Board of Directors

SUMMARY REPORT	Meeting Date:	23rd November 2022
	Agenda Item:	12

Report Title:	**LeDeR Learning from lives and deaths – People with a learning disability and autistic people- Annual Report 2021, and the context for Sheffield**	
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Accountable Director:	Dr Mike Hunter, Executive Medical Director	
Other meetings this paper has been presented to or previously agreed at:	**Committee/Tier 2 Group/Tier 3 Group**	N/A
	Date:	
Key points/ recommendations from those meetings		

Summary of key points in report

- The 2021 national LeDeR report shows that people with Learning Disability experience significant health inequalities in comparison to the general population. This includes an earlier median age of death and a greater percentage of deaths designated as avoidable.
- This paper provides an overview of the national report and a preliminary comparison with deaths of people in SHSC Learning Disability services in 2021, where individual LeDeR reports have been received to date.
- The paper also outlines how learning from the national and local LeDeR processes is informing the development of the transformation work in SHSC Learning Disability services.

Recommendation for the Board/Committee to consider:

Consider for Action		Approval		Assurance	x	Information	

- The Board is asked to receive information from the 2021 national LeDeR report and note that national learning points will be used to develop the SHSC Learning Disability service, along with information from local LeDeR reviews.

Please identify which strategic priorities will be impacted by this report:				
Covid-19 Recovering effectively	*Yes*	*x*	*No*	

CQC Getting Back to Good – Continuing to improve	*Yes*	*x*	*No*	
Transformation – Changing things that will make a difference	*Yes*	*x*	*No*	
Partnerships – working together to make a bigger impact	*Yes*	*x*	*No*	

Is this report relevant to compliance with any key standards ?					**State specific standard**
Care Quality Commission Fundamental Standards	*Yes*	*x*	*No*		Regulations of the Health and Social Care Act
Data Security and Protection Toolkit	*Yes*		*No*	*x*	
Any other specific standard?					

Have these areas been considered? YES/NO					If Yes, what are the implications or the impact? If no, please explain why
Service User and Carer Safety and Experience	*Yes*	*x*	*No*		Reducing premature mortality in people with Learning Disability is a key outcome in making improvements in care
Financial (revenue &capital)	*Yes*		*No*	*x*	These are outside the scope of this report, although improving care earlier in the lifespan generally improves efficiency in care systems
Organisational Development /Workforce	*Yes*	*x*	*No*		Improving the care of people with Learning Disability has implications for workforce development and training
Equality, Diversity & Inclusion	*Yes*	*x*	*No*		This report explicitly references new approaches to improving the safety of care for people from ethnically diverse backgrounds
Legal	*Yes*	*x*	*No*		Relevant legal frameworks include the Health and Social Care Act, Human Rights Act, Mental Health Act and Mental Capacity Act
Sustainability	*Yes*	*x*	*No*		For example, reducing inappropriate use of medication improves environmental sustainability in addition to direct health benefits

Name of Report

LeDeR Learning from lives and deaths – People with a learning disability and autistic people- Annual Report 2021, and the context for Sheffield

Section 1: Analysis and supporting detail

Background

1.1 Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR; 1) aims to:

1) improve care for people with a Learning Disability and autistic people
2) reduce health inequalities for people with a Learning Disability and autistic people and
3) prevent people with a Learning Disability and autistic people dying prematurely

Key Findings in the National LeDeR Report 2021

1.2 People with a Learning Disability have a considerably earlier median age of death in comparison to the general population (men: 61 years, women: 62 years).

There were more male than female deaths (56%) in the national cohort. Over 50% of all reported deaths were of those living in the most deprived areas.

The national cohort was predominantly White British and ethnicity was a significant predictor of death at a younger age. Being of Black, Black British, Caribbean or African ethnicity was associated with the highest risk.

In 2021, the most reported underlying causes of death were related to COVID-19, circulatory system diseases, respiratory system diseases, cancers and nervous system diseases. The five most frequently reported long-term health conditions for people who died in 2021 and received an initial LeDeR review were epilepsy, cardiovascular conditions, mental health conditions, sensory impairment and dysphagia.

In the national group, 49% of deaths were rated as "avoidable" in comparison to 22% for the general population. In terms of underlying cause, 17% of avoidable deaths were linked to respiratory conditions, 17% to diabetes, 14% to hypertension and 8% to cancer.

