Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) programme

Annual Report 2023/2024

Executive Summary

This annual report for 1st of April 2023 to 31st of March 2024 highlights the themes and trends, positive practice, learning ('local learning from action') and areas for improvements from completed Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) reviews. The report also acknowledges work undertaken throughout the year, activities, achievements and priority focus areas to be taken forward into next year 2024/25.

The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) LeDeR programme has continued to work closely together with system partners, to identify and lead on quality improvements to address the causes of early morbidity and preventable deaths for people in the local population with a Learning Disability and Autistic people.

There remains strong representation at the LeDeR Steering Group and LeDeR Governance Panel from Health, Social Care and Public sector organisations supported by experts by experience, together these partners have been instrumental in raising awareness of the programme. Partner organisations and stakeholders also continue to raise the profile of the programme within their own organisation.

Regular updates, along with positive practice, learning, improvements and actions are reported to the following groups across the ICB/ICS:

- Learning Disability, Autism and Down Syndrome Partnership Board (LDADSPB)
- Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board (SSASPB),
- Child Death Overview Panel (CDOP)
- System Quality Group (SQG)

The LeDeR Governance Panel has developed and strengthened significantly over the last year and provides an independent perspective on the LeDeR review sign off process. The panel ensures there is robust governance in place and includes those with lived experience; this helps ensure actions are meaningful. These actions are then driven through the LeDeR Steering Group for implementation and monitoring.

Introduction

Our vision, aim and objectives

The Staffordshire and Stoke-on-Trent LeDeR programme has maintained its primary commitment, an intention to tackle the causes of early morbidity and preventable deaths in people with a learning disability and autistic people by:

- Improving the quality of health and social care service delivery
- Reducing premature mortality and health inequalities.
- Positively influencing practice at individual, operational and strategic levels which affects the lives of the population with a learning disability and autistic people.
- Ensuring a positive patient and carer experience within the locality.

To continue achievement of these aims, the following objectives have been implemented and are currently being monitored:

- Timely allocation of notifications of death to the LeDeR platform.
- Timely completion of allocated reviews through the review team.
- Robust governance system which includes review, sign off and oversight of subsequent actions by the ICS's Local Area Contact (LAC).
- Close and collaborative working relationships with system partners to ensure identified actions are implemented and sustained.
- Raised awareness and education of the programme across the local population.

Our Statement of Purpose

In Staffordshire and Stoke-on-Trent, the LeDeR programme Statement of Purpose acknowledges that leadership is critical for the successful delivery of the LeDeR programme. The system has an Executive Senior Responsible Officer (SRO) for LeDeR and the local programme expects that local leaders at all levels will drive forward the learning outcomes from LeDeR reviews, with the Steering Group a key driver, along with positive practice, learning and improvements identified by the Governance Panel from LeDeR reviews. The intention within Staffordshire and Stoke-on-Trent, is to deliver the statement of purpose and its commitments under the NHS Long Term Plan through the ICS governance structure, with processes identified to tackle the causes of morbidity and preventable deaths in people with a learning disability and/or autism.

Progress of our LeDeR programme reviews

The contract with our commissioned partners at South Central and West (SCW) Commissioning Support Unit (CSU) commenced on the 1st of August 2021 for a period of 3 years (August 2021 - 31st July 2024). The service provision was to enable progress with the LeDeR programme reviews.

During 2023, the ICB identified several issues with the performance at SCW CSU and observed a significant reduction in the number of reviews adhering to the national 6-month deadline, along with concerns relating to the quality of the reviews being submitted and availability of reviewers and senior reviewers to undertake reviews in a timely manner. The ICB worked with the CSU on a contract variation to improve their performance and the quality of the reviews, unfortunately, the CSU were unable to sign the proposed contract variation. Therefore, towards the end of Quarter 3 of 2023/24, the decision was made by the ICB to invoke the 'step-in' (ICB taking over the completion of LeDeR reviews) process of the contract. On 1st February 2024, the contract with the CSU ceased and the responsibility and completion of LeDeR reviews was transferred back to the ICB.

The ICB have made significant progress since 1st February 2024, putting in new processes and addressing the backlog of reviews, with the help of clinical staff within the ICB Quality Team. All cases are now allocated to the ICB and cases transferred back by the CSU are being actively worked through. Whilst there are still several reviews in breach of their 6-month deadline, the position has improved and the number of breached reviews continues to

decrease. Bank staff were recruited (between January 2024 - March 2024) to the ICB to complete reviews and will begin working on reviews in 2024/25.

