Learning Disabilities Mortality Review (LeDeR)

Sussex CCGs Annual Report 2020-2021

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Contents

1 Executive Summary.

1.1 Thank you for your continued support to reduce the health inequalities people with learning disabilities, which are even more evident following an unprecedented year facing the impacts of COVID-19.

1.2 This is the Second annual report of the Sussex CCGs' LeDeR programme.

1.3 The LeDeR programme reviews the death of all people with learning disabilities over the age of four, to identify good practice or areas for improvements, which are then shared with relevant stakeholders to influence positive changes to service provision. Sussex is committed to people with learning disabilities living well and to taking action from the learning identified in completed reviews.

1.4 LeDeR in Sussex has completed all the reviews within the required time frame, which has been a significant undertaking as there was a considerable backlog at the start of 2020/21.

1.5 This report details the progress of the LeDeR programme in Sussex between 1st April 2020 and 31st March 2021. It aims to further mobilise support to reduce the health inequalities people with learning disabilities continue to experience in Sussex as well as outlining the improvements the system has made. Included is a breakdown of deaths by ethnicity, age and gender; details of the themes that were identified in the cause of deaths are provided as well as the recommendations that followed.

1.6 In this reporting period, COVID-19 was the most common cause of death for those with learning disabilities. The report contains information on what the Sussex system did to minimise the risks from COVID-19 before it was nationally identified that people with learning disabilities were at greater risk of death or serious illness. The increased risk is now thought to be linked to themes previously identified in LeDeR, e.g. the risks associated with chest infections.

1.7 The 'learning into action' section in this report sets-out the priorities for quality improvement plans over the next year, which are based on the aggregate learning points from the reports completed.

2 Key points.

2.1 Sussex has worked hard over the last year to achieve the completion of all reviews in the set timeframe.

2.2 The risks to people with learning disabilities in Sussex from COVID-19 are clear and documented in this report. We are pleased that the joint vaccination and immunisation committee included adults with learning disabilities as priority six for vaccination in February 2021. The Sussex system applied the methods previously used for the flu vaccination programme to support the uptake of the COVID-19 vaccinations; by April 2021, 86% of people with learning disabilities on their GP learning disabilities register in Sussex had received their first vaccine dose.

2.3 Annual Health Checks were paused at the start of the COVID-19 pandemic. In August 2020, NHSE issued the restart of annual health checks for all those on their GP learning disabilities register. Since then, the number of people receiving their annual health checks has met and exceeded the national target. Further work is now underway to achieve consistency, quality in Annual Health Check, and ensure that a check results in the completion of a health action plans.

2.4 Another success this year is associated with increased engagement of partner organisations, who have demonstrated their commitment to LeDeR by developing their own action plans based on learning identified. This evidences the quality improvements that can be achieved from this process.

2.5 Involving those with learning disabilities and their families and carers is fundamental to the success of the programme and is a core value of the Sussex team.

Learning Disabilities Mortality Review (LeDeR) Programme

3 Introduction.

3.1 The Sussex population is approximately 1.8 million people, given the prevalence of learning disabilities is approximately 2.6% nearly 39,000 people with learning disabilities will at one time receive health-care in Sussex.

3.2 The Learning Disabilities Mortality Review (LeDeR) Programme was established following recommendations of the Confidential Inquiry into Premature Deaths of People with Learning disabilities (CIPOLD). In June 2015, early implementer pilot sites started the reviewing process, with Sussex going live in September 2017. The initial aim was to ensure consistent identification of both good and bad practice in the care of people with a learning disability, with this being used to support quality improvements. It draws on the wider learning from deaths work undertaken by NHS Trusts, but places the person with learning disabilities at the centre of the review. A review should be completed for all those 4 years and over, who have a learning disability and are registered with a GP.

3.3 Initially the programme was set up with CCGs to monitor, allocate and quality-assure reviews. Reviewers were expected to complete reviews in addition to their substantive roles.

3.4 The NHS Long Term Plan supports the continuation of the LeDeR programme *“action will be taken to tackle causes of morbidity and preventable deaths in people with a learning disability and for autistic people”*

4 Acknowledgements.

4.1 The COVID-19 pandemic further highlighted the significant health inequalities people with learning disabilities encounter. Due to established and mature networks across Sussex, proactive mobilisation of a 'COVID Response Partnership' was enabled. This supported a targeted and coordinated path for information and practice guidance to reach people with learning disability, professionals working in the area and families. This would not have been possible without the proven commitment to and engagement in the LeDeR process across Sussex. Reviews continued throughout the pandemic, as did collection and dissemination of the learning.

4.2 Considerable acknowledgement and thanks go to all those who provided information when requested under the enormous pressures faced during the last year. Further thanks go to the reviewers for the compassion shown when completing the reviews, whilst keeping the person at the centre of the process, in order to identify learning and share good practice. This includes the North East Commissioning Support Services (NECS), who completed a significant number of reviews, allowing Sussex to achieve its current performance position. And at the core of LeDeR are the people and their families, so our thanks go to the incredible carers, families and friends of those who have died, for sharing their stories, sadness and laughter.

4.3 We give special thanks to the families who gave permission for the Pen Portrait of their loved ones to be used in this report.

