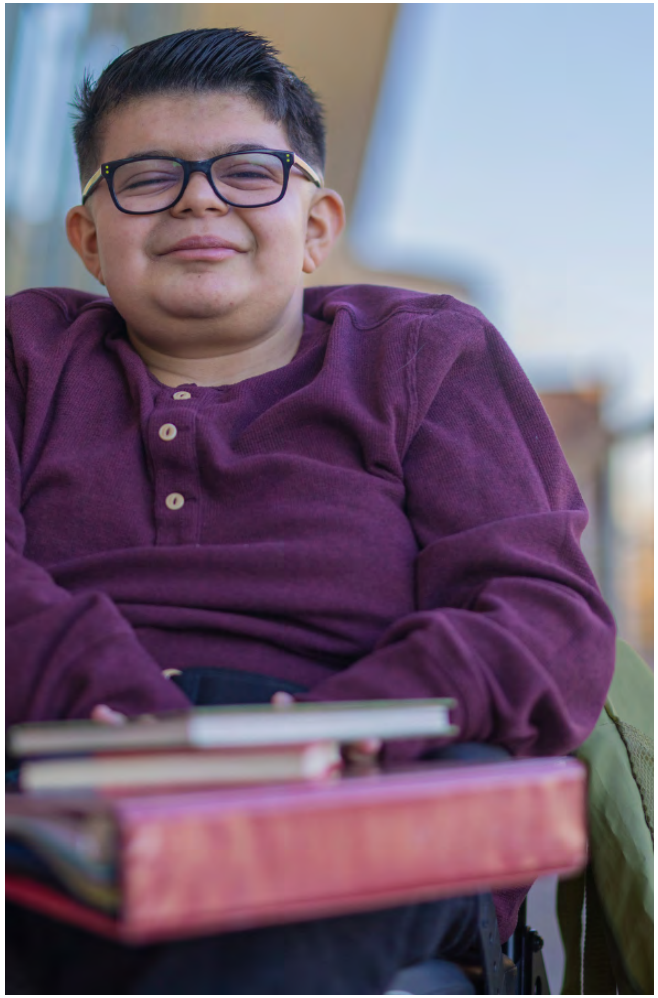
NHS Sussex

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

NHS Sussex: Annual Report 2022-23

Improving Lives Together

Contents



1 Executive summary

1.1 The Sussex learning from the lives and deaths of people with a learning disability programme (LeDeR) wishes to thank families, services and professionals across Sussex for their continued support and involvement.

1.2 This is the fourth 'LeDeR Annual Report' for Sussex. All previous reports are available on our **website**.

1.3 The LeDeR programme receives notifications for all deaths of people with a diagnosis of a learning disability and/or autism over the age of four. A review is completed which looks at each person's life and death to identify good practice and areas for improvement. This is then shared with relevant stakeholders to ensure that this learning is used to improve the services available for people with learning disabilities and their families.

1.4 This report details the progress of the LeDeR programme in Sussex between 1st April 2022 and 31st March 2023. During this reporting period, 111 notifications of death were received. People with a learning disability and/or autistic people die on average up to 27 years earlier than the general population.

1.5 Respiratory conditions are the most common cause of death in people with a learning disability and/or autism within the reporting period.

1.6 The thematic areas for improvement identified in this report are to address the variation in the application of the Mental Capacity Act for people with a learning disability and/or autistic people, and a lack of advanced care planning to support people dying in their place of choice.

1.7 Positive themes of practice identified within the report include carers going the extra mile to meet people's needs at the end of their lives, high levels of advocacy, regular and thorough reviews of needs in primary care, increased confidence in placements being maintained to manage increased personal needs, and good examples of coordinated care from acute hospital liaison services on discharge from hospital.

1.8 The 'learning into action' section of this report identifies the sustainable quality improvements that are needed to improve outcomes for people with a learning disability and/or autistic people. These actions reflect the findings of the 2022/23 annual report and also incorporate the learning and themes identified in previous LeDeR reports.

2 Introduction

2.1 The LeDeR programme set out a structured way to review the lives and deaths of people with a learning disability and/or autistic people. Sussex has a dedicated LeDeR review team who 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.

2.2 The total population of Sussex is approximately 1.8 million. Using the national learning disability prevalence rate (2.16%), an estimated 41,730 people with learning disabilities live within Sussex. The national autism prevalence rate (1%) would mean an estimated 7,200 autistic people living in Sussex, with an estimated 2800 also having a learning disability.

3 Acknowledgements

3.1 Considerable acknowledgement and thanks go to all those who provided information when requested, especially considering the pressures still felt in organisations. These include:

- Families
- GP surgeries
- NHS Trusts
- Local authority duty desks
- Home managers and their staff
- Governance group members

3.2 Further thanks go to the reviewers for their compassion when completing the reviews, and keeping the person at the centre of the process, to identify learning and share good practice. This compassion has been noted in feedback from families and partner organisations.

3.3 LeDeR is 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'. We thank these groups for helping us identify and articulate the service improvements required.

3.4 It is the people whose lives we were permitted to review that we thank the most; People who may have experienced care throughout much of their lives, families with loved ones who have died too early and whose premature deaths could have been avoided, people who throughout their lives have often faced adversity with courage. LeDeR in Sussex remains indebted to these extraordinary people.

4 Ensuring compliance with policy and best practice

4.1 The LeDeR programme in Sussex is fully compliant with national LeDeR policy.

4.2 A standard operating procedure (SOP) is in place to ensure that there are clear governance arrangements and agreed processes in place for all reviews, and to ensure they are completed within six months.

5 The inclusion of autistic people in LeDeR in Sussex

5.1 Further work has been undertaken this year to ensure that autistic people and their families, and organisations who work with and for them, are aware of the process for sending a notification into the Sussex LeDeR team. The LeDeR team has focused on developing the capacity, knowledge and skills required to ensure the reviews are completed to a high standard and in a timely manner.

5.2 Sussex received five notifications in relation to the death of an autistic person within this reporting year. These referrals came via hospitals, a community mental health trust, and a local authority. Under the current guidance, all notifications regarding an autistic person receive a focused review. At the time of writing, one review has been completed and four remain on hold pending statutory processes concluding.