Demographics of our Learning Disability and Autism population notifications.

In 2023/2024, the Staffordshire and Stoke-on-Trent system received a total of 111 LeDeR notifications; 108 adult reviews, 3 Child Death Overview Panel (CDOP) reviews and 3 reviews which were received significantly late to the LeDeR platform. (The three reviews received late were from 2022 but only received by the ICB in July 2023).

From July 2023, there was no longer a requirement for deaths of children to be notified to the LeDeR programme, with reporting to only go through the CDOP process. A regular update is obtained from the ICB’s CDOP Nurse and the LAC attends CDOP panels as and when required. Positive practice, learning and improvements identified from CDOP cases are reported into the LeDeR Steering Group and LeDeR Governance Panel.

Of the 108 adult cases, 104 were initial reviews; 89 initial LD, and 15 LD/A (dual diagnosis of LD and Autism) reviews, and 4 were focused reviews; 2 LD/A, 1 LD and 1 Autism only. At the time of writing, 30 of the initial reviews have progressed to focused reviews; mostly owing to the individual having a ReSPECT form in place (local focused criteria 2023/24), and a further 6 reviews have been deemed out of scope, owing to no formal diagnosis or evidence of the individuals having a Learning Disability and/or Autism.

As per the NHS England National Guidance and Policy, reviewers have 6 months to complete the review from the date of notification. At the time of writing, of the 108 adult notifications received for 2023/24, 35 (33%) reviews have been completed, quality assured and closed by the Staffordshire and Stoke-on-Trent system at year end. There are a total of 67 reviews to be completed in 2024/25 and these are at various stages. Their statuses are outlined below:

- 30 with ICB/Bank reviewers
- 27 new reviews currently unallocated to a reviewer
- 10 on hold owing to ongoing external investigations

Table:1 Breakdown of notifications over each quarter in 2023/24

Quarter	Total No. of reviews	Adults	CDOP	Initial	Focused	Out-of-Scope	Autism Only	LD/A (inc. in the Initial & Focussed)	Initial to Focussed
Q1	28	25	3	27	1	5	1	2	7
Q2	18	18	0	18	0	0	0	2	4

Quarter	Total No. of reviews	Adults	CDOP	Initial	Focused	Out-of-Scope	Autism Only	LD/A (inc. in the Initial & Focussed)	Initial to Focussed
Q3	34	34	0	34	0	1	0	9	13
Q4	31	31	0	28	3	0	0	6	6
Total	111	108	3	107*	4	6	1	19	30

*includes 3 CDOP cases

One of the main reasons reviews have been changed from initial to focused during 2023/24 is because the ICS wanted to undertake a deep dive on the quality of the ReSPECT documentation following some learning and improvements identified from reviews during 2022/23. A further reason that initial reviews have been converted to focused reviews was because several cases identified in the initial review that there was a significant amount of learning and improvements from the initial review.

Table 2 below demonstrates the comparison between 2022/23 and 2023/24 notifications and the type of notification received. The data demonstrates a 29% increase in the number of notifications received from the previous year. It is difficult to determine why there has been such an increase in notifications i.e. this may be a result of increased promotion of the programme in 2023/24, leading to increased notifications or it may unfortunately be because more people living with a learning disability and/or autistic people have died across Staffordshire and Stoke on Trent.

Table 2: Breakdown of notifications yearly comparison

Year	Total No. of reviews	Initial	Focused	CDOP	Out-of-Scope	Initial to Focussed	Autism Only	LD/A (inc. in the Initial & Focussed)
2022/23	86	66	7	11	2	5	1	2
2023/24	111	104	4	3	6	30	1	19
Trend	↑ (+29%)	↑ (+56%)	↓ (-43%)	↓ (-73%)*	↑ (+200%)	↑ (+500%)	→	↑ (+850%)

*Noting that only those CDOP cases from April to June 2023 were reported

Table 3 below shows the average age of death for 2023/24 and how this compares across the four quarters of the year. In 2023/2024, the Staffordshire and Stoke-on-Trent system have not observed much fluctuation in the average age at death; with Q1 at 62 and Q4 at 62 also, rising

slightly in Q2 to 63 and dipping slightly in Q3 to 61. These figures are significantly higher than the previous two years which only managed to reach 57 years, as demonstrated in Table 4.

These figures could potentially demonstrate that significant improvement has been made and seen over the last year to reduce the average age of death for people living with a Learning Disability and/or Autistic people. However, further work is still required to further improve the premature mortality of individuals with a Learning Disability and/or Autistic people.

Table 3: Breakdown of average age at death in 2023/24

Programme Dates	Quarter 1 01/04/23 to31/06/23	Quarter 2 01/07/23 to 30/09/23	Quarter 3 01/10/2023 to 31/12/2023	Quarter 4 01/01/2024 to 31/03/2024
Average age at death	62	63	61	62
Trend	→	↑	↓	↑

Table 4: Average age at death comparison with previous years

Year	2020/2021	2021/2022	2022/2023	2023/2024
Average age at death	**57**	**57**	**52**	**62**
Trend	↑	→	↓	↑

Table 5 below shows the age range at death for individuals in 2023/24 and how this compares across the four quarters of the year. The 0-19 age range saw a decline in notifications after Q1, going from 3 to 0. The 19-49 age range saw an initial decline in Q1, from 5 notifications to 1, but then went back up to 5 notifications in Q4. The 50-69 age range fluctuated across the year seeing a peak in Q3, increasing from 12 notifications in Q2 to 23 in Q3. The 70-84 age range saw a slight drop in notifications during Q2, 5 notifications down from 9 in Q1, but then increased to 8 notifications each in Q3 and Q4.

Table 5: Comparison of age range at death over the year

	Age ranges at Death				
Quarter	**0-18**	**19-49**	**50-69**	**70-84**	**85 and over**
01/04/23 to 31/06/23	3 (12%)	5 (20%)	7 (28%)	9 (36%)	1 (4%)
01/07/23 to 30/09/23	0 (0%)	1 (5%)	12 (67%)	5 (28%)	0 (0%)
01/10/23 to 31/12/23	0 (0%)	3 (9%)	23 (68%)	8 (23%)	0 (0%)
01/01/24 to 31/03/24	0 (0%)	5 (16%)	17 (55%)	8 (26%)	1 (3%)
Trend	→	↓	↑	↓	↑

Table 6 below shows the average age of death when compared with previous years, which highlights an increase of notifications within the higher age brackets (50-69, 70-84, 85 and over), which is positive to note and could be interpreted as an improving picture with

individuals living longer. However, there also been a slight increase in notifications within the 19-49 age bracket from previous years.

Table 6: Breakdown of age ranges at death from previous years

Age ranges at Death					
Year	**0-18**	**19-49**	**50-69**	**70-84**	**85 and over**
01/04/20 to 31/03/21	6 (7%)	19 (23%)	35 (43%)	16 (20%)	6 (7%)
01/04/21 to 31/03/22	9 (13%)	9 (13%)	33 (47%)	17 (24%)	2 (3%)
01/04/2022 to 31/03/23	9 (10%)	16 (19%)	40 (47%)	18 (21%)	1 (1%)
01/04/2023 to 31/03/2024	3 (3%)	14 (13%)	59 (55%)	30 (27%)	2 (2%)
Trend	↑	↑	↑	↑	↑

Although there was an increase in the total number of notifications this year when compared with figures from previous years, there was a smaller difference of 9% in male and female notifications.

Notifications of deaths from Ethnic Diverse Groups (EDG), continues to be extremely low, and for 2023/24 particularly, there was only one case identified as an EDG in comparison to 7 cases in the previous year. The system continues to observe consistently low notifications of deaths from our EDG population and is working collaboratively with system partners to continually raise awareness of the programme with ethnic diverse populations. At the time of writing, the team are currently waiting for translated materials to be printed so these can be shared with EDGs. LeDeR leaflets will be available in the following languages; English, Arabic, Bengali, Kurdish, Panjabi, Polish, Romanian and Urdu. Alternative and innovative ways to reach these groups are also being considered and attendance at local ethnic diverse groups has been now established, which have been very positive.

