

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

Annual Report
2022/2023

'Accepting that people with learning disability and autistic people will experience poor quality care and shortened lives is not tolerated here. We continue to work tirelessly to make sure the health inequality gap closes and people with learning disability and autistic people enjoy fulfilling, healthy, long and happy lives.'

Sam Allen

Chief Executive

North East and North Cumbria Integrated Care Board



Contents

Page 4	Section 1 - The green part Introduction
Page 6	Section 2 - The yellow part North East and North Cumbria demographic information
Page 7	Section 3 - The purple part Learning disability and autism population data for the North East and North Cumbria
Page 8	Section 4 - The pink part Feedback from the Stop People Dying Too Soon and Cumbria Confirm and Challenge Groups
Page 15	Section 5 - The orange part Pen pictures - Mary, a lady with learning disability and James, an autistic person
Page 17	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
Page 25	Section 7 - The grey part Summary of learning disability mortality data in the North East and North Cumbria
Page 26	Section 8 - The peach part Summary of autistic deaths in the North East and North Cumbria
Page 27	Section 9 - The turquoise part What we have learned about the deaths of people with learning disability and autistic people across the North East and North Cumbria
Page 28	Section 10 - The cream part What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

Section 1 - The green part

Introduction

Reducing health inequalities and premature death for people with learning disability and autistic people is a major priority for the ICB.

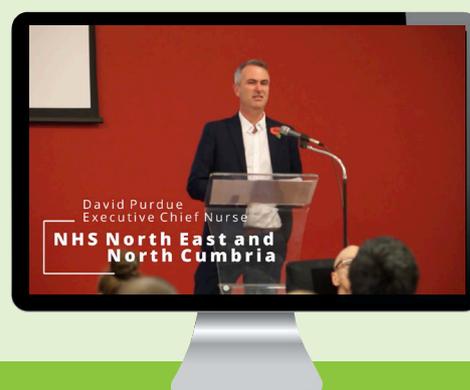
Accepting that people with learning disability and autistic people will experience poor quality care and shortened lives is not tolerated here. We continue to work tirelessly to make sure the health inequality gap closes and people with learning disability and autistic people enjoy fulfilling, healthy, long and happy lives. We know we haven't got everything right yet but we want the North East and North Cumbria to be the best place in England to live if you have a learning disability or are an autistic person and will not stop until this is achieved.

We are proud to be working alongside experts with lived experience of learning disability, autistic people and family carers who provide a critical role in steering, confirming, and challenging the LeDeR work and would like to express our sincere thanks and gratitude to the Stop People with Learning Disability Dying Too Soon and Cumbria Confirm & Challenge Groups.

During 2022 - 2023 we held a successful Learning & Sharing event with over 120 people coming along that has made sure our LeDeR work programme fully reflects what people have told us is important to them. Short films of each chapter of the event are available here. [Introduction - North East and North Cumbria Annual LeDeR Learning and Sharing Event - YouTube](#)

The work programme is divided into chapters of work:

- Minoritised ethnic communities
- Tackling health inequalities, early intervention & prevention
- Living with Autism
- Living with Long Term Conditions
- All About Equality



Section 1 - The green part

Introduction

We have set up our LeDeR arrangements making sure we are following the LeDeR policy. Our Executive Chief Nurse, David Purdue is the Senior Responsible Officer for LeDeR, the Learning Disability Network provides strategic leadership and co-ordination of the programme. The LeDeR Governance Group, chaired by our Deputy Executive Chief Nurse Ann Fox, is made up of multi-agency stakeholders meets very regularly making sure that LeDeR is being delivered in all places across the North East and North Cumbria and the learning from the lives and deaths of people with learning disability and autistic people is widely shared, understood and acted on.

The agreed common priorities for the NENC Learning Disability and Autism Workstream were developed in a series of workshops with people with a Learning Disability, Autistic people, their families and supporters, and partners from across the wider system. It was agreed that these priorities are in keeping with national and local thinking and should be the underpinning framework for the regional team workplan.

Sam Allen

Chief Executive

North East and North Cumbria Integrated Care Board

Priority Areas



Priority 1:

Best start in life

We believe in opportunities and possibilities for all children and young people to reach their full potential through early help and inclusive communities.

Priority 2:

Valued families

Work with and support families to use their valuable insight to inform and shape the workforce, commissioning and provision of services.

Priority 3:

Living well with good support

People will have the same life chances and opportunities of work, love, family, home and support as the rest of the population.

