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 2023

North East and Cumbria
learning
disability
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 2023.

This report covers the time between 1st January 2023 and 31st December 2023. This is the first time we have made the annual report for a calendar year rather than a financial year (April until March). This is because NHS England are making the national LeDeR report for the same calendar year.

During 2023 the North East and North Cumbria received 257 notifications of deaths of people with learning disability and autistic people.

Of these notifications **216** reviews were carried out and the learning from them is included in this report.

There were **208** reviews of people with learning disability who have died and **8** reviews of autistic people who have died.

There were a further **41** notifications of deaths during 2023 that were not completed within the timeframe of this report; These reviews are either in progress now or scheduled to be completed by the end of 2024.

This was because there weren't enough reviewers to carry out them out. When these outstanding reviews are completed and addendum to this report will be added early 2025 with learning from them.

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 now 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.

North East and North Cumbria Integrated Care System remains fully committed to improving the lives of people with learning disability and autistic people with our focus firmly on effective prevention, care, support and treatment.

We will continue to work with all our NHS and social care partners to reduce premature mortality of people with learning disability and autistic people and continue to close the health inequality gap faced by this group of people.

As I said last year, we will not tolerate premature mortality of people with learning disability and autistic people here, and through an effective LeDeR (Learning from the Lives and Deaths of People with Learning Disability and Autistic People) programme with strong links across all our multi-agency health and wellbeing programmes, we will continue to work very hard to make a big difference to lives.

Our work in the LeDeR programme continues to rely on the willingness of families and carers to take part in reviews about their loved one who has died, on behalf of the ICB, I am immensely thankful to them.

Professor Sir Liam Donaldson
Chair of the ICB

Contents

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We want:

Longer and healthier lives
Reducing the gap between how long people live in the North East and North Cumbria compared to the rest of England.

Fairer outcomes
As we know not everyone has the same opportunities to be healthy because of where they live, their income, education and employment.

Better health and care services
Not just high-quality services but the same quality no-matter where you live and who you are.

Giving our children the best start in life
Enabling them to thrive, have great futures and improve lives for generations to come.

Our work in the LeDeR programme is fully joined up with our ICB plans to make sure we continue to work together to prevent ill health and promote healthy lives and wellbeing for all our citizens. We know for people with learning disability and autistic people this is often harder to achieve because of the health inequality gap experienced by them.

Despite our ongoing work to tackle health inequalities, focus on effective prevention, the best care & support and treatment, we know there is much more to do to close the health inequality gap and eradicate premature mortality. We remain committed in NENC to strive further, reach higher and achieve better outcomes for our citizens with learning disability and autism.

