NHS
North East and North Cumbria

North East and North Cumbria
Integrated Care Board

Learning from the Lives and Deaths of people with Learning Disability and Autistic People

Annual Report
1st January - 31st December 2024

North East and North Cumbria
Learning Disability and Autism
Network

What is this report about?

This is the North East and North Cumbria Integrated Care Board's LeDeR (Learning from the Lives and Deaths of People with Learning Disability and Autistic People) Annual Report.

It is for everyone who is interested in understanding and learning from the lives and deaths of people from the North East and North Cumbria who died in 2024.

This report covers the time between 1st January 2024 and 31st December 2024.

There were 192 reviews of people with learning disability or learning disability and autism who have died and 3 reviews of autistic only people who have died.

What is LeDeR?

LeDeR is a national service improvement programme. This means that every death of a person with learning disability or an autistic person is reviewed using the national review process. Integrated Care Boards (ICB) need to make sure LeDeR reviews are completed based on the health and social care service received by people with learning disability and autistic people aged 18 and over who have died.

This helps the ICB find out about good practice, what has worked well as well as where improvements need to be made. This helps make commissioning decisions about services needed.

LeDeR reviews are not investigations or parts of complaints procedures, they are to help health and social care services know what the best care for people with learning disability and autistic people could and should look like.

LeDeR is exempt from 'national data opt out', so what this means is if a person opted out of sharing medical records, they will still receive a LEDER review.

Contents

As Chief Executive of the North East and North Cumbria Integrated Care Board, I am proud to present our annual LeDeR (Learning from the Lives and Deaths of People with Learning Disability and Autistic People) report for 2024.

This report is both a reflection and a call to action. It provides a detailed account of the lives and deaths of people with learning disability and autistic people across our region, and it is the result of the dedication and collaboration of many, families, carers, professionals, and, most importantly, people with lived experience.

Every life matters. Each review undertaken through the LeDeR programme is not just a statistic, but a story, one that helps us understand what we are doing well and, crucially, where we must do better.

Our commitment is to ensure that the learning from every review leads to meaningful change: improving services, reducing inequalities, and supporting people to live longer, healthier, and happier lives.

We are determined to act on what we learn from LeDeR reviews. This means:

- Embedding learning into our commissioning decisions and service improvements.
- Working with people with lived experience to co-produce solutions and drive change.
- Strengthening our processes to ensure every review is completed to a high standard and that learning is shared widely across our system.
- Launching targeted campaigns and training to address identified gaps, such as improving awareness of the needs of autistic people and people from minoritised ethnic communities.
- Monitoring our progress and holding ourselves accountable for delivering on the actions and recommendations that arise from LeDeR reviews.

This year's report highlights both progress and ongoing challenges. We have strengthened our processes, increased the consistency and quality of our reviews, and worked closely with experts by experience to ensure that the voices of people with learning disability and autistic people are at the heart of our work. However, we know there is more to do, particularly in addressing health inequalities, improving access to care, and ensuring that every death is reviewed and learned from.

I want to thank everyone who has contributed to this report and to the LeDeR programme. Your commitment, expertise, and compassion are making a real difference. Together, we will continue to listen, learn, and act, so that every person in our region receives the care, respect, and support they deserve.