6 Governance arrangements in the Sussex system

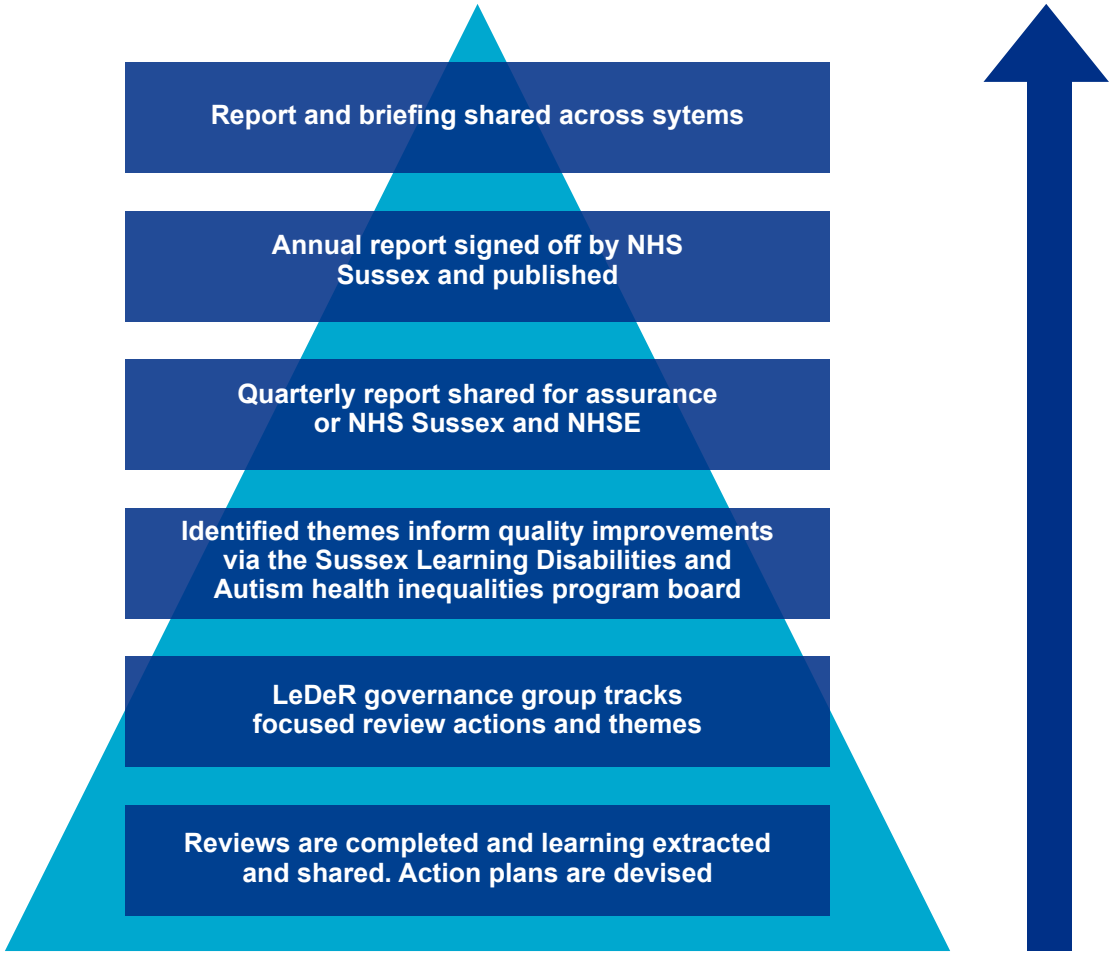
6.1 The Sussex LeDeR Governance Group was established in 2021 and is responsible for the governance and local implementation of the LeDeR programme.

6.2 There is ongoing commitment and consistent membership from partner organisations in Sussex including all three local authorities, NHS Sussex (safeguarding, quality and primary care teams), the NHSE regional team, Sussex Local Area Contacts (LACS), senior representatives within each NHS trust, and a Sussex-wide provider of residential and supported living services for people with learning disabilities.

6.3 The Governance Group also employs a lay member who is an expert by experience with considerable knowledge and expertise in the LeDeR programme.

6.4 The chart below describes the governance framework:

Chart 1: LeDeR Governance Process



6.5 The LeDeR policy describes a tiered system of review. For complex cases, and cases for autistic people without a learning disability, there are nationally and locally agreed criteria for undertaking a more detailed focused review.

6.6 Focused reviews are required by NHSE to be undertaken for all deaths of autistic people and all deaths of those from an ethnic minority background. Focused reviews in Sussex are undertaken for all deaths where: Families

- the person has both Down's syndrome and a diagnosis of dementia
- the person is funded by an out of area authority
- epilepsy is a contributing actor in cause of death
- the person has died from risks associated with long term constipation

6.7 Focused reviews are discussed at a panel with relevant stakeholders and experts who agree the actions to be taken from learning identified.

6.8 Reviews are shared with relevant stakeholders and followed up by reviewers for updates on progress against agreed actions.

6.9 The data from each notification and review allows the LeDeR team to identify thematic issues affecting people with a learning disability and/or autistic people. A quarterly report is produced on behalf of the Governance Group and circulated to the membership of the Sussex Learning Disability and Autism Board and Sussex Expert by Experience Shadow Board to provide oversight, support and challenge.

6.10 The LeDeR team reports quarterly into the Quality and Safeguarding Committee. This report is also shared with the NHSE South East Team.

6.11 An annual report is produced and presented at executive board level in the ICB and at various joint committees across Sussex. The three Sussex Health and Wellbeing Boards and Safeguarding Adult Boards receive the report for discussion, with the agreed version published online.

6.12 An accessible version of this report is shared with Learning Disability Boards in each local area and the NHS Sussex Shadow Learning Disability and Autism Board, which has a membership of service users and people with lived experience.

7 Performance

7.1 The national standard requires that all LeDeR reviews are completed within six months. In Sussex, a local target was agreed upon to ensure that all reviews were completed within four months of notification. 100% of reviews were completed within this timeframe.

7.2 Some reviews may breach the four-month standard. This happens when the initiation of the review is put on hold so that statutory processes – such as safeguarding adult reviews, serious incident investigations, or inquests – can be undertaken and concluded before the review can begin.