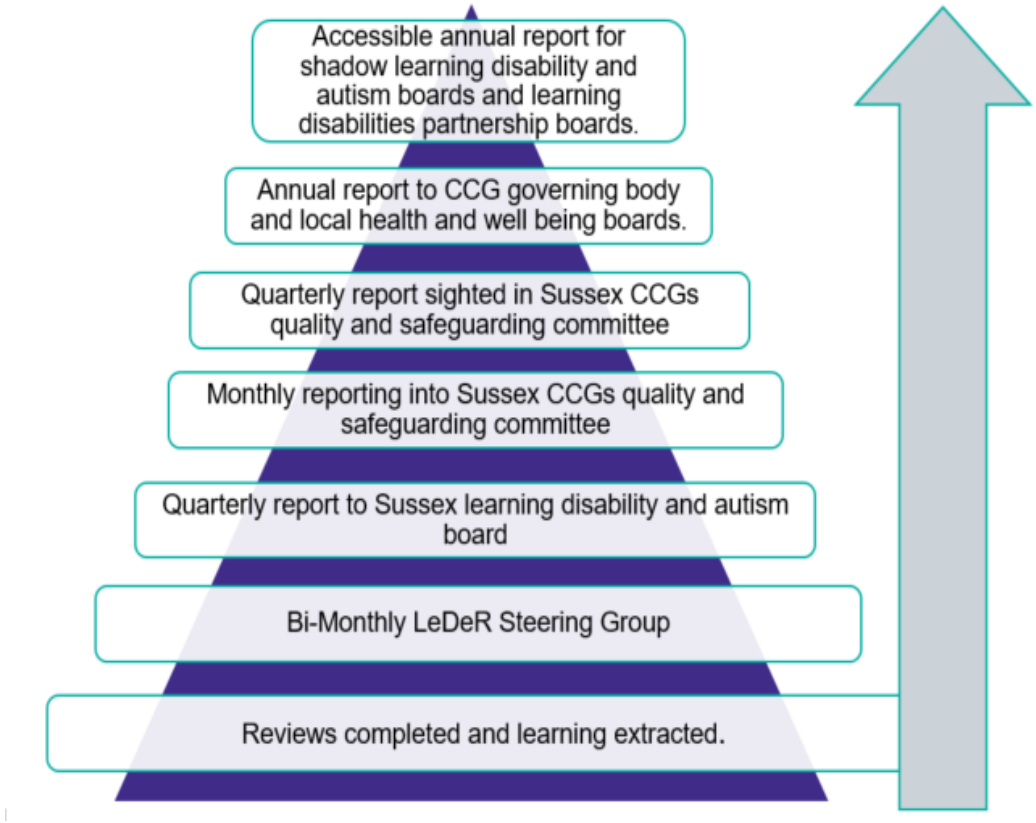
4.4 Of course it is the people whose lives reviewers were permitted into that we thank the most. People who may have experienced care all of their lives; people who were taken from their loving families' too early; people who throughout their lives often faced adversity with bravery. LeDeR in Sussex is indebted to the extraordinary people, from whom we are able to learn so much.

5 Governance arrangements in the Sussex system.

5.1 The Sussex LeDeR steering group remains responsible for the governance and implementation of the LeDeR programme. There is committed and consistent membership from the NHS Trusts in Sussex including: South East Coast Ambulance Trust, as well as a Sussex Coroner, all three local authorities via their safeguarding teams, Sussex CCGs, GP Clinical Lead for learning disabilities, NHSE regional co-ordinator, the Sussex Local Area Contacts (LACS) and a Sussex wide providers of residential and supported living services for people with learning disabilities.

5.2 The chart below describes the process, from completing the review to development of findings, learning and actions and their structure of reporting.

Chart 1: LeDeR Governance Process



5.3 When reviews are completed the information is shared, as appropriate, with the relevant organisations who agree their own action plans. These action plans are then shared at the LeDeR steering group along with other updates.

5.4 A quarterly report is produced and circulated to the membership of the Sussex Learning Disability and Autism Board to provide oversight and to support challenge, where needed, on performance and outcomes.

5.5 Furthermore, reporting to Quality and Safeguarding Committee occurs on a monthly basis and includes data with a brief narrative on themes and improvements underway. On a quarterly basis the full report is shared with this committee to provide assurance.

5.6 An annual report is produced, which will be presented at strategic CCG and joint committees across Sussex, following this it is then published on the CCGs websites.

5.7 An accessible version of this report will be shared with the Sussex CCGs Shadow Learning Disability and Autism Board, which is made up of service users and people with lived experience, and the place-based Learning Disability Partnership Boards.

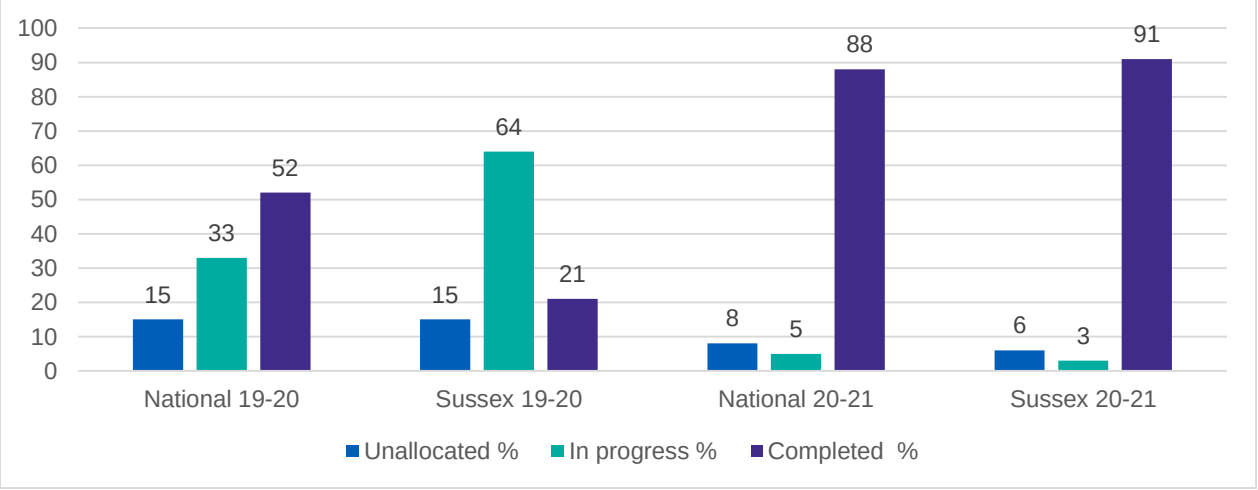
In the year ahead, the above governance processes will be reviewed and aligned to the new LeDeR policy and the Integrated Care System.

6 Performance.

6.1 In March 2020, Sussex was significantly behind the national position for the percentage of completed reviews. A recovery plan was developed and enacted. The plan included increasing local resource and the allocation of a number of reviews to North East Commissioning Support Unit (NECS), which was commissioned by NHSE/I to provide systems with additional capacity to conduct reviews.

	Notifications No. & %		Completions No. & %		Multi Agency Reviews	% of all Reviews completed within compliance:
2019/2020	91	24	69	35	2	8
2020/2021	122	32	80	70	2	70

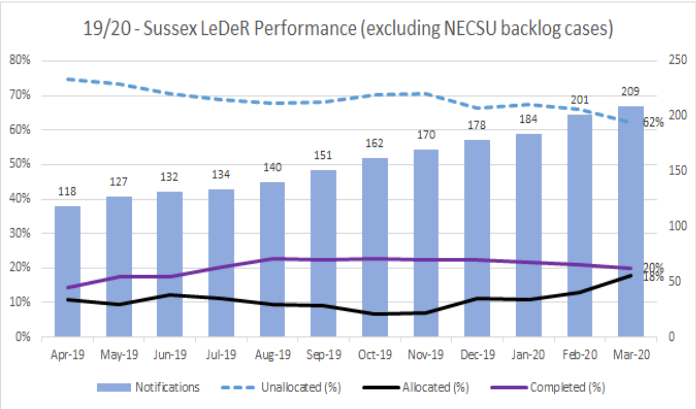
6.2 The following chart details the comparative performance data and demonstrates that Sussex is now in a higher position than the national average at the end of this reporting period