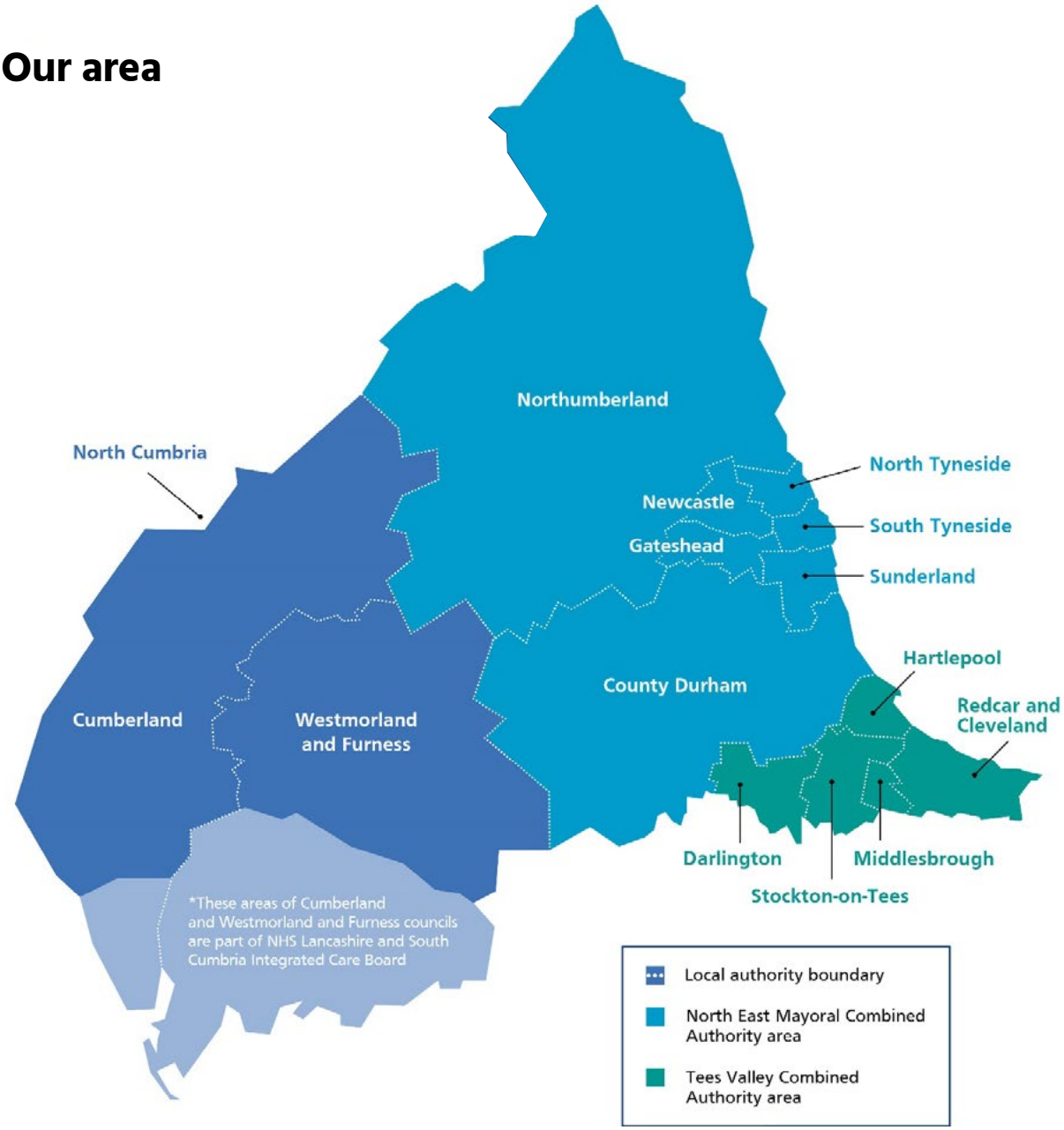
Thank you.

Samantha Allen, Chief Executive, NHS North East North Cumbria Integrated Care Board

NHS North East and North Cumbria Integrated Care Board (ICB)