7.3 Three Safeguarding Adult Reviews (SAR) have been published within this reporting year. A further two are in development and one has been referred for consideration by the Safeguarding Adults Board SAR subgroup. LeDeR maintains close links with the Safeguarding Adult Board SAR subgroup to ensure that action plans produced can also inform LeDeR recommendations in regard to service quality improvement.

7.4 At the time of writing, 485 LeDeR reviews have been completed in Sussex since the start of the programme. 16 reviews are currently on hold due to statutory processes being underway.

7.4 This year, due to quality issues within the national LeDeR dataset, there is no comparative data for benchmarking the performance of the LeDeR programme against organisations regionally or nationally.

8 Equality

8.1 Equality impact

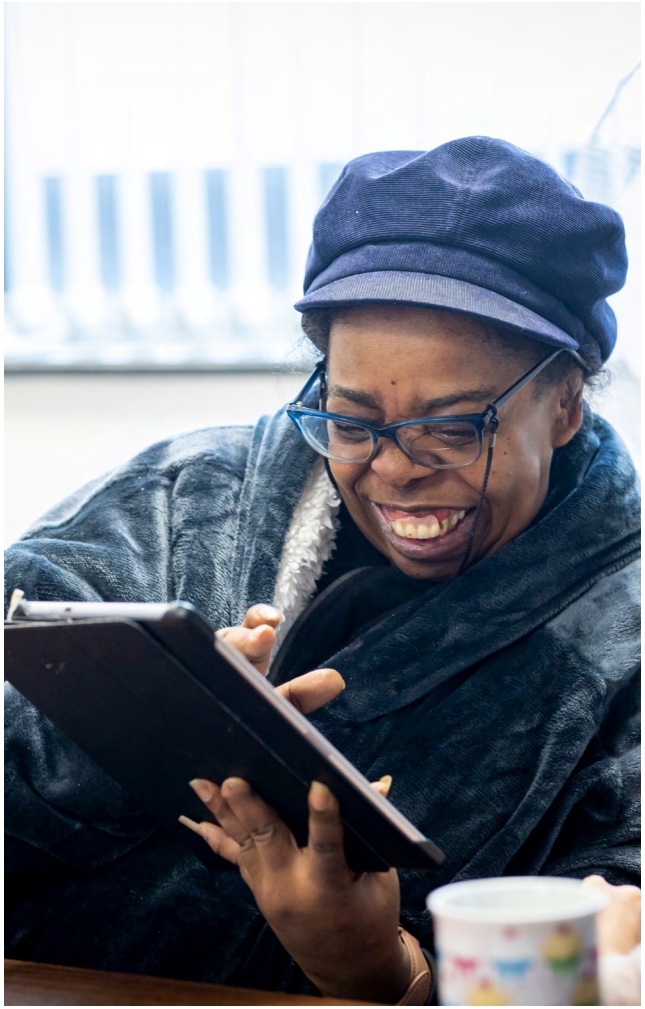
8.1.1 The purpose of the LeDeR programme is to reduce the health inequalities which people with a learning disability face, by attempting to understand the determinants that underpin them.

8.2 Four domains of analysis

8.2.1 This section of the report focuses on the analysis of all the reviews received and completed in the reporting period. Reporting from the national LeDeR platform remains unavailable and all data in this report is captured and stored locally.

These domains are:

- Sociodemographic statistics of all notifications received during the reporting period (age, gender, ethnicity)
- The cause of death as recorded on the medical certificate cause of death (MCCD
- Health conditions (in order of prevalence and multimorbidity)
- Themes identified in the recommendations made in completed reviews



8.3 Age

8.3.1 111 deaths (38 more than last year) were notified to LeDeR during the reporting period:

- The range of age of death was 4 - 91yrs
- The median age of death was 61

8.3.2 40 females with learning disabilities died during the reporting period:

- The range of age was 6 - 87
- The median age was 61

8.3.3 56 males with learning disabilities died during the reporting period:

- The range of age was 14 - 91
- The median age was 63

8.3.4 5 deaths were reported of people with autism during the reporting period. The median age of death for an autistic person without a learning disability was 31.

8.3.5 A total of 38 more deaths were reported to the LeDeR team compared with 2021/22. Compared with last year, there is a rise in the median age of death for both women (4yrs) and men (0.6yrs).

8.4 Age of children

8.4.1 5 child deaths (3 less than the previous year) were reported to LeDeR during the reporting period.

8.4.2 The range of age of death was 5 - 14, with a median age of death of 8.

8.4.3 All child deaths are reviewed by the Sussex Child Death Overview Panel which meets monthly and has responsibility for conducting the statutory independent review for all children normally resident in Sussex. There is LeDeR representation at all child death review meetings and CDOP panels, with the learning from each case embedded in the LeDeR service improvement recommendations.

8.5 Ethnicity

8.5.1 12 notifications were received for people from an ethnic minority background.

8.6.2 Nationally, the Race Equality Foundation and Learning Disability England have both been commissioned by NHS England to understand the specific inequalities that people with a learning disability and/or autistic people who are from an ethnic minority background face.

8.6.3 In Sussex, training has now been delivered to all local area contacts (LACs) and reviewers on the intersectionality of race, being from a minority ethnic community, and having a learning disability and/or being an autistic person.

A pen portrait to introduce some of the people who have died

We should always remember that the learning within this report and the LeDeR programme comes from the lives and deaths of real people who lived with their families or were supported by others in our Sussex communities. We take time to remember some of them here, and thank the families of Tash, Grace, Ronnie and Tony* for their permission to include details of their lives and deaths in this report. **Names have been changed.*

Natasha

Pen portrait:

Natasha, or Tash to her family, lived with her mum, dad and her best friend and brother, Matthew. Tash was a talented and creative person, changing her bedroom decorations with the seasons whilst Mamma Mia, Walking on Sunshine and Frozen played all year round.

Tash received NHS health funding for her care and was supported by personal assistants, her local GP and a physiotherapist and speech and language therapist from the specialist Community Learning Disability Team.

Tash had to deal with a lot of illness throughout her life, including many infections. Unfortunately, Tash was admitted to hospital as a result of her illness and there her family were helped by nurses to make plans with Tash about what was important to her and how best to help her. Tash was provided with end-of-life care, dying at the age of 26, with her family by her side.

At Tash's funeral, Matthew spoke about how "everyone had been told they should treat Tash like glass – no one told me that" whilst a slideshow of pictures played in the background of him pushing Tash around a skatepark in her wheelchair having the time of their lives.

Learning and Actions:

As part of the LeDeR Review, Tash's medical records were reviewed and lots of helpful details were shared. Tash had help and support in different ways throughout her life.

Tash's GP spoke to her carers frequently, but one thing that was noted was a Health Action Plan had not been completed in the last year. LeDeR shared this with Tash's GP surgery who said it was their policy to offer annual health checks annually but there was no follow up if someone didn't respond or chose not to come. As a result of the LeDeR review, the GP surgery made changes to its processes to ensure that if someone doesn't attend their Annual Health Check after the first invitation, they will proactively invite or make contact with everyone to attend. They hoped this would help people have another chance to come to their annual health check during the year.

Positive learning was also identified. The specialist health services who supported Tash had trialled using the ReSTORE2 mini tool with Tash. This tool helps to identify when someone may require additional help if their health starts to deteriorate, and helped Tash and her family to track her good days, bad days and when she needed more help. Feedback on the usefulness of this tool for both Tash and her family was fed back to service managers.

Grace

Pen portrait:

Grace was born in the early 1950's. During this time, parents of children with Down's syndrome were often advised that they should be put into hospital care. Under pressured to do this, her parents initially followed this advice but later brought Grace home after an upsetting family visit to the hospital.

Thanks to Grace's Mothers home tutoring, she grew into a creative and intelligent woman who enjoyed writing poetry. Grace had a wonderful sense of humour, having the best life and experiencing many holidays abroad with her family and friends.

When Grace's mother died her father remarried. Grace continued to live happily with her stepmother after his death when she was 49. When Grace was 60, her sister noticed a change - Grace was forgetting things such as where the dining room was when she came to stay. Grace was later diagnosed with dementia, and her GP surgery worked with her stepmother to develop an advanced care plan which advocated that Grace receive end of life care at home.

Grace's dementia advanced and she became increasing frail. Grace was cared for in her bed with two personal assistants supporting her. They knew Grace very well, but did not understand the risks involved in supporting her, particularly in regard to Grace's difficulty with swallowing food. Grace's stepmother also became frail, which significantly impacted on her ability to support Grace as her carer.

Grace developed pneumonia which increased her seizures and was admitted to hospital on a bank holiday weekend. The personal assistants tried to organise for Grace to come home when the hospital felt she was medically ft for discharge, but this was not arranged and sadly Grace died in hospital on her own.

Agreed Learning and Actions from Grace's review:

Despite the large number of agencies involved, no single agency or individual took responsibility for the coordination and planning of Grace's care. The Local Authority and Community Trust agreed that planning for future care is everyone's business when a person is diagnosed with dementia. They shared Grace's review with social care colleagues who reviewed the case management of Graces care to identify areas for improvement. The community Trust ensured that psychiatry made onward referrals for specialist support and made improvements to their referral pathways.

Praise was given to Grace's two personal assistants by Grace's sister and the Local Authority, who visited four times a day and went significantly above and beyond their roles in order to offer support to Grace and her stepmother. They both attended 'Stop Look Care' training to spot signs of deterioration in people with a learning disability and what support they could refer a person onto.

Ronnie

Pen portrait:

Ronnie was as a “happy go lucky person who always had a smile on his face”. Ronnie would tell people he was “retired”. Ronnie had a mild learning disability and moved to his last home in 2018, where the staff and residents quickly became his family. Ronnie loved farm animals and take-away meals, as well as various indoor activities and going out with his family. Due to a stroke affecting his mobility, he had a seated walking frame for indoors and a wheelchair for going outside.

In Spring 2022, Ronnie contracted Covid-19 and then a pneumonia from which he never really recovered. His health deteriorated and included progressive dysphagia, making eating and drinking any foods or fluids a risk, and he received regular support and care from the Speech and Language Therapists. He was admitted to hospital with aspiration pneumonia, with food and liquid breathed into the airway and lungs instead of being swallowed. Members of staff from Ronnie’s home took turns to sit with him and were with him when he passed away, “with a smile on his face right to the end”. Ronnie’s funeral was attended by staff from his residential home and his wake comprised of a takeaway meal back at the home in honour of his memory. Ronnie was 67 when he died.

Learning and Actions:

A ReSPECT form was completed whilst Ronnie was in hospital with Covid-19. There was no evidence that this was reviewed after his discharge from hospital (change in care setting) or as his health deteriorated. It was also not clear if Ronnie was involved in the decision making about his future care and treatment. A review of the ReSPECT form which considers changes in care settings and clinical condition should be carried out to ensure end of life care is carried out in accordance with each patient’s wishes. Ronnie’s GP surgery held a learning event and multidisciplinary meeting resulting in the production of a new policy which addresses all the learning and actions.

Positive practice:

Staff from Ronnie’s home provided round the clock support for him once he was admitted to hospital and one of them was with him when he died.

Tony

Pen portrait:

Tony grew up with his family in Southeast London and was a happy, lively, and energetic child. He loved slides and trampolines and would often be found jumping up and down on the sofa too. He enjoyed family holidays and outings, music, walks, and horse riding at school. When Tony and his family moved to East Sussex, he used community services and received regular respite care. His respite service eventually became his permanent home where he was described by staff as a “cheeky chappie”. Tony continued to lead a full and active life and his hobbies included swimming, bowling, live music and carnivals. He liked animals and had enjoyed holding the rabbits and small animals in the rescue animal centre. Tony particularly enjoyed the therapy (PAT) dog visiting the home. When his health started to deteriorate, Tony was supported by his GP, community district nurses, community rehabilitation team, speech and language therapist, dietitians and hospice care. Tony died peacefully at home aged 56.

Learning and Actions:

Tony’s medical records and other relevant information were shared and evaluated. The information indicated Tony had been in the last year of his life, but this was not fully recognised by everyone involved in his care. There were late conversations around his dietary needs at the end of his life. The feedback has promoted positive contact and discussion around dietary and end of life care.