Priority 4:

Good health for longer lives

Good information and good access for early help to make sure good health is enjoyed by all and people stop dying too soon.

Priority 5:

Good care and treatment in specialist hospitals

People in hospital will have good quality care, which is timely, safe and right for the person.

Section 2 - The yellow part

North East and North Cumbria demographic information

What does the North East and North Cumbria Integrated Care Board look like?

Publications: North East and North Cumbria NHS

www.northeastnorthcumbria.nhs.uk

NHS North East and North Cumbria Integrated Care Board (ICB) - our area



North East and North Cumbria

North Cumbria

Population: 324,000

Primary care networks: 8

1 NHS foundation trust:
North Cumbria Integrated Care (NCIC)

1 ambulance NHS trust:
North West Ambulance Service

2 local authority areas: Cumberland and Westmorland and Furness (also cover part of NHS Lancashire and South Cumbria ICB*)

North

Population: 1,079,000

Primary care networks: 22

3 NHS foundation trusts: Northumbria, Newcastle, Gateshead

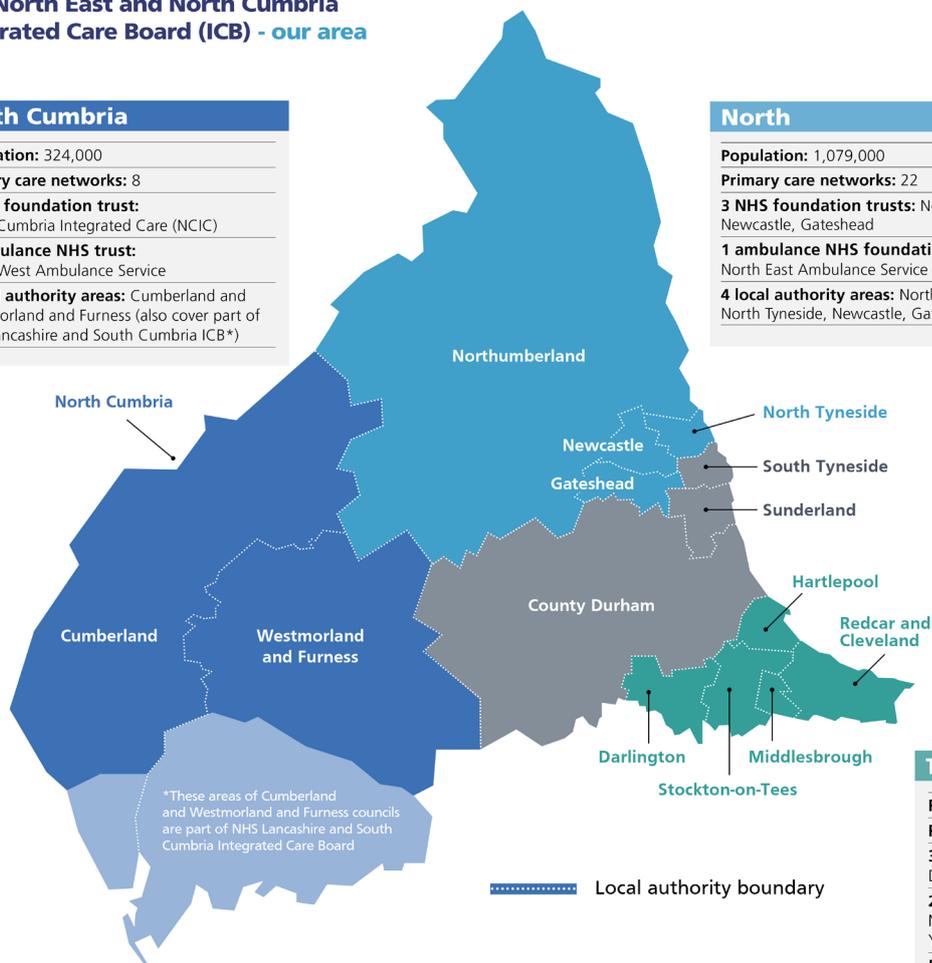
1 ambulance NHS foundation trust:
North East Ambulance Service

4 local authority areas: Northumberland, North Tyneside, Newcastle, Gateshead

North East and North Cumbria

2 mental health NHS foundation trusts:

Cumbria, Northumberland, Tyne and Wear, Tees, Esk and Wear Valleys



Central

Population: 997,000

Primary care networks: 22

2 NHS foundation trusts: South Tyneside and Sunderland, County Durham and Darlington

1 ambulance NHS foundation trust:
North East Ambulance Service

3 local authority areas: South Tyneside, Sunderland, County Durham

Tees Valley

Population: 701,000

Primary care networks: 14

3 NHS foundation trusts: County Durham and Darlington, North Tees and Hartlepool, South Tees

2 ambulance NHS trusts:
North East Ambulance Service (FT)
Yorkshire Ambulance Service

5 local authority areas: Hartlepool, Stockton-on-Tees, Darlington, Middlesbrough, Redcar and Cleveland

Section 3 - The purple part

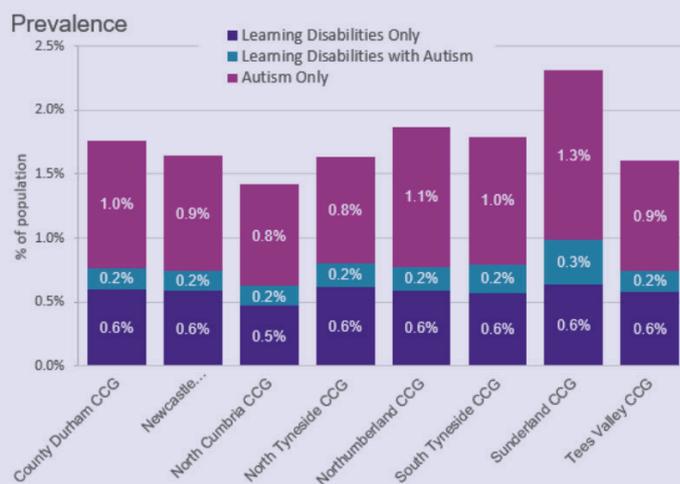
Learning disability and autism population data for the North East and North Cumbria

Learning Disability and Autism demographic data for North East and North Cumbria



Within North East and North Cumbria

- 0.8% (23,900 people) of the population have a learning disability recorded
- 1.1% (35,520) have autism
- Of these, 5750 have both learning disabilities and autism



Expected prevalence:

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

necu.nhs.uk

RAIDR Source: Primary Care Dashboard > Patient Care > Learning Disabilities

¹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>

² <https://researchbriefings.files.parliament.uk/documents/POST-PN-0612/POST-PN-0612.pdf>

Section 4 - The pink part

Feedback from the Stop People Dying Too Soon and Cumbria Confirm and Challenge Groups

Our work 2022 - 2023

We have been doing work on what a good death is. Choice and rights at the end of life, and everyone having the chance to think about their wishes at the end of their life. We have looked at funeral planning and helping people get more comfortable talking about death and dying.

We have connected this to our ongoing work on Do Not Resuscitate decisions. Continuing to speak up when this is done wrong, especially when learning disability, Down's Syndrome or other such things are put as the reason for not resuscitating. We campaigned for the Ministerial Oversight Group on DNACPR to admit people with lived experience as members, writing an open letter which got over 300 signatures. As yet they have not listened to our requests.

We created a response to last years' national LeDeR annual report and worked with a musician and an animator to create a hard-hitting video [Stop People Dying Too Young \(the LeDeR programme\) - Inclusion North](#)

We co-produced and co-ran the annual Learning and Sharing event in Durham.

We won a national Learning Disability and Autism Leaders List Award in the category of self-advocacy and citizenship.

We took part in filming a Panorama documentary about people with a learning disability dying too young, but unfortunately our bit did not make it into the programme.

We made a response to Clive Treacy's death.

We worked with the palliative care team to co-produce information about [Emergency Health Care Plans and we created easy read and a film here](#)



Section 4 - The pink part

Feedback from the Stop People Dying Too Soon and Cumbria Confirm and Challenge Groups

Our hopes for disabled people

The Stop People with Learning Disability & Autistic People Dying Too Soon Group have set out what their hopes and fears are for people with learning disability and autistic people in the North East and North Cumbria.

Good quality, equal care right from birth.



No differences in how we are treated.



More people feeling comfortable talking about death and dying, it not being taboo or frightening. So, people can have their rights and choices heard and respected at death.

Everyone's life is valued equally.



Care that meets people's individual needs.



Good mental and physical health for all.



Enough liaison nurses, including for children.



Family carers are respected and listened to.



Emergency care is as good as planned care can be.



Section 4 - The pink part

Feedback from the Stop People Dying Too Soon and Cumbria Confirm and Challenge Groups

Our fears for disabled people

The Stop People with Learning Disability & Autistic People Dying Too Soon Group have set out what their hopes and fears are for people with learning disability and autistic people in the North East and North Cumbria.

Things aren't changing - another letter came out reminding doctors not to put learning disability or Down's Syndrome on a death certificate or Do Not Resuscitate.

Too many avoidable deaths in care settings and hospitals - lack of training, lack of suitable community support services, bad management.

People with a learning disability and autistic people dying too young is still not well known about - it should be a national scandal.

Staff lack of knowledge about disability "when you go into hospital you put your trust in them".



People still being given too much anti-psychotic medication.



People still spending too long in hospital.



People still going into the criminal justice system rather than getting the right support.



Problems with the system - management, training, attitudes, action, outcomes.



Section 4 - The pink part

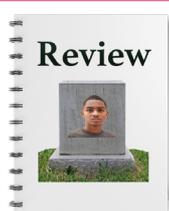
The Cumbria Confirm and Challenge Group



We are the Cumbria Confirm and Challenge Group.



We are a group of experts with lived experience and professionals who work with people with learning disabilities and/or autistic people.



Our role within LeDeR is to review reports of the lives and deaths of people with learning disabilities and/or autistic people.



We do this by meeting every 6 weeks on a Wednesday to discuss the reports we have received.



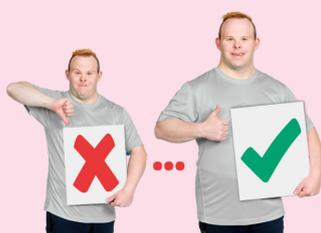
We review an anonymised report completed by the LeDeR reviewer and make notes of any good practice, anything that we think needs improved or something that we think was missed in the care, treatment or support a person received during their life.



Our different experiences and roles help us to have a wider view of the experience a person has had throughout their life.



We then report this information back to the LeDeR Governance Sign Off Panel.



We hope that the information we feedback will help prevent the early deaths of people with learning disabilities and/or autistic people and improve their quality of life and service they receive.

Section 4 - The pink part

Reviews and themes



The Confirm and Challenge Group started in June 2019. Many of our experts with lived experience still work with the Confirm and Challenge Group.



Between April 2022 – March 2023 we have reviewed 8 LeDeR reviews and provided the LeDeR Governance Sign Off Panel (previously shared at the Action from Learning Group) with feedback.



Some of the challenges we have picked up on include:



- Lack of appropriate independent support such as Advocacy



- Lack of sharing information on individuals' rights to Advocacy



- Making decisions on behalf of a person without consulting family and friends when deeming the person to lack capacity to make that decision



- Lack of end-of-life planning

Section 4 - The pink part

Campaign work



Since reviewing the LeDeR reports and noticing the common themes in each report, the confirm and challenge group are working on campaigns to raise awareness on end-of-life planning and advocacy.



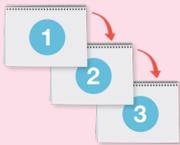
We are creating some easy read documents on what end-of-life planning is and why it is important.



It is a difficult subject, but it is important that everyone understands their rights and choices.



We will share our easy read information with our self-advocacy groups across Cumbria and Lancashire and gather their feedback.



Once we have received their feedback, we will then decide on our next steps as a group.



Another campaign we will also run is about advocacy awareness.



We have seen a trend in recent reviews where the person has not always had the appropriate support when decisions were being made about their care, support and treatment.



This means the person's views and wishes may not have been listened to.



It is important that every person is involved in decisions that are made about them.



We will partner up with our Advocacy team during Advocacy Awareness Week to run this campaign.

Section 4 - The pink part

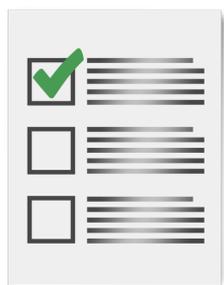
Learning and sharing event



On November 8th 2022 the Cumbria Confirm and Challenge group attended the North East and North Cumbria Learning and Sharing Event in Durham.



One of our members and co-chair of our group, Mary, recorded an interview style video about her life, what the autism assessment process was like for her, her experience at school, reasonable adjustments that were made throughout Mary's life and her hopes for the future.



Mary's video is very important as it highlights the struggles that people with autism may face throughout their life but also the things that can be done to include them and make the world around them more inclusive.

Section 5 - The orange part

Pen pictures - Mary, a lady with learning disability and James, an autistic person

Mary, a lady with learning disability

Mary was a 76 year old lady who initially lived with her parents in their family home. When they passed away, she remained in the family home and acquired the tenancy and with support provided by 24-hour carers so she was able to live independently.

She maintained a close relationship to her sister, and her nieces. She was able to communicate using spoken language but found it difficult to follow a conversation if she was agitated.

She was mischievous, had a good sense of humour, and liked to joke. She loved watching television and listening to music, she had her own tablet and earphones. She liked Abba and more recently One Direction. She enjoyed rolling and unrolling till rolls and used a peg board to occupy her hands.

Mary liked to go out for planned activities such as concerts and enjoyed holidays to Blackpool and more recently at a local caravan park.

Mary had good and bad days and was described as someone who preferred order and routine. She had limited patience, and this often led to outbursts. She disliked crowds and liked peace and quiet.

Mary died suddenly at home, her cause of death was a heart attack.

RIP Mary.



Section 5 - The orange part

Pen pictures - Mary, a lady with learning disability and James, an autistic person

James, an autistic person

James died at home aged 37 of multiple drug toxicity. He lived at home with his parents, he was dependant on them to take him places and accompany him in situations where he would be anxious.

From age 3 he was noted to do things like have all his toy wagons lined up, and not like the order to be disturbed, and was described as 'hard work' from age 6, needing constant attention, he found it hard to relate to others and had difficulty making friends. He was "picked" on at school by other children, he would attend school for registration but then would play truant, he didn't excel at school he finished school with average GCSE attainments.

Following school, he had several manual/mental jobs; roofer, painter and decorator, bar work but ended up getting sacked for wandering off, or when he had money, he just didn't turn up at work.

He liked music, watching films and playing computer games he liked solitary activities. He also liked to play golf with his father and godfather. He suffered from social anxiety and started taking drugs from about age 15 to combat this; cannabis initially, but would take whatever was available, and ultimately had a heroin addiction.

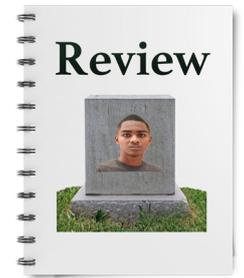
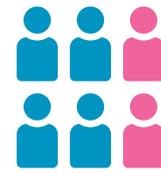
Over the years James was imprisoned on two occasions for 10 offences, which include theft and armed robbery. It was in prison at the age of 26 that he was diagnosed with Asperger's Syndrome. He did well in prison, he was polite and got on well, he started doing an extension on a Maths A Level and ended up gaining a Maths Degree with distinction.



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 **6 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



5 completed reviews were **initial reviews**



1 completed review was a **focussed review**



4 of the people were **men**



2 of the people were **women**



1 person was **31-40 years old**



1 person was **41-50 years old**



3 people was **51-60 years old**



1 person was **61-70 years old**



3 people died **at home**



3 people died **in hospital**



5 of the people were **white**



1 person was from an **unknown ethnic origin**

There were **0** completed reviews of **autistic people in North Tyneside**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **Northumberland**

In **Northumberland** we completed **10 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



All **10** completed reviews were **initial reviews**



4 of the people were **men**



6 of the people were **women**



3 people were **51-60 years old**



4 people were **61-70 years old**



3 people were **71-80 years old**



1 person died **at home**



5 people died **in hospital**



4 people died **in residential care**



All **10** people were **white**



There were **0** completed reviews of **autistic people in Northumberland**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **Newcastle/Gateshead**

In **Newcastle/Gateshead** we completed **19** reviews of people with a learning disability who died between 1st April 2022 - 31st March 2023



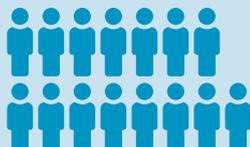
All **16** completed reviews were **initial reviews**



3 of the completed reviews were **focussed reviews**



15 of the people were **men**



4 of the people were **women**



1 person was **14-20 years old**



1 person was **21-30 years old**



1 person was **31-40 years old**



2 people were **41-50 years old**



3 people were **51-60 years old**



9 people were **61-70 years old**



1 person was **71-80 years old**



1 person was **81+ years old**



8 people died **at home**



8 people died **in hospital**



3 people died **in residential care**



18 people were **white**



1 person was **Asian or Asian British**

There were **0** completed reviews of **autistic people in Newcastle/Gateshead**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **North Cumbria**

In **North Cumbria** we completed **18 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



All **12** completed reviews were **initial reviews**



6 of the completed reviews were **focussed reviews**



9 of the people were **men**



9 of the people were **women**



3 people were **14-20 years old**



1 people were **21-30 years old**



2 people were **31-40 years old**



1 person was **41-50 years old**



5 people were **51-60 years old**



2 people were **61-70 years old**



2 people were **71-80 years old**



2 people were **81+ years old**



9 people died **at home**



7 people died **in hospital**



2 people died **in residential care**



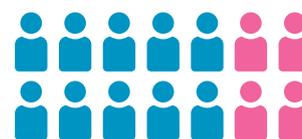
All **18** people were **white**

There were a **very small number** of completed reviews of autistic people in **North Cumbria**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **Sunderland and South Tyneside**

In **Sunderland and South Tyneside** we completed **14 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



All **12** completed reviews were **initial reviews**



2 of the completed reviews were **focussed reviews**



10 of the people were **men**



4 of the people were **women**



2 people were **under 14 years old**



2 people were **41-50 years old**



1 person was **51-60 years old**



4 people were **61-70 years old**



3 person was **71-80 years old**



2 person was **81+ years old**



4 people died **at home**



7 people died **in hospital**



3 people died **in residential care**



13 people were **white**



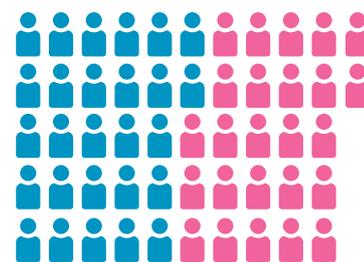
1 person did **not wish to disclose ethnicity**

There were **0** completed reviews of **autistic people in Sunderland and South Tyneside**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **Durham**

In **Durham** we completed **52 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



All **41** completed reviews were **initial reviews**



11 of the completed reviews were **focussed reviews**



27 of the people were **men**



25 of the people were **women**



2 people were under **14 years old**



1 person was **14-20 years old**



2 people were **21-30 years old**



2 people were **31-40 years old**



3 people were **41-50 years old**



15 people were **51-60 years old**



11 people were **61-70 years old**



12 people were **71-80 years old**



4 person was **81+ years old**



11 people died **at home**



20 people died **in hospital**



16 people died **in residential care**



1 person died **at the home of a friend or relative**



1 person died **in a hospice**



3 people had **no specified place of death**



All **53** people were **white**

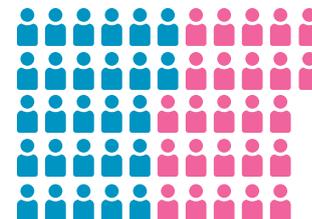


There were **0** completed reviews of **autistic people in Durham**

Section 6 - The blue part

Information about the deaths of people with learning disability and autistic people from **Tees Valley**

In **Tees Valley** we completed **44 reviews** of people with a learning disability who died between 1st April 2022 - 31st March 2023



All **32** completed reviews were **initial reviews**



12 of the completed reviews were **focussed reviews**



25 of the people were **men**



19 of the people were **women**



1 person was **under 14 years old**



2 people were **21-30 years old**



6 people were **31-40 years old**



4 people were **41-50 years old**



1 person was **14-20 years old**



10 people were **51-60 years old**



14 people were **61-70 years old**



5 people were **71-80 years old**



1 person was **81+ years old**



10 people died **at home**



23 people died **in hospital**



8 people died **in residential care**



1 person died **at the home of a friend or relative**



2 people died **in a community hospital**



43 people were **white**



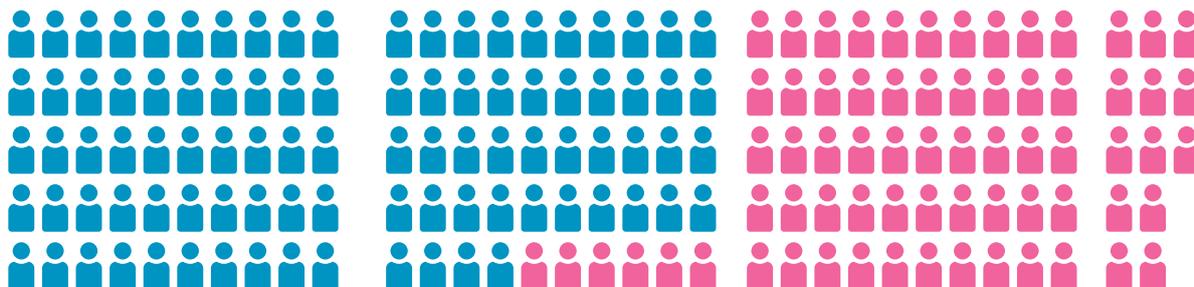
1 person was of **unknown ethnicity**

There were a **very small number** of completed reviews of autistic people in **Tees Valley**

Section 7 - The grey part

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

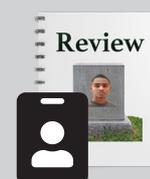
In the **North East and North Cumbria Integrated Care System** we reviewed the deaths of **163** people with a learning disability



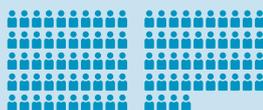
128 of the reviews were **initial reviews**



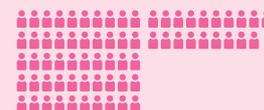
35 of the reviews were **focussed review**



94 of the people were **men**



69 of the people were **women**



8

people were **under 14 years old**



4

people were **14-20 years old**



5

people were **31-40 years old**



12

people were **31-40 years old**



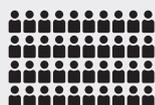
13

people were **41-50 years old**



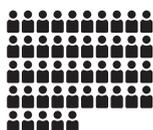
40

people were **51-60 years old**



45

people were **61-70 years old**



26

people were **71-80 years old**



10

people were **81+ years old**



Section 7 - The grey part

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

Where people died

46 people died **at home**



73 people died **in hospital**



36 people died **in residential care**



2 people died **at the home of a friend or relative**



1 person died **in a hospice**



2 people died in a **Community Hospital**



3 people had no specified place of death 

Ethnicity

159 people were white



1 person was Asian/Asian British

2 people were of unknown ethnicity

1 person had non disclosure

What People Died from in the North East and North Cumbria

Top 11 causes of death:

17 people died from problems with their heart.



17 people died from aspiration pneumonia.



11 people died from cancer.



10 people died from sepsis.



8 people died from dementia.



6 people died from COVID.



6 people died from frailty.



2 people died from problems with their lungs.



2 people died from epilepsy.



2 people died from renal failure.



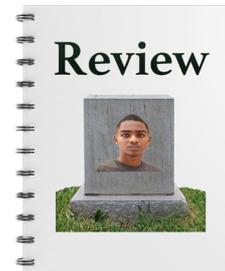
38 people died from pneumonia.



Section 8 - The peach part

Summary of autistic deaths in the North East and North Cumbria

In the **North east and North Cumbria Integrated Care System** we reviewed the deaths of **4** people with a autism diagnosis.



All **4** of the people were **men**



1 person was **21-30 years old**



2 people were **31-40 years old**



1 person was **51-60 years old**



2 people died **at home**



2 people died **in hospital**



All **4** of the people were **white**



What People Died from in the North East and North Cumbria

2 people died from **complications with drug misuse**



1 person died from **cardiac issues**



1 person died from **suicide**



Section 9 - The turquoise part

What we have learned about the deaths of people with learning disability and autistic people across the North East and North Cumbria

What we have learned from the deaths of people with learning disability and autistic people as a result of their LeDeR review

- There has been no 'new' specific learning from previous years.
- 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 are very different from reviews of people with learning disability. They take much longer to do and require reviewers to expand their skills to make sure all learning is gathered.
- The reasons autistic people die appear quite different from learning from deaths of people with learning disability.
- COVID did not feature as a major factor of the deaths of people with learning disability and autistic people this year.
- End of Life planning has improved since last published summary report, 22/23.
- There is an increase in uptake of annual health checks, flu and covid immunisation across NENC.



Section 10 - The cream part

What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

What we are doing across the North East and North Cumbria LeDeR Governance Group led work



Recommending the ICB Executive Board **support proposals to establish a centralised LeDeR reviewing team.**



Make **strong links** with the NENC Health Inequalities Programme.



Raising awareness of the LeDeR programme with people from minoritised communities.



Making a LeDeR communication plan to promote the programme across NENC.



Standardised processes at Place to **quality assure and 'sign off' completed LeDeR reviews.**



Submit NHS England North East & Yorkshire **quarterly reports & attendance at assurance panels.**



Receives assurance from the Learning Disability Network about progress with NENC wide **improvement work to tackle inequalities.**



Receives assurance from Place about progress with local improvement work and **completing reviews** within timescales.



NENC LeDeR Learning & Sharing conference will be delivered during Spring 2024.

Section 10 - The cream part

What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

Learning Disability Network led improvement work across NENC

- Region wide **hypertension case finding work** underway led by the Learning Disability Network with the Physical Health and Long-Term Conditions Network.
- Creating a toolkit to support **reasonably adjusted respiratory clinics** across NENC building on existing best practice examples.
- Developing a NENC wide approach to **improving epilepsy care** for people with learning disability and autistic people.
- Region wide **'Be Epilepsy Aware'** in partnership with Epilepsy Action being codesigned and to be co-delivered training led by and for people with learning disability and autistic people for launch 23/24.
- Further roll out of reasonably adjusted structured education on **Type 2 diabetes** for people with learning disability and autistic people including an independent evaluation led by an academic partner.
- Designing a **reasonably adjusted weight management programme** based on LEAN learning.

Region wide **flu and covid vaccination** campaigns planned for autumn/winter 23/24 led by the Learning Disability Network with the System Operation Vaccination Centre.



Dysphagia website including toolkit, resources and workforce education developed to be launched summer 23.



Section 10 - The cream part

What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

Learning Disability Network led improvement work across NENC

- With Macmillan working on national easy read holistic needs assessment.
- Roll out of mandatory Learning Disability and Autism Awareness training to the health and social care workforce (Oliver McGowan) underway.
- Piloting use of 'Bubbl App', for people with learning disability and autistic people to track their health and wellbeing.
- With Skills for People, implementing the Live Well programme promoting good health and wellbeing for people with learning disability and autistic people using social media.

'Be Screening Aware' and **'Be Cancer Aware'** training led by and for people with learning disability and autistic people continuing to be rolled out across the region.



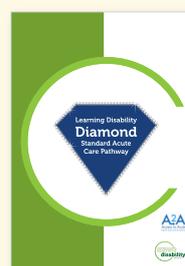
With the **Northern Cancer Alliance** working on the health inequalities programme.



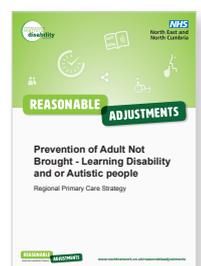
Completed health quality checks on all **breast and bowel screening services**. Now looking for funding to roll out for AAA screening.



Further develop the **Learning Disability Diamond Pathways & workforce education** to include autism for implementation in every acute hospital.



Region wide implementation of the **Prevention of Adult Not Brought plan** and the **Reasonable Adjustments Campaign** launched during Learning Disability Awareness Week 23.



Section 10 - The cream part

What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

Place based improvement work

North Cumbria



Improvement of the Learning Disability Health Action Plan - A multi-partner task and finish group was established to review the national Health Action Plan template; this work was co-produced with a local learning disability advocacy group and with a group of young people along with their families and carers. The key ambition of the project was to improve the quality of the Health Action Plan output in terms of making it more holistic and user friendly, easier to complete, and more visual for users.



The revised template has been shared with the **national EMIS and SystemOne Teams**.

North (Northumberland, Newcastle/Gateshead and North Tyneside)



Malnutrition guidelines developed to provide advice in relation to risk and management for people with learning disability. Ongoing guidance and support given to GP practices by the GP lead for Learning Disability and Mental Health. A local newsletter also provides up to date training guidance and information. Development of local learning disability screening report, providing an overview of Annual Health Checks, Flu vaccinations and cancer screening programmes.



LeDeR Quality Improvement panel in place.



Monthly Mortality review meetings with cross organisational stakeholders.

Section 10 - The cream part

What is happening in the North East and North Cumbria to make the lives of people with learning disability and autistic people better.

Place based improvement work

Central (Durham, South Tyneside & Sunderland)



Roll out of **'Learning from LeDeR'** briefings and dedicated awareness sessions; including sessions for social prescribers and care co-ordinators working within Primary Care Networks.



Promotion of **Restore2 Mini Training** in County Durham for unpaid carers.



Launch of **County Durham Oral Health promotion strategy 2023-2028** – includes a commitment toward improving oral health and dental services for children and adults with learning disability.

South (Tees Valley)



Education and training with primary care specific to the learning identified from the LeDeR reviews has been proactively delivered to GP's and primary care.



Implementation of the **Learning Disability Diamond standards** in acute hospital.



Development of a **practice-based audit in relation to 'Did Not Attend'**.



Development of place-based **quality assurance panel**.

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

Annual Report 2022/2023

Weblinks

North East and North Cumbria NHS

northeastnorthcumbria.nhs.uk

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

neclidnetwork.co.uk

NHS LeDeR LeDeR - About LeDeR

Report a death to LeDeR Report the death of someone with a learning disability

leder.nhs.uk

Twitter

North East and North Cumbria ICB

 twitter.com/NENC_NHS

North East and Cumbria Learning Disability Network

 twitter.com/neclidnetwork



Photographs © Photosymbols Ltd.
All Rights Reserved 2023.



**North East and
North Cumbria**