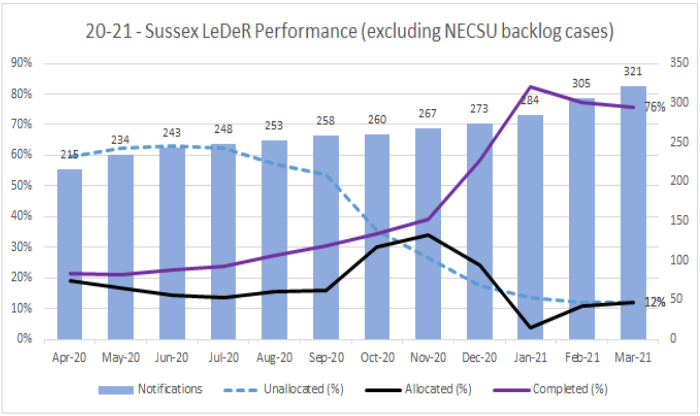


6.3 All Sussex reviews are now completed within six months from notification, which is the required standard, with the exception of those that are subject to an alternative process such as safeguarding enquiry, safeguarding adult review, serious incident investigation or an inquest.

6.4 The number of multi-agency reviews has remained the same as previous years, although it has been seen that there are a growing number of reviews that have involved of multiple agencies, outside the formal multi-agency review process. It is thought this may be due to ever-increasing understanding and support for the programme.

6.5 Sussex is proud to celebrate its achievement, having completed all reviews within scope by 30th April 2021. Reviewers and Leads devised clear work-plans and achieved the set trajectories. Sussex is committed to maintaining this position and has plans in place to ensure it continues through 2021-22 and beyond.





6.6 National benchmarking

6.6.1 The National LeDeR report was published on the 10th June 2021. Although this covers a different reporting period, which acts as a final report from the three year project run by Bristol University, some comparisons can be made.

6.6.2 Nationally COVID accounted for 23% of the deaths reported through the LeDeR system; Sussex was comparable, with 23% of deaths being attributed to COVID as the primary cause of death.

6.6.3 Sussex finished above the national average for compliance with the target set for completing reviews in 6 months from notification.

6.6.4 All regional reports are expected to be available from the 30th June 2021, which will enable further comparison of data across the South East region.

6.7 Sussex reviewer arrangements

6.7.1 LeDeR reviewers in Sussex come from a variety of backgrounds; this includes general nurses, child nurses and staff from community learning disability teams. Staff with a background in advocacy and inspection have also undertaken reviews. Reviewers are required to have a background in learning disabilities but a professional registration is not required.

6.7.2 Some reviewers were paid by the CCG to complete reviews as they completed the reviews outside of their normal working arrangements.

6.7.3 Reviewer's skills and knowledge are, wherever possible, matched to the reviews they are allocated. Support via peer supervision is facilitated by the LeDeR Case Manager and or the LACs.

7 Equality.

7.1 Equality Impact

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

7.2 Four domains of analysis

7.2.1 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 and level of learning disability.
- The cause of death as recorded on the death certificate of completed reviews.
- The quality of care of all reviews completed, which is determined by a grading system that LeDeR uses.
- Themes identified in the recommendations made in completed reviews.

7.3 Age

7.3.1 One hundred and twenty two deaths were notified to LeDeR during the reporting period.

- The range of age of death was 4-94
- The mean average age of death was 59
- The median age of death was 61

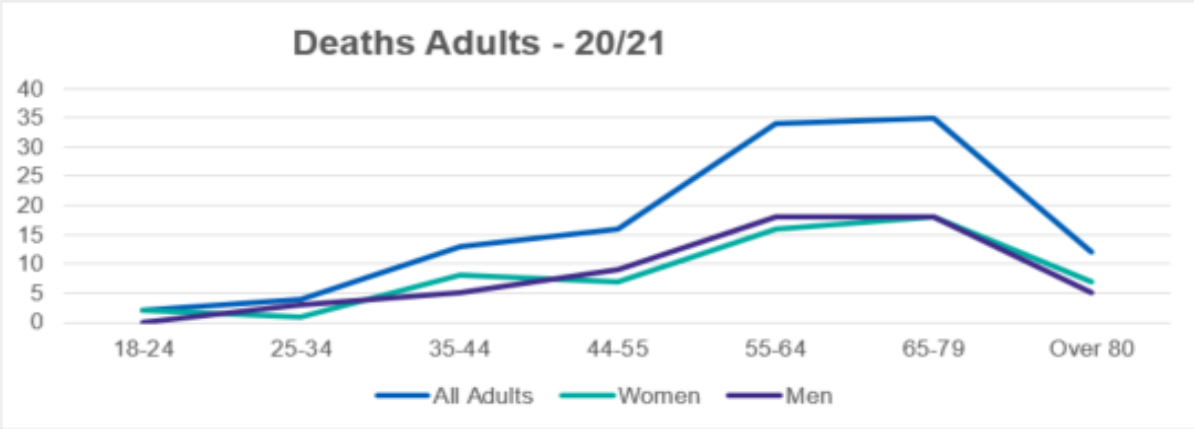
7.3.2 Fifty six women with learning disabilities died during the reporting period.

- The range of age was 4-94
- The mean average age of death was 58.5.
- The median age was 61

7.3.3 Sixty one men with learning disabilities died in the reporting period

- The range of age was 17-91
- The mean average age of death was 59.6
- The median age of death was 60

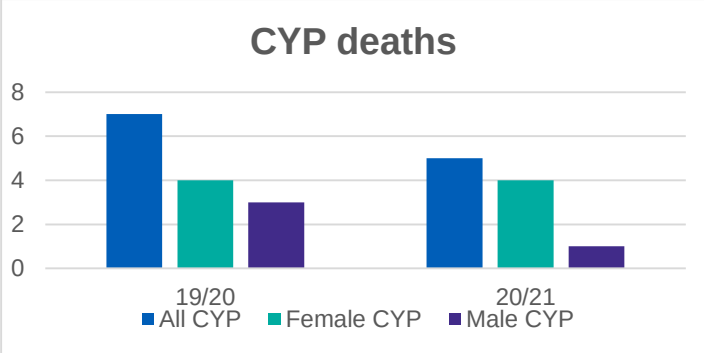
7.3.4 The following graph shows a visual representation of the age ranges reported to LeDeR in the period.



