Staffordshire and Stoke-on-Trent Integrated Care System (ICS)

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

Annual Report 2021/22

Executive Summary

This annual report highlights the activities and focus of the Staffordshire and Stoke-on-Trent Integrated Care System LeDeR programme for 2020/2021. It includes recommendations from the LeDeR reviews and actions undertaken to implement system learning from the 1st of April 2021 - 31st of March 2022, as well as highlighting recommendations for 2022/2023.

The past year has seen a continued improvement of the LeDeR programme within Staffordshire and Stoke-on-Trent with commitment across the system with regards to effective communication and collaborative working relationships. The CCGs effectively secured a contract for LeDeR reviews with the South Central and West Commissioning Support Unit (CSW CSU) which has supported an effective review allocation and reporting process. This contract has further enhanced access to patient records which has enabled reviewers to critically identify any local issues and action necessary learning. This has resulted in a rapid turnaround of reviews with a greater number of completed reviews in the last year. Supported by an NHS England and Improvement (NHSE/I) initiative, the Staffordshire and Stoke-on-Trent LeDeR programme has also worked collaboratively with the North of England Commissioning Support Unit (NECS) to ensure timely completion of “stacked reviews” which were LeDeR review cases accrued due to the transfer of the national LeDeR platform from the University of Bristol to South Central and West CSU in the summer of 2021.

The local LeDeR Steering group, whose membership includes those who will be influential in making changes within the system continues to be instrumental in the findings and implementation of recommendations from reviews. The group has maintained an active shift in focus from reporting on data, to providers reporting demonstrable actions and impact through a standardised reporting process which can also be used within each organisation to illustrate changes across the ICS, and, therefore, continuous improvement.

The LeDeR Governance Panel as mandated within the new LeDeR Policy published in March 2021, commenced in March 2022, and has been developed with a focus on ensuring an independent perspective and the voices of those who have lived experience. This has been achieved through the acquisition of representatives from the police service, charities and chaired by a mother whose child’s life was reviewed as part of the LeDeR initiative.

The Staffordshire and Stoke-on-Trent LeDeR programme continues to demonstrate its commitment to tackling the causes of early morbidity and preventable deaths in people with a learning disability and autism and embrace the changes outlined in the new LeDeR policy of 2021.

*****Stacked reviews- LeDeR review cases accrued due to the transfer of the national LeDeR platform from the University of Bristol to South Central and West CSU in the summer of 2021.

Introduction

In Staffordshire and Stoke-on-Trent, the LeDeR programme remains integral to the overall commitments of the Learning Disabilities (LD) and Autism Programme (LDAP) and system partners; University Hospitals North Midlands Trust (UHNM), Midlands Partnership NHS Foundation Trust (MPFT), University Hospitals of Derby and Burton NHS Foundation Trust (UHDB), North Staffordshire Combined Healthcare NHS Trust, Healthwatch Staffordshire and Stoke on Trent, Staffordshire County Council and Stoke-on-Trent City Council.

The local programme has worked collaboratively with system partners, and through the use of the national platform, maintains a comprehensive monthly record of the deaths of people with LD and autism. This supports the forecasting and planning of services for patients with LD and autism which identifies required service changes.

Our vision, aim and objectives

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

- Improving the quality of health and social care service delivery for people with learning disabilities.
- 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 autism.
- 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 maintained:

- Timely allocation of notifications of death to the LeDeR platform.
- Timely completion of allocated reviews through locally CSU commissioned services.
- Robust governance system which includes review sign off and oversight of subsequent actions by the ICS's Local Area Contact (LAC).
- Close working relationships with system partners to ensure identified actions are implemented and sustained.

As indicated in our 3-year strategy and demonstrated through ongoing reporting, the Staffordshire and Stoke-on-Trent LeDeR programme will continue to ensure the application of matrix working across the system, including the LDAP Board, LeDeR

Steering Group and Safeguarding Board in order to ensure and evidence that the system acts on the findings from our reviews.

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 with the Steering Group membership being a key driver. 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 autism.

In January 2022, the Staffordshire and Stoke-on-Trent LeDeR programme commenced work to embed the requirement for autism into the local LeDeR programme. The system has continued to raise awareness of this inclusion through the activities of the LeDeR Steering group with support from communication colleagues and primary care leads.

