Staffordshire and Stoke-on-Trent
Integrated Care System

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

Annual Report 2024/25

Executive summary

This annual report for the year from 1 April 2024 to 31 March 2025 highlights the themes and trends, positive practice, learning and areas for improvements from completed reviews carried out by the LeDeR programme – learning from the lives and deaths of people with a learning disability and autistic people. The report also acknowledges work undertaken throughout the year, activities, achievements and priority focus areas to be taken forward into next year, 2025/26.

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

Regular updates, along with positive practice, learning, improvements and actions are reported to the following groups across the Integrated Care Board (ICB) and ICS:

- Learning Disability, Autism and Down's 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 provides an independent perspective on the LeDeR review sign-off process. This has developed and strengthened significantly over the last year. The panel ensures there is robust governance in place and includes those with lived experience which helps ensure actions are meaningful. These actions are then driven through the LeDeR Steering Group for implementation and monitoring.

Introduction

Our vision, aims 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 the 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
- A robust governance system which includes review, sign-off and oversight of subsequent actions by the Integrated Care System’s Local Area Contact (LAC)
- Close and collaborative working relationships with system partners to ensure identified actions are implemented and sustained
- Increased awareness and education about 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.

This is initiated with the Steering Group, along with positive practice, learning and improvements identified from LeDeR reviews by the Governance Panel. The intention in 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.

Progress of our LeDeR programme reviews

As advised in our 2023/24 annual report, NHS Staffordshire and Stoke-on-Trent ICB had identified several issues with the performance at South Central and West Commissioning Support Unit (CSU) – the commissioned provider to complete LeDeR reviews on behalf of the ICB.

There was 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 the 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 performance and the quality of the reviews, but unfortunately the CSU were unable to sign the proposed contract variation.

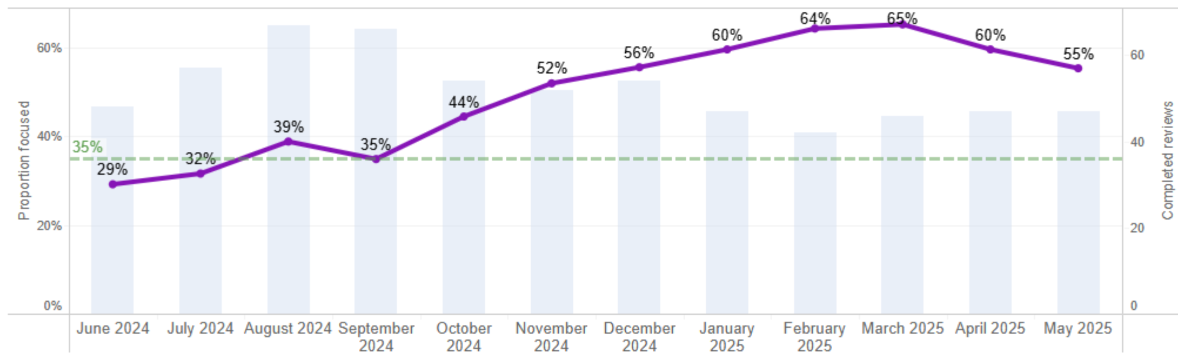
Towards the end of 2023/24, the ICB decided to invoke the 'step-in' (where the ICB takes over the completion of LeDeR reviews) process of the contract. On 1 February 2024, the contract with the CSU ceased and the responsibility for completion of LeDeR reviews was transferred back to the ICB.

Since that time, the ICB has recruited and established an internal bank LeDeR review team, with performance against the national key performance indicators (KPIs) improving month on month (see Figure 1 below). Reviews were also completed by clinical staff within the ICB Chief Nursing and Therapies Officer (CNO) Directorate while the LeDeR review team was being recruited.

The ICB completed the backlog of all historic reviews inherited from the previous service provider, closing 47 reviews relating to notifications in 2022/23 and 2023/24.

Figure 1: Proportion of all reviews completed within 6 months of notification (6-month rolling period) – Staffordshire and Stoke-on-Trent ICB

Figure 2: Proportion of completed focused reviews (6-month rolling period) – Staffordshire and Stoke-on-Trent ICB



Demographics of our learning disability and autism population notifications

In 2024/25, the Staffordshire and Stoke-on-Trent system received a total of 71 LeDeR notifications; 65 adult reviews and 6 Child Death Overview Panel (CDOP) reviews.

From July 2023, there was no longer a requirement for deaths of children to be notified to the LeDeR programme. Instead, these are reported through the CDOP process. A regular update is obtained from the ICB's CDOP Nurse, and the Local Area Contact 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 65 adult cases, the reviews were categorised as follows:

- 34 initial learning disability (LD)
- 2 LD/A (dual diagnosis of LD and autism)
- 5 focused reviews (4 LD and 1 autism only), with 23 reviews converted to focused reviews as the cause of death was respiratory related (local focused criteria for 2024/25).