Positive practice:

Tony received person-centred care to enhance his wellbeing. At the end of Tony’s life, he was able to die at home peacefully surrounded by people who knew and cared about him

8.7 Cause of death

8.7.1 In 2021-22, cardiovascular disease was the most common cause of death and pneumonia second.

8.7.2 Within this reporting period, respiratory conditions are the most common cause of death in people with a learning disability.

Top 5 causes of death in people with a learning disability and/or autistic people in Sussex who are known to the LeDeR programme		
1	Pneumonia	12
2	Aspiration pneumonia	12
3	Sepsis	8
4	Cardiovascular disease	7
5	Cancer	5

8.7.3 In comparison to 2021-22, notifications to the programme this year demonstrate a reduction in the incidence of death that can directly attributed to having a learning disability.

8.8 Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

8.8.1 Health and care professionals making DNACPR decisions for people with a learning disability and/or autistic people is inappropriate and unlawful. To support discussions around DNACPR that are appropriate and specific to individual circumstances, the Sussex palliative and an end-of-life care strategy continues to support the implementation of the ReSPECT process.

8.8.2 This includes bespoke training on the benefits of the ReSPECT process and how it can support people with a learning disability, and their families and/or carers, to understand what it is important to them and what is realistic in terms of care and treatment.

8.8.3 Many health and care providers now have actions plans to address the inappropriate use of completed DNACPR forms within their organisation.

8.9 Recommendations made in completed reviews

8.9.1 In the new format, initial reviews allow two identified learning recommendations to be made and two aspects of good practice to be shared.

8.9.2 The two main areas of concern are the same as those identified in 2021/22.

Theme
A lack of advanced care planning and discussions around dying in their place of choice
Variable application of the Mental Capacity Act

8.10 Positive practice themes

8.10.1 Positive practice continues to be identified in an increasing number of LeDeR case reviews.

Theme
Carers going the extra mile including meeting needs at a person's end of their life.
Placements being maintained despite a person's needs increasing
Shared lives carers providing a high level of advocacy
Capacity assessment undertaken with specialist easy read resources
Regular and thorough reviews by primary care
Acute liaison nurses enabling coordinated care on discharge

9 Action from learning: What we have learned

9.1 Best practice and areas for improvement

Best practice and positive outcomes we have learned from reviews
Appropriate challenge was available when decisions re: DNACPR/ReSPECT may not have been in a person's best interest
There is increasing evidence of person-centred and collaborative care between individuals, families and agencies
Single points of contact for palliative and end of life care coordination promote better outcomes in line with the wishes of individuals and their families
Information used from a hospital passport ensuring that staff in A&E had Disney music playing when a lady was admitted at the end of her life
Care settings are identifying their own learning via reflective practice and making improvements between the time cases are referred to LeDeR and when the reviews are completed
Evidence of excellent communication between GPs and care settings
Thorough, structured judgement reviews undertaken when a person dies in hospital identify learning and opportunities for improvement quickly
High quality learning disability liaison nursing is available in Sussex and valued by families and carers
Staff supporting people whilst they were in hospital promoted better outcomes including being by their side when they died
Structured medication reviews by a primary care pharmacist are being undertaken in some areas as part of learning disability annual health checks
Stop the over medication of people with a learning disability (STOMP) is being referenced during medication reviews
Collaborative advance care planning increases the likelihood of people being able to die in their preferred place of death

The areas for improvement that were identified in recommendations from reviews

Despite people being identified as frail, validated tools for advance care planning are not always used and appropriate referrals to organisations are not always made
The Mental Capacity Act is not always applied appropriately, and decision making is often collaborative but specific capacity assessments are not always undertaken and family members are not always consulted
Advanced care planning, including ReSPECT, is not undertaken by specialists – this can present an ongoing risk to the health of people requiring care
Health action plans are not always developed after an annual health check
Wellbeing services and social prescribing are underutilised for those with a learning disability and/or autistic people
When multiple professionals are involved in a person's care, there is limited evidence of a coordination role being allocated to ensure that care is appropriately joined up and planned
Individuals whose funding authority is not within Sussex are less likely to have referrals made to the specialist services they require
Access to acute learning disability liaison nursing in Sussex is inequitable depending on where people live
The enhanced health in care homes direct enhanced service is provided differently to learning disability care settings

9.2 Impact

9.2.1 The LeDeR Team in Sussex have worked hard to increase the impact of completed reviews.

9.2.2 This includes delivering briefing presentations with a co-produced easy read version to a range of stakeholders:

- Safeguarding Adult Boards
- Trust mortality and end of life strategic boards
- Learning disability and autism partnership boards
- Shared lives carers
- Local authority social work teams
- Primary care weekly webinar
- All age continuing care

9.2.3 The work was well received by a range of partners.

"Just wanted to say that I have had some great feedback from both Practices and our team in Primary Care following your Webinar about LeDeR last week"

- Primary care network manager

"I wanted to thank you for yesterday, presenting and answering several of our questions at our team meeting. It was fantastic to have such an overview and hear all about the service.

I had lots of feedback from the team yesterday and they found it really positive and informative".

– Shared lives team manager

"We don't want to talk about death - we want to talk about living well."

– Learning disability partnership board co-chair

"…….it is always so helpful to have that face to face contact……. Our team will remember Abby and what LeDeR do and her offer of ongoing contact for queries was really appreciated. We are as a team very aware of health inequalities and often advocate for our service users when services fall short. However, learning more about the role and work of LeDeR has been very beneficial when thinking about the wider context."

- Local authority duty team manager

"It was excellent training, it totally made me think about those conversations about constipation when reviewing care and added to a repertoire of other health topics, constipation had a renewed focus. Some of the figures and information were shocking and really bought home the importance of the discussion."