The LeDeR Local Area Contact (LAC) continues to work collaboratively with the South Central and West Commissioning Support Unit to ensure that all reviews are quality assured and completed in a timely manner.

Demographics of our Learning Disability and Autism population notifications.

In 2021/2022, the Staffordshire and Stoke-on-Trent system received a total of 70 notifications. Of these:

- 9 were Child Death Overview Panel (CDOP) cases (61 adult cases)
- 2 from an ethnic diverse population group
- 2 represented a dual diagnosis of LD and autism
- 0 with a clinical diagnosis of autism only.

Of the 61 adult cases, 58 are initial reviews from which 2 cases progressed to a focussed review while 3 cases were notified as focussed reviews. Reviews take up to 6 months to complete, from the date of notification. As a consequence, 48 (79%) cases have been completed and quality assured with 13 (21%) cases currently at different review stages. It is too early to determine how many of the 13 outstanding cases will progress from initial to a focussed review. 2 cases were marked out of scope as there was no diagnosis of LD or autism noted.

Table:1 Breakdown of notifications.

Total No. of reviews	Initial	Focussed	CDOP	Out-of-Scope	Initial to Focussed	Autism Only	LD/A (inc. in the Initial & Focussed)
70 (100%)	54 (77%)	5 (7%)	9 (13%)	2 (3%)	2	0	2

In 2021/2022, the Staffordshire and Stoke-on-Trent system observed a consistency in the average age of death with the previous year, at 57 years of age, although higher than demonstrated in 2019/20 (Table 2). The system started the first 3 quarters of this year with an average age of 60 but experienced a significant drop due to a greater number of notifications from the 0-18 and 19-49 age ranges in Quarter 4. The local LeDeR programme continues to play a significant role at the Child Death Overview Panel and continues to support the learning from this cohort.

Table:2 Breakdown of average age at death.

Programme Dates	01/04/19 to 31/03/20	01/04/20 to 31/03/21	01/04/21 to 31/03/22
Average age at death	46	57	57

Table 3 below shows the average age of death for 2021/22 and how this compares with previous years. Differences were experienced in the number of notifications within the 0-18 age group which increased by 6% when compared to the previous year. There

was also a reduction in notifications from the 19-49 age range when compared with 2020/2021 figures. The reduction within this age group may be attributed to the effective Covid-19 vaccination campaign for this population within the Staffordshire and Stoke-on-Trent system. Consistency was observed with notifications in the 50-69 and the 70-84 age ranges and a significant drop in the 85+ age range when compared with last year's figures.

Table 3: Comparison with previous years.

Age ranges at Death	0-18	19-49	50-69	70-84	85 and over
01/04/19 to 31/03/20	4 (9%)	8 (17%)	23 (49%)	9 (19%)	3 (6%)
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%)

Although there was a slight reduction in the total number of notifications this year when compared with figures from last year, there was still a 14% gap difference in male and female notifications, which is a significant difference from 20% and 34%, respectively (see table 4 below). Notifications of deaths from Ethnic Diverse Groups (EDG), continues to be low, with only 2 reported in 2021/22. Raising awareness with Ethnic Diverse Group populations remains a priority for Staffordshire and Stoke-on-Trent and the local LeDeR programme is collaborating with system partners to explore ways of further involving the EDG population.

Table 4: Comparison of gender and ethnicity with previous years.

Gender & Ethnicity	01/04/19 to 31/03/20		01/04/20 to 31/03/21		01/04/21 to 31/03/22	
Gender	Male	Female	Male	Female	Male	Female
	28 (60%)	19 (40%)	55 (67%)	27 (33%)	40 (57%)	30 (43%)
Ethnicity	White	EDG	White	EDG	White	EDG
	45 (96%)	2 (4%)	81 (99%)	1 (1%)	68 (97%)	2 (3%)

Data for 2021/2022 highlights that out of the 70 notifications received, 41 individuals died in a hospital setting, 19 in nursing or residential homes, 8 in their own homes and 2 in other places that are not part of the above (Table 6). This data is currently helping to target improvement initiatives with relevant services.

Table 5: Breakdown of place of death.

