

REPORT CLASSIFICATION	✓	CATEGORY OF PAPER	✓
Official	✓	Proposes specific action	✓
Official: Sensitive Commercial		Provides assurance	✓
Official: Sensitive Personal		For information only	

BOARD

25 NOVEMBER 2025

Report Title:

North East and North Cumbria ICB Annual Report – Learning from the Lives and Deaths of People with Learning Disability and Autistic People (LeDeR)

Purpose of report

The LeDeR Annual Report, is a statutory requirement that provides assurance about delivery of LeDeR including numbers of reviews, causes of death and learning/improvement action undertaken across North East and North Cumbria.

Key points

Background:

This LeDeR Annual Report, a statutory requirement as set out in the national LeDeR policy, is the inaugural annual report from the NENC ICB. It fulfils all requirements as directed by NHS England including both summarised NENC information as well as detail from each place.

Current position:

During 2024 the North East and North Cumbria carried out LeDeR reviews of 195 deaths of people with learning disability and autistic people.

There were reviews of people with 192 learning disability or learning disability and autism who have died and 3 reviews of autistic people who have died. 97 were about men and 95 about women who have died. 170 reviews were initial and 22 were focussed.

What the Board should focus on:

In 2024 we carried out 195 reviews where the most common reasons people died prematurely was largely unchanged from previous years.

The reviews of autistic people, a relatively new addition to the LeDeR policy, take much longer to complete and reviewers are required to expand their skills and knowledge to ensure all learning is gathered. The reasons autistic people die early appear to be different from people with learning disability. There were only 3 reviews of autistic people, all of whom died by suicide. Given the numbers are so low it is very difficult to carry out any meaningful analysis.

End of life planning and an increase in uptake of annual health checks, flu and covid immunisation is playing a significant role in lengthening the lives of people with learning disability.

NHS England have advised a significant announcement regarding the future of LeDeR is expected late 2025, to date, there is no indication of what this could be.

Risks and issues

The current number of LeDeR reviewers within the ICB will not enable compliance with current and future requirements and demands which requires attention. Plans are in place to expand the number of reviewers.

Reviews are tightly managed within a national KPI framework (all deaths require a review), nationally the main reasons people die prematurely hasn't changed and significant new learning is not evident, however we anticipate the national NHSE LeDeR announcement will affect future plans for the programme.

Learning from reviews and associated improvement initiatives are aligned with ICB work programmes, particularly health inequalities, early intervention, and prevention programmes. The NHS 10-Year Plan provides opportunity to embed learning from LeDeR into all future strategic commissioning decisions.

LeDeR is identified as a risk on the ICB Corporate Risk Register.

Assurances and supporting documentation

The NENC LeDeR Governance Group, chaired by Ann Fox (Deputy Chief Nurse), strategic leadership provided by Judith Thompson (Learning Disability Network) and co-ordination by Amy Hocking (Learning Disability Network) is responsible for assuring the ICB LeDeR is delivered effectively, efficiently and in a coordinated way across NENC. It has a business cycle with regular reporting schedule with the System Quality Group and Quality and Safety Committee and receives regular reporting from the Learning Disability Network and the Learning Disability and Autism transformation programme.

The NHSE national announcement regarding LeDeR (due winter 2025) will impact on the future direction of travel of LeDeR.

Attached documentation

Appendix 1 – Annual Report Learning from the Lives and Deaths of People with Learning Disability and Autistic People

Appendix 2 – LeDeR Learning into Action Report 2024

Appendix 3 – LeDeR Annual Report 2024 - Easy Read Short Summary

The Quality and Safety Committee received the report on 13 November 2025 and recommended to the Board for publication on the ICB website.

Recommendation/action required

The Board is asked to note the LeDeR Annual Report and Learning into action Report 2024 and approve for publication on the ICB website (as required by LeDeR policy).

Acronyms and abbreviations explained

LeDeR – Learning from the Lives and Deaths of People with Learning Disability and Autistic People
NENC – North East and North Cumbria

Sponsor/Approving Executive Director	Hilary Lloyd, Chief Nurse and AHP Officer / LeDeR SRO
Date approved by Executive Director	17 November 2025
Report author	Judith Thompson, NENC Learning Disability and Autism Network Manager

Link to ICP strategy priorities

Longer and Healthier Lives	✓
Fairer Outcomes for All	✓
Better Health and Care Services	✓
Giving Children and Young People the Best Start in Life	✓

Relevant legal/statutory issues						
Note any relevant Acts, regulations, national guidelines etc						
Any potential/actual conflicts of interest associated with the paper? (please tick)	Yes		No	✓	N/A	
Equality analysis completed (please tick)	Yes		No		N/A	✓
If there is an expected impact on patient outcomes and/or experience, has a quality impact assessment been undertaken? (please tick)	Yes		No		N/A	✓
Essential considerations (must be completed)						
Financial implications and considerations	None					
Contracting and Procurement	N/A					
Local Delivery Team	No					
Digital implications	No					
Clinical involvement	Dr. Kathy Petersen, Chair, LeDeR Panel					
Health inequalities	Learning from LeDeR provides evidence base of tackling health inequalities faced by people with learning disability and autistic people.					
Patient and public involvement	Stop People Dying Too Soon Group (facilitated by Inclusion North) Cumbria Confirm & Challenge Group (facilitated by People First)					
Partner and/or other stakeholder engagement	None					
Other resources	None					