

# Board of Directors - Public

## SUMMARY REPORT

Meeting Date:

27 March 2024

Agenda Item:

22

<b>Report Title:</b>	LeDeR: National and Local learning	
<b>Author(s):</b>	Dr Hassan Mahmood, Clinical Director Dr Helen Crimlisk, Interim Executive Medical Director	
<b>Accountable Director:</b>	Dr Helen Crimlisk, Interim Executive Medical Director	
<b>Other meetings this paper has been presented to or previously agreed at:</b>	<b>Committee/Tier 2 Group/Tier 3 Group</b>	Executive Management Team
	<b>Date:</b>	7 March 2024
<b>Key points/recommendations from those meetings</b>	Request from Board noted for Learning Disability (LD) specific learning to be drawn out from SHSC mortality reports. EMT recognise need to feed into LD Transformation Programme	

### Summary of key points in report

The purpose of this report is to outline the key points of the national LeDeR report, key risks and our recommendations.

Attention is drawn to minor improvements in median age at death, however, mortality gap remains clear and significant. Intersectionality with deprivation should be noted.

Learning in Sheffield will be drawn out in LD Transformation work, with particular focus on case load management and risks with comorbid dementia. Limited data is available with regards to Autism, so recommendations are preliminary, but the excess of deaths associated with suicide should be noted.

Appendix 1 – shared as a link given the size of the report

LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People

<https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf>

### Recommendation for the Board/Committee to consider:

<b>Consider for Action</b>		<b>Approval</b>		<b>Assurance</b>	x	<b>Information</b>	x
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The Board of Directors are asked to take assurance from a robust LeDeR process, with learning from both national and local reports.

Please identify which strategic priorities will be impacted by this report:					
Effective Use of Resources	Yes	x	No		
Deliver Outstanding Care	Yes	x	No		
Great Place to Work	Yes		No		x
Ensuring our services are inclusive	Yes	x	No		
<b>Is this report relevant to compliance with any key standards ? State specific standard</b>					
Care Quality Commission Fundamental Standards	Yes	x	No		Person Centred Care and Dignity and Respect
Data Security and Protection Toolkit	Yes		No	x	
Any other specific standard?	Yes	x			National Guidance on Learning from Deaths (2017) Suicide Prevention Strategy for England (2023)
<b>Have these areas been considered ? YES/NO</b>					
					If Yes, what are the implications or the impact? If no, please explain why
Service User and Carer Safety, Engagement and Experience	Yes	x	No		Involving carers and families to ensure their rights and wishes are respected.
Financial (revenue & capital)	Yes		No	x	There are no financial implications in the mortality process. The Better Tomorrow project is funded through the Back to Good improvement funding.
Organisational Development /Workforce	Yes	x	No		OD input in relationship to LD Transformation and cultural change
Equality, Diversity & Inclusion	Yes	x	No		The mortality processes are inclusive of all ages, genders and cultural and ethnic backgrounds. It is known that intersectionality with ethnically diverse communities may increase mortality because of deprivation indices and /or overuse of medication
Legal	Yes		No	x	No identifiable impact
Environmental sustainability	Yes	x	No		Sustainable process with no direct impact on environment

## **Section 1: Analysis and supporting detail**

### **Background**

The 2022 LeDeR report seeks to investigate and learn from the avoidable deaths of people with a Learning Disability in England. It is the first report to investigate deaths of autistic adults without a Learning Disability due to concerns that autistic people may also experience health inequalities that could lead to avoidable deaths.

Amongst people with a Learning Disability who died in 2022:-

- 55% were male
- 94% were denoted as “white”
- 25% lived in the most deprived neighborhoods by decile, in comparison to 10% in the least deprived
- Median age at death for people with a Learning Disability in 2022 was 62.9 years old, in comparison to 61.8 years in 2018.

In 2022, the most commonly reported underlying causes of were related to the following International Classification of Diseases, Tenth Revision (ICD-10) chapters: diseases of the circulatory system, diseases of the respiratory system, neoplasms, diseases of the nervous system, congenital malformations, deformations and chromosomal abnormalities.

In 2022, the five most common leading causes of death in people with a Learning Disability were: 1) Congenital Malformations and Chromosomal abnormalities 2) Cancers 3) Influenza and Pneumonia 4) Cerebral Palsy 5) Ischaemic Heart Diseases.

When adjusting for sex, region, deprivation, place of death, and type of accommodation, people from all ethnic minority groups died at a younger age compared to people of “White” ethnicity.

The long-term condition most strongly associated with death at a younger age was Epilepsy.