A breakdown for each quarter can be found in Table 1 below. The ICS sought to undertake a more detailed review in relation to causes of death where the medical death certification was 1a) respiratory related. A further reason that initial reviews were converted to focused reviews was because the initial review phase identified a significant amount of learning and improvements for the system and providers.

A total of 5 reviews were deemed out of scope, owing to no formal diagnosis or evidence of the individuals having a learning disability.

As per NHS England's national guidance and policy, the ICB has 6 months to complete each LeDeR review from the date of notification. Of the 65 adult notifications received for 2024/25, 32 (49%) reviews have been reviewed, completed, quality-assured and closed by the Staffordshire and Stoke-on-Trent system at year end. A total of 33 reviews remain to be completed.

These are at various stages:

- 20 reviews are currently allocated to a reviewer and being worked on, all within the 6-month timeframe. None of these reviews have breached the 6-month deadline.
- 13 reviews are on hold owing to ongoing external investigations, such as coroner inquests, police investigations or Adult Safeguarding Reviews.

Table 1: Breakdown of notifications over each quarter in 2024/25

Type of notification	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25	2024/25 total
Total number of reviews (excludes out of scope)	**20**	**15**	**21**	**15**	**71**
Adults	18	13	19	15	65
Child Death Overview Panel (CDOP)	2	2	2	0	6
Initial	8	5	11	10	34
Focused	1	0	3	1	5
Out of scope	1	0	1	3	5
Autism only	0	1	0	0	1
LD/A (includes in the initial and focused)	0	0	1	1	2
Initial to focused	9	7	4	3	23

Table 2 below demonstrates the comparison between 2022/23 and 2024/25 notifications and the type of notification received. The data demonstrates a 26% decrease in the number of notifications received from the previous year.

It is difficult to determine why there has been such a decrease in notifications. This could be interpreted positively as a consequence of improvements made in the care and services provided to people with a learning disability and autistic people, resulting in a reduction in the number of deaths and therefore notifications from the previous year.

Autism-only notifications remain low, which is consistent with previous years. In 2024/25, the LeDeR programme team worked with local autism charities, the local authorities and mental health providers to increase the number of autism-only notifications. Intelligence and information from these meetings show only a small number of deaths for autistic people locally, which is a positive. The number of CDOP cases increased from last year but is lower than that reported in 2022/23.

Initial reviews to focused reviews are on a downward trend from last year. However, as illustrated in Figure 2 above, the ICB has overachieved against the national target for the proportion of completed reviews that were focused reviews (35% or more).

Table 2: Number of notifications yearly comparison

Type of notification	2022/23	2023/24	2024/25	Trend
Total number of reviews	**86**	**111**	**71**	↓ (-26%)
Initial	66	104	65	↓ (-37%)
Focused	7	4	5	↑ (+20%)
Child Death Overview Panel (CDOP)	11	3	6	↑ (+50%)
Out of scope	2	6	5	→
Initial to focused	5	30	23	↓ (-23%)
Autism only	1	1	1	→

Table 3 below shows the average age of death for 2024/25 and how this compares across each quarter of the year. In 2024/25, the Staffordshire and Stoke-on-Trent system observed a decrease in the average age at death during the year: 63 in Q1, 62 in Q2, decreasing in Q3, but increasing again in Q4. The average age at death is lower than the previous year, but higher than in 2022/23 and 2020 to 2022, as demonstrated in Table 4.

This data demonstrates that more improvement is still required to reduce the average age of death for people living with a learning disability and autistic people. It could be interpreted that the average age of death has decreased in line with the reduction of notifications in 2024/25, mirroring that of previous years (2021–23). However, the ICS acknowledges that further work is still required to further reduce the premature mortality of individuals with a learning disability and autistic people.

Table 3: Breakdown of average age at death in 2024/25

Average and trend	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25
Average age at death	63	62	56	58
Trend	→	→	↓	↑

Table 4: Average age at death comparison with previous years

Average and trend	2020/21	2021/22	2022/23	2023/24	2024/25
Average age at death	57	57	52	62	59
Trend	↑	→	↓	↑	↓

Table 5 below shows the age range at death for individuals in 2024/25 and how this compares across each quarter of the year. The 0–18 and 19–49 age ranges saw an increase in each quarter after Q1. The 50–69 age range decreased from Q1 over Q2–Q4. The 70–84 age range observed a fairly consistent number of notifications across the year. It's positive to observe the increase in notifications in the 85 and over age range in Q3 and Q4.