NHS
North East and
North Cumbria

Our area



Section 3 - The purple part

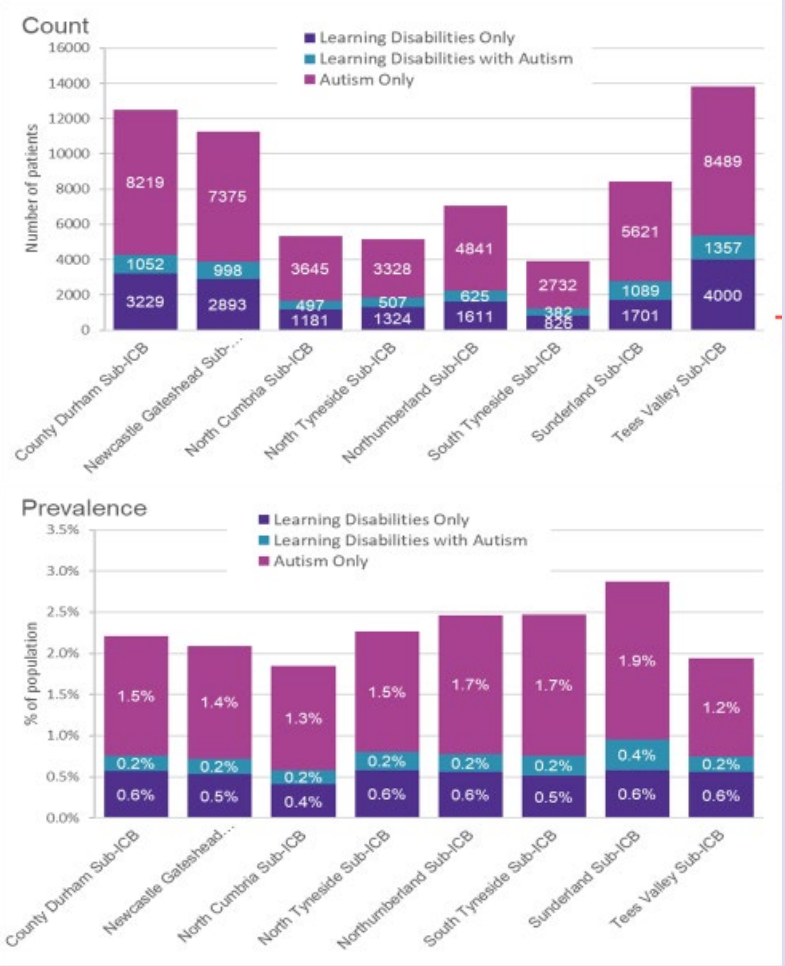
People with learning disability and autistic people registered with general practice in the North East and North Cumbria.

Within North East & North Cumbria (Data September 2024):

- 0.8% (23,272 people) of the population have a learning disability recorded
- 1.7% (50,757) have autism.
- Of these, 6,507 have both learning disability and autism.

Expected prevalence:

- Learning disability - 2%+ 1,2
- Autism - Global prevalence estimated at 1.04%; children in UK 1.6% 3



1. https://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf
2. https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability
3. https://researchbriefings.files.parliament.uk/documents/POST-PN-0612/POST-PN-0612.pdf

Section 4 - The pink part

The North East and North Cumbria Confirm & Challenge Groups

In the North East and North Cumbria, we have two lived experience groups working on the issues around LeDeR – Stop People Dying Too Soon Group and Cumbria Confirm & Challenge Group.

Both groups have worked together for the 6th year on the LeDeR programme.

We are the Stop People Dying Too Young Group. A big part of our work is around preventing people with a learning disability and autistic people dying too young.

We welcome the LeDeR programme because it gives us the chance to learn from people's lives and experiences.

Each review helps us see where care has worked well and where changes are needed, so that people with a learning disability and autistic people can live healthier, longer lives.

We know that making reasonable adjustments really does save lives, by making care more accessible and reducing barriers that people often face.

Campaigns like the flu vaccination programme are also so important in preventing avoidable deaths and protecting people in our communities.

At the same time, there are challenges we must face together. We are concerned about the shortage of learning disability nurses, whose skills and understanding are vital to good care. We are also deeply worried about the high rates of suicide among autistic people, which show how much more we need to do to provide the right support.

Section 4 - The pink part

The North East and North Cumbria Confirm & Challenge Groups

The needs of autistic people are often very different for people who have a learning disability.

We are committed to listening, learning, and acting on what LeDeR shows us, so that every person's life and every review leads to real change.

The Stop People Dying Too Soon Group is facilitated by Inclusion North and is made up of experts with lived experience including people with learning disability, autistic people and family carers.

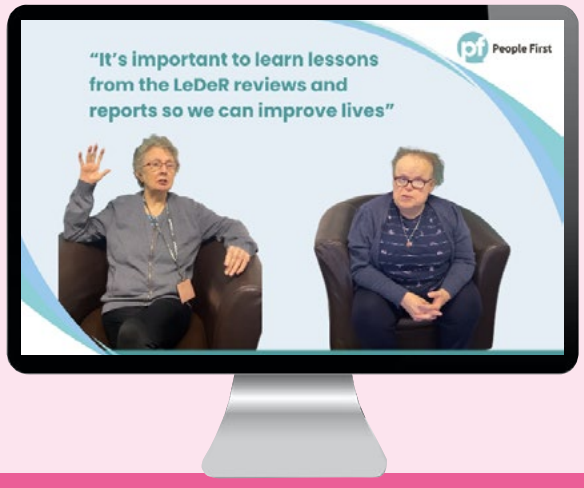
inclusion north

We are the Cumbria Confirm and Challenge Group. Together, we are passionate about reducing health inequalities and raising awareness about campaigns that will support people with a learning disability and autistic people to live longer, healthier lives.