7.4 Age of children.

7.4.1 Five child deaths were reported to LeDeR during the reporting period.

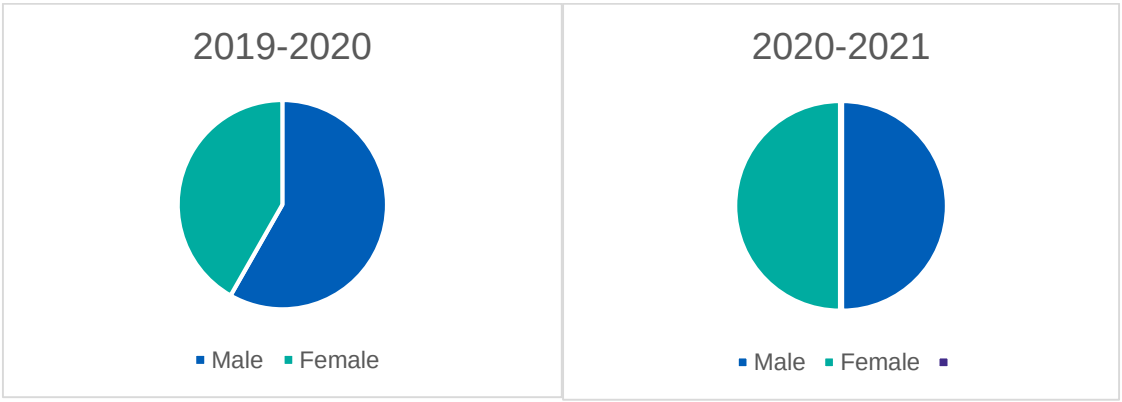
- The range of age of death was 4-17
- The average age of death was 10
- The median age of death was 6



7.5 Gender

7.5.1 During 2020-2021 there has been and overall increase in the numbers of LeDeR reviews undertaken with a 34% growth when compared to the previous year. There has also been a swing in the gender split, with equal numbers of reviews undertaken for males and females during 2020-2021.

	2019-2020		2020-2021	
	Male	Female	Male	Female
No	53	38	61	61
%	58	42	50	50



7.6 Ethnicity

7.6.1 Nationally COVID-19 has disproportionately impacted people from black or minority ethnic backgrounds in the general population. This has been seen in the learning disability community too, with local population data showing those with learning disabilities, from minority ethnic groups, being overrepresented in the numbers of notified deaths.

7.6.2 The table below provides further information related to the ethnicity of people whose deaths were notified to LeDeR. Also included is comparative data for the wider population of Sussex.

Ethnicity	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	104	0	0	3	0	0	0	2	0	2	2	0	1	0	0	0	0	7
% of all reported deaths	85	0	0	2.4	0	0	0	1.6	0	1.6	0.8	0	0.8	0	0	0	0	5.7
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	

7.6.3 LeDeR in Sussex supports the increased focus on those with learning disabilities from minority ethnic groups and seeks to increase its understating of the additional impact of ethnicity on outcomes for people with a learning disability.

7.6.3.1 It is imperative that those reading this report are reminded that the learning comes from the lives and deaths of real people, who lived their lives with families or other support in our Sussex communities. This work could not happen without them and so we take time to remember some of them; Ula, Jack, Doris and Erhard* whose families we thank for their permissions to include in our report.

7.6.3.2 The following pen portraits provide a brief outline of the person and the circumstances of their life and death:

Ula was only 42 when she died in hospital from pneumonia, a complication of her spinal curvature and swallowing difficulties.

Ula loved chatting and being funny with people and was skilled in using Makaton. She was known by those who cared for her for her love of life. She particularly enjoyed a karaoke night. Ula was brave.

Ula had lived in her home for the last 12 years and was loved by those who cared for her. Both of her parents had died and at the end of Ula's life, her step-mother was not recognised as being able to represent her views and wishes if needed.

Jack died in hospital of COVID-19

Jack was described as a happy soul. He like music and knew the words to lots of songs, particularly Michael Jackson. He always had his current favourite cuddly toy on him.

His speech was hard to understand and people had to 'tune in to him' after knowing him a while. He enjoyed being with people and was very sociable. Jack had difficulty co-ordinating his movements and needed support to hold drinks and phones. His carers helped him with his needs.

His mum said that he would not have understood why he needed to wash his hands regularly during the COVID pandemic but he was supported to do this by staff in his home.

Doris died peacefully in her sleep at 94.

Doris was an inspiration. Her approach to any adversity was to get back to normal as quickly as possible and then you will feel better.

Doris moved to a long stay hospital when she was 15 and she often spoke fondly of her time there.

When it closed she moved to the home with nine of her friends where she lived until her death. Doris identified with the important people in her life, in the 22 years her support worker had known her. She had 3 key workers and she called each of them mum. Her learning disability was mild and she enjoyed being a crucial member of her community and liked to be involved in the running of her home. Doris was never unhappy, she saw the best in everything.

Doris was fiercely independent and never lost her sense of humour, even at the end of her life.

Erhard died peacefully at home of bowel cancer. He was 42.

Erhard would have a go at everything. After he left school he attended college courses and then worked in a day centre where horticulture was his favourite. He liked to write about his days in a journal and was a keen snooker fan. He was known out and about in his community and was respected. He had lots of friends.

Erhard had multiple operations and chemotherapy to treat his cancer.

His family thought the world of him.

*names changed

7.7 Level of learning disability

7.7.1 For every review carried out the level of learning disability for that person is confirmed and recorded as mild, moderate, severe, or profound/multiple.

7.7.2 Based on information from the 2019/2020 Sussex annual LeDeR report fewer people with mild learning disabilities died this year, when compared with previous years.

7.7.3 More people with severe learning disabilities have died this year with the national data last year reporting 27%, compared to a 2020/21 percentage of 31%.

7.7.4 Sussex has a higher than national average number of care homes that are registered to look after people with severe learning disabilities.

7.7.5 The information below shows a breakdown of the level of learning disability for all reviews completed in the reporting period.