Table 7: Comparison of gender and ethnicity in 2023/24

Gender & Ethnicity	**Quarters in 2023/24**							
	01/04/23 to 30/06/23		**01/07/23 to 30/09/23**		**01/10/23 to 31/12/23**		**01/01/24 to 31/03/24**	
Gender	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
	11 (42%)	13 (50%)	11 (61%)	7 (39%)	19 (56%)	12 (35%)	16 (52%)	15 (48%)
Ethnicity	**White**	**EDG**	**White**	**EDG**	**White**	**EDG**	**White**	**EDG**
	23 (88%)	1 (4%)	17 (94%)	0 (0%)	28 (82%)	0 (0%)	28 (90%)	0 (0%)

** EDG = Ethnic Diverse Group*

Please note: For 2023/24 there were 5 cases where gender was stated as ‘prefer not to say’ and 12 cases where the ethnicity was stated as ‘prefer not to say’.

Table 8: Comparison of gender and ethnicity in previous years

Gender & Ethnicity	Year 2020/21 01/04/20 to 31/03/21		Year 2021/22 01/04/21 to 31/03/22		Year 2022/23 01/04/2022 to 31/03/2023		Year 2023/24 01/04/2023 to 31/03/2024	
Gender	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
	55 (67%)	27 (33%)	40 (57%)	30 (43%)	49 (60%)	32 (40%)	57 (51%)	47 (42%)
Trend	→	→	↓	↑	↑	↓	↓	↑
Ethnicity	**White**	**EDG**	**White**	**EDG**	**White**	**EDG**	**White**	**EDG**
	81 (99%)	1 (1%)	68 (97%)	2 (3%)	65 (90%)	7 (10%)	97 (87%)	1 (1%)
Trend	→	→	↓	↑	↓	↑	↓	↓

Please note: For 2023/24 there were 5 cases where gender was stated as ‘prefer not to say’ and 12 cases where the ethnicity was stated as ‘prefer not to say’.

Table 9 below highlights that out of the 35 cases reviewed and closed, most of the individuals died in their Residential/Nursing Homes, Hospices and Supported Living settings (17), this was closely followed by acute settings (16) and two individuals died in their own homes.

In comparison with previous years, this shows a significant improvement in the number of deaths in residential/nursing homes, supported living and hospices and similarly a significant reduction in the number of deaths in acute settings.

Whilst this data is a move in the right direction, it highlights that there continues to be too many people dying in an acute setting, when their ReSPECT form outlines that their preferred place of death is an alternative location (their home, hospice etc). Work will continue with system partners to improve awareness and promote the involvement of our Learning Disability Nurses and Learning Disability Acute Liaison Nurses, to better support a personalised approach to End of Life Care planning and use of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) documentation to support people with a Learning Disability and/or Autistic people to express their choices and wishes in the event of an emergency. We will also work closely with the LDADSP Board on the Joint Strategic Needs Assessment (Housing subgroup) on how we can support people to remain in their own home if that is their preference as they enter the end stages of their life.

Table 9: Breakdown of place of death in 2023/24

Place of death	Hospital (Acute/Community)	Nursing/ Residential/Hospice	Own Home	Other
Total number	16	17	2	0

Table 10: Comparison of place of death in previous years

Year	Place of death			
	Hospital (Acute/Community)	Nursing/ Residential/Hospice	Own Home	Other
2021/22	41 (59%)	19 (27%)	8 (11%)	2 (3%)
2022/23	39 (63%)	13 (21%)	7 (11%)	3 (5%)
2023/24	16 (45%)	17 (49%)	2 (6%)	0 (0%)
Trend	↑	↑	↓	↑

Findings from our reviews

As previously mentioned, during 2023/24, the ICB LeDeR programme team wanted a more thorough review on the quality of ReSPECT documentation following learning identified in 2022/23. All reviews where an individual had a ReSPECT form in place at the time of their death (in an acute setting or residential/care home), therefore triggered a focused review to be completed. Due to the issues outlined with SCW CSU, these reviews have not progressed and completed as planned. However, the ICB are currently in progress of completing these reviews and learning will be shared via the quarterly reports in 2024/25.

Table 11 below provides an overview of the causes of death for the 35 notifications reviewed and closed in 2023/2024. **Please note: 3 reviews within the data below were from reviews notified in 2022/23 but completed and closed in 2023/24.**

Please note that the remaining 67 reviews have not yet been completed so, whilst some cases have an identified cause from the cause of death certificate for example, others have not had this available and will be confirmed upon completion.