Appropriate medical treatment and prevention, such as vaccinations to protect against COVID-19 and pneumococcus and mental health treatments (medications), are associated with a reduction in the risk of an earlier age at death.

42% of deaths were deemed “avoidable” for people with a Learning Disability, a reduction from 50% in 2021.

Men were 22% more likely to die from an avoidable cause of death than women. 26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding COVID-19), and 15.7% to cancers.

July 2022 recorded the highest number of notifications of deaths in 2022, 13% of which occurred on 19th and 20th of July. 19th of July saw a record high temperature in England. This spike in deaths appeared to be linked to extreme heat.

### **Autistic Adults with a Learning Disability**

- 178 people
- 68% male, 30% female
- 84% who died in 2022 were “white”
- Median age at death - 55 years
- Excluding “other”, most frequent causes of death according to ICD-10 codes were: respiratory conditions, cardiovascular conditions, cancer, COVID-19 and stroke, cerebral haemorrhage or embolism.

### **Autistic Adults with no Learning Disability**

- 36 completed reviews
- 81% male, 19% female
- 91% denoted as “white”
- Median age of death- 53 years
- Reviews are not representative of all autistic adults without a Learning Disability, and only limited conclusions can be made.
- Increased reporting is required to be able to better determine areas for improvement in the care of autistic adults without a Learning Disability
- Underlying causes of death were (i) Suicide, misadventure or accidental death: includes drug and alcohol related deaths that were not thought by the coroner to be intentional, (ii) Respiratory conditions, (iii) Cardiovascular and stroke related, (iv) Cancer and (v) Other

### **LeDeR and the context for Sheffield**

#### **1. People with Learning Disability**

In 2022, there were 30 patient deaths in the SHSC Learning Disability service. All of these were reviewed in the weekly mortality review and reported in the quarterly reporting to Quality Assurance Committee and Trust Board. All were referred to the Sheffield LeDeR process.

Regarding the 30 deaths, further information is as follows:-

- 3 opted out of record sharing so no LeDeR review was completed
- 5 deaths that were reported to LeDeR in 2022 received completed LeDeR reviews in 2022
- 18 deaths that were reported to LeDeR in 2022 received completed LeDeR reviews in 2023
- 4 deaths that were reported to LeDeR are still awaiting completed LeDeR reviews
- No information is available about “avoidable” deaths

We are currently not able to pull together learning as this is all embedded separately in each LeDeR review.

The median age at death was 63.5 years. 13 were male and 17 were female.

The Sheffield LeDeR report for 2022 has not yet been published.

Information regarding reported deaths of people with a Learning Disability in Quarters 1-3 in 2022/23 is as follows –

a) Quarter 1: Two deaths were reported. One was an “Expected Death (Information Only)” and the other was an “Unexpected Death (Suspected Natural Causes). 46 LeDeR Reviews were outstanding from the ICB as of the end of Q1. During Q1 there were 0 actions identified for SHSC from the 3 LeDeR reviews that were completed and returned by the ICB. All 3 LeDeR reviews were shared with the Learning Disability team in order to promote wider learning.

b) Quarter 2: Three deaths were reported. Two were “Expected Deaths-Information Only”, whilst one death was an “Unexpected Death- SHSC Community.” 39 LeDeR Reviews were outstanding from the ICB as of the end of Q2. There was a SHSC LeDeR action, which was as follows:-

“Issue: The Community Learning Disability Team were unaware of the patient’s death even though he was on an active caseload. The patient passed away on the 17th November 2021 and CLDT were informed of his death on 22nd March 2022.

Learning: The Community Learning Disability Team (CLDT) Management are undertaking work to clarify expectations of “active caseload” as part of LD Transformation work

Learning: Work has taken place related to dementia with a workshop being held in September.

c) Quarter 3: 12 deaths were reported. Three were “Expected Deaths-Information Only,” Five were “unexpected deaths- SHSC Community”, and four were “unexpected death (natural causes).” 47 LeDeR Reviews were outstanding from the ICB as of the end of Q3.

During Q3 there were no actions identified for SHSC from the 7 LeDeR reviews that were completed by the ICB. All seven LeDeR reviews were shared with the Learning Disability team in order to promote wider learning.

d) Quarter 4: Three deaths were reported. Two were “Expected Deaths-Information Only”, whilst one death was “Unexpected Death- SHSC Community.” 44 LeDeR Reviews were outstanding from the ICB as of the end of Q4.

During Q4 there were 7 actions identified for SHSC from the 4 LeDeR reviews that were completed by the ICB. All 4 LeDeR reviews were shared with the Learning Disability team in order to promote wider learning. The 7 actions identified were all in relation to the care and treatment of a person using the Assessment and Treatment Unit (ATU) at Firshill Rise. This service user died in 2021 as a result of COVID-19. Whilst learning was identified and shared, the LeDeR report outlined that there were no unique acts or omissions in relation to care provided that had a direct impact on outcome.

## **2. People with Autism and no Learning Disability**

6 deaths were reported to LeDeR in 2022

- Regarding 1 death that was reported in 2022 – this remains an open LeDeR as work needs to be done around pathways between mental health and Autism services
- 5 deaths that were reported in 2022 are pending LeDeR reviews. Some causes of death were suicide.

The deaths were all under investigation for police or coronial processes, which have impacted on the ability to complete LeDeR reviews.

Main issues have been around management of mental health rather than Autism.

People had been under services such as community mental health services and substance misuse services, but there was no active involvement with the SAANS service.

## Section 3: Risks

### 3.1 KEY RISKS AND HOW THESE ARE BEING MITIGATED

There are a number of risks and mitigations are written below and also in the recommendations.

- 1) There are risks that people with Learning Disability will be disproportionately affected by heatwaves.
  - Mitigations: Developing Easy Read information about staying safe during heatwaves.
- 2) There are risks that the service will not be able to meet the needs of diverse communities.
  - Mitigations: Ongoing co-production and engagement work. “Engagement with ethnic minority groups workstream”, which is also attended by colleagues in South Yorkshire ICB.
- 3) There is a risk that people with Learning Disability are at risk of avoidable deaths.
  - Mitigations: Community Nursing colleagues monitor physical health routinely as part of initial assessments and provide support with health passports. The service will continue to work closely with colleagues in Sheffield Teaching Hospitals’ Learning Disability and Autism team where required to ensure that people with a Learning Disability receive reasonable adjustments and are therefore able to access high quality care for their physical health needs.
- 4) There are risks that Autistic Adults without a Learning Disability may die through suicide, misadventure or accidental death.
  - Mitigations: Training around awareness about Autism and reasonable adjustments for mainstream mental health services. This could include how mental illness may present in autistic adults and development of crisis plans for autistic adults.

### 3.2 RECOMMENDATIONS

#### **How learning points are being addressed by the SHSC Learning Disability Service**

1. Stopping Overmedication of People with Learning Disability and/or Autism (STOMP) programme: A STOMP action plan is being developed following an audit of psychotropic medication of the psychiatry caseload within the service. STOMP information leaflets in multiple languages are available at the reception of Firshill Rise to ensure the STOMP agenda meets the needs of diverse communities in Sheffield.
2. ICS Provider Collaborative is led by SHSC Medical Director with successful involvement of a Health Foundation supported QI programme focusing on STOMP
3. “Oliver McGowan Mandatory Training” is part of SHSC mandatory training
4. The service will continue to embed the use of the Moulster and Griffiths Nursing Model. This is an evidence-based model designed specifically for people with Learning Disabilities and is linked to the health equalities outcomes measures framework.

5. The service is developing Easy Read information about staying safe during heatwaves.
6. Understanding the needs of people with a Learning Disability from ethnic minority groups is crucial to increase their access to the SHSC Learning Disability Service. There is ongoing work around engagement and co-production, which includes engaging with voluntary sector hubs that serve areas with a large population of people from ethnic minority groups.
7. The service will continue to support with interventions such as desensitisation for needle phobia and subsequent blood tests, as well as monitoring of physical health during initial assessments, identifying health related needs and providing appropriate interventions, signposting and supporting access to mainstream physical health services and the development of health passports.
8. The service will continue to work closely with colleagues in Sheffield Teaching Hospitals' Learning Disability and Autism team where required to ensure that people with a Learning Disability receive reasonable adjustments and are therefore able to access high quality care for their physical health.
9. The service is ensuring that service users are followed-up appropriately through development of multi-disciplinary team working within the SHSC Learning Disability Service, care co-ordination where required, and "Lead Professional" for service users within the new clinical model.

### **How learning points will be addressed by SHSC for people with Autism without a Learning Disability**

A total of 36 reviews were completed nationally in 2022, which the researchers stress means that only limited conclusions can be made. However, the data does highlight the need for improvements to be made in specific areas, such as better mental health care for autistic people due to deaths as a result of suicide, misadventure or accidental death. People with autism are recognized as a group at risk of suicide in the Suicide prevention in England Strategy (2023).

