.2 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.

7.3 Age

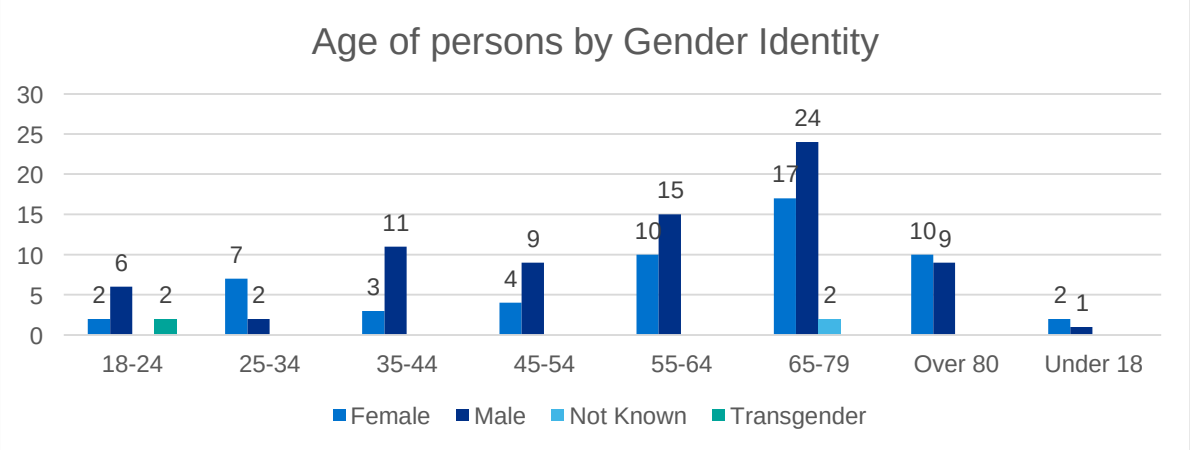
138 deaths were notified to LeDeR during the reporting period.

- The range of age of death was 18-98.
- The median age of death was 65.

7.4 Gender

- 55 females died in the reporting period.
- 77 males died in the reporting period.
- 2 people who died identified as transgender.

The following illustrates the age range by gender for the reporting period.



	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White	White & Black	White & Black	White & Asian	Any other mixed	Indian	Pakistani	Bangladesh i	Any other Asian	Caribbean	African	Any other Black	Chinese	Any other ethnic	Not stated
No. of reported deaths	131	0	0	0	1	0	0	0	1	1	1	0	0	1	0	0	1	1
% of all reported deaths	94	0	0	0	0.72	0	0	0	0.72	0.72	0.72	0	0	0.72	0	0	0.7	0.72
Ethnicity% of local populace	89	1	0.1	4	0.3	0.3	0.5	0.5	0.8	0.3	0.3	0.7	0.2	0.5	0.1	0.4	0.3	

7.5 Ethnicity

LeDeR in Sussex is committed to developing a better understanding of the intersectional needs of our minority ethnic communities. The table above details the ethnicity of notifications received into Sussex for this period.

Whilst improved reporting is still required for those who have a learning disability or who are autistic this year demonstrates improvement in receiving notifications from the Asian community in Sussex.

In July 2023 the NHS Race and Health Observatory published their report into the health inequalities experienced by those with a learning disability from a minority ethnic community. This found that the life expectancy of this group was 34.This will be addressed in our priorities.

7.6 Cause of death

In 2023/24 pneumonia was the most common cause of death in those with a learning disability. This is in line with national trends. This year's interpretation into the cause has included the influencing factors of the whole medical certification into the cause of death (MCCD).

This is due to the consideration that a death is not avoidable when it is known that a person is in the last year of their life due to their frailty which is included in the MCCD.

Top five causes of death of people with a learning disability in Sussex	
Diseases of the respiratory system	18
Frailty	15

Diseases of the circulatory system	14
Cancer	11
Sepsis	10

The inclusion of frailty as the second most common cause of death is important when considering whether a death is considered avoidable. LeDeR defines avoidable deaths as determined by the Organisation for Economic Co-operation and Development (OECD).

The other top four causes of death have remined in the top five since LeDeR began reporting in Sussex in 2019. LeDeR also collects data on the long-term conditions a person has and below is taken from the LeDeR power BI data tool.

7.7 Recommendations made in completed reviews

Sussex recognises the importance of learning and making improvements based on the findings of reviews.

Learning and actions in initial reviews are also themed using the same grouping. This grouping is included in table 2 below. This enables aggregated themes to be collected from both initial and focused reviews. Initial reviews are in depth reviews, but which allow for two areas of learning and action. They are signed off by a LeDeR local area contact. Focused reviews required more details about a person's health and social care, for example treatment and outcomes of specific health conditions, and actions are agreed by a panel of senior decision makers and experts by experience.

Focused reviews are undertaken for all autistic people, all from an ethnic minority, where a family member requests one, where a reviewer feels there is need and when a local priority is met.

The following were the local priorities in Sussex for 2023-24.