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

Age range at death	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25	2024/25 total	Trend
0–18 (includes CDOP cases)	2 (10%)	2 (13%)	3 (14%)	0 (0%)	**7**	↓+
19-49	0 (0%)	2 (13%)	3 (14%)	4 (27%)	**9**	→
50-69	13 (65%)	6 (40%)	7 (34%)	6 (40%)	**32**	→
70-84	5 (25%)	5 (34%)	4 (19%)	4 (27%)	**18**	→
85 and over	0 (0%)	0 (0%)	4 (19%)	1 (6%)	**5**	↓-

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 (70–84 and 85 and over), which could be interpreted as an improving picture with individuals living longer.

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

Age range at death	2020/21	2021/22	2022/23	2023/24	2024/25	Trend
0–18	6 (7%)	9 (13%)	9 (10%)	3 (3%)	6 (9%)	↑-
19-49	19 (23%)	9 (13%)	16 (19%)	14 (13%)	9 (12%)	↓+
50-69	35 (43%)	33 (47%)	40 (47%)	59 (55%)	32 (46%)	→
70-84	16 (20%)	17 (24%)	18 (21%)	30 (27%)	18 (26%)	→
85 and over	6 (7%)	2 (3%)	1 (1%)	2 (2%)	5 (7%)	↑+

Although there was a decrease in the total number of notifications this year when compared with figures from previous years, there remains a small difference of 12% in male and female notifications.

In 2024/25, notifications of deaths from ethnic diverse groups (EDG) continued to be extremely low, and mirrored the same number received in 2023/24 (1). The system continues to observe consistently low notifications of deaths from our EDG population and has worked with system partners to continually raise awareness of the programme with ethnic diverse populations.

Please see the **high impact section** of the report which provides further detail and information on the actions taken during the year to address this issue.

Table 7a: Comparison of gender in 2024/25

Gender	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25
Male	14 (78%)	5 (30%)	10 (53%)	6 (40%)
Female	4 (22%)	7 (62%)	9 (47%)	8 (53%)
Preferred not to say	0 (0%)	1 (8%)	0 (0%)	1 (7%)

Table 7b: Comparison of ethnicity in 2024/25

Ethnicity	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25
White	17 (94%)	12 (92%)	17 (89%)	14 (93%)
Ethnic diverse group	1 (6%)	0 (0%)	0 (0%)	0 (0%)
Preferred not to say	0 (0%)	1 (8%)	2 (11%)	1 (7%)

Table 8a: Yearly comparison of gender

Gender	2020/21	2021/22	2022/23	2023/24	2024/25
Male	55 (67%) →	40 (57%) ↓	49 (60%) ↑	57 (51%) ↓+	35 (56%) ↓+
Female	27 (33%) →	30 (43%) ↑	32 (40%) ↓+	47 (42%) ↑	28 (44%) ↓+

Table 8b: Yearly comparison of ethnicity

Ethnicity	2020/21	2021/22	2022/23	2023/24	2024/25
White	81 (99%) →	68 (97%) ↓	65 (90%) ↓	97 (87%) ↓	60 (98%) ↑-
Ethnic diverse group	1 (1%) →	2 (3%) ↑	7 (10%) ↑+	1 (1%) ↓-	1 (2%) ↓-

Table 9 below highlights that, out of the 32 cases reviewed and closed, most of the individuals died in an acute setting/hospital (20) in comparison with the previous year (please see Table 10). Compared with 2023/24, there was an increase in the number of deaths in an acute setting/hospital and a reduction in the number of individuals dying in their own home or a residential home, nursing home or hospice.

Further improvement work is required in relation to advanced care planning, end of life care and ReSPECT forms, as there continues to be too many people dying in an acute setting.

Please see the **high impact actions** section which provides detail and information on the actions being taken to address this issue.

Table 9: Breakdown of place of death in 2024/25

Place of death	2024/25
Hospital (acute or community)	20
Hospice	2
Residential home or nursing home	5
Own home	5

Table 10: Places of death compared with previous years

Place of death	2021/22	2022/23	2023/24	2024/25	Trend
Hospital (acute or community)	41 (59%)	39 (63%)	16 (45%)	20 (62%)	↑-
Residential home, nursing home or hospice	19 (27%)	13 (21%)	17 (49%)	7 (22%)	↓-
Own home	8 (11%)	7 (11%)	2 (6%)	5 (16%)	↑+
Other location	2 (3%)	3 (5%)	0 (0%)	0 (0%)	↑+

Findings from our reviews

During 2023/24, the ICB LeDeR programme team sought a more thorough review of the quality of ReSPECT documentation following identified learning from reviews completed 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 a residential or care home) automatically triggered a focused review.

A deep dive analysis was completed in October 2024 and the findings from these reviews (positive practice, learning and improvements required) have been shared with relevant services and presented at ReSPECT and end of life care meetings across the ICS.