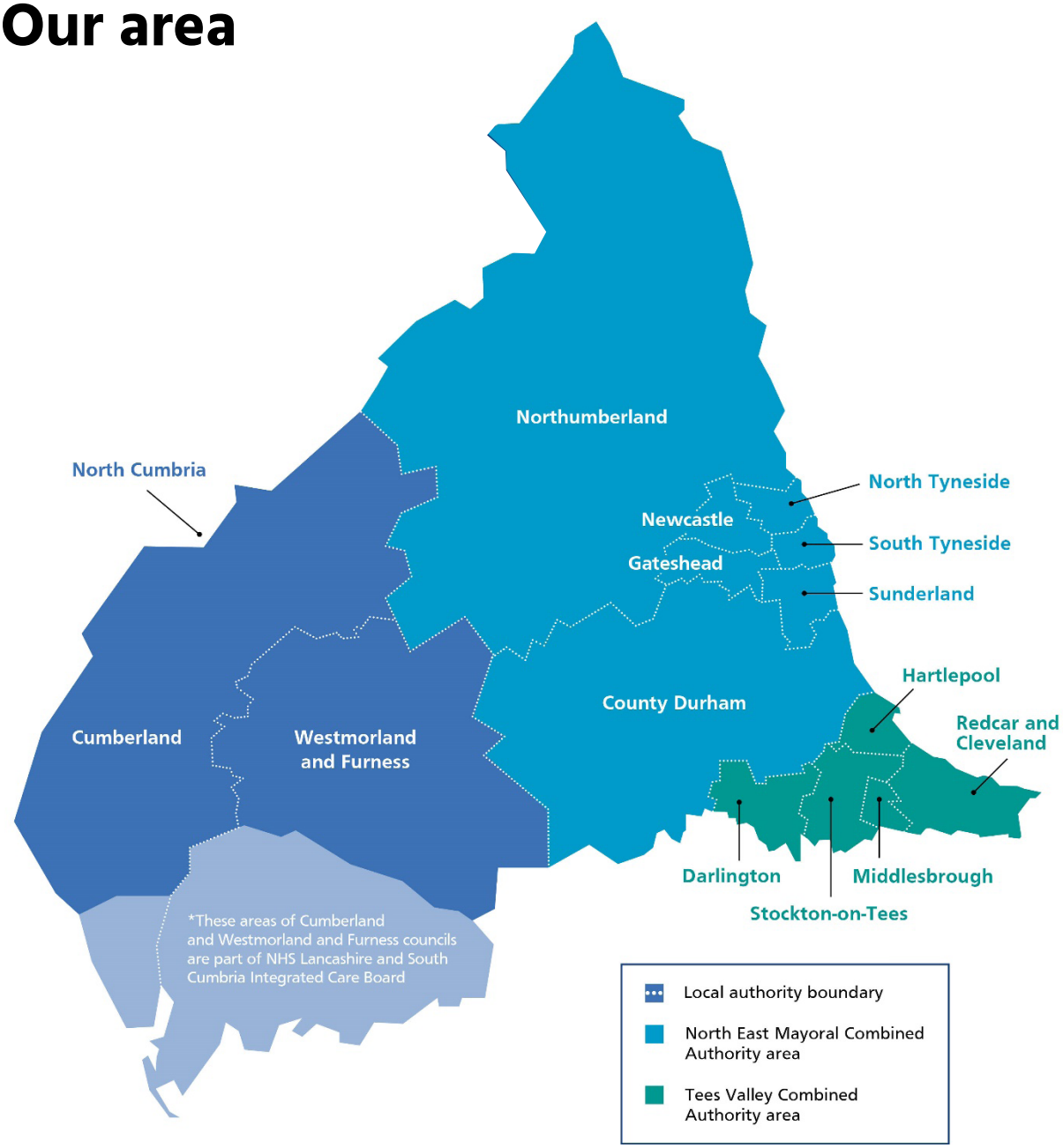
The newly reorganised ICB has given us a great opportunity to improve how we deliver LeDeR across NENC. We now have a centralised reviewing team who work across our ICB, standardised ways of doing things and the Learning Disability Network are providing leadership across the entire programme. This will give us greater opportunity to gather all of the learning, best practice, and areas for improvement from reviews and use the information to inform commissioning and health and care improvement work.