- Where a person is placed into Sussex by an out of area funding authority.
- Where epilepsy is associated with the cause of death.
- Where there are concerns that have met the threshold for a safeguarding enquiry.

Here is the break down for the reasons focused reviews were undertaken(1).

TABLE 1

The person was from an ethnic minority community	8
The person was autistic	3
Epilepsy was associated with the cause of death	2

The reviewer felt further review was warranted.	7
The person was placed into Sussex from another area	8
The person had experienced care that required a safeguarding enquiry	11

The LeDeR platform groups actions by themes and the following is the analysis of grouping of action by theme (2).

TABLE 2

Theme	Learning	Positive practice
Learning disability awareness	9	0
DNACPR decisions and end of life care	8	4
Deterioration	3	0
Care pathways	21	2
Involving the coroner	0	0
Family and care awareness of available support	8	
Transition	2	0
Safeguarding	13	1
Training on specific conditions	14	0
Professional practice and provision of care.	63	30

7.8 Examples of learning and positive practice from reviews

Theme	Positive practice
Safeguarding	Good application of MCA to promote rights
Professional practice and the provision of care	Good application of frailty and the provision of accessible information
	Duty desk providing a high level of flexible support
	Good multi-disciplinary working in the community.
	Highly person-centred care and health advocacy and literacy from the care provider
	Improved outcomes due to good learning disability liaison support.
	Supportive and responsive care by the GP
	Specialists going above and beyond.
DNACPR and end of life care	Flexibility by the care provider to enable a person to die at home.
	Early identification of end-of-life care needs and co-ordination.
	Person centred visiting policies.

	Flexibility to enable end of life medications to be given by a familiar carer.
Care pathways	Person centred discharge planning.
	Acute liaison nurses enabling coordinated care on discharge.
Learning disability awareness	Good use of easy read material.

Theme	Learning
DNACPR recommendations and end of life care	Poor exploration of advocacy
	Lack of involvement of the person or their representative.
Safeguarding	Inadequate safety alarms
	Lack of formal advocacy requirements when needed.
Learning disability awareness	Screening not undertaken due to a lack of reasonable adjustments.
	Not being flagged on the GP learning disability register
	Annual health checks not being undertaken when living in an older person's care setting.
Deterioration	Lack of swallowing assessment in hospital
Family and carer awareness of available support.	Lack of bereavement support.
	Lack of available respite.
	Lack of carers assessment
Training on specific conditions	Poor understating of the risks of constipation
	Historical use of seizure prevention medication not reviewed.
	Poor understanding and recognition of frailty
	Lack of neurology support to enable de prescribing
	A lack of autism affirmative care.
Care pathways	Lack of specialist referrals

	Vaccines not administered as required
	Lack of community nursing
	Poor application of NICE weight management guidance
	Key worker scheme being too narrow.
	Lack of referral to prevention services, particularly weight loss and tobacco dependency
	Women with a learning disability not receiving mammograms.
	Health action planning not addressing a lack of screening.
Transition	No handover from out of area funding authority
	Poor transition to adult services.
Professional practice and the provision of care	Prescribing contrary to the principles of STOMP
	Lack of co-ordination and care planning from specialist (neurology) services
	Lack of social care review and poor monitoring of out of area placements.
	Timely completion of structured judgement reviews
	Seizure prevention prescribing contrary to NICE guidance.
	A lack of recognition of family/carer expertise
	Screening not undertaken as required

8 Action from learning

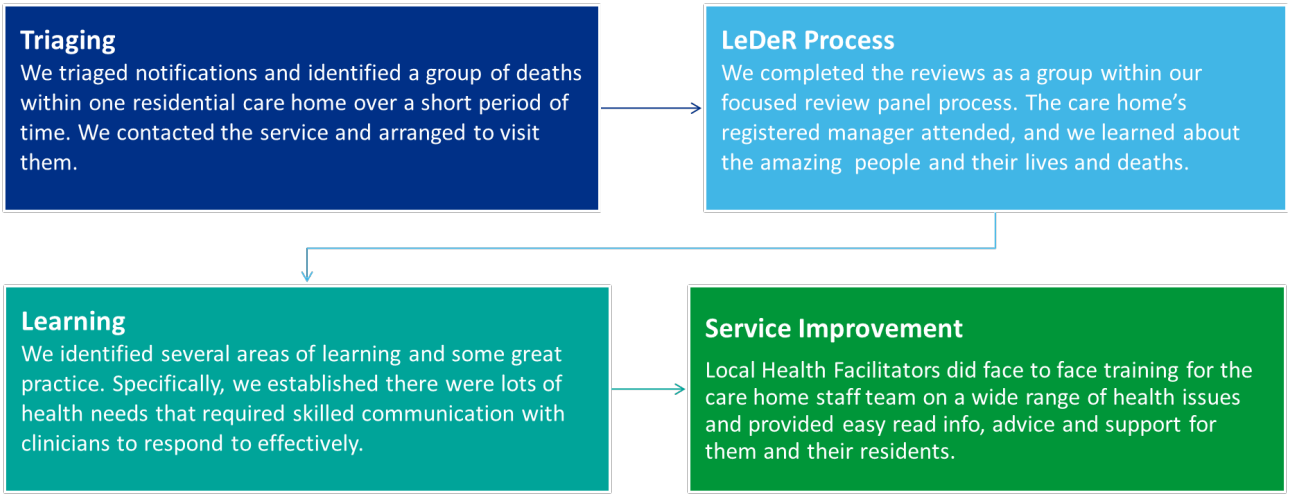
8.1 What we have learned:

Best practice and positive outcomes we have learned from reviews.	
	More people are living for longer in Sussex.
	That single points of contact enable person centred and co-ordinated end of life care.
	That care providers feel well supported by their GP when there is regular “ward round” contact.
	That care providers support people when they are in hospital despite not being paid to do so.
	That agencies work together when there are high risks

	associated with the person's behaviour.
	That learning disability liaison nursing improves the outcome when a person is in hospital.
	Identifying that a person is living with frailty supports collaborative advance care planning.
	That identifying when a younger person with profound disabilities and multiple health conditions is living with frailty supports early discussions about advanced care planning.
	Structured medication reviews by a primary care pharmacist being undertaken as part of an annual health check adopt the principles of STOMP and initiate deprescribing.
	That hospices are crucial in supporting care services with limited experience in palliative and end of life care, to enable a person to die at home.
	That a provider is employing a learning disability nurse to support the needs of the people with profound and multiple learning disabilities based on learning from LeDeR
The areas for improvement that were identified in recommendations from reviews.	
	That reasonable adjustments are not universally available.
	That people remain on medications that are not always reviewed under the principles of STOMP (stop the over medication of people with a learning disability).
	That medical certification and cause of death (MCCD) still, if occasionally, uses protected characteristics in part 1 without explaining how these contributed to the person's cause of death.
	That the language of frailty in those who are younger but have multiple morbidities resulting in multiple admissions to hospital is not used and advanced care planning is not undertaken.
	That people with a learning disability who have non-diabetic hyperglycaemia (previously pre-diabetes), or type 2 diabetes do not receive structured education due to their learning disability.
	That annual health checks for those with a learning disability who have a body mass index of over 30 (obese range) do not result in structured weight loss support.
	That capacity is not formally assessed when the decision

	a person is making places them at risk of self-neglect.
	That women with a learning disability have died of breast cancer when they are of screening age and where screening has not been undertaken.
	That the additional needs of an autistic person such as their sensory needs and processing needs are not well understood in services that are supporting them.

Below is an example of how LeDeR supported a care home to make service improvements when a number of people they supported died over a short period of time. LeDeR received feedback that the home felt supported by this.



8.2 Impact

Increasing the impact of completed reviews in Sussex is a large part of the work undertaken by the LeDeR team and it works hard to drive the service improvements made because of reviews.

A LeDeR briefing was produced after last year's annual report and then revised when the national report was published. It includes the findings of the annual report and details of all the service improvement work undertaken as a result.

An easy read version of the briefing is also produced. This is sharded with learning Disability Partnership Boards and self-advocacy groups in Sussex.

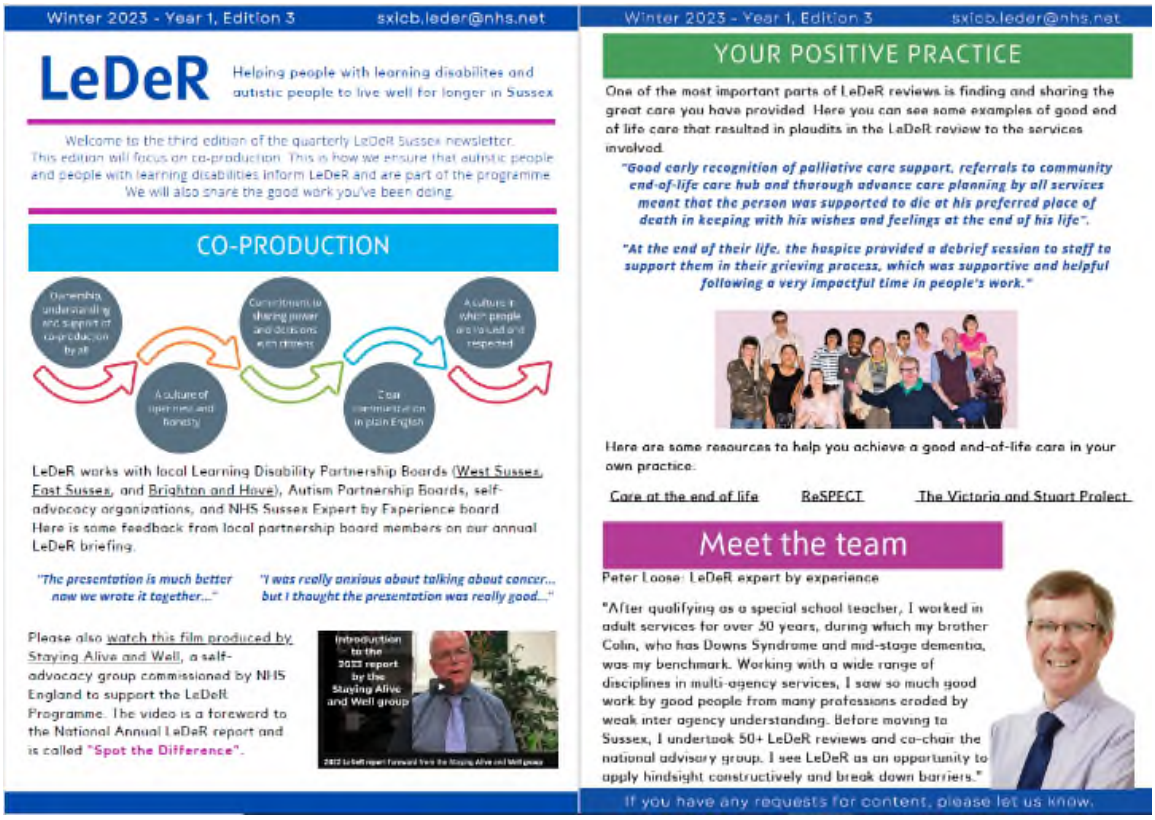
The briefing has been presented at strategic and operational forums including.

- NHS Sussex staff webinar.
- Chief nursing directorate meetings.

- NHS Trust mortality meetings.
- The safeguarding adults' boards in Sussex.
- All age continuing care meetings.
- Learning disability partnership boards.
- Autism partnership boards.
- Local authority social work teams.
- Local authority forums in Sussex.
- Shared lives teams.
- Parent carer forums.

LeDeR produces a quarterly newsletter. This is public facing newsletter and is widely circulated and well received. An example of the newsletter is below, and the following feedback was received from strategic health facilitator

"*Amazing – your introduction in the LeDeR newsletter is fantastic – I love the fact that you are flying the flag for neuro diversity."*



Winter 2023 - Year 1, Edition 3 sxicb.leder@nhs.net

LeDeR

Helping people with learning disabilities and autistic people to live well for longer in Sussex

Welcome to the third edition of the quarterly LeDeR Sussex newsletter. This edition will focus on co-production. This is how we ensure that autistic people and people with learning disabilities inform LeDeR and are part of the programme. We will also share the good work you've been doing.

CO-PRODUCTION

LeDeR works with local Learning Disability Partnership Boards (West Sussex, East Sussex, and Brighton and Hove), Autism Partnership Boards, self-advocacy organizations, and NHS Sussex Expert by Experience board. Here is some feedback from local partnership board members on our annual LeDeR briefing.

"The presentation is much better now we wrote it together..."

"I was really anxious about talking about cancer... but I thought the presentation was really good..."

Please also watch this film produced by Staying Alive and Well, a self-advocacy group commissioned by NHS England to support the LeDeR Programme. The video is a foreword to the National Annual LeDeR report and is called "Spot the Difference".

Introduction to the 2023 report by the Staying Alive and Well group

Winter 2023 - Year 1, Edition 3 sxicb.leder@nhs.net

YOUR POSITIVE PRACTICE

One of the most important parts of LeDeR reviews is finding and sharing the great care you have provided. Here you can see some examples of good end of life care that resulted in plaudits in the LeDeR review to the services involved.

"Good early recognition of palliative care support, referrals to community end-of-life care hub and thorough advance care planning by all services meant that the person was supported to die at his preferred place of death in keeping with his wishes and feelings at the end of his life".

"At the end of their life, the hospice provided a debrief session to staff to support them in their grieving process, which was supportive and helpful following a very impactful time in people's work."

Here are some resources to help you achieve a good end-of-life care in your own practice:

Care at the end of life ReSPECT The Victoria and Stuart Project

Meet the team

Peter Loose: LeDeR expert by experience

"After qualifying as a special school teacher, I worked in adult services for over 30 years, during which my brother Colin, who has Downs Syndrome and mid-stage dementia, was my benchmark. Working with a wide range of disciplines in multi-agency services, I saw so much good work by good people from many professions eroded by weak inter agency understanding. Before moving to Sussex, I undertook 50+ LeDeR reviews and co-chair the national advisory group. I see LeDeR as an opportunity to apply hindsight constructively and break down barriers."

If you have any requests for content, please let us know.

LeDeR has strong links with both local and national providers. One provider is employing a learning disability nurse to support their services for those with profound and multiple learning disabilities based on learning from LeDeR. Below is

an example of how a LeDeR review supported change.