As previously advised, 33 reviews await completion. Their statuses are outlined below:

- 20 reviews are currently allocated to a reviewer and being worked on; all are within the 6-month timeframe
- 13 reviews are on hold owing to ongoing external investigations, such as coroner inquests, police investigations or Adult Safeguarding Reviews.

Tables 11 and 12 on the following pages show the different causes of death and their prevalence over

Table 11: Causes of death in reviews notified, reviewed and closed in 2024/25

Causes of death	2023/24	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25
Pneumonia or respiratory-related	9 (9%)	8 (50%)	3 (37.5%)	0 (0%)	1 (33.3%)
COVID-19	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Epilepsy	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Diabetes	0 (0%)	0 (0%)	1 (12.5%)	1 (14.2%)	0 (0%)
Cardiovascular diseases	13 (13%)	2 (12.5%)	1 (12.5%)	1 (14.2%)	1 (33.3%)
Pulmonary embolism	3 (3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Kidney failure	0 (0%)	0 (0%)	0 (0%)	1 (14.2%)	0 (0%)
Dementia	1 (1%)	1 (6.25%)	0 (0%)	1 (14.2%)	0 (0%)
Natural causes	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Parkinson's disease	0 (0%)	1 (6.25%)	0 (0%)	0 (0%)	0 (0%)
Cancer (end stage and metastatic)	3 (3%)	0 (0%)	0 (0%)	1 (14.2%)	1 (33.3%)
Multi-organ failure	0 (0%)	0 (0%)	1 (12.5%)	0 (0%)	0 (0%)
Batten disease	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Gut failure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Liver failure	0 (0%)	0 (0%)	0 (0%)	1 (14.2%)	0 (0%)
Gallbladder failure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Sepsis	3 (3%)	2 (12.5%)	1 (12.5%)	0 (0%)	0 (0%)
Brain tumour	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Renal disease	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Inanition or malnutrition	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	2 (12.5%)	1 (12.5%)	1 (14.2%)	0 (0%)

Table 12 below provides a summary of the causes of death for the reviews completed in 2024/25 and how they compared to cause of deaths in previous years. The data demonstrates that aspiration pneumonia or respiratory-related diseases and issues remained the highest cause of death of individuals with a learning disability, which is consistent with previous years' data.

Please see the **high impact actions** section highlighting the work currently being undertaken across the ICS to address these issues.

Table 12: Causes of death compared with previous years

Causes of death	2021/22	2022/23	2023/24	2024/25	Trend
Pneumonia or respiratory-related	10 (14%)	26 [3] (52.7%)	9 [16] (31.6%)	12 (37.5%)	↓+
COVID-19	3 (4%)	2 (3.6%)	0 (0%)	0 (0%)	-
Epilepsy	1 (1%)	1 (1.8%)	1 (1.2%)	0 (0%)	-
Diabetes	0 (0%)	0 (0%)	0 (0%)	1 (3%)	-
Cardiovascular diseases	8 (11%)	7 (12.7%)	13 [4] (21.5%)	5 (16%)	↓+
Pulmonary embolism	2 (3%)	0 (0%)	3 [3] (12.6%)	0 (0%)	↓+
Kidney failure	3 (4%)	0 (0%)	1 (1.2%)	1 (3%)	-
Dementia	8 (11%)	2 (3.6%)	1 [1] (2.4%)	2 (6%)	-
Parkinson’s disease	0 (0%)	0 (0%)	0 (0%)	1 (3%)	↑+
Natural causes	8 (11%)	2 (3.6%)	1 (1.2%)	0 (0%)	-
Cancer (end stage and metastatic)	5 (7%)	7 (12.7%)	3 [5] (10.1%)	2 (6%)	↓+
Multi-organ failure	0 (0%)	0 (0%)	2 (2.4%)	1 (3%)	↓+
Batten disease	1 (1%)	0 (0%)	0 (0%)	0 (0%)	-
Gut failure	1 (1%)	0 (0%)	0 (0%)	0 (0%)	-
Liver failure	0 (0%)	0 (0%)	0 (0%)	1 (3%)	↑+
Gallbladder failure	0 (0%)	0 (0%)	0 (0%)	0 (0%)	-
Choking	1 (1%)	0 (0%)	0 (0%)	0 (0%)	-
Sepsis	3 (4%)	4 (7.2%)	3 [3] (7.5%)	3 (6%)	→
Brain tumour	0 (0%)	0 (0%%)	1 (1.2%)	0 (0%)	↑+
Renal disease	0 (0%)	0 (0%)	1 [1] (2.4%)	0 (0%)	↑+
Inanition or malnutrition	0 (0%)	0 (0%)	3 (3.6%)	0 (0%)	↑+
Other	5 (7%)	1 (1.8%)	4 (4.8%)	0 (0%)	↓+
Awaiting outcome of LeDeR review	0	1*	5*	33 (13*)	-

Numbers in blue are reviews that were notified in 2022/23 and 2023/24 but completed and closed in 2024/25, part of the backlog inherited from the previous commissioned provider.
** Represents reviews which are currently on hold pending external investigations.*

CDOP findings

Table 13 provides a summary of information relating to CDOP cases (where the child had a diagnosis of a learning disability and/or autism) signed off by the system in 2024/25.

Table 13: CDOP cases in 2024/25

Information	Q1: 01/04/24 to 30/06/24	Q2: 01/07/24 to 30/09/24	Q3: 01/10/24 to 31/12/24	Q4: 01/01/25 to 31/03/25
Age at death	11 years 10 months	-	-	11 years 4 years 7 months
Sex	Male	-	-	Male x2
Ethnicity	White British	-	-	White British x2
Cause of death	Sudden unexpected death in epilepsy	-	-	Chickenpox pneumonia Septic shock due to acute bacterial infection

The above cases identified the following learning points:

- Actions to develop a Standard Operating Procedure around treating all pyrexia as potential line infections
- Discussion with the acute learning disability team to aid with communication tools
- Audit the number of parenteral nutrition patients who have required admission with pyrexia during chickenpox; use to consider vaccination for this group
- Discuss starting acyclovir early for central venous line patients
- Share learning of a child presenting with disseminated varicella zoster infection to county-wide forum
- Consider incorporating blood glucose in paediatric assessment in the emergency department
- Nursing staff to undertake triage training to aid decision making in emergency department.

Positive practice identified from LeDeR reviews in 2024/25

Many of our reviews continue to identify positive practice, which includes the following:

- Good use of reasonable adjustments for individuals in primary and secondary care. For example:
    - Face-to-face appointment always given
    - Allowing staff/family to be present on hospital admission
    - Longer GP appointment time
    - GP home visits (where required)
    - Explaining surgery in a simplified manner so that the person understood the process
    - Parents/carers allowed to stay with their loved one, for example support provided by hospital staff to family in the last days/hours of life, including allowing them to visit at any time
    - Care provider staff allowed to remain with individuals during their final hospital admission, ensuring that they were with people who knew them well at the end of their lives
    - Day care centre staff offering to stay with individuals in hospital when family were unable to attend.

- Most individuals received a comprehensive, holistic annual health check (AHC).

- Good communication between health and social care teams and professionals. There was also good collaborative and/or multi-disciplinary team (MDT) working between services.

- Regular medication reviews and long-term conditions monitored, with referrals to specialist services where needed/required.

- Individuals up to date with vaccinations.

- Individuals were offered and some of them received age-appropriate screening.

- Excellent care provided by Acute LD Liaison Nurses and hospital staff when individuals were inpatients in hospital.

- End of life plans:
    - ReSPECT forms were completed by people involved in the person's care
    - End of life care plans, which individuals had been involved in developing, were in place
    - Wishes in end of life care plans were respected
    - Personalised end of life care plans detailed people's preferences.

- Several reviews identified good end of life care which is well co-ordinated. Individuals were managed and supported by the care provider to die in their home (including a care home, residential home, or supported living).

- Good monitoring of long-term conditions by GP practices.

- Regular monitoring of individual conditions by specialist services. Examples include Parkinson's Nurse, Neurology Consultant, and Epilepsy Nurse Specialist.

- Good evidence of mental capacity assessments completed in relation to ReSPECT forms, medication and feeding.

- Very comprehensive Distress and Discomfort Assessment Tools (DISDAT) completed by care home staff. This enabled them to understand when people with a learning disability were content or distressed.

- Comprehensive documentation outlining individuals' daily routine and holistically addressing all needs and preferences.

- Regular ward rounds between GPs and care providers.

- Excellent care provided by care staff within care providers. This was regularly mentioned by family members.

- Good/excellent care provided by hospital staff, nursing staff and LD nurses.

- Good use of advocates and advocacy services.

Learning identified from LeDeR reviews in 2024/25

Our reviews however, also identified some areas of learning and improvement, including:

- Not all individuals were registered on the LD Register at their GP practice. This meant they did not receive an annual health check.
- Some individuals were registered on the LD Register but did not receive an AHC.
- In some cases, AHCs were not completed at all, or did not cover all aspects of health. For example – there was no epilepsy review, or no follow-up health action plan.
- Those with an AHC completed did not always have a health action plan produced or provided to them, their carers or their family.
- Topics were discussed during annual health reviews, but not all actions were transferred through to health action plans with accountability and timely review dates.
- Some AHCs were completed over the telephone and not in person.
- Lack of reasonable adjustments made. Particularly in relation to non-attendance at appointments.
- Pneumococcal vaccine, cervical screening and other age-appropriate screening not offered to individuals. In some cases, there was a lack of documentation about the reasons for this.
- Not all individuals received medication reviews. Some of those completed did not include which medication was being reviewed or missed other important information. There is no evidence of STOMP reviews to stop over medication of people with a learning disability and autistic people.
- Regular long-term condition reviews were not completed.
- In some reviews, there did not appear to have been formal assessments of capacity under the Mental Capacity Act 2005. There was also not always a ‘best interests’ meeting in relation to screening, vaccination, medication, or ReSPECT.
- Lack of hospital passport to support individuals at appointments and during inpatient stays in hospital.

