

Item: 17.2

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

BOARD

1 OCTOBER 2024

Report Title:

NENC ICB Learning from the Lives & Deaths of People with Learning Disability and Autistic People (LeDeR) Annual Report January – December 2023

Purpose of report

To provide the Board with the LeDeR Annual Report 1st Jan – 31st Dec 2023, the Learning into Action Report, and the easy read version.

Key points

- LeDeR is a national service improvement programme for people with learning disability and autistic people aged eighteen and over.
- Its purpose is to identify good practice, what is working well and where improvements should be made.
- The ICB LeDeR Annual Report 2023 has changed its reporting schedule (from financial year) to fall in line with the same reporting schedule from NHS England (calendar year).
- There were 257 notifications to the national LeDeR platform about people with learning disability and autistic people who had died from NENC during 2023.
- 216 reviews have been conducted (including 26 focussed reviews), of these 216 were about people with learning disability and 8 about autistic people. The remaining forty-one reviews are now in progress and will be reported as an addendum to this report early 2025.
- Place breakdowns are included providing information about gender, age, place of death and ethnicity.
- The most common causes of death during 2023 were pneumonia, aspiration pneumonia, heart disease, respiratory disease, and cancer.
- Significant learning points and actions:
 - ICB 2.0 provided an opportunity to centralise, streamline and standardise LeDeR across NENC with the Learning Disability Network providing strategic leadership across all elements of the programme (operational, learning into action & assurance). Expect full BAU model to in train no later than March 24.
 - Notifications of autistic people who have died has remained low. NHSE nationally are working on an awareness raising campaign and a NENC awareness raising campaign will be undertaken.
 - Notifications of people from minoritised ethnic backgrounds has remained low. A lead is to be identified within the LeDeR programme, the work is to be embedded within the ICB Health Equity & Inclusion programme & an awareness raising programme to be delivered.
 - More information is needed to understand the quality of care received by people with learning disability and autistic people. Roll out of mandatory learning disability & autism awareness training is underway.
- Learning into action has been widely implemented across NENC including:

- Reasonably adjusted NENC winter vaccination programme
- Hypertension case finding
- Be Screening Aware & Be Cancer Aware peer education
- Health Quality Checks of breast & bowel screening programmes and recommendations reported to programme boards
- Annual Health Check prompt sheets
- Reasonable adjustment campaign
- Prevention of Adult Not Brought strategy, workforce education & resources

This report was presented to the Quality and Safety Committee 12th September 2024

Risks and issues

LeDeR process and capacity Risk NENC/0051, residual risk reduced to nine after mitigating activity undertaken outlined below.

Assurances

The report provides assurance that delivery of LeDeR is fully in line with national policy and aligned to ICB strategic plans and learning into action is delivered at scale.

Further to options appraisal work undertaken and ICB 2.0 reorganisation NENC LeDeR is now standardised across NENC, eradicating variation, and enabling widely shared learning from reviews. A full refresh of all LeDeR arrangements is completed resulting in a centralised LeDeR reviewing team, NENC wide panel (focused review sign off requirement) chaired by Dr. Kathy Peterson, learning into action group chaired by Judith Thompson and assurance/governance group chaired by Ann Fox.

Recommendation/action required

The Board is asked to approve the LeDeR annual report (as recommended by Quality and Safety committee 12th September 2024) and to publish on the ICB website.

Acronyms and abbreviations explained

Explained throughout the report.

Sponsor/approving executive director	David Purdue, Chief Nurse, AHP and People Officer
Date approved by executive director	17 September 2024
Report author	Judith Thompson, North East and Cumbria Learning Disability Network Manager Ann Fox, Deputy Chief Nurse

Link to ICP strategy priorities (please tick all that apply)

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	
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, has a quality impact assessment been undertaken? (please tick)	Yes		No		N/A	<input checked="" type="checkbox"/>
Key implications						
Are additional resources required?	No					
Has there been/does there need to be appropriate clinical involvement?	Ongoing clinical involvement as needed					
Has there been/does there need to be any patient and public involvement?	Ongoing involvement of patients and public as needed					
Has there been/does there need to be partner and/or other stakeholder engagement?	Broad stakeholder engagement across the work programme					
Has there been/does there need to be appropriate finance or digital involvement?	No					