A person's story

Rashid
Rashid was of Black African descent and a non-practicing Muslim; he moved to residential care under a care order just before his 18th birthday. Rashid loved being read stories, watching action films and listening to pop music. Rashid was not a fan of Elvis and whenever Elvis was on, Rashid would take himself to his room and play The Carpenters instead. Rashid was described as a cheeky monkey, he loved nothing more than pulling over chairs, turning on taps and watching and giggling as people tidied up his mess, he had a collection of stuffed toys which were all monkeys, and he would choose one to sleep with every night. Rashid had diagnosis of Spastic Quadriplegia Cerebral Palsy, Scoliosis and Microcephaly, he had some mild hearing loss and refractory Epilepsy. Rashid was described as having signs of a temperature and cold then some pain before appearing to have a sudden deterioration in his health requiring hospital admission. Rashid required acute treatment but sadly this wasn't effective, and Rashid passed away on the ward at the age of 35 of Sepsis. Rashid had lived at his care service for over 20 years, he was estranged from his family at the time of his death and his friends at his home had a memorial and remember and miss Rashid.
Learning and Actions
Rashid's review was presented at focused review panel where some of the learning identified, and actions agreed were: Rashid died of Sepsis which continues to be not well recognised in some settings and remains a leading cause of death for people with learning disabilities. As a team we provided comms and resources to providers in community services via provider forums and our newsletter to improve Sepsis awareness. Rashid had lots of conditions known as multi-morbidities resulting in high risk of early and preventable death and he died at a very young age. The service supporting Rashid implemented the use of a Decision Support Tool for Physical Health. This is a risk stratification tool that can help identify underlying health needs that contribute to poor health outcomes. It aims to reduce the need for acute hospital admissions and focus on interventions to improve health outcomes.

Rashid had lived at a full-time care service for over 20 years and was estranged from his family at the time of his death. His early history and family background was quite poorly known but very impactful on his care needs.

We did a life story presentation with the local provider forum, service and the organisation's manager conference. We shared the learning and resources for them to take forward to other care services across the country.

8.3 The Sussex NHS Learning Disability and Autism Health Inequalities Project Board

This integrated care system board was established to drive the service improvements identified as a result of LeDeR.

The board is co-chaired by NHS Sussex and the Clinical Director from Sussex Partnership NHS Trust who delivers specialist learning disabilities and neurodevelopmental services in Sussex. It has membership of self-advocacy organisations, parent carer groups, primary care, and other NHS workstreams such as cancer screening, diabetes and social prescribing.

Clinical priorities for the group are set by the thematic analysis of LeDeR and this year has seen a focus on respiratory health as well as the completion on a project supporting better heart health.

Based on local and national LeDeR priorities work groups for the LDA HI Project Board are focused on the following clinical areas:

- Respiratory.
- Immunisation and vaccinations.
- Cardiovascular disease.
- Hearing and sight checks in residential special schools.
- Bowels/constipation.
- Diabetes – flash glucose monitoring.
- Epilepsy awareness.
- Cancer and cancer screening.

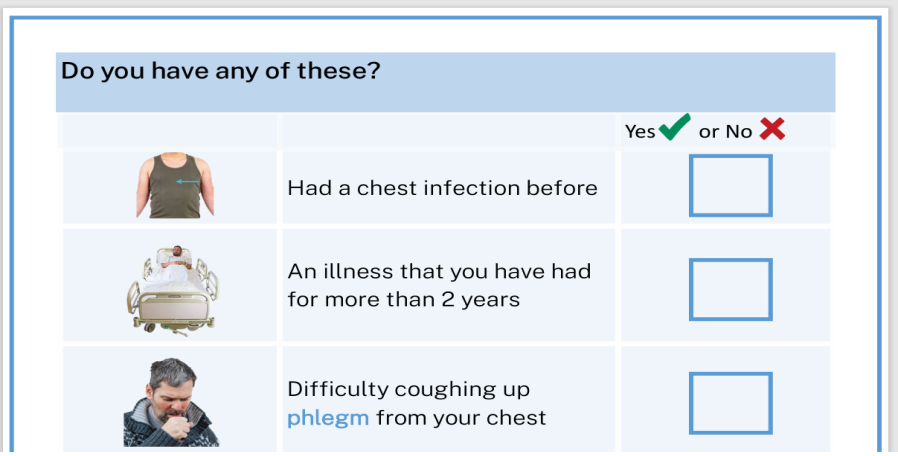
Members of this group have also worked with the NHS Sussex digital comms team to make the Sussex Health and Care website more accessible.

9 Learning into action

9.1 Respiratory

A Sussex wide project was undertaken and presented at a NHS Sussex ‘reducing health inequalities in infection prevention and control’ conference.

This project has been sustained by making all the resources developed and training delivered on the Sussex Health and Care website. This also includes a co-produced easy read checklist for preventing pneumonia.



Sussex Partnership NHS Foundation Trust continue to support people referred with linked dysphagia and respiratory care pathways. Since their Sussex-wide project and increased engagement with respiratory services, we are making more onward referrals and carrying out joint clinical appointments with specialist physio and respiratory consultants to reduce and optimise community acquired pneumonia risk factors.

Specialist speech and language therapy and physio have looked in more detail at the evidence around saliva and reflux management in order that their pathways reflect evidence and national guidance.

The Trust has also established a Positive Expiratory Pressure clinic for those who have difficulty clearing sputum (phlegm) from their lungs. With improved governance those needing this support will be overseen by specialist physiotherapists.