- Lack of appropriate referrals to specialist services and ensuring that these were followed up. Examples include weight management, diabetic input, LD team support, cardiology, nephrology (kidney health), cancer nurse and palliative care.

- Do Not Attempt Resuscitation decisions were based on the person having a learning disability and not their clinical condition.

- Poor completion of ReSPECT forms. Examples include incomplete sections, no involvement of family/next of kin, their learning disability was cited as reason for instigation, not legible, no clear clinical indications, no clinical rationale and contradictory information. ReSPECT documents were not always followed by services.

- End of life care and community palliative care was not considered following terminal diagnosis.

- Families' concerns regarding learning disability being cited as a secondary cause of death on the death certificate.

- Telephone rather than face-to-face consultations completed by health professionals.

- Lack of documentation and communication between services and with families.

- Lack of explanation and support provided to families when individuals were inpatients in hospital.

- In some instances, recognising deterioration of individual could be further improved by care providers, particularly in relation to sepsis.

- Lack of acute LD nurse provision or input during individuals' inpatient stays in hospital.

- Lack of multi-agency working and MDT approach. This includes between the care provider and the GP, and between the care provider and the acute provider.

- Lack of multi-agency working and MDT approach in 3 reviews. All these cases have resulted in a referral and approval for an Adult Safeguarding Review to be completed.

Once all reviews have been completed and positive practice, learning and actions have been agreed at the local LeDeR Governance Panel, the approved redacted review is then shared with relevant services to enable improvements to be undertaken and completed.

Where themes and trends of learning and improvement have been identified from reviews, these are formulated into priority areas, documented and monitored via the ICS LeDeR System Wide Action Plan.

Improvements and achievements in 2024/25

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 2024/25, the progress of which is captured below.

Please note: Actions progressed during 2024/25 are also included in the 6 high impact actions section below, but are not listed here to avoid duplication.

In 2024/25, the LeDeR Steering Group has gained increased representation and engagement, achieved via face-to-face quarterly meetings. Following face-to-face meetings/workshops throughout the year, the ICS LeDeR System Wide Action Plan has been updated and refreshed in relation to 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.

- Continued delivery of dysphagia training across the whole county. This has been completed by the Speech and Language teams at Midlands Partnership University NHS Foundation Trust (MPFT) and North Staffordshire Combined Healthcare NHS Trust (NSCHT) as part of ‘Local Action into Learning’ identified from previous reviews.

- Delivery of face-to-face epilepsy awareness training sessions across the county. NSCHT (Stoke-on-Trent) and MPFT (South Staffordshire) have delivered this training to care providers, day services and supported living providers.

- The Local Area Contact has attended bi-annual NHS England Midlands LeDeR Quality Peer Review meetings. The focus has been to peer-evaluate focused reviews completed by the integrated care boards across the West Midlands. Learning and improvements identified for all ICBs and systems have been fed back locally to the LeDeR Governance Panel for improvements to be made.

- Work continues to progress in obtaining input from experts by experience (EBEs: those living with a learning disability and autistic people) into the LeDeR programme. The LAC attends monthly EBE groups and provides feedback from these groups to the LeDeR Steering Group and Governance Panel. EBEs have been integral to the improvements made in relation to screening videos, easy read leaflets and improvement projects.

- A bi-monthly LeDeR briefing has been produced by the programme team for both health and social care colleagues. The briefings highlight positive practice, learning and improvements identified from reviews, along with useful resources and best practice guidance to support health and social care staff caring for people with a learning disability or autistic people.

- The LAC has undertaken significant promotion of the LeDeR programme to health and social care colleagues. The LAC has presented the themes and trends of positive practice, learning and improvements identified from reviews to:
    - 3 GP locality engagement meetings to promote awareness and education
    - Staffordshire and Stoke-on-Trent Care Commissioning team
    - Supported Living Providers Forum
    - Care Home Providers Forum
    - Local authorities' care home provider meetings.

- The LAC attended and presented at the ICS Patient Safety Learning Conference in October 2024. This was an opportunity to promote the LeDeR programme locally and increase notifications for autistic people and ethnic diverse groups.

- The quality of annual health checks has continued to be reviewed. This includes ensuring feedback is provided to the ICB Primary Care team and GP practices. Feedback is also provided to primary care LD nurse specialists to facilitate and support practices to improve their care and practice.

- A dedicated LeDeR webpage has been produced for GP365 (a website resource for local GPs). It has information, briefings and resources to support primary care staff when they provide care to people with a learning disability and autistic people.

- Refreshing and amending the LeDeR webpages of the ICB website with a focus on ensuring they are more user-friendly to individuals with a learning disability and autistic people. This work has been undertaken with the ICB Communication and Engagement team.

- The programme has continued to work collaboratively with the Learning Disability, Autism and Down's Syndrome Partnership Board. The focus has been on the ICB/ICS Learning Disability and Autism 5-Year Plan, aligning local LeDeR priorities and 'learning into action' with the LDADSP Board workstreams.

Actions progressed in relation to the 6 High Impact Actions set by NHS England Midlands Team

1. Reduce avoidable mortality in the 3 clinical priority areas for Learning Disability and Autism

Regarding the key clinical priority areas, in the final quarter of 2024/25, funding via the Locality Improvement Framework (LIF) was allocated to 12 localities across Staffordshire and Stoke-on-Trent. This allocation was based on health inequalities and defining the local Core20 priorities at community level within their localities. The programme is only just commencing, with workshops scheduled throughout May and June 2025 to support the localities in applying for the funding and defining their business cases.

Cancer

The easy read bowel cancer screening video has been completed and shared with people with lived experience and experts by experience for review and feedback. Once feedback has been collated, the final changes will be made.

Easy read videos are also being considered for other cancer screening services, for example cervical and lung screening. In 2024/25, meetings were held with colleagues from the Planned Care (Cancer) portfolio to discuss how to reduce health inequalities and to collaborate on cancer awareness campaigns which are inclusive and target people with a learning disability and autistic people.

Respiratory

Face-to-face dysphagia training sessions have been taking place since October 2023, as respiratory-related deaths (particularly aspiration pneumonia) continue to be one of the highest causes of death locally.

A further 12 sessions were secured with the funds from 2024/25 and provided across the county. The LeDeR programme team are now members of the pneumonia pathway working group.

The current focus is implementation of the management pathway within primary care. Work has been undertaken around follow-up pathways, an acute pathway and a discharge bundle.

The next step is to undertake work in relation to health inequalities, looking at high-risk people to ensure they are receiving vaccinations, reasonable adjustments and safety netting. The LeDeR programme team will be sharing a deep dive presentation of the completed focused reviews for 2024/25 to the working group in July/August 2025.

Cardiovascular

As above update for cancer.

2. Focus on co-morbidities associated with premature death and DNACPR/ReSPECT

In 2024/25, the Local Area Contact met with the End of Life Care Transformation Lead for the ICS/ICB to discuss findings, themes and trends of the focused reviews completed for 2023/24 relating to the quality of ReSPECT forms. Several actions were agreed and have now formed part of the ICS System Wide Action Plan and the ICS End of Life Ambitions Action Plan.

The LAC is now a member of the ICS ReSPECT Steering Group and All Age End of Life Clinical and Professional Group (EOLCPG). The LAC presented the findings/analysis from the focused reviews (where the person had a ReSPECT form in place at the time of their death) to the All Age EOLCPG. The group acknowledged the findings and will factor these into the All Age Palliative and End of Life Care Strategy for the ICS.

The LAC also attended the Staffordshire and Stoke-on-Trent ICB All Age Palliative and End of Life Care Strategy online engagement event in September 2024, to provide themes and trends for future learning and improvements identified from completed focused reviews.

3. Assure and sustain performance (understand, address and monitor variation in performance in the region)

The ICB LeDeR review team has been in post for nearly 12 months and is now fully established and secure, with high-quality reviews being produced. The programme team continue to refine processes to maintain and improve performance against the national KPIs.

4. Improve the quality of LeDeR reviews and actions from learning

Since the establishment of the internal LeDeR review team in the ICB, the quality of the reviews has improved considerably in 2024/25.

A Governance Panel face-to-face workshop took place in September 2024 to discuss how to strengthen the panel. This was a very positive event, with useful improvements identified. The LeDeR Governance Panel is now operating more efficiently and effectively, with high-quality reviews and effective presentation of reviews by reviewers.

Learning and actions identified from reviews are now more defined and specific to relevant services/system colleagues. They continue to be incorporated into the LeDeR System Wide Action Plan priority areas and workstreams/portfolios across the ICS.

5. Improve access and understanding of the importance of LeDeR reviews

In 2024/25, LeDeR leaflets and flyers in plain English and easy read have been delivered to community groups, faith groups and religious leaders across the county. They have been translated into the following languages:

- Arabic
- Bengali
- Kurdish
- Punjabi
- Polish
- Romanian
- Urdu.

In 2024/25, several meetings have taken place between the LeDeR programme and the ICB Communication and Engagement team to discuss how to increase notifications from ethnic diverse groups and under-represented groups.

The LeDeR programme team has also attended several events across the county with voluntary sector organisations Support Staffordshire and VAST. These have provided the opportunity to increase awareness of the programme among ethnic diverse communities and groups, plus autistic groups and charities across the county.

6. Improve accuracy of Learning Disability Registers and increase the quality and uptake of annual health checks

The LAC has continued to communicate and liaise with ICB Learning Disability, Autism and Down's Syndrome programme colleagues and ICB primary care colleagues around learning from reviews, and shares data relating to annual health checks and their quality.

The quality of AHCs has continued to be reviewed as part of the LeDeR review process and ensuring feedback is provided to the ICB Primary Care team and GP practices. Feedback is also provided to primary care learning disability nurse specialists to facilitate and support practices to improve their care and practice.

A bi-monthly LeDeR briefing is produced by the LeDeR programme team and shared via the ICB GP bulletin and GP365. These briefings highlight positive practice, learning and improvements identified from reviews, along with useful resources and best practice guidance to support GP practice staff.

Actions to be taken forward into next year (2025/26)

- **Feedback on learning, improvements and positive practice** will continue to be shared with relevant services/providers and stakeholders.
- Task and finish groups will be set up to address and **work on the priority areas within the LeDeR action plan** with the first of these in relation to ReSPECT.
- Promotion and awareness of **the importance of vaccinations, age-appropriate screening and completion of health action plans** will continue to be shared with the ICB Primary Care team and care providers.
- The LeDeR programme team will continue to work with both local authorities to **promote use of the LeDeR briefing** across the social care sector, with the aim of creating a dedicated resource page within MiDOS (website/system provided by the local authority to support care providers) and to provide support and resources to those caring for people with a learning disability and autistic people. Bitesize training will also be explored, with the aim of this being located within the Social Care Academy for care providers to access.
- Continued delivery of face-to-face **epilepsy awareness training sessions** across the county by NSCHT (Stoke-on-Trent) and MPFT (South Staffordshire).
- Continued delivery of face-to-face **dysphagia training** across the whole county by the Speech and Language teams at MPFT and NSCHT.
- Continued production of the **bi-monthly briefing** which will be shared with health and care professionals and teams, highlighting positive practice, learning, and improvements identified from reviews, along with useful resources and best practice guidance.
- **Focused reviews** will continue where individuals have died from respiratory-related conditions such as aspiration pneumonia and community-acquired pneumonia. This will allow further learning and improvements to be identified with system partners to raise awareness and make necessary improvements.
- **Continued quality reviews of annual health checks** as part of the LeDeR review process and ensure feedback is provided to the ICB Primary Care team, GP practices and learning disability nurse specialists.
- Continued work on **screening videos** to raise awareness about the national cancer screening programmes (cervical and lung) aimed at those living with a learning disability and autistic people.
- We will continue to work with the ICB Communication and Engagement team to **refresh and amend the ICB LeDeR webpages** to ensure they are more user-friendly to individuals that have a learning disability and autistic people.
- Continued **promotion of the programme with autism groups, ethnic diverse groups and stakeholders**, to increase notifications from these groups and communities, to further enhance learning and identify health inequalities.
- The ICB LeDeR programme team will **review the LeDeR strategy** and priorities to ensure they reflect the planned future work.

Conclusion

In 2024/25, the LeDeR programme team achieved their main priorities – to tackle the backlog of reviews inherited from the previous commissioned provider and improve performance against the national KPIs. The local LeDeR programme has also made steady progress to improve the quality of health and social care service delivery for people living with a learning disability and autistic people. This is demonstrated by the achievements during the year and progress made against the high impact actions.

In 2025/26, the ICB will continue to work with system partners to address the priority areas defined within the LeDeR System Wide Action Plan – to reduce premature mortality and health inequalities and to improve outcomes for people with a learning disability and autistic people. Respiratory-related deaths (particularly aspiration pneumonia) continue to be the highest cause of death identified from reviews, so it is hoped the system-wide pneumonia pathway and continued delivery of dysphagia training will address this.

Given that performance has improved, there will be more focus next year on tackling the priority areas and high impact actions within the LeDeR System Wide Action Plan. This will be achieved via task and finish groups, with a quality improvement methodology being set up for each priority area. Further work will be required to increase both the number of notifications from ethnic diverse groups and autism-only notifications, to further enhance learning and identify health inequalities.

There remain challenges for the local system to address moving forward into 2025/26. System working and collaboration will be fundamental for health and social care services/providers to deliver the necessary improvements and reduce premature mortality and health inequalities for people with a learning disability and autistic people.