The LeDeR programme is at the centre of the work we do. People with a learning disability and autistic people are still dying far too early. Sometimes the deaths are preventable, and we want that to change. For us, learning lessons from the LeDeR reviews is the key to making sure the life of every person makes a difference. We can learn from good examples of care, and examples of care which could and should have been better.

The LeDeR reviews have shown us that good care involves reasonable adjustments and clear communication. Reasonable adjustments can be different for each individual, and they a vital part of breaking down barriers and supporting people to get the care they deserve.

We know that developing awareness of cancer screening and vaccinations are making a positive impact, but reasonable adjustments are needed for these to be successful and accessible for everyone.



Section 4 - The pink part

The North East and North Cumbria Confirm & Challenge Groups

We believe that good care begins with good communication - listening to people with lived experience, their family or their carers. Sometimes a death is not preventable, but people should have the right to have a voice in decisions about how they live and how they are cared for. Furthermore, having clear communication systems between professionals and service providers at all levels is essential.

As a group, we recognise this is challenging work, but we are determined to continue because it is important and needed. We will keep speaking up, collaborating with others, and together we will make an impact.

We have made a short animation explaining how the LeDeR process works LeDeR - What is it and how does the process work.

People First

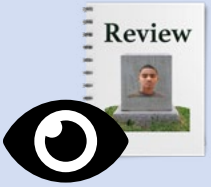
The Cumbria Confirm & Challenge Group is facilitated by People First, Cumbria and is made up of experts with lived experience including people with learning disability, autistic people and family carers.

Section 5 - The blue part

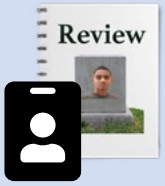
Place breakdowns

In North Tyneside we completed 9 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

8 completed reviews were **initial reviews**



1 completed reviews were **focussed reviews**



2 were **men**

7 were **women**

0	1	1	4	2	1
were **21 - 30 years old**	was **31 - 40 years old**	was **41 - 50 years old**	were **51 - 60 years old**	were **61 - 70 years old**	was **71 - 80 years old**

0 died in **own home**	**8** died in **acute hospital**	**1** died in **residential /nursing home**	**0** died in **supported living**	**0** died **somewhere else**

8 were white British

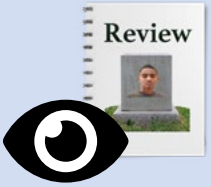
0 were from minority ethnic backgrounds

1 preferred not to say

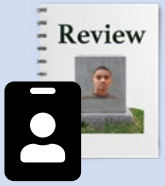
Section 5 - The blue part
Place breakdowns

In Northumberland we completed 16 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

13 completed reviews were **initial reviews**



3 completed reviews were **focussed reviews**



6 were **men**

10 were **women**

0 were 21 - 30 years old	0 were 31 - 40 years old	2 were 41 - 50 years old	5 were 51 - 60 years old	5 were 61 - 70 years old	4 were 71 - 80 years old

7 died in own home	**7** died in acute hospital	**1** died in residential /nursing home	**1** died in community hospital	**0** died somewhere else

14 were white British

1 was black/ African/ Caribbean British

1 was white other

Section 5 - The blue part
Place breakdowns

In Newscastle & Gateshead we completed 27 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

24 completed reviews were **initial reviews**

3 completed reviews were **focussed reviews**

12 were **men**

15 were **women**

1 was **31 - 40 years old**

1 was **41 - 50 years old**

8 were **51 - 60 years old**

7 were **61 - 70 years old**

9 were **71 - 80 years old**

1 was **81+ years old**

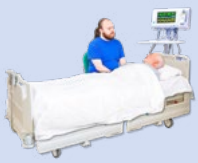
3 died in **own home**

16 died in **acute hospital**

5 died in **residential /nursing home**

3 died in **a hospice**

0 died **somewhere else**



27 were white British

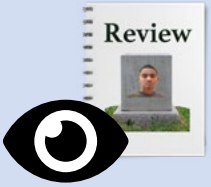
0 were from minority ethnic backgrounds

0 preferred not to say

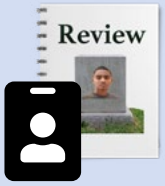
Section 5 - The blue part
Place breakdowns