– Social Worker

9.2.4 The Sussex LeDeR Team undertook a survey to determine what was known about LeDeR locally and what could be done to raise its profile and its work to reduce health inequalities for those with a learning disability and autistic people. In total, 78 people responded:

- **83%** were aware of the LeDeR programme
- **58%** knew the process for making a notification
- **56%** knew that the deaths of autistic people were now included in the LeDeR programme and referral criteria
- **36%** had direct experience of participating in a review
- **40%** had received feedback from participating in a review

As part of the survey, we asked people to report where they worked:

I am a family carer	3%
I work in a private provider	15%
I work in a voluntary or charitable organisation	32%
I work in a local authority	24%
I work in the NHS	24%
Other	2%

9.2.5 We asked people to suggest ways in which the LeDeR programme could improve:

- Continue to share outcome of reviews and improve awareness
- Provide feedback at home manager and carer level
- Ensure that all people involved in a person's life are consulted as part of the review, as there is evidence this didn't happen in recent serious cases
- To continue reviewing cases with sensitivity, especially with family members
- Ensure that discussion can be both informative and enjoyable
- Continue the vital work of promoting the right to good palliative and end of life care
- Increase the focus on the lives and deaths of autistic people
- Increase engagement with care homes
- Increased involvement in safeguarding discussion

9.2.6 Results from the survey will inform the 2023-24 communications plan and a review of our standard operating procedure.

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

9.4.1 The Learning Disability and Autism Health Inequality Project Board was established to ensure that the health inequalities identified through the LeDeR Programme and the Sussex LDA Strategy, are addressed.

9.4.2 The board includes representation of people with lived experience, families and carers and links to wider population health workstreams in NHS Sussex.

9.4.3 Clinical priorities for the group have been set in accordance with last year's LeDeR data and cardiovascular disease has been the focus for 2022/23.

9.4.4 Based on local and national LeDeR priorities working groups for the LDA HI Steering Group 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

Further details on how the Board is turning Learning into Action in these areas are included in the next section.

10 Learning into action: Changes we have implemented in 2022-23

10.1 Respiratory

10.1.1 A community trust in Sussex is leading work to support pathway change and service improvement for people with a learning disability and autistic people in preventing and treating pneumonia, using new draft NHSE guidance developed by the British Thoracic Society and the NHS Right Care programme. The trust plans to do this by delivering three education sessions to those working with people with a learning disability and autistic people, including families, carers, professionals working in secondary care and child development centres. The training will also incorporate advanced care planning.

10.1.2 An engagement event has been held including the Sussex Respiratory Network and clinical leaders in Sussex.

10.2 Immunisation and vaccinations

10.2.1 Vaccination rates continue to be lower in people with learning disabilities and/or autistic people than the general population.

10.2.1 The LeDeR programme was involved in the development of a number of initiatives to improve the uptake of the COVID-19 vaccination for people with a learning disability and/or autistic people. This included:

- Meeting the accessible information standard to ensure people with a learning disability had access to easy read information and access to professional advice if required
- Providing sufficient reasonable adjustments under the 2010 Equality Act, including quiet spaces and sessions for vaccination outside of core hours
- Advice on the use of the Mental Capacity Act within the context of vaccination consent

10.2.3 This year will see a significant focus on improving uptake of the seasonal flu vaccination. People who have a learning disability can be more susceptible to the effects of flu, and are therefore at an increased risk of developing bronchitis or pneumonia. Messages around flu vaccination will be communicated to people with learning disabilities and their carers / family members, and the LeDeR programme will work with primary colleagues to look at how the vaccination can be delivered opportunistically through annual health checks and other appointments within the health and care system.

10.3 Cardiovascular disease

10.3.1 Funding to address inequities in CVD prevalence and outcomes in people with a learning disability and/or autistic people has been secured via the population health management hypertension surveillance programme.

10.3.2 Phase 1 of this funding will be used to develop co-produced resources that address the following:

- Highlighting the role of lifestyle factors in CVD disease, with a focus on physical activity, healthy weight, dietary advice and smoking cessation support
- Adapting 'Know your Numbers' comms into an easy-read format to highlight the importance checking blood pressure regularly and how to access this support
- Adapting Sussex 'BP@Home' materials to enable more people with learning disabilities who are hypertensive to monitor their BP and submit to their readings to primary care
- Develop educational videos for people with a learning disability on anatomy and physiology, extending to coronary heart disease, hypertension, atrial fibrillation, hypercholesteremia and other risk factors
- Training for families, carers and organisations to support behavior change in people with a learning disability

10.3.3 The remaining funding will be used for a project manager to oversee the following:

- Primary care training and webinars that identify how the learning disability annual health check can be used to reduce CVD risk and ensure that health action plans directly raise awareness around CVD
- Mapping what data is available across universal services in Sussex to understand how this can be used to plan and target resources for people with a learning disability and/or autistic people
- Work with universal providers to support the delivery of awareness training, provided by autistic people and people with a learning disability, around hypertension
- Create a CVD risk detection dataset which will provide an accurate baseline of CVD risk for people with a learning disability and/or autistic people, and support the work of the LeDeR programme
- Established links with existing CVD Prevention programmes to maximise opportunities for the increased identification or people at risk of CVD and improved management of those diagnosed with hypertension

10.4 Reducing risks associated with constipation

10.4.1 Following on from a recommendation in last year's LeDeR report, a webinar was jointly delivered with a person with a learning disability to a number of different organisations across Sussex. The webinar covered a number of areas including:

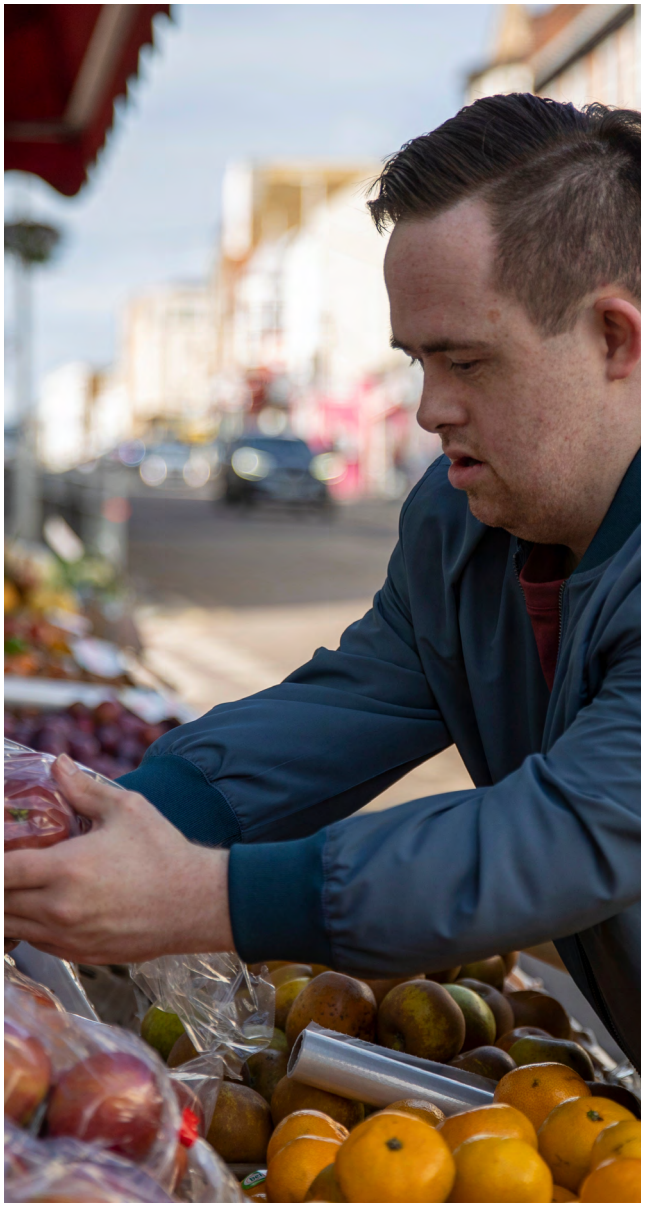
- Providing health promotion advice on lifestyle factors (hydration, diet and exercise)
- Ensuring good monitoring of bowel health when medication is provided
- Ensuring the availability of accessible resources and reasonably adjusted health promotion
- Promoting the importance of the faecal immunochemical test (FIT)
- Ensuring specialist involvement (bladder and bowel) when constipation remains problematic
- Increasing the understanding of good bowel health in preventing bowel cancer
- Ensuring that surveillance and management is clear when there may be a risk of volvulus.

10.4.2 Examples of Feedback received.

"I thought the constipation webinar was great and I showed the Poobusters film in Thumbs Up this afternoon. They are keen to do some peer education work on the subject, so something to think about in the new year."

- Self-advocacy group co-ordinator

"Thanks, just watched it and extremely interesting and helpful!" **– Provider organisation**



10.5 Cancer and cancer screening

10.5.1 Work has been undertaken across Sussex to improve the uptake of cancer screening in people with a learning disability. Engagement events have been held to increase the awareness of faecal immunochemical testing (FIT) and the plan to reduce the screening age to 50. A number of videos were commissioned and co-produced to provide information to people with a learning disability and their carers on

- What is cancer and bowel cancer screening?
- What is cancer and breast cancer screening?
- What is cancer and cervical cancer screening?

10.5.2 Short films that support people with a learning disability and/or autistic people around what to do if their screening result comes back as abnormal are currently being planned.

10.6 Decision Support Tool for Physical Health

10.6.1 The Decision Support Tool for Physical Health (DST-PH) identifies the level of risk of premature mortality for people with a learning disability and provides guidance for the actions to be taken to best support a person depending on their risk level.

10.6.2 The tool was developed by Cheshire & Wirral Partnership NHS Trust, with funding from NHS England, in response to the LeDeR programme which highlighted the significant disparity between age at death for people with a learning disability and the general population. The tool identifies those at greater risk of premature mortality due to their physical health conditions or factors which affect them.

10.6.3 Sussex Partnership NHS Foundation Trust has piloted how the DST-PH could be implemented into Sussex Primary Care through one GP practice in each Sussex locality. It is now being considered how to extend this pilot across PCNs in 2023 to explore the feasibility of delivering the tool with LD Annual Health Checks, and to develop a series of user-friendly resources.

10.7 Advance, anticipatory and end of life care planning

10.7.1 Training has been provided to community learning disability and health facilitation teams across Sussex to roll out ReSPECT. Understanding frailty and how to plan for the person's last year of life is being included in the community learning disability team's physical healthcare training plan.

10.7.2 Learning from LeDeR has been included in the Sussex palliative care and end of life strategy. Examples of where single points of contact promoted better outcomes for people have been collated, as have barriers or gaps within services that have resulted in a person not dying in their preferred place.

10.8 Identifying a deteriorating patient - Stop Look Care

10.8.1 Stop Look Care is a NICE recognised tool and handbook for care workers and carers which is used to support the identification, prevention and appropriate response to deterioration among older people in the health and care sector.

10.8.2 Health facilitation teams have delivered training on its implementation and use across Sussex on a quarterly basis. 102 people received the training this year.

10.8.3 Funding is being sought to create a new Learning Disability and Autism version of the Stop Look Care booklet for the LeDeR programme. This will include guidance on epilepsy care, postural and respiratory management, the prevention of chest infections, and STOMP.

10.9 Annual Health Checks

10.9.1 Throughout 2022-23 Sussex has been working towards a target of 75% of people on the GP learning disability register having an annual health check with 100% of those resulting in a health action plan.

10.9.2 An additional incentive scheme resulted in 450 annual health checks for people with a learning disability being undertaken for those who did not have one last year.

10.9.3 Four practices have been awarded the Thumbs Up quality kite mark award which recognises their proactive commitment to improving outcomes for people with a learning disability.

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

10.9.5 The Involvement Matters Team have developed and shared a presentation on the barriers experienced in accessing primary care and two webinars have been delivered to approximately 120 primary care staff.

10.9.6 In 2023-2024 we will develop ‘not brought to appointment’ guidance to ensure that safeguarding is considered when a person misses an appointment and is in receipt of support.

10.9.7 We will reinstate monthly comms to all partners with a focus topic each month.

10.9.8 A focused review was undertaken for a person who died whist in prison. This review identified learning in annual health checks being undertaken by prison health services. A plan of work was devised with NHSE, who have responsibility for the commissioning of prison health services, to address this.