Place of death	Hospital (Acute/Community)	Nursing/ Residential/Hospice	Own Home	Other
Total number	41 (59%)	19 (27%)	8 (11%)	2 (3%)

There are still far too many people dying in an acute setting, and too few in their own home. To help address this, the local LeDeR programme is working with system

partners on improving the presence of our Learning Disability Liaison nurses within our acute hospitals.

Progress of our LeDeR programme reviews

The launch of the new platform was delayed until July 2021, impacting upon notifications and, therefore, the completion of reviews. These delayed reviews were referred to as 'stacked reviews' and completed by North of England CSU (NECS) who were commissioned by NHSE/I on behalf of all CCGs. 20 'stacked reviews' were identified for Staffordshire and Stoke-on-Trent. One case was deemed 'out of scope', reducing the number to 19, with 10 completed within the 6-month target time. This delay impacted on the system's ability to achieve the 3-month case allocation and 6-month case completion LeDeR KPIs. As a result, the local system reported 8 breaches from cases notified in the last quarter of 2020/2021.

The Staffordshire and Stoke-on-Trent LeDeR programme has been able to respond to the new LeDeR Policy and platform and implement changes to the way reviews are managed, through the commissioning of South Central and West (SCW) CSU. Working collaboratively with system partners and our commissioned partners at SCW CSU, the backlog was swiftly addressed and the LeDeR programme resumed.

In 2021/2022, the Staffordshire and Stoke-on-Trent LeDeR programme reported a breach of an Ethnic Diverse Group (EDG) case which was notified at the end of Q2 (September 2021). Reviewers reported difficulties in involving the family in the review process due to a further bereavement within the family. A decision was made by system partners to recognise and respect the needs of the family by extending the timeline. A decision which was endorsed and supported by NHSE/I.

Thirteen cases were carried through into 2021/2022, all at different review stages. There are many different factors that can result in cases breaching, primarily challenges in accessing all the necessary information and documentation, but at the present time no further breaches are anticipated for those 13 cases. The LAC continues to meet weekly with partners at SCW CSU to monitor the progress of individual cases and ensure they are completed in a timely way.

Findings from our reviews

Table 6 below provides a summary of the causes of death for the 70 notifications received in 2021/2022 and how they compared to deaths recorded for the same cause in previous years.

Table 6. Cause of death.

Main causes of death from notifications	2019/2020		2020/2021		2021/2022	
	No.	%	No.	%	No.	%
Pneumonia	14	33%	7	9%	10	14%
Covid-19			5	6%	3	4%
Epilepsy					1	1%

Cardiovascular Diseases	4	9%	4	5%	8	11%
Pulmonary Embolism			1	1%	2	3%
Kidney Failure					3	4%
Dementia	3	7%	3	4%	8	11%
Natural causes	9	21%	3	4%	8	11%
Cancer (end stage and metastatic)	6	14%	3	4%	5	7%
Batten's Disease			1	1%	1	1%
Gut Failure					1	1%
Choking					1	1%
Sepsis			1	1%	3	4%
Unknown			6	7%	5	7%
Awaiting outcome of LeDeR Review					11	16%

Pneumonia and pneumonia related illnesses (14%) accounted for the major cause of death within the Staffordshire and Stoke-on-Trent system. This was closely followed by cardiovascular diseases, dementia and natural causes which reported 11% respectively. Final figures for the cause of death in 2021/2022 will be subject to some change as we receive the review outcomes for the 11 outstanding cases.

Of the 70 notifications received for 2021/2022, 48 reviews had been completed, quality assured and closed by the Staffordshire and Stoke-on-Trent system at year end.
The majority of reviews continued to identify consistent positive themes in all quarters of the year, including:

- Good level of care even in cases where concerns were raised
- Positive involvement of GPs and primary care services
- Excellent end of life care
- Positive family involvement
- Good support for patients from our residential provider partners
- Positive collaboration between services within the system.

Our reviews however, also identified some areas for improvement, with specific themes around communication, documentation and care planning, including:

- Documentation on the needs of patients
- Delays in identifying appropriate next of kin (NoK)
- Issues around ReSPECT and DNACPR documentation
- Inconsistency in the use of the Hospital Passport
- Hospital discharge issues
- Poor communication between acute hospitals, care homes and residential placements
- Lack of clarity around care planning and advanced care planning.