Level of learning disability	No	%
Mild	23	29
Moderate	17	21
Severe	25	31
Profound and multiple	10	12
Unknown	5	5

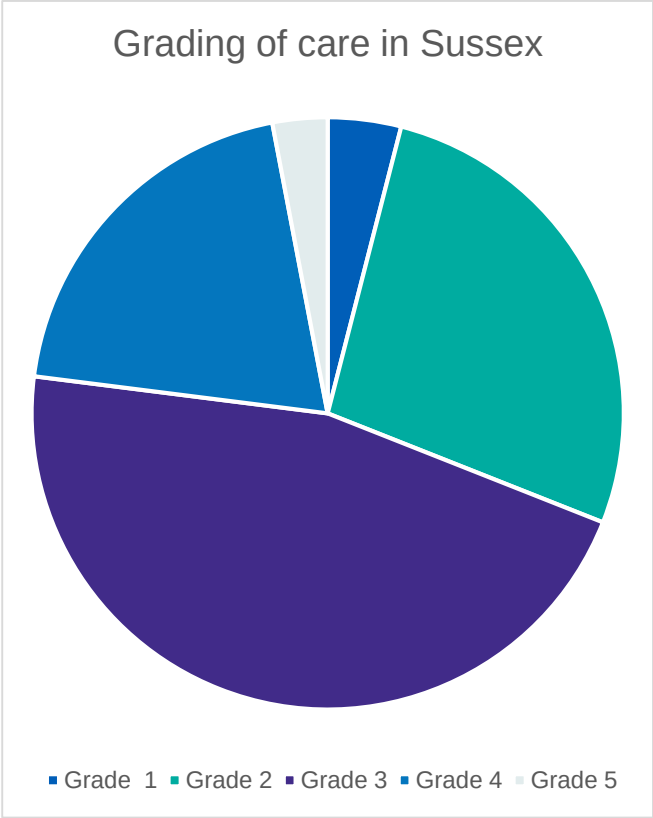
7.7.6 Deaths from COVID-19, confirmed or suspected for the period were as follows: Twenty Eight people with learning disabilities died of COVID-19 in the reporting period:

- The range of death was 44-90
- The average age at the time of death was 62
- The median age of death was 62
- 16 men died of COVID-19
- 12 women died of COVID-19

7.8 Quality of care

7.8.1 Below is the LeDeR criteria for the grading of care and the Sussex percentages for the grading of care:

Grade	Grading of Care
1	This was excellent care (it exceeded expected good practice).
2	This was good care (it met expected good practice).
3	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's well-being).
4	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.
5	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
6	Care fell far short of expected good practice and this contributed to the cause of death.



7.8.2 Three reviews received the highest score possible for care delivery and were thought to demonstrate excellent care. They reported positive practice in application of the Mental Capacity Act and showed highly person-centred approaches.

7.8.3 Twenty-one reviews were rated as evidencing good care, including good quality hospital passports in place, flexible approaches to enable a person to remain in their home and collaborative best interest decision making.

7.8.4 Most reviews in Sussex identified satisfactory care, examples of why these did not meet the good care criteria are;

- End of life care that did not demonstrate advanced care planning,
- A lack of evidence where 'Best Interests' decisions were made on behalf of a person,
- A lack of face-to-face contact with care and support providers due to the COVOD-19 pandemic,
- Annual health checks that did not result in a health action plan.

7.8.5 Fifteen reviews found care that fell short of good practice. This included certification of death that was attributed to a syndrome, safeguarding plans regarding health not being shared with GPs, poor application of the Mental Capacity Act and not identifying deterioration early enough.

7.8.6 Two reviews fell short of expected good practice, where the care was thought to have a significant impact to the person's wellbeing. A safeguarding enquiry and complaints procedures were conducted and multi-agency reviews undertaken.

7.8.7 The improvements made to address the areas of concern are highlighted later in this report.

7.9 Cause of Death.

7.9.1 It is now known that people with learning disabilities are at increased risks from COVID-19 and that, unlike the general population, this is across all age groups.

7.9.2 In the previous year (2019-20) pneumonia was the most common cause of death and sepsis was second although it is noted that this year, sepsis is the most common secondary cause of death.

7.9.3 The most common cause of death this year was COVID-19, with 29 deaths being attributed to COVID-19, which represents 23% of all deaths this year. Analysis is underway to understand if this is a trend seen nationally.

7.9.4 The table below shows the top five primary and secondary causes of death.

No	Primary Cause of Death	No	Secondary Cause of Death
1	COVID-19	1	Sepsis
2	Pneumonia	2	Frailty
3	Cancer	3	Learning disability and cerebral palsy
4	Heart disease	4	COVID-19
5	Aspiration pneumonia	5	Alzheimer's/dementia

7.10 DNACPR – Do Not Attempt Cardio-Pulmonary Resuscitation.

7.10.1 During the first wave of the Covid-19 pandemic, concerns were raised about the potential for “blanket” decisions being made around resuscitation, particularly for more vulnerable populations. As a result, the Care Quality Commission undertook a review of practice across a number of systems. This review examined the understanding and application of the Mental Capacity Act, in relation to both clinical decision-making and the importance of representing the views of the individual.

7.10.2 Do not attempt cardio-pulmonary resuscitation (DNACPR) decisions are designed to protect people from unnecessary suffering through chest compressions and/or shocks in order to restart their heart. DNACPRs are often in place when the individual does not want it, when it is unlikely to work or when the harm outweighs the benefit. The DNACPR decision making process should always take account of the benefits, risks and burdens of CPR and consider the individual person’s wishes and preferences, the views of the healthcare team and, when appropriate, those close to the person.

7.10.3 Hospital Trusts and other providers are legally obliged to have a clear DNACPR policy for staff to follow. It must be accessible so that the patients and/or their families are able to understand the decision-making process.

7.10.4 In Sussex it was recognised that further advice and support was required to ensure that DNACPRs were being applied lawfully. Prompt rapid reviews, introduced at the start of the pandemic, identified the use of poor language and a lack of consultation in some DNACPR documentation.

7.10.5 In acute trusts concerns were escalated to medical directors.

7.10.6 In primary care, training was provided via a webinar, which covered application of the Mental Capacity Act, the importance of recording the clinical reasoning for the DNACPR decision, and the importance of avoiding discriminatory language.

7.10.7 LeDeR recommendations were shared with the Sussex-wide CCGs End of Life Commissioners and Clinical Leads, which resulted in a roll-out of ReSPECT training. Safeguarding discussions were held and concerns were raised to enable an enquiry to take place. Easy read information and top tips were made available on the CCGs website.

7.11 Recommendations made.

7.11.1 The table below shows the thematic analysis of recommendations made as a result of reviews in the period 2020-2021.

Theme	% featured
Application of the Mental Capacity Act	19
A lack of advanced care planning	13
Prevention of deterioration	11.5
STOMP/STAMP	8.5
Poor completion of DNACPR orders	8.5
The importance of reasonable adjustments	8.5
Annual health checks	8
Poor co-ordination of care	7
Screening not undertaken	4
Access to health promotion	3.5
Diagnostic overshadowing causing delays	3.5
Coronial difficulties	2.5

7.11.2 Examples of recommendations made in reviews include:

"Adequate information should be recorded in the notes, this would have provided greater assurance about the cause of the weight loss, and an assessment of the person's swallow arranged"

"The principles of STOMP should be included in medication reviews as part of an annual health check"

"General practice should ensure that individuals with learning disabilities and mental health needs have access to the appropriate specialist input"

"Behaviour guidelines should be available and followed to ensure that restrictive practices are minimised and safety maximised."