11 Action from learning: How we have identified our priorities for 23-24

Planning for a good death

Issues identified include:

- Lack of clear information shared regarding the risks and outcomes of cardiopulmonary resuscitation
- Lack of referrals made to hospices when needed
- Staff may not always understand the prognosis when a person has congestive heart failure
- Advance care planning not undertaken when a person has dementia and dysphagia
- ReSPECT forms not reviewed despite clear changes in prognosis resulting in multiple hospital admissions
- Missed opportunities for conversations with people about their preferred place of death
- People being conveyed to hospital whilst dying do a lack of clear information in their ReSPECT form
- A lack of understanding and support in understand frailty and planning accordingly

Positive practice identified:

- Substandard DNACPR forms quickly revoked by acute learning disability liaison nurses
- Well-coordinated care from a single point of contact promoting the person's end of life care wishes

Care co-ordination

Issues identified include:

- No lead being taken in developing advance care planning despite multiple professionals being involved
- Annual health checks not resulting in referring on as needed
- Referrals delicenced by specialist services without safety netting
- A lack of formal implementation of the self-neglect guidance contained in the Pan Sussex Safeguarding Adult Policy and Procedures
- A lack of advocacy enabling the person's voice to be heard

Positive practice identified

- End of life single point of contact hubs promoting better outcomes

Cardiovascular disease (CVD)

Issues identified

- Lack of referral to heart failure nurses
- Blood pressure not being monitored due to a lack of suitable cuffs
- Difficulties with accessing doppler scanning
- Home monitoring not being undertaken
- Difficulties accessing well-being services
- Annual health checks not resulting in referrals for social prescribing regarding smoking cessation, weight loss and diet
- A lack of understating of prevention and management by people with a learning disability, autistic people and those who support them

Preventing community acquired pneumonia

Issues identified

- Increased risks from chest infections not explained when there was significant increase in spinal curvature
- Poor compliance with adjuncts such as CPAP and a lack of planning for the risks of not using them
- A lack of advance care planning when a person has an eating and drinking plan that does not remove the risk of aspiration

12 Our priorities for 2023-24

12.1 Working with public health wellbeing services and social prescribing to improve access to services that can reduce avoidable and harmful health inequalities.

12.2 Continued delivery of the ‘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.

12.3 Developing the Decision Support Tool for Physical Health to support an increase in annual health checks and health action planning.

12.4 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.

12.5 Using the British Thoracic Society guidance to support the redesign of clinical pathways for people with learning disabilities who have respiratory needs that require specialist input.

12.6 Work with the population health management and personalisation team at NHS Sussex to focus on how reasonable adjustments can be implemented to make services more accessible and reduce health inequalities

13 Action from learning: Evaluating the impact

13.1 LeDeR in Sussex will continue to report into the strategic leadership across the Sussex system.

13.2 LeDeR in Sussex will promote our “living well for longer” work to ensure that people with a learning disability and/or autistic people can stay well and have good access to healthcare and support of a high standard, with a clear ambition to increase their life expectancy and reduce avoidable health inequalities in Sussex.

13.3 LeDeR will continue to collect and improve the quality of information held on causes of death to monitor for changes and improvements, and increase the information held on the lives and deaths of autistic people.

13.4 Thematic analysis and briefings will continue to be promoted across services to ensure that all stakeholders are familiar with the areas of learning and implement the quality improvements.

13.5 Learning from LeDeR will continue to be shared to inform service development, delivery and the commissioning of services across Sussex.

14 Conclusion

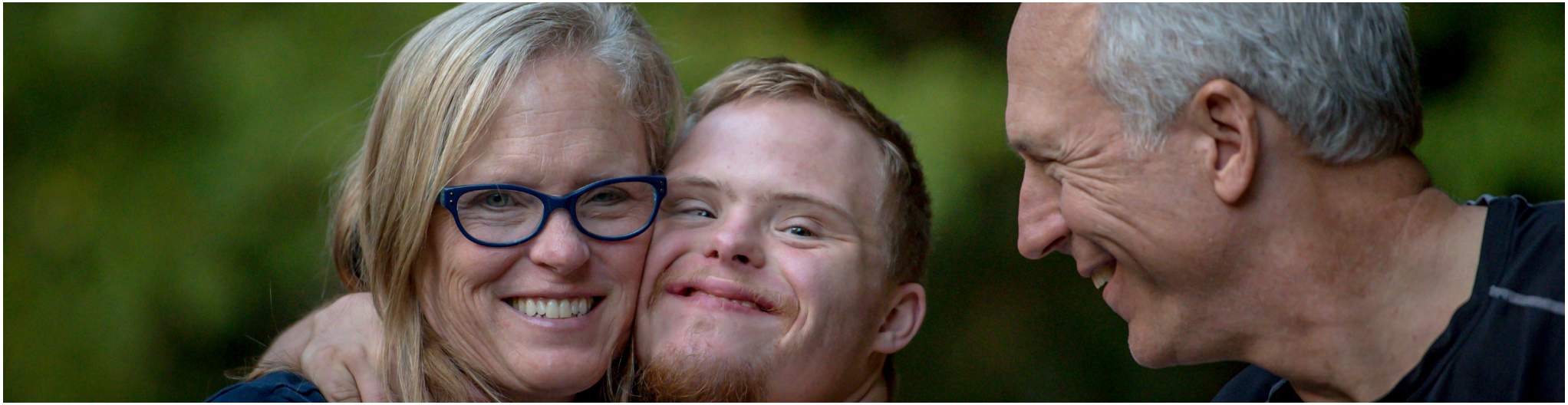
14.1 LeDeR in Sussex continues to play a pivotal role in identifying and addressing the health inequalities experienced by people with a learning disability and/or autistic people. Whilst this report highlights a range of good practice across Sussex, the continued reporting of premature deaths shows the enduring need for the LeDeR Programme to support further development of good practice across Sussex and address variations in both quality and access to health and care services.

14.2 This report demonstrates the continued focus on the learning from reviews to ensure there are quality improvements in operational services and strategic planning.

14.4 There is an ongoing commitment within the Sussex system to address the health inequalities experienced by people with learning disabilities and autistic people.

14.5 Meaningful involvement of people with learning disabilities, autistic people, and their families/ carers in service improvement continues to develop and strengthen, with strong links to the Sussex Learning Disability and Autism Shadow board, local self-advocacy groups, local authority-led Learning Disability Partnership boards, and Autism Partnership boards.

14.6 Sussex continues to be proud of, and indebted to, the participation of families and experts by experience in the LeDeR programme.



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