These areas for improvement have been prioritised and taken forward as 'Learning into Action' themes during 2021/2022, the progress of which is captured below.

This has led to the production and rollout of our new system wide Health Passport, which specifically seeks to address issues around communication and documentation, with a focus on embedding the use of the Health Passport within the system during 2022/23.

Furthermore, the programme is engaging and working with system partners to continue to improve on the following areas:

- **Annual Health Checks** (AHCs) – Work continues with partners from Primary Care services to ensure that individuals are supported to access services for their AHC through the provision of tailored reasonable adjustments. Actions on this domain are reported and monitored at the systemwide Steering Group through the use of a slide deck.
- **Timely medication reviews** – The programme continues to work collaboratively with system partners from both the Primary Care and the Medicines Optimisation teams to ensure that individuals receive timely reviews. Actions are reviewed at the Steering Group as work continues towards achieving the requirements of the STOMP (Stopping the over-medication of children and young people with a learning disability, autism or both) and STAMP (Supporting treatment and appropriate medication in paediatrics) initiatives for the resident population.
- **LD Champions** – The programme is also working collaboratively with the Community LD services, Health Facilitation Service and LD Champions to continue to create awareness on the importance of early deterioration detection for those with LD and Autism. Work continues to create awareness of the LeDeR programme as well as its aims and objectives amongst this important group of professionals who have direct contact with our LD and Autism population.

Actions completed in 2021/2022.

In 2021/2022, the Staffordshire and Stoke-on-Trent system worked collaboratively with system partners to ensure that the findings from LeDeR reviews around issues such as documentation and communication, were addressed. Some of the actions completed this year include:

- **Proactive contract management** – We meet weekly with our commissioned partners at SCW CSU to ensure the timely 'front door' quality checks and allocation of all newly notified cases. We also agreed on a set of additional trajectories to ensure cases are completed in a timely manner. These include prompt requests for documentation and timely escalation to the LAC if requests are not met after 2 weeks. We also set a 5-month submission timeframe for cases to ensure the LAC and senior reviewers have enough time to go through a thorough quality assurance process.
- **LeDeR Policy implementation** – We have ensured full implementation of the requirements of the national policy, launched in March 2021, with the implementation of the new review process as described above, and, more latterly, commencement of a Governance Panel in March 2022. We have secured good

***F**ront door quality checks – robust checks carried out on all notifications to ensure accuracy.

representation, independent of our other LeDeR forums and including the local police service, a local charity and chaired by a patient advocate with a personal experience of the LeDeR programme. The panel adds additional scrutiny and challenge to the review process with findings and actions shared at the LDAP Board.

- **Autism rollout** – We have worked well to embed and integrate the new autism initiative into the local LeDeR programme. We utilised our existing communication routes to create awareness of the launch within the system and continue to raise awareness at different governance forums and training programmes as well as any meetings we attend. We have not experienced the anticipated increase in notifications to date, however through robust contract management with SCW CSU the additional reviews have been mitigated and funding secured should it be needed.
- **Inclusivity** – We continued to champion the inclusion of families, carers, people with lived experiences as well as Ethnic Diverse Group populations in all activities within the system and have ensured that all LeDeR governance groups have representation from each of the groups mentioned above. We continue to enjoy the company of an expert by experience and her carer at the monthly Steering Group and continue to champion the role of families in our reviews where possible, even if this creates a delay, as occurred more recently, and described within the report.
- **Robust governance structure** – We have ensured a robust governance and reporting structure by linking the LeDeR programme to relevant workstreams within the system. These include representation and monthly updates to CDOP, the Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board (SSASSPB) and the Learning Disability and Autism Partnership (LDAP) Board for which the LeDeR programme remains an important standing agenda item. We have also continued to raise awareness of the activities of the programme to these governance structures through the use of presentations which presents an opportunity for transfer of ideas within the system.
- **The LeDeR Steering Group** - The group continues to make significant progress by capturing the excellent work within the system and which has been informed by the findings from our reviews and enjoys representation from all system partners. The reports on actions and impact from system partners continues to show improvements in the area of AHCs, medication reviews, early deterioration detection, screening, End of Life care, care reviews, constipation management, support for our EDG, healthy living promotion as well as efforts to improve the application of Mental Capacity and Deprivation of Liberty Safeguards within the system. We continue to work on understanding the impact of these actions and the differences they make to our population with a Learning Disability and Autism.
- **Health Passport production** – As our learning into action project, the system worked collaboratively in the production of a Health Passport document which is aimed at:
  - addressing the need to improve consistency in communication and information sharing across all pathways (health, social care, education etc.).
  - addressing issues of health inequalities which directly impact on reduced life expectancy and premature mortality of this population.