9.2 Sepsis

Work has been undertaken across NHS Sussex to identify opportunities for

improvement in the current Sepsis pathways in Sussex specifically

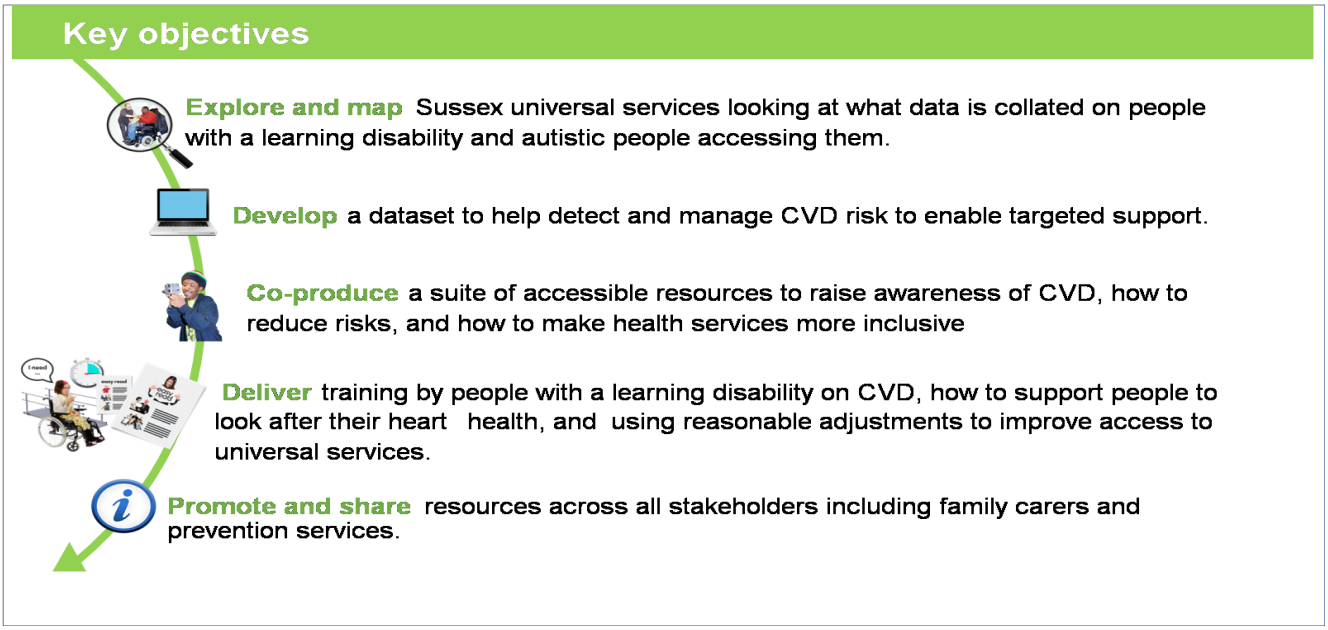
- General compliance within providers
- Training re sepsis, to ensure alignment to roles and responsibilities
- Review any unwarranted harm in the Sussex pathway due to gaps/challenges

Learning from LeDeR was included in this work and supported the survey of those supporting people with a learning disability and autistic people.

Themes identified include:

- More awareness needed in the general population, including public health and the social care workforce
- Pathways are not always effective.
- That there are no untoward or unusual sources of infection, however there are challenges in prescribing when infections may be more long term.

9.3 Cardiovascular disease prevention and management



Sussex has produced a comprehensive suite of accessible resources for carers to use to support CVD prevention and management for people with a learning disability and/or autism.

- Two films for people with a learning disability
  - How to look after your heart
  - Getting your blood pressure checked.

- Two films for carers and health professionals
  - Making health choices together- the role of carers and families.
  - Supporting people with a learning disability – making reasonable adjustments to ensure universal services are inclusive.

Resources were used as part of training packages for carers in each Sussex locality. The training was delivered by two trainers with a learning disability. The training sessions were attended in total by 58 webinar participants, and 20 face-face participants. 40 surveys were completed across these sessions.

resources provided will be very useful for me to share with team and people I work with'

the presenters were outstanding. really well done

listening to the trainers' experiences was useful, also finding out more about AHC challenges

tips about how to make our service more relevant and accessible for clients with LD or autism - was the most useful

The films were launched at a public event in a local cinema where they were followed by a panel questions and answers session with those who wrote, made, and acted in the films and delivered training.

9.4 Reducing risks associated with constipation.

The focus this year has been to ensure the sustainability of work undertaken last

year. This includes:

- Inclusion of the webinar on the Sussex Platform for Education, Careers and Skills (SPECS).
- Inclusion of the webinar and blurb in the LeDeR newsletter.
- A slide on the webinar and link to the Poo Busters film in all briefings.
- Promotion of the work at provider forums.

9.5 Cancer and cancer screening

The suite of developed resources explaining cancer screening for people with a learning disability is available under the “Help to prevent cancer” tab of our website. These were runners up for an award from the Patient Experience Network National Awards (PENNA) in the “Cancer experience of care” award.

Two subsequent films have been made to support this work. One shorter film explaining the importance of understanding how to apply the Mental Capacity Act to protect rights and another which details the undertaking of a capacity assessment and best interest decision making where a colonoscopy is needed due to a positive faecal occult test for possible bowel cancer.