In North Cumbria we completed 19 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

17 completed reviews were **initial reviews**



2 completed reviews were **focussed reviews**

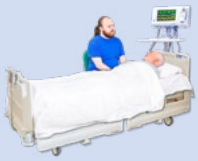


11 were **men**

8 were **women**

1 was **21 - 30 years old**	**1** was **31 - 40 years old**	**3** were **41 - 50 years old**	**3** were **51 - 60 years old**	**6** were **61 - 70 years old**	**5** were **71 - 80 years old**

1 died in **own home**	**10** died in **acute hospital**	**5** died in **residential /nursing home**	**1** died in **a hospice**	**2** died **community hospital**



19 were white British

0 were from minority ethnic backgrounds

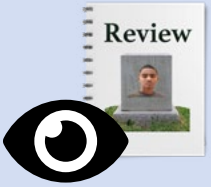
0 preferred not to say

Section 5 - The blue part

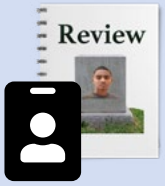
Place breakdowns

In Sunderland we completed 28 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

25 completed reviews were **initial reviews**



3 completed reviews were **focussed reviews**



11 were **men**

17 were **women**

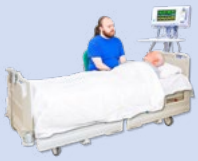
1	3	2	5	8	6	3
was **21 - 30 years old**	were **31 - 40 years old**	were **41 - 50 years old**	were **51 - 60 years old**	were **61 - 70 years old**	were **71 - 80 years old**	were **81+ years old**

7 died in **home/ home of family member**

14 died in **acute hospital**

3 died in **residential /nursing home**

4 died in **a hospice**



0 died **somewhere else**

27 were white British

1 was black/ African/ Caribbean British

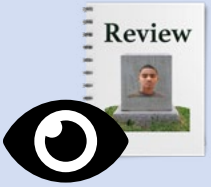
0 preferred not to say

Section 5 - The blue part

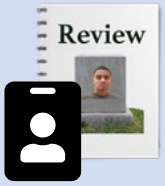
Place breakdowns

In South Tyneside we completed 17 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

16 completed reviews were **initial reviews**



1 completed reviews were **focussed reviews**



10 were **men**

7 were **women**

1 was **31 - 40 years old**

2 were **41 - 50 years old**

4 were **51 - 60 years old**

6 were **61 - 70 years old**

3 were **71 - 80 years old**

1 was **81+ years old**

3 died in **home/ home of family member**

5 died in **acute hospital**

2 died in **residential /nursing home**

6 died in **community hospital**

1 died **somewhere else**

17 were white British

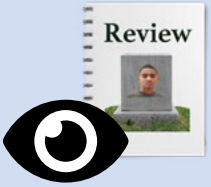
0 were from minority ethnic backgrounds

0 preferred not to say

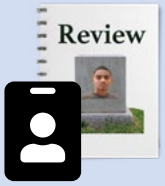
Section 5 - The blue part
Place breakdowns

In County Durham we completed 41 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

37 completed reviews were **initial reviews**



4 completed reviews were **focussed reviews**



24 were **men**

17 were **women**

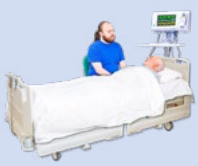
3 were **21 - 30 years old**	**1** was **31 - 40 years old**	**3** were **41 - 50 years old**	**14** were **51 - 60 years old**	**8** were **61 - 70 years old**	**7** were **71 - 80 years old**	**5** were **81+ years old**

9 died in **home/ home of family member**

25 died in **acute hospital**

6 died in **residential /nursing home**

0 died in **a hospice**



1 died **somewhere else**

37 were white British

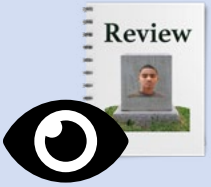
1 was Asian / Asian British

3 preferred not to say

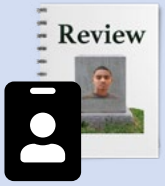
Section 5 - The blue part
Place breakdowns

In Tees Valley we completed 35 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2024 – 31st December 2024.