SHSC is committed to a programme of improving staff knowledge and skills in relation to supporting autistic people. This is reflected in:

1. SHSC has updated its mandatory training e-learning on autism to include LeDeR information and how to reduce barriers to access to health that result in increased health vulnerabilities. Training has been coproduced with staff members with lived experience and guidance from the disability staff network group.
2. SHSC has a specialist autism diagnostic service (SAANS) who also provide post diagnostic support and green light consultation/specialist training across the organisation.
3. Mandatory Oliver McGowan Training Programme.
4. February 2024 Quality Improvement Forum – focused session on reducing barriers to health care for autistic people with presentations from adult mental health, learning disabilities and the engagement teams.
5. Sensory assessment of ward environments has produced recommendations that are being implemented as part of the ward rebuild/refurbishment programme (e.g., carpets in place of safety to reduce echo and noise).
6. Staff across community and inpatient settings accessing the National Train the Trainers programme (Anna Freud).
7. Four staff are being trained in the National Autism Society SPELL framework.
8. Employment of two Peer Support Workers in SAANS, a lead autism nurse in our crisis pathway, a Consultant Nurse based in Community Mental Health Team (CMHT) North who is completing a MA in Autism and a Consultant Psychologist providing consultancy into inpatient wards.
9. In 2024 an Autism 'Community of Practice' will be launched for staff which will focus on improving feedback channels for autistic people to comment on their experience of services.
10. SHSC is working with Sheffield ICB to develop pathways and systems (i.e., Dynamic Support Register (DSR), Local Area Emergency Protocol and Care Education and Treatment Reviews(CeTRs)).

11. SHSC leads are working closely with Sheffield Autism Partnership Board and voluntary sector organisations to deliver the autism strategy at a local level.

## Section 4: Assurance

### Benchmarking

- 4.1 There is triangulation with learning extracted from Serious Incident investigations into the deaths of service users.

### Triangulation

- 4.2 The current process for reviewing deaths reported within SHSC includes contact with bereaved relatives and carers to express the Trust condolences and ask for feedback on the quality of the service provided to their family member.

Structured Judgement Review process requires that all completed reviews and the learning from those reviews is presented to the individual teams that provided care to the deceased patient.

Identified increased risk of suicide in those with Autism will be explored as part of the response to the learning for Suicide prevention in England Strategy (coming to Board later in 2024)

### Engagement

- 4.3 The current process for reviewing deaths reported within SHSC includes contact with bereaved relatives and carers to express the Trust condolences and ask for feedback on the quality of the service provided to their family member.
- 4.4 The LD Transformation work has coproduction at its heart.

## Section 5: Implications

### Strategic Priorities and Board Assurance Framework

1. Effective Use of Resources
  2. Deliver Outstanding Care
  3. Great Place to Work
  4. Ensuring our services are inclusive
- 5.1 BAF.0024: There is a risk that we will be unable to deliver essential improvements in the quality of care in all services within the agreed time frame to comply with the fundamental standards of care; caused by leadership changes, short staffing, cultural challenges, the lead in time for significant estates and ISMT actions and the impact of the global pandemic; resulting in risk of harm to people in our care and a breach in the Health and Social Care Act.
    - CQC Regulation 18: Notification of other incidents
    - CQC's Review of Learning from Deaths
    - LeDeR Project
    - NHS Sheffield CCG's Quality Schedule
    - NHS England's Serious Incident Framework
    - SHSC's Incident Management Policy and Procedures



- SHSC's Duty of Candour/Being Open Policy
- SHSC's Learning from Deaths Policy
- National Quality Board Guidance on Learning from Deaths

### Equalities, diversity and inclusion

5.2 The report has been reviewed for any impact on equality in relation to groups protected by the Equality Act.

### Culture and People

5.3 The LD Transformation Programme will include an Organisational Development to address cultural and workforce transformation aspects.

### Integration and system thinking

5.4 The Health Foundation supported ICS STOMP programme has the SHSC MD as Executive lead and will take a Quality Improvement (QI) approach to reducing medication use in LD which is a contributor to early mortality.

### Financial

5.6 The LD Transformation funding is agreed.

### Compliance - Legal/Regulatory

5.7 As described above in section 4.1.

### Environmental sustainability

5.8 LD Transformation will provide care in the community closer to home with focus on non-medication psychosocial support which will have a positive impact on environmental sustainability and progress towards NHS net Zero.

## Section 5: List of Appendices

LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People 2022, Kings College London- [Master LeDeR 2023 \(2022 report\)](https://www.kcl.ac.uk/lede/2022-report) ([kcl.ac.uk](https://www.kcl.ac.uk))