The pan Sussex health facilitation teams are collaborating to update guidance for primary care in how to improve access to all screening for people with a learning disability including proactively advising about reasonable adjustments, good application of the Mental Capacity Act and following up non-attendance in annual health checks.

9.6 Improving tobacco dependency treatment for those with a learning disability and autistic people in Sussex.

Smoking is a leading risk factor for the development of cardiovascular disease, respiratory disease and cancer. Smoking significantly raises the risk of developing type 2 diabetes, eye disease and dementia. It leads to decreased bone mineral density and is associated with increased risk of osteoporosis, bone fractures, back pain and degenerative disc disease. Secondary conditions such as type 2 diabetes, are highly prevalent among adults with learning disabilities. Smoking harms nearly every organ in the body.

Personalised reasonable adjustments are crucial tools to support people to access mainstream services and reduce health inequalities. These should be available across all smoking cessation services in Sussex. Nationally and locally resources to facilitate reasonably adjusted smoking cessation have not been identified.

Sussex is therefore undertaking a project to meet the following objectives utilising and existing service provided by Sussex Partnership NHS Foundation Trust.

This project has an established steering group with public health membership of all three local authorities in Sussex and a project plan working to agreed time frames.

9.7 Advance, anticipatory and end of life care planning.

Specialist learning disability services in Sussex have all received bespoke training in the importance of initiating ReSPECT when a person has multiple health conditions that cannot be cured. This includes when treatment is indicated but where a review is required if they experience repeat episodes of illness and are becoming more unwell over time.

Understanding frailty and how to plan for the person's last year of life has been included in the community learning disability team's physical health care suite of training.

LeDeR continues to provide data and stories into the pan Sussex Palliative and End of Life Oversight Group. Here are two stories that demonstrate the benefit of a single point of contact when a person is entering the last phase of their life. This is something that the group is work on as this is not currently pan Sussex.

Some stories.

Jim	Jim's LeDeR Review Learning	Ronald	Ronald's LeDeR Review Learning	Thematic Learning and Service Improvement
Jim lived in Sussex all his life, he had jobs in civil service, supported the Albion and always had a cup of tea with his daily newspaper. He had a mild learning disability with cerebral palsy and a long history of cardiovascular disease. He moved to a care home in his late 60s up to his death from Frailty, Old Age and Cerebral Palsy at 76 years old.	Jim was referred to ECHO. His advanced care plan wishes were for symptom management so he was comfortable and could remain at home to die. In his last few weeks, he got up every day, the hospice nurses administered medications as needed and Jim passed away peacefully in his sleep with his carers.	Ronald had lived independently until he was 70. His favourite hobby was to smoke outside and provide a commentary on his surroundings to anyone who would listen. He had a mild learning disability with long term respiratory issues, kidney disease, cardiovascular issues and Type 2 Diabetes before dying of community acquired pneumonia, influenza and COPD at the age of 73.	Ronald was known to have a moderate level of frailty; he had developed some dysphagia needs and experienced a fall before presenting with a chest infection in the week before his death. He was admitted to hospital with no advance care plan and no DNACPR in place. He died alone on the ward in the hospital and had a 'non-attended' funeral.	People with access to ECHO in the Coastal area of West Sussex typically have better outcomes at the end of their life than others in Sussex. LeDeR has provided regular evidence to the Palliative Care and End of Life Care (PCEoLC) Programme oversight group. NHS Sussex ICB have signed off a proposal to utilise Macmillan Social Finance to develop a Pan-Sussex 24/7 PCEoLC coordination service.

9.8 Identifying a deteriorating patient – Restore 2, Restore 2 mini and Stop Look Care

Learning disability services are experts in advocating for the right to inclusive and meaningful lives. However, LeDeR reviews in Sussex identified that ill health was not escalated early enough due in part to a difficulty in having the right information to handover in a meaningful way to a health care professional.

Stop Look Care is a NICE recognised tool and handbook for care workers and carers, which is used to identify, prevent and respond to deterioration among older people in the health and care sector.

Training in using Stop Look Care in a learning disability care setting has been provided by NHS Sussex since 2021. This training is adapted to be inclusive of the variety of settings that a person with learning disability may live in and with different models of support. It contains case studies based on LeDeR and outside of the usual residential care setting. It also includes a basic set of observations (Restore 2 mini) and the SBARD handover tool.

It is now delivered online and quarterly by health facilitation teams supported by LeDeR team members across Sussex. 218 people received this training over the year which is an increase of 116 from the year before.

A Learning Disability and Autism version of the Stop Look Care booklet has been co-produced. This includes additional guidance on epilepsy care, postural and respiratory management, the prevention of chest infections, and STOMP as identified by LeDeR. It also contains a “staying well for longer” section with details of annual health checks, the reasonable adjustment digital flag and care passports.

The following are quotes from people who have attended this training.

9.9 Annual Health Checks

LeDeR reviews examine the undertaking of AHCs and their output and is a member of the Sussex AHC steering group which is responsible for their delivery.

Sussex achieved its target of 75.