30 completed reviews were **initial reviews**



5 completed reviews were **focussed reviews**



21 were **men**

14 were **women**

5 were **31 - 40 years old**

2 were **41 - 50 years old**

6 were **51 - 60 years old**

9 were **61 - 70 years old**

10 were **71 - 80 years old**

3 were **81+ years old**

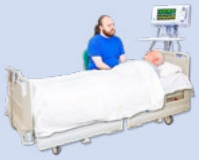
8 died in **home/ home of family member**

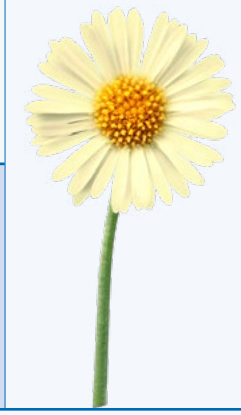
20 died in **acute hospital**

5 died in **residential /nursing home**

1 died in **community hospital**

1 died in **a hospice**





34 were white British

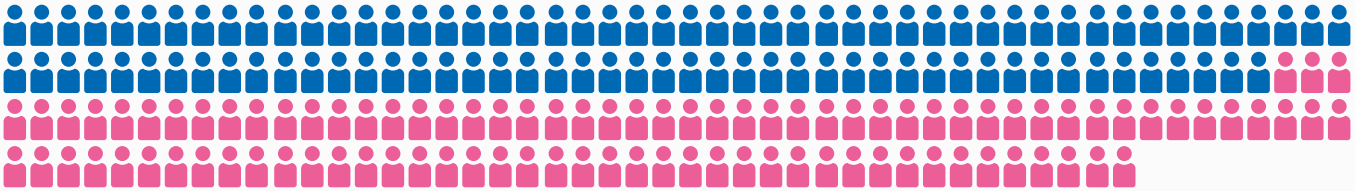
1 was Asian / Asian British

0 preferred not to say

Section 6 - The grey part

Summary of learning disability mortality data for the North East & North Cumbria

In the North East and North Cumbria Integrated Care System we reviewed the deaths of **192 people with a Learning Disability or Learning Disability and Autism in 2024.**



97 were **men**		**95** were **women**	
170 completed reviews were **initial reviews**		**22** completed reviews were **focussed reviews**	
1 was **18 - 21 years old**		**4** were **21 - 30 years old**	
13 were **31 - 40 years old**		**16** were **41 - 50 years old**	
49 were **51 - 60 years old**		**51** were **61 - 70 years old**	
45 were **71 - 80 years old**		**13** were **81+ years old**	

183 were White/ White British	**1** was White/ White Other	**2** were black, African, Caribbean or black British	**2** were Asian / Asian British	**4** preferred not to say

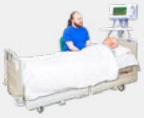
Section 6 - The grey part

Summary of learning disability mortality data for the North East & North Cumbria

105 died in **acute hospital(s)**

28 died in **residential/nursing home**

38 died in **home/ home of family member**



9 died in **a hospice**

10 died in **community hospital**

2 died **somewhere else**

What did people die from?

38 died from **Pneumonia**

9 died from **Sepsis**

8 died from **Frailty**

31 died from **Aspiration pneumonia**

6 died from **neurological conditions**

14 died from **issues relating to their organs**

28 died from **issues relating to their Heart**

5 died from **Dementia/ Alzheimers**

13 died due to **Respiratory problems**

6 died from **Epilepsy/seizures**

5 died from **Bowel problems**

1 died from **obesity**

3 died from **Infection**

1 died from **a Stroke**

1 died from **natural causes**

20 died from **Cancer**

2 died from **something else**

1 death **was not evident in review**

Section 7 - The peach part

Summary of mortality data for autistic people from the North East and North Cumbria

In the North East and North Cumbria Integrated Care System we reviewed the **deaths of 3 autistic people,** all of the reviews were **focussed reviews** as per the LeDeR policy.

2 were **men**

1 was a **women**

1 was **21-30 years old**

1 was **31-40 years old**

1 was **41-50 years old**

2 died **in home/ home of family member**

1 died **somewhere else**

3 were **white British**

3 died **by suicide**

Section 8 - The turquoise part

What does all this data and information tell us?

We now have a centralised LeDeR reviewing team working across NENC chronologically, that means in the order the notifications are made onto the LeDeR platform no matter where in NENC they have come from.