"GP/primary care to have a process to follow up on health screening when there is no response especially of those in risk groups. This to be clearly evidenced in the person's medical records".

8 Learning from older reviews completed in 2020-2021

8.1 In order to achieve our current review performance, a large number of reviews were completed that had originally been notified before the start of this reporting period.

8.2 A detailed report is planned to encapsulate this separate dataset.

8.3 A theme consistent across the majority of the reviews related to the difficulties experienced by reviewers in getting the information necessary to complete the Pen Portraits

8.4 Below is an example of a project aimed at improving this:

Working with older people in West Sussex

In response to a local LeDeR review recommendation on the importance of knowing a person's 'life story' to promote personalised care at the end of life, West Sussex made a successful bid for funding from the learning disabilities task and finish group, as part of the West Sussex wider dementia strategy and from the CCG to deliver 'life story' training in the region.

Life story work with people with dementia, supported by their families and/or carers helps build a personal biography of memories, photos, music and important events. It is also integral to enabling a person-centred approach in dementia and end of life care.

The series of training workshops was offered to anyone caring for, or supporting someone with a learning disability, including shared lives carers (where a person with learning disabilities lives with carers often as part of a family), care managers, community learning disability teams and those working in day services.

Facilitated by a writer – an expert in life story – and a learning disability dementia expert, the learning from the sessions will be adapted for anyone with, or at risk of, early-onset dementia and older people living in shared lives. Attendees will commit to deliver life story work before the project is evaluated for sustainability.

The life story initiative is part of a wider task and finish chairs group enabling increased awareness of those with learning disabilities in all groups including inclusion from minority ethnic communities and improving the use of technology to maintain independence.

9 Action from learning

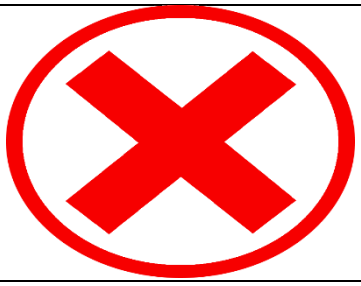
9.1 What we have learned:

Best practice and positive outcomes we have learned from reviews.	
	Nurses working behind the scenes to minimise distress and promote end of life wishes
	Person centred care being delivered including funded packages of care that are flexible and dynamic
	Services going the extra mile to enable people to die in their home, surrounded by carers they care for and who care for them
	Hospital staff going out of their way to ensure planning and reasonable adjustments are in place.
	Application of reasonable adjustments including appointments being held in a car
	Excellent bereavement support from hospices following the death of a child
	Good application of the Mental Capacity Act- supporting people to make their own decisions, which were respected
	Compassionate care in hospital when a transfer was delayed
	Collaborative care, ensuring that decisions made on behalf of someone were in-line with their beliefs and wishes
	People with learning disabilities and their carers being enabled to grieve together during the COVID pandemic
The areas for improvement that were identified in recommendations from reviews.	
	People remaining on medications without specialist oversight and/or clear diagnosis
	A lack of understanding of the importance of oral care including dentistry in the prevention of chest infection
	Better understanding of the processes and language used when completing DNACPR/ReSPECT forms
	Better care co-ordination to improve and ensure a consistent approach when a person with learning disabilities has co-morbidities
	To increase and improve the understanding of when to implement advance care planning
	The understanding and application of the Mental Capacity Act
	Access to good public health and reasonably adjusted social prescribing

	The recording of the application of the Mental Capacity Act in health records

9.2 Action from learning: What we learned about deaths from COVID-19

Best practice and positive outcomes we have learned from reviews.	
	Top tips to primary care in the flu vaccination campaign including application of the Mental Capacity Act
	We promoted pulse oximetry and made equipment available which resulted in the early identification of COVID in the first wave
	Working with and for people with learning disabilities to receive their COVID-19 vaccination including a locally enhanced service for GPs resulted in at least 86% of people receiving their first dose by 16th April 2021
	That acute hospitals went the extra mile to allow families to see or be with their loved one when they died. That this was valued by families
	We shared resources from the palliative care for people with learning disabilities network and Books Beyond Words to all those bereaved by the pandemic
	Care homes valued the regular if virtual contact they received from their GPs
	An increase of joint working was seen due to the pandemic, e.g. hospice and community teams worked more closely together
	We provided training to 207 people across Sussex in the use of RESTORE 2 mini to improve the quality of observations for people with learning disabilities.
	Further evidence that good application of the Mental Capacity Act, including the use of simple information and collaboration, enables people's wishes to be respected.
	We worked closely with the CCGs infection prevention and control team to ensure support was tailored to learning disability care settings.
The areas for improvement were identified in recommendations from reviews.	
	Visitor guidance in carers being allowed to provide support in hospitals was not always followed.
	The lack of GP face to face assessments meant that physical assessments, e.g., listening to a person's, chest were not undertaken
	Better understanding of the process and language used in the completion of DNACPR/ReSPECT forms.

	Evidence of poor application of the Mental Capacity Act.
	Face to face access to learning disabilities liaison nurses in hospital is essential

9.3 The Sussex Learning Disabilities COVID Response Partnership

9.3.1 A Sussex-wide Learning Disabilities COVID Response Partnership was established in April 2020 with four main functions:

1. To ensure that guidance and easy read information produced at pace was circulated across the system from a central point for implementation and use.
    - Across the system means NHS services including GPs, local authorities, care homes, carers, families and people with learning disabilities.

2. To promote initiatives agreed by the group as key to reducing the known inequalities people with learning disabilities experienced in this pandemic.
    - This has included training in the identification of deterioration, the importance of the flu vaccine and making sure that people with learning disabilities receive the COVID vaccination as soon as they are eligible.

3. To enable system escalation of concerns and issues that may have resulted in further inequalities for people with learning disabilities.
    - This included raising issues about care and treatment decisions, including those around resuscitation.

4. To take action as a collaborative in order to work towards overcoming the barriers that people with learning disabilities and their families and or carers may face under the circumstances of the COVID pandemic.

9.3.2 The group is inclusive, meets virtually on a fortnightly basis, and is chaired by a member of the CCG Learning Disability and Autism Team. Membership includes specialist NHS learning disability services, all three local authority commissioners in Sussex, experts in infection, prevention and control and public health, a GP, a member of the academic health sciences network and carers support. Guest speakers are welcomed and have included those running arts projects or undertaking research.

10 Learning into action:

10.1 Addressing the National Themes

10.1.1 National Sepsis Week 2020 had a learning disabilities focus. This was undertaken jointly with CCGs Quality Teams and included easy read materials as well as the publication of the 'Purple Stars Sepsis' song.

10.1.2 Training is being delivered weekly until July 2021 in Stop Look Care: identifying deterioration in people with learning disabilities. Across all care settings, this will be evaluated on conclusion of the current offer.

10.1.3 Pathways have been developed between specialist learning disability services and acute respiratory care to reduce deaths due to pneumonia. This has started in one part of Sussex with the aim of rolling it out across Sussex.

10.1.4 LeDeR is a standing agenda item at the Sussex STOMP/STAMP action group. Case studies are presented to inform prescribing practice and a business case has been developed for a specialist pharmacist in this area.

10.1.5 There was early involvement in CCG-wide flu board and subgroups, ensuring high profile communications across Sussex.

10.1.6 The Sussex 'Thumbs up' award seeks to improve the uptake, quality and outcomes of annual health checks. A kite mark to support quality improvement has been co-produced and rolled-out and there has been funding approval for a health facilitation team in East Sussex with five posts currently being recruited to.

10.1.7 There is commitment to a pan-Sussex Learning Disability and Autism Strategy, which has been signed off by the CCG in May 2021 and supports the implementation of a dynamic support register for physical health, with clear and co-ordinated outcome pathways for those at greatest risk of hospital admission.

10.1.8 Sharing learning across the CCG into multiple work-streams regarding the implementation of ReSPECT. Working across hospices, primary care networks, community Trusts and acute Trusts. Training delivered jointly with the local Academic Health Sciences in RESTORE 2 mini. (207 people have received this training so far with further sessions planned).

10.2 Sussex implementation of actions

10.2.1 Due to the unique nature of the reporting period covered in this report, a number of supplementary processes were established to ensure a quick response to recommendations coming from COVID rapid reviews and full LeDeR reviews. These included the Sussex COVID Response Partnership, which provided a mechanism for implementation and monitoring of recommendations across a range of providers, e.g. the increased use of pulse oximetry to monitor for early warning signs of silent hypoxia.

10.2.2 Provider Forums also expedited the process of learning to ensure that risks were quickly understood, mitigated and any necessary training was highlighted to staff groups, e.g. Restore-2 Mini.

10.2.3 Recommendations that were less immediate in nature, formed the basis of the Sussex Learning Disability and Autism Strategy's Health Inequalities actions, to ensure Sussex wide implementation and monitoring processes are in place.

10.3 Action from learning; Annual Health Checks

10.3.1 Throughout 2020/21 Sussex has been working towards a target of at least 67% completed for those eligible to have a health check.

10.3.2 We welcome Sussex as a county exceeding this target with performance 69.2% of eligible people receiving their health check. Our ambition for 2021/2022 is to increase this to achieve and maintain 75% by 2023-2024 while concurrently increasing the number of people with a learning disability on GP registers

	2019-20			2020-21		
CCG	Checks	Q4 Register	AHC %	Checks	Q4 Register	AHC %
Brighton and Hove	529	1412	37.5%	799	1,492	53.6%
East Sussex	1388	2984	46.5%	2,283	3,208	71.2%
West Sussex	2388	4475	53.4%	3,413	4,690	72.8%
Sussex Total	4305	8871	48.5%	6,495	9,390	69.2%

10.4 An example: The thumbs up campaign

10.4.1 Health facilitation teams in Sussex helped identify realistic targets for GP practices and Primary Care Networks and worked with them to gather the evidence required for submission. The templates were based on those requested by CQC which will also be used for any future inspections.

The award has been designed to support practices with:

- Improving the identification of people with a learning disability
- Improving the care available to patients with a learning disability
- Supporting the quality outcome framework (QOF) quality improvement (QI) domain for 20/21 and CQC evidence.

10.4.2 The Thumbs Up quality award will be presented to practices upon completion of specific areas of quality improvement for people with learning disabilities, to be defined by the self-assessment checklist. There are bronze, silver and gold level awards to be achieved by practices who can evidence the standards for being a Learning Disabilities friendly practice.

10.4.3 A full package of support is available to guide practices through the Thumbs Up self-assessment from the Sussex health facilitation teams with a self-assessment toolkit available. Quality checkers with learning disabilities have been trained to give feedback and a communications pack is available.

10.5 Action from learning: the role of cancer screening.

10.5.1 No deaths during 2020-2021 were recorded as being the result of non-attendance at cancer screening. However, recommendations were made regarding the need of attendance at abdominal aortic aneurysm (AAA) screening where deaths were attributed to cardiovascular disease.

10.5.2 Recommendations were also made regarding the need for better uptake of cancer screening including:

- A lack of follow-up when bowel screening was declined.

- No documented evidence of assessment of capacity when cervical screening was deemed not to be in a woman's best interest.
- No evidence of reasonable adjustments available to enable screening.

10.5.3 The Sussex Learning Disabilities and Autism team are working with the screening programme to increase uptake. A training, education and support plan is in development for those caring for people with learning disabilities. This is aimed at highlighting the importance of screening and the need for reasonable adjustments.

10.6 Action from learning - improving respiratory care: an example

Specialist learning disability physiotherapy, speech and language therapy teams presented, along with a respiratory consultant from an acute NHS Trust at the South East (SE) Clinical Forum. The presentation focused on work happening in Sussex led by colleagues in Sussex Partnership NHS Foundation Trust (SPFT) with Surrey and Sussex NHS Healthcare Trust focusing on all aspects of respiratory health and to booster links within the South East's respiratory sector.

The Sussex team presented a comprehensive approach to respiratory care within the network with an aim to share best practice and develop consistent pathways and training programmes across the South East region.

A new task and finish group, led by NHS England/Improvement SE, including SPFT colleagues, aims to benchmark and understand where the SE area is in relation to known best practice, for dysphagia (swallowing difficulties) pathways and training, posture and respiratory pathways, particularly aiming at those who have respiratory risks and symptoms which lead to pneumonia and increased mortality. They are undertaking a scoping exercise across the SE in April, and are planning to use the results of the scoping exercise to recommend improvements across the South East. SPFT colleagues are also now linked to the SE Respiratory Collaborative.

10.7 Action from learning: the evidence base for local priorities 2021/2022

Applying the Mental Capacity Act Recommendations raised issues with its application include:

- Assuming incapacity.
- Lack of available assessment of capacity.
- Poor understanding of the role of the independent Mental Capacity Advocate and how to seek their involvement
- Not applying the best interest checklist.

Practice to share:

- Evidence of excellent application in maximising understanding to promote choice, rights and dignity in death.
- Evidence of supported decision making in the completion of DNACPR

Prevention of deterioration Recommendations include:

- Training staff in the competencies required to undertake observations.
- Utilising tools such as stop look care RESTORE 2 mini and SBARD (situation, background, assessment, Recommendation and decision: and escalation/handover tool known to improve safety) in care settings.
- Improving the understanding of the importance of good oral hygiene in the prevention of infection.
- Ensuring that those with learning disabilities have equal access to the enhanced care home support being developing in primary care.

Practice to share:

- the use of pulse oximetry.

A lack of advanced care planning Recommendations include:

- Improving the skills in identifying that a person with dysphagia who is experiencing multiple chest infections, should have a plan recognising their views and wishes about their death.
- The need for a lead clinician to develop advance care plans.
- The need for speech and language to develop contingency and/or advance care planning when delivering ‘risk feeding ’care plans.
- Better understanding of the application of frailty scores and models for those with multi morbidities.
- Earlier referrals to hospice by acute liaison nurses and primary care.
- People should not be discharged from hospital without hospice involvement if their prognosis is terminal.

Practice to share:

- Learning disability liaison nurses working behind the scenes to enable good hospice support.
- Hospices employing learning disability facilitators.

STOMP/STAMP
Recommendations include:

- Ensuring that when a person is on more than one drug that effects mood and behaviour, without clear diagnosis, their care is overseen by a psychiatrist.
- That GPs should know when and how to refer for specialist pharmacy advice when medication is prescribed contrary to STOMP/STAMP.
- Physical health tests must be undertaken in-line with prescribing guidance, and contingency plans made when the person is unable to have such tests,

Poor completion of DNACPR orders
Recommendations include:

- Doctors ensuring that they consult others to ensure their assessment of the person's abilities are robust and balanced and don't fully rely on the current presentation. Knowing when it is required to instruct an IMCA and how to do this.
- Understanding that capacity must be formally assessed before a decision is made in the person's best interest.
- Ensuring that language used in the completion of forms is not discriminatory.
- The need to raise safeguarding concerns where appropriate.

Practice to share

- The benefit in using accessible resources in gaining consent to complete DNACPRs.

The importance of Reasonable Adjustments.
Recommendations include:

- Ensuring health promotion advice and support, such as weight loss and smoking cessation, is available to people with learning disabilities.
- That acute Trusts ensure that access to family and carers is consistent for all those with learning disabilities.
- That face to face GP appointments are available to ensure physical assessment.
- That translators are available and used when English may not be the first language of a person with learning disabilities and their family.
- For providers to ensure that they know the legal right to request reasonable adjustments for health appointments.

Practice to share

- Good planning and facilitation in reasonable adjustments.
- The benefit in video conferencing in developing trust and rapport.

10.8 Action from learning: Local priorities for delivery in 2021/2022 based on the learning from reviews locally and nationally.

10.8.1 Sussex continues to increase the rates of annual health checks for people with learning disabilities. Using the 'Thumb's Up' mark there will also be increased focus on quality and good health action plans as outcomes.

10.8.2 Cross-working between annual health checks and STOMP steering groups is needed to reduce the prescribing of medication that affect mood and behaviour without robust clinical rationale.

10.8.3 Further work with local authorities, 'Skills for Care' and Health Education England to develop a workforce plan that embeds Stop Look Care, including the development of a learning disabilities specific booklet.

10.8.4 Piloting a dynamic support tool for physical health and clear outcome pathways, including public health and social prescribing.

10.8.5 Continued work with academic health sciences network to embed RESTORE 2 mini, including in their 'deteriorating patient' safety work-stream.

10.8.6 Sussex will develop innovative ways of delivering annual health checks for those with learning disabilities and autistic people. Including pilot health checks for autistic people and delivery though secondary care, co-produced with autistic people for design, test and implementation by December 2022.

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

10.8.8 Clear pathways for people with learning disabilities who have respiratory needs requiring specialist care will be developed across the whole of Sussex.

10.8.9 Active involvement of people with learning disabilities, their families and carers will ensure improvements are co-produced.

10.9 Action from learning: the Sussex Learning Disabilities and Autism Strategy

10.9.1 A Sussex-wide strategy has been developed and ratified following broad engagement with system partners and their networks. The strategy makes the following commitments:

- To fully implement a dynamic support system for physical health inequalities by September 2022
- Community Learning Disabilities (CLDs) services: create a single service and outcomes specification that reflects recommended best practice. To work with commissioners and local providers to implement across Sussex by 2024.

- To pilot a community autism service to assess the benefits of strengthening care-co-ordination.
- Learning Disability Improvement Standards: the Sussex Learning Disabilities and Autism Health Inequalities Partnership to review the bench marking data as it becomes available and to support each provider to have plans to meet these standards by April 2024
- To develop innovative ways of delivering annual health checks for the learning disabilities and autism communities by becoming a pilot site for health checks for (1) autistic people and (2) delivery through secondary care. Working closely with experts by experience to design and test implementation by December 2022.
- To establish a STAMP service (stopping over medication of children with learning disabilities and autism) by April 2024.
- Work with experts by experience to identify and implement reasonable adjustments to the current bowel screening programme to increase uptake by people with learning disabilities including looking at younger people not yet eligible for screening by April 2022.

10.10 Action from learning: evaluating the impact

10.10.1 Learning from LeDeR and subsequent action plans will be presented to the Sussex Learning Disabilities and Autism Board (LDA Board) and health inequalities steering group. This is to ensure all parts of the system commit to understanding the needs of those with learning disabilities; to overcome the barriers to, and improve access to, good health care. Furthermore, to share learning and good practice across the system to enable the work to be embedded.

10.10.2 The LeDeR Steering Group will report into the Sussex LDA Board.

10.10.3 The Sussex LDA Board has a newly appointed shadow board made up of people with learning disabilities and autistic people. This group will act as the reference group for learning from LeDeR with biannual workshops to coproduce service improvements.

10.10.4 It is hoped that future reviews will show improvements in outcomes; such as an increase in reviews scoring 1-3 (excellent- good) and a reduction reviews scoring 4-6 and related statutory processes.

11 Conclusion

11.1 Given the unprecedented constraints placed upon individuals, families, services and systems by the Covid-19 pandemic, this report highlights a number a range of elements of good practice across Sussex as well as areas of improvement needed to ensure that we prevent premature deaths.

11.2 The significant recovery programme has been made possible with investment and system-wide commitment to mobilising resource.

11.3 Sussex has moved from being an outlier nationally, with performance being considered poor, to being regarded as progressive and responsive to the needs of the populations it serves.

11.4 Most importantly, this report highlights the systematic way by which Sussex is pursuing improvements borne out of local and national learning from LeDeR reviews. We hope that this report demonstrates the system-wide commitment to improving services for those with learning disabilities in order to ensure that the health inequalities they experience, which have been amplified by the COVID -19 pandemic, are reduced and people are supported to live fulfilling lives

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