During 2021, the rate of excess deaths amongst people with a Learning Disability was more than two times higher than the general population. For people with a Learning Disability, COVID-19 was the leading cause of death and those unvaccinated were nine times more likely to die of COVID-19 than another cause compared to those vaccinated.

Areas of concern in the national report included:-

- Lack of preventative healthcare (screening programmes and vaccinations) and difficulties accessing appointments
- Lack of reasonable adjustments in various settings
- Missed or inadequate annual health checks
- Lack of adherence to the Mental Capacity Act
- Long-term antipsychotic prescription without adequate review and physical health not being monitored appropriately.

Information about deaths in Sheffield Health and Social Care NHS Foundation Trust Learning Disability service in 2021

In 2021, there were 24 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.

The median age at death was 65 years. Sixteen were male and eight were female.

The Sheffield LeDeR report for 2021 has not yet been published and SHSC has received reviews back for 10 of the 24 deaths to date. A preliminary review of learning points for SHSC shows main themes related to (1) scope for more effective use of health passports and (2) improvements to be made in “head to toe” health assessments.

Of the 10 LeDeR reviews received to date, none categorised the death as “avoidable”.

How learning points will be addressed by the SHSC Learning Disability Transformation Plan

Reducing health inequalities, including premature death in people with Learning Disability, is a key theme of the SHSC Clinical and Social Care Strategy and the Learning Disability Services Transformation Programme.

In relation to issues of physical health and appropriate use of medication, the SHSC Learning Disability transformation plan is being built around national agendas, including the Stopping Overmedication of People with Learning Disability and/or Autism (STOMP) agenda. A robust STOMP programme is being developed. The importance of medication safety has already been emphasised through an event for SHSC in October 2022 where the mother of Oliver McGowan spoke about “Oliver’s Story and Oliver McGowan Mandatory Training”.

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. The transformed services will engage people from a range of backgrounds. Multicultural STOMP, innovated in 2020, was a national first, aimed at improving STOMP implementation for people with Learning Disability and/or Autism from an ethnic minority background. Recognised as “outstanding practice” following a CQC inspection in another Trust in 2020, Multicultural STOMP is now being developed within the SHSC transformation work.

The clinical model in the transformed SHSC service emphasises advocacy for people with a Learning Disability to ensure they receive the required physical health support. Examples of current work provided in the service includes desensitisation for needle phobia and subsequent blood tests, and making improvements to “head to toe” assessments.

There will be continued engagement with the local LeDeR Steering Group, led by the ICB at Sheffield Place. Once released, the 2021/22 Sheffield LeDeR report will be shared with all colleagues in the Learning Disability service for learning will be used to further inform the development of the Learning Disability service. The report will also be attached to the relevant mortality review quarterly reporting to Quality Assurance Committee and Board of Directors.

Section 2: Assurance

LeDeR Reporting and Governance

2.1 Deaths of people with a Learning Disability aged 18 years and over are mandated for a LeDeR review. Following confirmation that the death is within scope of the programme, a trained LeDeR reviewer will gather details on the death and start the review process, with a target for this to be completed within 6 months. This will lead to a comprehensive and focused review, looking very closely at the person's life and circumstances of death. These focused reviews, once completed, are then sent to the SHSC Mortality Review Group (MRG) with areas of good practice, any areas of concern, and wider learning from the case being outlined. Once presented to the MRG each review is submitted to the Community Learning Disability Team (CLDT) for consideration in team governance, dissemination and, where relevant, implementation of recommendations.

2.2 All SHSC patient deaths of those with a Learning Disability and, since an expansion of the scope of LeDeR in January 2022, Autism have been reported for LeDeR review.

2.3 SHSC works in collaboration with the South Yorkshire Integrated Care Board (ICB) in ensuring all received actions are taken through the relevant local governance process.

Triangulation

2.4 Sheffield LeDeR data can be mapped against national data. This report provides a preliminary account, which will be expanded when the full Sheffield LeDeR report for 2021 is published.

Engagement

2.5 The LeDeR reviewers engage with family and significant others when LeDeR reviews are commenced. SHSC engage with family during the initial review of a death where appropriate.

List of References

1. LeDeR Annual Report 2021: https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf