



North East and North Cumbria
Integrated Care Board

LeDeR Annual Report 2024

Easy Read Short Summary

Learning from the lives and deaths of people with a learning
disability and autistic people

A black, rectangular headstone with a slightly curved top, standing on a green lawn. The text 'In loving memory' is inscribed on it in yellow.

In loving
memory

North East and North Cumbria
**Learning Disability
and Autism**
Network

Contents

Page

What this report is about	3
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Learning from people's lives	5
------------------------------	---

Working with people with lived experience	5
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What happened in 2024	8
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What we found out	12
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What we will do	14
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What this report is about



We are the North East and North Cumbria Integrated Care Board (ICB).



The ICB is part of the NHS. It buys and checks health and care services in our area.



This report looks at the lives and deaths of people with a learning disability and autistic people who died in 2024.



Autistic people are **neurodivergent**. We say neurodivergent like this: new-roe-die-ver-jent.

Neurodivergent means your brain works in a different way to most people.





Every area in England must follow the government LeDeR plan.

LeDeR means Learning from the Lives and Deaths of People with a Learning Disability and Autistic People.



By looking at why people died, we can see what worked well and what needs to change.

We want people to get better care so they can live longer, healthier lives.

Samantha Allen, the big boss of the ICB, says:



“Together, we will continue to listen, learn, and act, so that every person in our region receives the care, respect, and support they deserve.”

Learning from People's Lives



We want to stop people with a learning disability and autistic people dying too young.



LeDeR helps us learn from each person's story.

We look at what went well and what needs to change.



This learning helps improve care for everyone.



Working with People with Lived Experience

Lived experience means knowing what something is like because you have been through it yourself.



We work with people who have a learning disability and who are autistic.

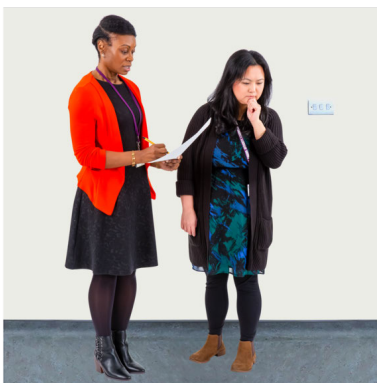
We plan and check our work together. This is called co-production.



Working with people who have a learning disability or autism is important because:



- They help us understand what life was really like for the person who died



- They can spot things in care that others might miss.

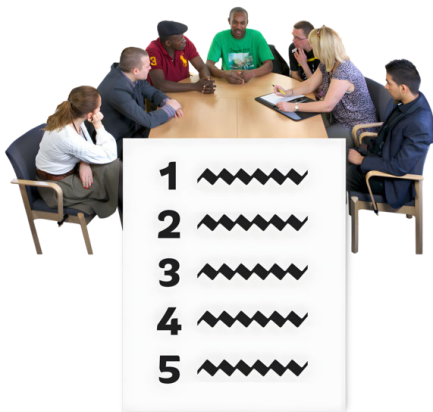
- They help make **reviews** better for people.



A **review** means looking carefully at someone's care after they have died.

This can help stop others dying too soon.

Learn More about LeDeR



We have made a short film that shows how LeDeR works and why it is important. Please click the link below:

[LeDeR and how it works](#)

What Happened in 2024



People with a Learning Disability

We looked at 192 deaths in our area.
97 were men and 95 were women.

Ages



People were aged from 18 to over 80.
Most were between 50 and 80.
5 people were aged 18 to 30.

Ethnicity



Most people were White British.
2 were Asian, 2 were Black, and a few
did not say.

Where People Died

Most people died in hospital.





Some died in residential care or at home with their families.

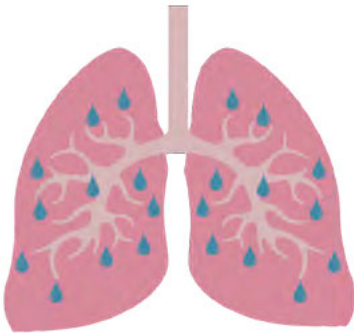
Main Causes of Death

Breathing problems, such as:



Pneumonia

This is an illness where the lungs fill with fluid.



It makes it hard to breathe.

Aspiration pneumonia

This happens when food or drink goes into the lungs.

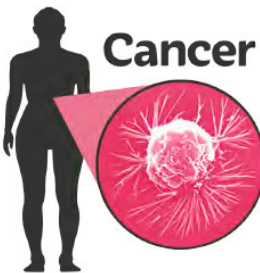


It can make people very ill.



Respiratory disease

This means problems with breathing, like asthma or bad chest infections.



Other causes were:

- Cancer
- Heart problems



Smaller numbers of people died from:

- **Dementia** – an illness that slowly affects the brain and memory.
- **Epilepsy** – when a person has seizures or fits.

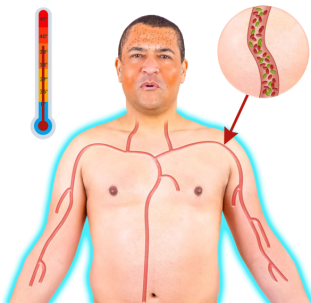




- **Stroke** – when blood cannot reach part of the brain. This can stop parts of the body working properly.



- **Bowel problems** – when the stomach or intestines are blocked or not working properly.



- **Infection** – when germs get into the body and make you ill.



People with Autism

We looked at 3 deaths of autistic people.

2 were men and 1 was a woman, aged between 21 and over 40.

All were White British.





2 people died at home, and 1 died elsewhere.



All deaths were by suicide.

What We Found Out



People with a learning disability and autistic people still die too young.

Many deaths could be stopped with better care and support.



Making **reasonable adjustments** saves lives.

A **reasonable adjustment** means changing care to meet a person's needs.

Thing like:



- Longer appointments



- Using Easy Read



- Letting someone bring a carer to the doctors help them understand



These small changes help people get the right care and stay safe.



Good communication is very important.

Listening and sharing clear information helps people stay safe.



Our area has got better at working together.

We have learned a lot from the LeDeR reviews.

But there is still more work to do.



We need to look closely at every person's story.

This includes autistic people and people from all backgrounds.

We must learn from every life to make care fair for everyone.



What We Will Do

We will run campaigns to help people understand more about learning disability and autism.



We will make sure every review is done well.

We will share what we learn with others. This will make care better.



We will look more closely at some health problems.

This will help people live longer and healthier.



We will work with local community leaders and families.

Together, we will make care fair for all groups.



We will give more training about learning disability and autism.

This will help health and care staff understand people's needs.



We will check how well we are doing and keep our promises.



We will make sure we hear more views from autistic people and people from different ethnic backgrounds.

North East and North Cumbria Integrated Care Board

northeastnorthcumbria.nhs.uk

X [@NENC_NHS](https://twitter.com/NENC_NHS)

North East and Cumbria Learning Disability Network

necldnetwork.co.uk

in [@north-east-cumbria-learning-disability-network](https://www.linkedin.com/company/necldnetwork)

▶ [@necldnetwork](https://www.youtube.com/channel/UCnecldnetwork)

X [@necldnetwork](https://twitter.com/necldnetwork)

✉ 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