

Item: 10.1

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

BOARD

28 NOVEMBER 2023

Report Title:

North East & North Cumbria Learning from the Lives and Deaths of People with Learning Disability and Autistic People Annual Report 2022 – 2023 (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 fulfills all requirements as directed by NHS England including both summarised NENC information as well as detail from each place.

Current position:

During 2022/23 163 reviews were completed after the deaths of people with learning disability. Of these, 128 were initial reviews and 35 focused reviews. 94 were men and 69 were women. The top 3 causes of death were pneumonia, Cardio Vascular Disease (CVD) and aspiration pneumonia.

During 2022/23 4 reviews were completed following the deaths of autistic people. All were men and all focused reviews (as LeDeR policy requires). The causes of death were complications with drugs misuse, Cardiovascular disease and suicide.

There is a wide-ranging work programme to deliver improvement work across the health and care system as a result of learning from reviews.

What the Board should focus on:

Learning from reviews remains largely unchanged from previous years and the reasons people with learning disability die early in the North East and North Cumbria are the same as the rest of England.

The reviews of autistic people, a 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 although the numbers are very low of completed reviews. Further analysis of this will take place next year.

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.

Risks and issues

Ongoing risks and concerns:

The current number of reviewers will not enable compliance with current and future requirements and demands which requires attention.

Concern that reviews are tightly managed within a national KPI framework (all deaths require a review) although no new learning is being uncovered.

Learning from reviews and associated improvement initiatives should be closely aligned with ICB work programmes, particularly the health inequalities, early intervention and prevention programmes.

Assurances

The NENC LeDeR Governance Group, chaired by Ann Fox (Deputy Chief Nurse), strategic leadership provided by Judith Thompson and co-ordination by Amy Hocking is responsible for assuring the ICB LeDeR is being delivered effectively, efficiently and in a co-ordinated way across NENC. It has a cycle of business 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.

Recommendation/action required

The ICB is asked to approve this annual report for publication.

Acronyms and abbreviations explained

LeDeR – Learning from the Lives and Deaths of People with Learning Disability and Autistic People.
CVD – cardio vascular disease

Sponsor/approving executive director	David Purdue, Executive Chief Nurse
Date approved by executive director	13 July 2023
Report author	Judith Thompson, Learning Disability Network Manager

Link to ICB corporate aims (please tick all that apply)

CA1: Improve outcomes in population health and healthcare	✓
CA2: tackle inequalities in outcomes, experience and access	✓
CA3: Enhance productivity and value for money	
CA4: Help the NHS support broader social and economic development	

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	
If yes, please specify						
Equality analysis completed (please tick)	Yes		No		N/A	✓
If there is an expected impact on patient outcomes and/or experience,	Yes		No		N/A	✓

has a quality impact assessment been undertaken? (please tick)						
Key implications						
Are additional resources required?	NA					
Has there been/does there need to be appropriate clinical involvement?	There has been clinical involvement via LeDeR reviewers and members of the LeDeR governance group.					
Has there been/does there need to be any patient and public involvement?	There has been engagement and involvement via the members of the LeDeR governance groups – Stop People Dying Too Soon and Cumbria Confirm and Challenge Groups.					
Has there been/does there need to be partner and/or other stakeholder engagement?	There has been engagement and involvement via the members of the LeDeR governance groups – Stop People Dying Too Soon Group and Cumbria Confirm and Challenge Group.					