The reason some cases do not have a confirmed cause of death can be for the following reasons:

- Review is on hold as part of a sperate investigation process – e.g. Police, Coroner, Legal
- We are awaiting further information or documentation
- There is a backlog or blockages in the completion of Structured Judgement Reviews with acute provider
- The review has not yet been completed.

The local LeDeR programme continues to work closely with all system partners to address barriers and prevent any delays, where possible.

Table 11. Cause of death

Main causes of death from notifications	01/04/23-30/06/23		01/07/23-30/09/23		01/10/2023-31/12/2023		01/01/2024-31/03/2024	
	No.	%	No.	%	No.	%	No	%
Pneumonia/respiratory	5	14%	2	6%	3	8%		
Brain Tumour					1	3%		
Cardiovascular Diseases	7	20%	5	14%	5	14%		
Dementia	1	3%						
Natural causes/old age					1	3%		
Cancer (end stage and metastatic)	2	6%			2	6%		
Sepsis	1	3%	2	6%				
Renal					1	3%		
Reviews not yet completed or out of scope								
Awaiting outcome of LeDeR Review	6	5%	5	4%	25	22%	31	28%
LeDeR reviews out of scope	5	4%			1	1%		

Table 12 provides a summary of the causes of death for the reviews completed in 2023/24 and how they compared to cause of deaths in previous years.

Table 12. Cause of death previous years comparison

Main causes of death from notifications	2021/22		2022/23		2023/24		Trend
	No.	%	No.	%	No.	%	
Pneumonia/respiratory	10	14%	26	37%	9	9%	↓
Covid-19	3	4%	2	3%			
Epilepsy	1	1%	1	1%			
Cardiovascular Diseases	8	11%	7	10%	13	13%	↑
Pulmonary Embolism	2	3%			3	3%	→
Kidney Failure	3	4%					
Dementia	8	11%	2	3%	1	1%	→
Natural causes	8	11%	2	3%	1	1%	↓
Cancer (end stage and metastatic)	5	7%	7	10%	3	3%	↓

Main causes of death from notifications	2021/22		2022/23		2023/24		Trend
	No.	%	No.	%	No.	%	
Batten's Disease	1	1%					
Gut Failure	1	1%					
Choking	1	1%					
Sepsis	3	4%	4	6%	3	3%	↓
Brain tumour					1	1%	→
Renal disease					1	1%	→
Unknown	5	7%					
Awaiting outcome of LeDeR Review	11	16%	19	27%	67	66%	↑

Data demonstrates that cardiovascular disease was the main cause of death of individuals with a Learning Disability and/or Autistic people during 2023/24. Cardiovascular disease is a general term that describes a disease of the heart or blood vessels and can include conditions such as coronary heart disease and strokes. There are many contributing factors that may cause cardiovascular disease for example; high blood pressure, diabetes and being overweight/obese.

There is ongoing work within the system to support individuals with a learning disability and/or Autistic people to access groups which will help them with their diet and fitness. Annual Health Checks are also completed by the GP yearly, which helps identify any areas where the individual may need support and also the creation of a health action plan. Further work and engagement is required from our Health Inequalities colleagues within the ICB portfolio to link the improvement work into the core 20+5 programme of work across the system.

Pneumonia and respiratory illnesses continued to be one of the highest causes of deaths after cardiovascular disease, so the decision has been made by the ICB to complete focused reviews in 2024/25, where the cause of death is pneumonia or community acquired pneumonia or other respiratory related causes of death. In the meantime, training continues to be provided to care providers and carers in relation to dysphagia. It could be suggested that the significant reduction of deaths from aspiration pneumonia from previous years (from 37% to 9%) may well be due to the training that has already been provided by the Speech and Language Team during this year.

For completeness, the causes of death for three CDOP cases reported during Q1 are detailed below. Only one of the three cases has been closed at the time of writing, the remaining two are ongoing, so formal causes of death will be confirmed upon completion.

Table 13. Cause of death for CDOP cases

Main causes of death from notifications	01/04/23-30/06/23		01/07/23-30/09/23		01/10/2023-31/12/2023		01/01/2024-31/03/2024	
	No.	%	No.	%	No.	%	No	%
Krabbe Disease	1	33%						

Positive Practice identified from reviews in 2023/24

Many of our reviews continued to identify positive practice across all quarters of the year, which included the following:

- Regular medication reviews
- Good use of Hospital Passport for individuals
- Individuals up to date with vaccinations
- Individuals offered and some also received screening.
- Good communication between GP practice and care home, residential and supported living
- Regular ward rounds between GPs and care settings
- Excellent care provided by LD nurses to individuals.
- Excellent care provided by care staff within care providers.
- Good/excellent care provided by Hospital staff.
- Good use of advocates and advocacy services
- Good use of reasonable adjustments for individuals, by Primary and Secondary Care
- Good collaborative/MDT working between services.
- Regular reviews in Primary Care e.g. Asthma, Epilepsy, Dementia, Diabetes etc
- Day care centre staff offering to stay with individuals at hospital when family were unable to attend.

Learning identified from reviews in 2023/24

Our reviews however, also identified some areas for improvement, including:

- Availability of acute liaison nurse to individuals
- Lack of input from Community Learning Disability Team
- End of Life care should have been considered sooner.
- Lack of communication to inform services that individuals have died e.g. Epilepsy
- One individual would have benefitted from an autism diagnosis.
- Several individuals should have received the pneumococcal vaccination.
- Individuals not receiving bereavement support or necessary referrals for counselling.
- No emergency medication for Epilepsy

Where reviews highlight quality issues with the independent care sector i.e. care homes, work is ongoing with local authorities to ensure this is captured and fed in as soft intelligence to the

relevant local authority who have a responsibility under the Care Act 2014 to quality monitor this sector.

Improvements made as a result of reviews completed in 2023/24

Where learning and improvements have been identified from reviews, these have been discussed at the LeDeR Steering Group, themed/trended, prioritised, and taken forward as ‘Learning into Action’ during 2023/24, the progress of which is captured below:

- The Steering group now has more representation from providers across the system which allows the group to share learning and improvements, reaching a wider audience.

- A LeDeR conference was hosted on the 6th July 2023, to highlight and raise awareness of the LeDeR programme locally outlining work undertaken to date and services/support that is available across Staffordshire and Stoke-on-Trent. This involved key speakers locally from the ICS/ICB (Primary Care, Acute Hospitals, Community Healthcare Providers, Voluntary sector, Social Care) and regionally (NHSE, LeDeR Programme Leads and people with lived experience). The event was well attended from partners across the system and was a huge success. Feedback provided by delegates was very positive, with minor improvements areas identified.

- Advocacy Hub website produced by Asist (local advocacy service) for families, carers and professionals. The aim of the website is to provide advocacy support and resources for those caring for individuals living with a learning disability and/or autistic people. Please see link: Home | The Advocacy Hub

- Continued promotion of health passport with Primary Care and the care sector. A FAQ (Frequently Asked Questions) document has been produced to sit alongside the Health Passport following feedback from the local population and experts by experience, this provides clarity on common questions about the health passport.

- Creation of pre-awareness animation video about Dysphagia, produced for LD and Autism residential homes, care homes and supported living providers to promote uptake of Dysphagia training. Please see link to the video. https://www.youtube.com/watch?v=TKU3xo8VmZ4&feature=youtu.be

- Rollout and implementation of Dysphagia training across the whole county by the Speech and Language Teams at MPFT and NSCHT as part of ‘Local Action into Learning’ identified from previous reviews.

- A system wide LeDeR Action Plan has now been produced, the action plan outlines the system wide priority areas for the LeDeR Programme. The action plan is presented to the LeDeR Steering group on a quarterly basis for review, oversight and assurance.

- Further work has progressed to obtain input from experts by experience (those living with a Learning Disability and/or Autism) into the LeDeR Programme. The LAC attends and will continue to attend the Men Embracing Learning Disability (MELD) Group. The group is co-ordinated and chaired by Midland Partnership Foundation University Trust. The LAC attends to promote LeDeR and obtain the groups views and input in relation to learning and improvements for those living with a Learning Disability and/or Autism. The LAC and LD Nurses (NSCHT) established an expert by experience group which will takes place monthly to obtain their views, input and expertise into the LeDeR Programme and improvements.

- A local LeDeR video has been produced and includes experts by experience. The video has been shared via social media channels, on the ICS/ICB website and with the Steering Group and Governance Panel members for wider dissemination.

- The Programme has continued to work collaboratively with the LDADSP Board on the ICB/ICS Learning Disability and Autism 5 year plan, aligning local LeDeR priorities and ‘learning into action’ with the LDADSAP Board workstreams and Joint Strategic Needs Assessment (JSNA) (October 2022) findings and recommendations.