- We have streamlined the way to complete LeDeR reviews across NENC, so every review is completed in the same, high-quality way.
- We have a NENC multi-agency panel including experts with lived experience to sign off all focussed reviews and identify SMART objectives.
- We have a NENC Learning into Action group including experts with lived experience that make sure all SMART objectives are acted on and learning from reviews is shared across the entire system.
- We have an established LeDeR Governance & Assurance Group that effectively identifies themes and patterns and raise concerns about any variation in the LeDeR programme across NENC

LeDeR is everyone's business, and everyone needs to know how to notify a death Report the death of someone with a learning disability or an autistic person leder.nhs.uk.

There are still far too few notifications of autistic people's deaths on the LeDeR platform across NENC.

In 2024 there were only 3 LeDeR reviews of autistic people who had died.

What will we do about this?

- We will carry out focussed discussion groups with autistic people and families to seek their advice and support in raising the profile of LeDeR.
- We will launch a major awareness raising campaign across health & social care about the inclusion of autistic people in the LeDeR programme.

The national NHS England target is 35% of all reviews should be focussed. In the NENC we achieved 11.5% in 2024.

What will we do about this?

- Subject to receiving awaited information about the future of the LeDeR programme nationally (expected winter 2025), we plan to develop new criteria for focussed reviews for NENC to provide our system with more detailed learning e.g. in particular disease groups or long-term conditions, to inform commissioning and improve services.

Across NENC there were only 4 reviews (out of 195) carried out of people from minoritised ethnic communities.

What will we do about this?

- Embed LeDeR into the ICB Health Equity & Inclusion work programme.
- Develop strong links with minoritised ethnic community leaders and other key stakeholders such as community & voluntary sector organisations who may be able to assist e.g. Healthwatch, Haref Network (Health equality for ethnically marginalised communities). This will be subject to NHS England issuing new guidance about the future of the LeDeR programme (expected winter 2025)

Every life matters: Each LeDeR review is not just a statistic, but a story that helps the system understand what is working well and where improvements are needed.

Progress and challenges: The region has strengthened review processes, improved consistency and quality, and worked closely with people with lived experience. However, significant challenges remain, especially in addressing health inequalities, improving access to care, and ensuring every death is reviewed and learned from.

Collaboration: The report is the result of dedication and collaboration among families, carers, professionals, and people with lived experience.

Key Learning for all of us

Health inequalities persist: People with learning disability and autistic people continue to die prematurely, often from preventable causes such as pneumonia, aspiration pneumonia, heart issues, and cancer.

Reasonable adjustments save lives: Making care more accessible and reducing barriers is crucial. Campaigns like flu vaccination and cancer screening are important but must be accessible and reasonably adjusted to all.

Communication is vital: Good care begins with good communication, listening to people with lived experience, their families, and carers, and ensuring professionals communicate effectively.

Need for focussed reviews: The region is not meeting the NHS England target for focussed reviews (only 11.5% completed vs. a 35% target), and there are very few reviews of autistic people and people from minoritised ethnic communities.

Call to Action for all of us

Embed learning into commissioning and service improvement: Use findings from reviews to inform decisions and drive change.

Increase awareness and inclusion: Launch campaigns to raise awareness about the inclusion of autistic people and people from minoritised ethnic communities in the LeDeR programme.

Strengthen processes: Ensure every review is completed to a high standard and learning is shared widely.

Develop new criteria for focussed reviews: Go beyond the national requirements to provide more detailed learning, especially for specific disease groups or long-term conditions.

Prioritise work with minoritised ethnic communities: Identify leads, develop SMART objectives, and work with community leaders and organisations to improve engagement and outcomes.

Roll out mandatory training: Accelerate the implementation of learning disability and autism awareness training across health and social care.

Monitor progress and accountability: Hold the system accountable for delivering on actions and recommendations from LeDeR reviews.

Section 10 - The cream part

What is happening across NENC to make lives of people with learning disability and autistic people better and longer?

This year we have made a separate report about work that is happening across NENC to improve the health and wellbeing of people with learning disability and autistic people and reduce premature mortality.

It is called LeDeR: Learning into Action 2024. This report and the Learning into Action report should be read together.

You can find that report at: **https://necldnetwork.co.uk/work-programmes/leder/learning-from-leder/learning-in-to-action**

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nencicb.learningdisabilitynetwork@nhs.net

NHS LeDeR - About LeDeR
Report a death to LeDeR Report the death of someone with a learning disability
leder.nhs.uk

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V1.0 Published September 2024