- supporting timely care provision across all pathways.
- ensuring a patient-centred approach to support high quality, safe and effective clinical and social care management.
- reducing additional anxieties for families who are constantly made to repeat themselves across services.
- upholding patient choice, autonomy and voice.
- responding to specific learning from the Covid-19 pandemic.

This document was produced following an in-depth quality analysis of our reviews which produced themes specific to the local system and the need for a robust system wide communication tool. During the pandemic, we became aware of the challenges of individuals being hospitalised and who were without their usual support, making communication with the staff, very difficult. Systemwide collaboration through the LeDeR Steering group has ensured the involvement of all system partners including individuals with lived experience, which has enabled full oversight of all relevant care pathways (health and social care). A nurse-led task and finish group was established together with nursing and patient focus groups to further develop the initiative which was overseen by the LeDeR Steering Group.

The document is available in hard copy and digitally via an electronic link and a QR (Quick Response) matrix barcode. Hard copies have been distributed to over 300 care and residential homes and all major local acute and community hospitals, community Learning Disability Services as well as families who would require them.

Preliminary feedback from the nurse-led task and finish group highlights that the document has been well received from local services, patients, families and carer groups. We have also received interest from those involved with Special Educational Needs and Disability (SEND), Children and Young People, Mental Health, Older Adults and End of Life services who wish to adapt the document.

Co-production and collaborative working with system partners continues to be of paramount importance. We have continued to grow and develop relationships through robust governance and links with programmes across the wider system.

Actions planned for 2022/2023.

Actions planned and currently progressing in 2022/2023 include:

- Continue to embed Autism into the local LeDeR programme and promote notifications. Communications have been shared with system partners to inform them of this addition and we will continue to work collaboratively to ensure that those with Autism are appropriately represented.
- Continue to improve participation from our Ethnic Diverse populations with plans in place to subtitle all promotional campaign material into 4 different languages and ensure distribution to most appropriate locations, as advised, including public places, such as hospitals and GP surgeries.
- To continue to embed the use of the Health Passport and measure its effectiveness, as well as ensure its appropriate use within the system. An online training module is planned for both practitioners and families. This training module will be supported by a videography which will be subtitled into 4 different languages as well as Makaton.

- Continue to work with various media and communication groups on awareness campaigns to promote and embed the Health Passport as well as improve the awareness of the programme across the system. These campaigns will be available both digitally and in hard copy formats and will include easy read versions, Makaton and British Sign Language, where appropriate.
- We will continue to champion the inclusion of families, carers and people with lived experiences by ensuring that they are represented, and their voices heard in all local LeDeR activities.
- Following an action mandated by our local LeDeR Governance Panel from the outcome of one of our reviews, we are working collaboratively to develop system wide Dysphagia Awareness training for our nursing, residential and supported living homes. This will represent one of our 'Learning into Action' projects in 2022/23.
- Work with the regional team to support residential settings for those with LD and Autism, to be acknowledged as key contacts (with appropriate permission of the next of kin) to ensure two-way communication about the individual, particularly when detained outside their usual place of residence, i.e., in an acute setting.

In summary, inclusion, collaboration and co-production remain the priorities for the LeDeR programme in Staffordshire and Stoke-on-Trent. We will maintain the close working relationship we have built within the system to ensure we continue to improve the lives of our population with a Learning Disability and Autism.

A rag rating is consistently applied to each of the areas identified above and features on the respective slide deck at the Steering Group and further quality improvement opportunities continue to be discussed. Using the rag rating below, as recommended by NHSE/I, all areas would be rated as "On Track" (green) as all are making expected progress.

	On Track	LeDeR programme Action for Learning on track No concerns around delivery of action from learning
	Some Concerns	Some concerns around delivery of Action from Learning Recoverable
	Off Track	Action from Learning off track Considerable concerns
	Other	Not possible to RAG rate the Action from Learning for the quarter Programme not started