Sam Allen
Chief Executive
North East and North Cumbria Integrated Care Board

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

NHS
North East and
North Cumbria

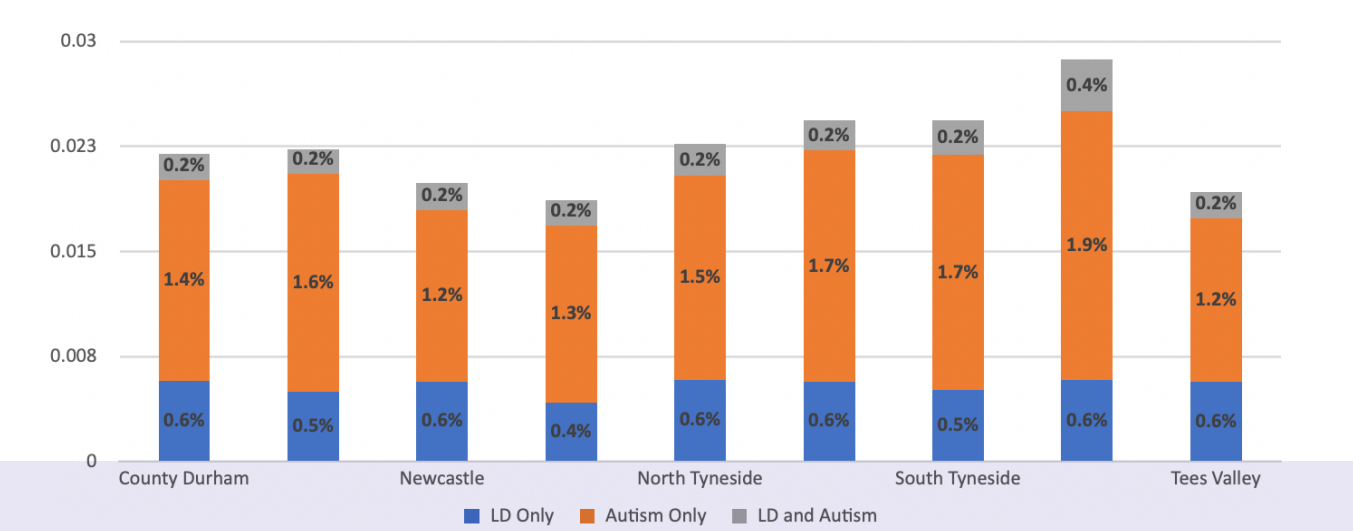
Our area



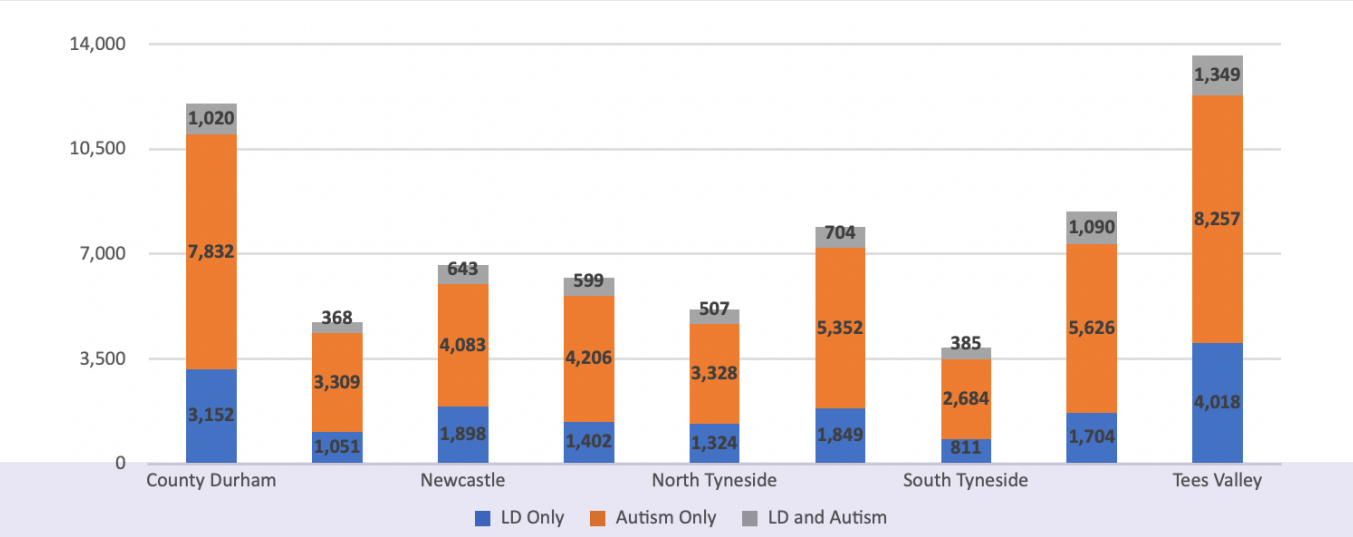
Section 3 - The purple part

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

Percentage of Population Diagnosed with Learning Disability or Autism



Estimated Numbers Diagnosed with Learning Disability or Autism



Section 4 - The pink part

The North East and North Cumbria Confirm and Challenge Groups

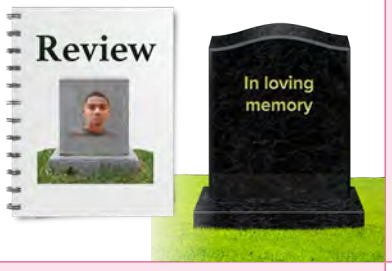
In the North East and North Cumbria, we have a two lived experience groups working on the issues around LeDeR - Stop People Dying Too Soon Group and Cumbria Confirm & Challenge Group.

Both groups have worked together for the 5th year on the LeDeR programme. We used what was in the 2021-22 LeDeR Annual Report to decide what priorities and work plan should be.

Our focus over the past year have been:

To make sure the deaths of ethnically minoritised people are reported to LeDeR. We need to learn what impact race has on the health inequalities of people with a learning disability and autistic people.

To make sure the deaths of autistic people are reported to LeDeR. We need to know more about the health inequalities that autistic people face and if these are different to those people with a learning disability face.



To make the rights and choices we have at the end of our life more accessible to people with a learning disability and autistic people, including around 'Do Not Resuscitate' decisions.

Better understanding of the Mental Capacity Act.

More focus on reasonable adjustments.

For services to focus again on constipation training. This came after the group looked at the inquest into Sally Lewis' death.

Section 4 - The pink part

The North East and North Cumbria Confirm and Challenge Groups

The themes the groups have highlighted from looking at reviews this year are:

Lack of Advocacy Support

People are not getting enough support to make their voices heard in their care.

Limited Use of Mental Capacity Assessments

These assessments are not being used enough.

Understanding of Annual Health Checks

There is a lack of understanding about annual health checks among people with learning disabilities, their families, and professionals.