- The ICB successfully in-housed the LeDeR programme review service from SCW CSU. Bank reviewers have been appointed and the backlog of reviews is being worked through.

- The LAC has attended several events/meetings across the system to present and promote the LeDeR Programme, including EDG events and groups.

- An easy read Breast Screening video has been produced and is aimed at promoting awareness of the service for those living with a learning disability and/or autistic people. A Makaton version is currently being produced. Positive feedback has been received from the experts by experience that it has been shared with.

Actions to be taken forward into next year 2024/25

- Feedback on learning, improvements and positive practice will continue to be shared with relevant services and stakeholders.

- Promotion and awareness of the importance of screening and completion of health action plans will continue to be shared with the ICB Primary Care Team and Dr Waheed Abassi (Clinical Director for the ICB Mental Health Portfolio).

- The LAC will continue to work with both Local Authorities to promote LeDeR and the use of the health passport across their commissioned care settings (supported living, residential homes, care homes etc).

- Continued production of a bi-monthly briefing which will be shared with health and care professional/teams, highlighting positive practice, learning and improvements identified from reviews.

- It has been recognised following learning from local reviews and the publication of the Clive Treacy Guidance and Checklist, that providers would benefit from epilepsy awareness training. Funding has been secured via the 'Local Learning into Action' Funding for 2024/25.

- Going forwards into 2024/25, a focused review will be undertaken where individuals have died from respiratory related conditions i.e. Aspiration pneumonia, community acquired pneumonia. This will allow learning and improvements to be identified with system partners to raise awareness and make necessary improvements.

- The quality of Annual Health Checks will continue to be reviewed as part of the LeDeR review process and ensure feedback is provided to the ICB Primary Care Team and GP practices.

- Continued work around a suite of videos to raise awareness about the national cancer screening programmes aimed at those living with a learning disability and/or autistic people.

- Circulation of the translated leaflets and flyers previously discussed will take place once printed. The leaflets and flyers will be available in English, Arabic, Bengali, Kurdish, Panjabi, Polish, Romanian and Urdu. It is hoped that this will increase our notification from EDGs.

- We will continue to work with the ICB Communication and Engagement Team to refresh and amend the ICB LeDeR website pages to ensure they are more user friendly to individuals that have an LD and/or Autism. e.g. Information provided in read easy format, social stories, translated into different languages for EDG, videos in BSL and Makaton.

- Increase engagement and gain more experts by experience/people with lived experience across the county to become members of our Steering Group and Governance Panel, particularly those from EDGs.

- To promote the programme with Autism groups, EDGs and stakeholders.

- The ICB LeDeR programme team will review the LeDeR strategy to ensure it reflects the work planned over the coming years.

Conclusion

In summary, huge amounts of progress has been made by the local LeDeR Programme in 2023/24 to improve the quality of health and social care service delivery for people living with a Learning Disability and/or Autistic people, reducing premature mortality and tackling health inequalities. The ICB will continue to work with system partners to further promote the Health Passport, the importance of Annual Health Checks and produce informative resources for example screening videos and easy read/accessible leaflets and flyers along with many more things to help make the life of those living with a Learning Disability and/or Autistic people more accessible and reduce health inequalities. Translated leaflets and flyers

will be distributed to those hard-to-reach groups and more work will be undertaken to better understand how they can be supported.

Aspiration pneumonia has remained a high cause of death identified from reviews in 2023/24, following the trend of previous years. The pre awareness video aims to further raise awareness and educate carers/care providers of the importance of safer eating and drinking, and training sessions will continue to be delivered during 2024/25.

The LeDeR Programme action plan for 2024/25 is currently being refreshed and co-produced with system partners to ensure full system ownership and involvement. Progress of the plan will be monitored by the LeDeR Steering Group on a quarterly basis, with updates provided to the LDADSPB, SSASPB, CDOP and SQG.

Regardless of the achievements and improvements made in 2023/24, there remains challenges for the local system to address moving forward into 2024/25. Progress is being made daily with the backlog of reviews inherited from SCW CSU, and it is hoped that over the next few months we will be in a better position, with national timelines being met. Improvement work will also be a main priority across the system to ensure that those living with a Learning Disability and/or Autistic people continue to get the support they need and that it is accessible and equal to all.