				M12 - 23-24 Target	
	Checks M12 YTD	Register	Performance	YTD	Performance
Brighton and Hove	1,195	1,695	70.5%	1,204	75%
East Sussex	2,744	3,498	78.4%	2,534	75%
West Sussex	3,926	5,131	76.5%	3,713	75%
Sussex	7,865	10,324	76.2%	7,451	75%

Sussex has a large number of people with a learning disability who are not on their GPs learning disability register and the steering group is working to improve this.

Sussex supports GPs to work towards a quality kite mark called the Thumbs Up. Five practices have now been awarded the quality kite mark award and here is a link to a short film about a surgery winning a gold award.

Easy read appointment summary and medication information sheets have been distributed to all practices and all clinical content relating to AHCs and learning disability and autism has been updated on the ICB website.

The Involvement Matters Team have developed and shared a presentation on the barriers experienced in accessing primary care and this continues to be presented in training to primary care.

'Was not brought' guidance has been developed to ensure that safeguarding is considered when a person misses an appointment and is in receipt of support.

10 How did we do? Achievements against Local priorities for delivery in 2022-23

"Working with public health and well-being services to improve access to services"

- We trained 74 health care professionals working in NHS and local authority prevention services including third sector providers.
- Public health are members of the tobacco dependency project steering group.

- We are working with public health colleagues who lead on suicide prevention strategies based on learning we have identified and suicide being the most common cause of death if you live in Sussex and are an autistic person.

Continue the delivery of ‘Stop Look Care’ training to social care to ensure the tool becomes embedded and development of a version of the booklet based on the learning from LeDeR.

- We have increased the number of people being trained in Stop Look Care by 314 in this reporting year.
- A co-produced booklet is going through the final preparations to print.
- We have several providers who would like to test the use of the booklet so that we can evaluate its benefit.

Sussex will continue to look to develop innovative ways of delivering Annual Health Checks for autistic people. Including the co-production of these health checks via the Sussex experts by experience board and Autism partnership boards.

- We have met with Autism partnership boards and heard that they are keen to have annual health checks.
- We have provided information about the reasonable adjustment digital flag, and its benefit for autistic people.
- We will continue to gather more information the health inequalities autistic people experience to drive improvements.

Sussex will continue to provide training and support to health and social care partners to ensure reasonable adjustments are understood and implemented in order to improve access to universal services such as screening.

- We have supported the development of the campaign to launch the reasonable adjustment digital flag formally in Sussex.
- We have commissioned training delivered by people with a learning disability in why reasonable adjusted are needed and how NHS services can better meet their duties under the Equalities Act.
- 74 people have received this training, and recordings are available to ensure a training legacy.
- We have met jointly with health facilitation colleagues to speak to Sussex mammographers to help them understand how to overcome the barriers woman with a learning disability experience when called for their mammogram.

Building on the British Thoracic society guidance and training provided, clinical pathways have been developed across Sussex for people with learning disabilities who have respiratory needs requiring specialist care.

Sussex continues to increase the rates of Annual Health Checks for people with learning disabilities, and the 'Thumb's Up' campaign supports the focus on quality check with an additional focus on the health action plan produced.

- We have doubled the number of surgeries that have achieved the Thumbs Up award from three to six.
- We have produced guidance on what a good health check should look like and what is generated in the health action plan.
- We have worked with providers to ensure that they understand every AHC must result in an outcome.

Continued work with the population health management and personalisation team at NHS Sussex to enable a focus on reasonable adjustments to reduce health inequalities.

- We have presented project closure reports to prevention boards.
- We have maintained relationships with those still working in the this are but where there have been significant organisational changes.

11 Our priorities for 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 reduce the barriers to mammography for woman who have a learning disability or are autistic.

LeDeR continues to identify a gap 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.

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 ICB colleagues of the barriers identified in reviews.

LeDeR will work with stakeholders to increase the use of continuous glucose monitoring and in line with guidance.

Sepsis continues to result in too 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 will build on relationships formed to formalise work to improve the treatment of epilepsy in peoples with a learning disability and autistic people. This includes the promotion of the Clive Treacy check list and working with commissioning colleagues in the ICB.

LeDeR will undertake a deep dive into deaths where frailty is included in the MCCD to ensure that its application is appropriate.

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.

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

12 Conclusion

LeDeR is proud of the role in plays in driving service improvement in how people with a learning disability and autistic people receive personalised health care. But it acknowledges that too many reviews find learning that it is not new, and people continue to be unable to live well for as long as possible.

The life expectancy of a person with a learning disability from a minority ethnic community is simply not acceptable and we continue to better understand these intersectional needs.

LeDeR continues to value the story of incredible people including brave families and carers who share often very sad stories. We are grateful to use these to influence how services operate and how strategy is developed.

Most of all it is the meaningful involvement of people with learning disabilities, autistic people, and their families/carers in service improvement continues to develop and strengthen. We are particularly grateful to our colleagues with a learning disability and our autistic colleagues for their help in making real change.

LeDeR in Sussex is also able to demonstrate the benefit of committing resource and adopting a truly integrated care system approach to addressing inequalities and it is nice to see that this has been nationally recognised.