Access to Annual Health Checks

Many people are missing out on annual health checks because they are not on the learning disability register.

Communication Issues

There is poor communication between different service providers.

Declining Screening Opportunities

People and or their families on their behalf are often declining health screening opportunities.

The Stop People Dying too Young group made a film about end-of-life planning. You can find it here www.youtube.com/watch?v=Rv-8Sdbye6A

They also worked with song writers O'Hooley and Tidow to develop a song to raise awareness of the health inequalities faced by people with a learning disability and autistic people. You can listen here www.youtube.com/watch?v=PM_CMJ7qYI0

John was a 71-year-old man who lived in a residential care home for over 25 years, following the death of his parents.

He had a close relationship with all of the staff and thought of them as his family.

John was able to engage in community activities both independently and sometimes with support from carers. He particularly loved anything to do with music and signing and his music could often be heard throughout the care home.

Described by staff as a happy, enthusiastic character John was able to live a full and vibrant life, doing things he loved, and he always maintained a positive outlook.

The staff at the care home note how quiet the home feels since John has passed but make a point to play his favourite music regularly.
John passed away from a heart condition.

RIP John.

What did we learn from John's story?

John was supported by a staff team that understood the importance of Annual Health Checks and health monitoring. His wishes were listened too and respected and he was able to make choices throughout his life and for his end of life.

Thea died at home aged 26 of multiple drug toxicity.

Following a short period of homelessness, they recently moved to supported accommodation with access to staff to help with their mental health, anxiety, and depression.

From a young age they struggled with making friends and did not engage in education environment despite being 'very bright'.

Since age of 13 they engaged in drinking alcohol and drug taking and continued to take a variety of drugs throughout their life, often to try to cope in social situations or supress feelings of anxiety.

They received a diagnosis of autism when they were 22. Their family had a lack of understanding of autism and mental health conditions but did their best to support and were devastated at the loss of their life.

They preferred spending time alone and particularly enjoyed computer games and spending time online, finding communication easier in a virtual world.

RIP Thea.

What did we learn from Thea's story?

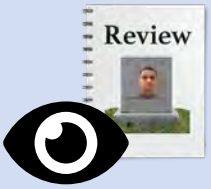
Thea received an autism diagnosis as an adult - if there had been early intervention and earlier access to services this may have made a difference. Thea would have benefitted from reasonable adjustments around communications in order to support daily living.

Section 6 - The blue part

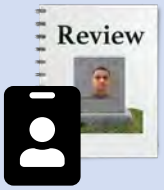
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In North Tyneside we completed 5 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

4 completed reviews were **initial reviews**



1 completed reviews were **focussed reviews**



1 were **men**

4 were **women**

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

0 died in **own home**

5 died in **acute hospital**

0 died in **residential/ nursing care home**

0 died in **supported living**

0 died **somewhere else**

5 were **white British**

0 were from minority ethnic backgrounds

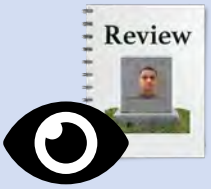
0 preferred not to say

Section 6 - The blue part

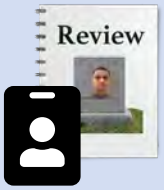
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In Northumberland we completed 6 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

6 completed reviews were **initial reviews**



0 completed reviews were **focussed reviews**



5 were **men**

1 was a **women**

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

own home	acute hospital	residential/ nursing care home	supported living	somewhere else	
0 died in	**3** died in	**2** died in	**1** died in	**0** died	

6 were **white British**

0 were from minority ethnic backgrounds

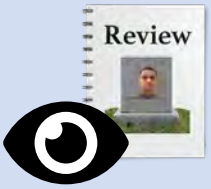
0 preferred not to say

Section 6 - The blue part

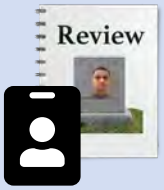
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In North Cumbria we completed 27 reviews
of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

19 completed reviews were **initial reviews**



8 completed reviews were **focussed reviews**



22 were **men**

5 was a **women**

2 were **21 - 30 years old**

2 were **31 - 40 years old**

4 were **41 - 50 years old**

10 were **51 - 60 years old**

6 were **61 - 70 years old**

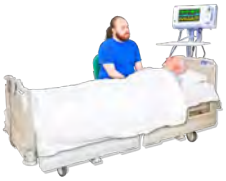
3 were **71 - 80 years old**

0 died in **own home**

18 died in **acute hospital**

5 died in **residential/ nursing care home**

2 died in a **hospice**



2 died in a **community hospital**

small local hospitals

27 were **white British**

0 were from minority ethnic backgrounds

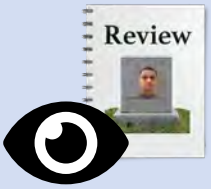
0 preferred not to say

Section 6 - The blue part

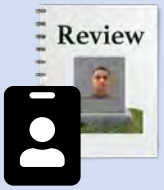
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In Newcastle and Gateshead we completed 40 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

37 completed reviews were **initial reviews**



3 completed reviews were **focussed reviews**



22 were **men**

18 were **women**

1 were **21 - 30 years old**

2 were **31 - 40 years old**

2 were **41 - 50 years old**

5 were **51 - 60 years old**

14 were **61 - 70 years old**

14 were **71 - 80 years old**

3 died in **own home**

22 died in **acute hospital**

10 died in **residential/ nursing care home**

4 died in **supported living**

1 died **somewhere else**

2 were **81+ years old**

39 were **white British**

0 were from minority ethnic backgrounds

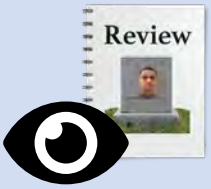
1 preferred not to say

Section 6 - The blue part

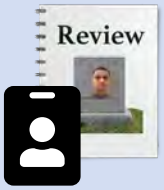
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In Sunderland and South Tyneside we completed 33 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

31 completed reviews were **initial reviews**



2 completed reviews were **focussed reviews**



17 were **men**

16 were **women**

0 were **21 - 30 years old**

3 were **31 - 40 years old**

4 were **41 - 50 years old**

5 were **51 - 60 years old**

14 were **61 - 70 years old**

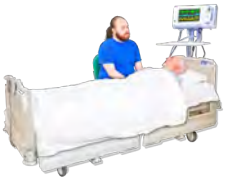
7 were **71 - 80 years old**

2 died in **family home**

19 died in **acute hospital**

9 died in **residential/ nursing care home**

1 died in a **hospice**



1 died in a **community hospital**

small local hospitals

1 died in **supported living**

32 were **white British**

0 were from minority ethnic backgrounds

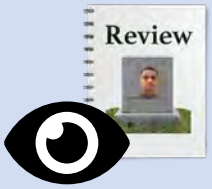
1 preferred not to say

Section 6 - The blue part

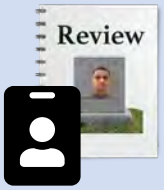
Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

In County Durham we completed 51 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023

44 completed reviews were **initial reviews**



7 completed reviews were **focussed reviews**



32 were **men**

19 were **women**

3 were **21 - 30 years old**

9 were **41 - 50 years old**

12 were **51 - 60 years old**

14 were **61 - 70 years old**

11 were **71 - 80 years old**

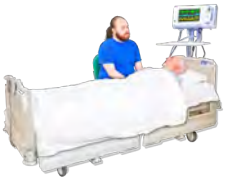
2 were **81+ years old**

2 died in **family home**

22 died in **acute hospital**

24 died in **residential/ nursing care home**

0 died in a **hospice**



0 died in a **community hospital**

small local hospitals

2 died in **their own home**

50 were **white British**

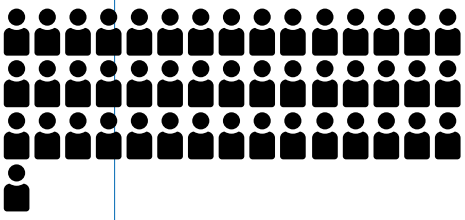
0 were from minority ethnic backgrounds

1 preferred not to say

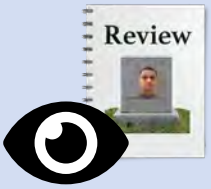
Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from every place in the North East and North Cumbria

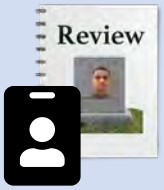
In Tees Valley we completed 46 reviews of people with a learning disability whose deaths were notified to the LeDeR platform between 1st January 2023 - 31st December 2023



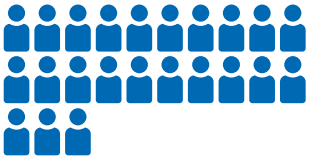
41 completed reviews were **initial reviews**



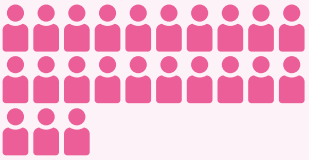
5 completed reviews were **focussed reviews**



23 were **men**



23 were **women**



1 were **21 - 30 years old**

3 were **31 - 40 years old**

5 were **41 - 50 years old**

7 were **51 - 60 years old**

16 were **61 - 70 years old**

11 were **71 - 80 years old**

1 died in **own home**

20 died in **acute hospital**

20 died in **residential/ nursing care home**

2 died in **family home**

3 died **somewhere else**

3 were **81+ years old**

42 were **white British**

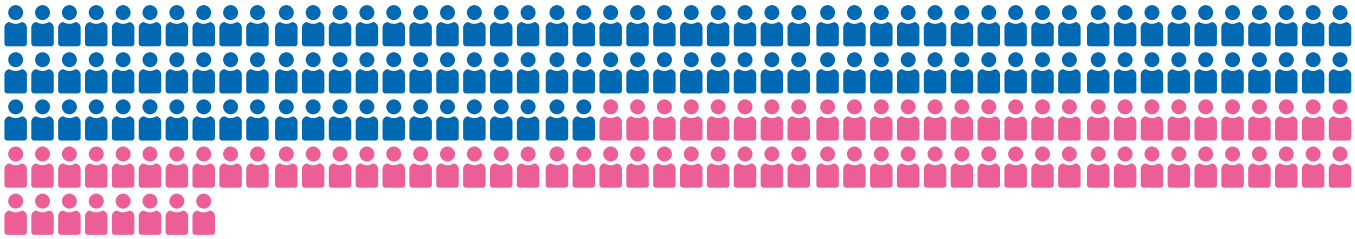
1 were from minority ethnic background

3 preferred not to say

Section 7 - The grey part

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

In the North East and North Cumbria Integrated Care System we reviewed the **deaths of 208 people with a Learning Disability or Learning Disability and Autism.**



122 were **men**

86 were **women**

182 completed reviews were **initial reviews**

26 completed reviews were **focussed reviews**

8 were **21 - 30 years old**

13 were **31 - 40 years old**

26 were **41 - 50 years old**

39 were **51 - 60 years old**

67 were **61 - 70 years old**

48 were **71 - 80 years old**

7 were **81 + years old**

201 were **white British**

1 were **Asian British**

6 preferred not to say

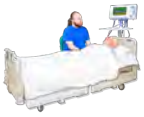
Section 7 - The grey part

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

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

7 died in their **family home**

70 died in **residential/nursing home**



3 died in a **hospice**

6 died in **their own home**

3 died in **community hospital**

6 died in **supported living accommodation**

4 died **somewhere else**

What did people die from?

36 died from **pneumonia (3 covid related)**

9 people died from **issues relating to their blood**

34 died from **aspiration pneumonia**

9 died from **dementia**

23 died from **issues relating to their heart**

6 people died from **bowel problems**

22 died due to **respiratory problems**

4 people died from a **stroke**

18 died from **cancer**

4 people died from **something else**

13 died from **frailty**

3 died from **neurological conditions relating to the brain**

13 died from **sepsis**

3 died from **infection**

9 died from **issues relating to the organs in their body**

2 died from **epilepsy**

Section 8 - 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 8 people with an autism only diagnosis,** all of the reviews were **focussed reviews** as per the LeDeR policy.

5 were **men**

3 were **women**

1 were **18-20 years old**

1 were **21-30 years old**

4 were **31-40 years old**

2 were **51-60 years old**

1 died in **acute hospital**

5 died in **own home**

1 died in **family home**

1 died **somewhere else**

3 died from complications with **drug misuse**

1 died from a **Sudden Unexpected Death in Epilepsy (SUDEP)**

1 died from **cancer**

1 died from **suicide**

1 died from **liver disease**

1 died from **brain abscess**

6 were **white British**

2 were **Asian British**

0 preferred not to say

As part of a focussed review the reviewer has to look at the 'quality of care' that is given to the person with learning disability or autistic person. This is called 'grading of care'.

The reviewer looks for evidence of care given at 3 specific times:

1. When the initial diagnosis (when the person is told about their health condition) of the health condition is made and how the person is supported/care for with their condition.
2. How the person is supported/cared for with their condition from initial diagnosis to critical illness (when the person became much more poorly).
3. How the person is supported/cared for during their final illness before they died.

The national LeDeR policy grades care from 1 (very poor care) to 6 (very good care).

In NENC the 26 focussed reviews in 2023 were graded as follows:

- There were **7** focussed reviews where the care was **graded as 5** - this is good care.
- There were **7** focussed reviews where the care was **graded as 4** - this is satisfactory care but fell short of expected good practice in some areas.
- There were **9** focussed reviews where the care was **graded as 3** - care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.
- There were **3** focussed reviews where the care was **graded as 2** - care fell short of expected good practice and this did impact on the person's wellbeing and may have contributed to the cause of death.

Level of learning disability

Focussed reviews include information about 'level of learning disability' if it is known about the person who has died. This is not collected in an initial review. This information is provided as a percentage so is not identifiable.

In NENC the 26 focussed reviews in 2023 included the following level of learning disability:

- **4%** of people had profound & multiple learning disability
- **12%** of people had 'severe' learning disability
- **36%** of people had 'moderate' learning disability
- **48%** of people had 'mild' learning disability.

Learning Disability - Applying All Our Health - **www.gov.uk**

There is a lot of variation across NENC about how many notifications are made on the LeDeR platform and then reviews completed between different places. There appears to be significant under reporting in some places of deaths on the LeDeR platform.

What will we do about this?

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

We also need to make sure everyone understands LeDeR is everyone's business and knows how to notify a death **Report the death of someone with a learning disability or an autistic person leder.nhs.uk.**

This is included in the mandatory Oliver McGowan Learning Disability & Autism Awareness training that all health and care staff must do. In addition to this we will launch a major awareness raising campaign across NENC.

There are still not many notifications of autistic people's deaths on the LeDeR platform across NENC. In 2023 there were only 8 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.

Across NENC we are not reaching the NHS England target of completing 35% of focussed reviews. In 2023, 12.5% of the NENC reviews completed were focussed.

What will we do about this?

In addition to those reviews that are automatically focussed reviews (autistic people and people from minoritised ethnic communities) we will also 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 3 reviews (out of 216) carried out of people from minoritised ethnic communities.

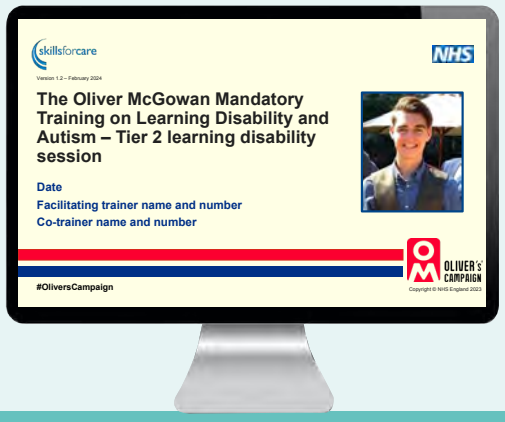
What will we do about this?

- Identify a lead person on the NENC Assurance/Governance Group for minoritised ethnic communities. (Our previous lead has since left the organisation).
- Prioritise our minoritised ethnic communities work programme and develop a series of SMART objectives linked to these priorities.
- Work with the ICB Director of Health Equity & Inclusion to seek support to promote the importance of LeDeR in minoritised ethnic communities across NENC.
- 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).

The national LeDeR policy requires information about the quality of health and/or social care people received before they died in focussed reviews only. This information is very important to help the System understand the needs of the workforce e.g. training and development.

What will we do about this?

Roll out the Oliver McGowan mandatory learning disability and autism awareness training as quickly and effectively across NENC, health & social care.



Section 11 - The cream part

What is happening across North East and North Cumbria 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 2023. 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/**

NHS
North East and
North Cumbria

North East and North Cumbria Integrated Care Board
northeastnorthcumbria.nhs.uk
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North East and Cumbria Learning Disability Network
necldnetwork.co.uk
@necldnetwork
𝕏 @necldnetwork
nencicb.learningdisabilitynetwork@nhs.net

NHS LeDeR - About LeDeR
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leder.nhs.uk

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