

North East and North Cumbria  
Integrated Care Board

# LeDeR Learning into Action Report

2023

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## Section 1 - The green part

### What is this report about?

**This report is to give clear information about what we have learned about the lives and deaths of people with learning disability and autistic people from the North East and North Cumbria who died in 2023.**

This report is called, '**LeDeR: Learning Into Action**'. This means it is a collection of lots of examples of work that has already happened in North East and North Cumbria as a result of what we have learned from LeDeR reviews.

It also includes examples of best practice work that has happened because of what people with learning disability, autistic people and family carers have told us in a variety of events, focussed group discussions and informal feedback throughout the year.

It is very important for the **North East and North Cumbria Integrated Care System** to understand this information to make sure **commissioning decisions and service improvement initiatives for health and social care** are relevant, current and based on good evidence to **improve the lives and wellbeing** of people with learning disability and autistic people from all the North East and North Cumbria.



## Section 1 - The green part

### What is this report about?

#### The North East and North Cumbria Integrated Care System's four goals are:

- Longer & healthier lives
- Fairer outcomes for all
- Better health & care service for all
- Giving children & young people the best start in life

Our plans are to reduce the health inequality gap by 10% by 2030 for the whole population, this includes people with learning disability and autistic people.

This '**Learning into Action**' report is key to being able to reassure our population that the NENC plans and LeDeR are fully joined up and we have taken every opportunity to make sure we deliver **LeDeR** as a '**service improvement programme**' rather than a 'mortality review programme'. We know the health inequality gap is wider for people with learning disability and autistic people, so we are fully committed to using every opportunity we have to improve the lives, health, and wellbeing of people with learning disability and autistic people across NENC.



## Section 2 - The blue part

What we learned, what we did, what happened?

**The most common cause of death in NENC in 2023 was pneumonia & respiratory disease.**

**We learned 36 people died from pneumonia. We learned 34 from respiratory disease.**



## Flu

**2 strategic ICS wide communications plan developed and shared across partners. 1 for adults and 1 for children and young people.**

### **This included:**

- 7 flu myth busting films developed and promoted
- Easy read invite letter produced
- Social care workforce education package
- Primary care resource pack
- Targeted social media campaign
- Alignment to NENC ICB winter immunisations communications programme
- 2 animations aimed at family carers and children and young people with a learning disability to be promoted in schools

**We are currently working on a Winter Vaccination Programme for 2024.**

- All the toolkits will be updated & circulated across NENC.
- We are working with community pharmacy to vaccinate people in their local communities.
- We are working with contracting colleagues to explore whether District Nursing Teams can vaccinate people at home where they can't come into General Practice.

## Section 2 - The blue part

What we learned, what we did, what happened?

# Reasonably adjusted respiratory clinic and toolkit

**24%** of avoidable deaths were due to respiratory conditions excluding covid (LeDeR 2022). **1 in 10** patients with a learning disability have a diagnosis of asthma compared to **1 in 14** of patients without learning disability.

In November 2023 we launched a [film](#) showcasing good practice at Sunderland Royal Hospital chest clinic who offer a reasonably adjusted clinic for patients with a learning disability and asthma.

A [toolkit](#) was also created & launched to provide professionals with practical support and resources to embed this into their way of working - the information is transferable across all long-term condition areas and both primary and secondary care.

The main **9-minute film** has had over **650 views** and the shorter soundbites have had over **4400 views**.



## Section 2 - The blue part

What we learned, what we did, what happened?

We learned **23** people died because of problems with their heart.

We learned **4** people died because of stroke.

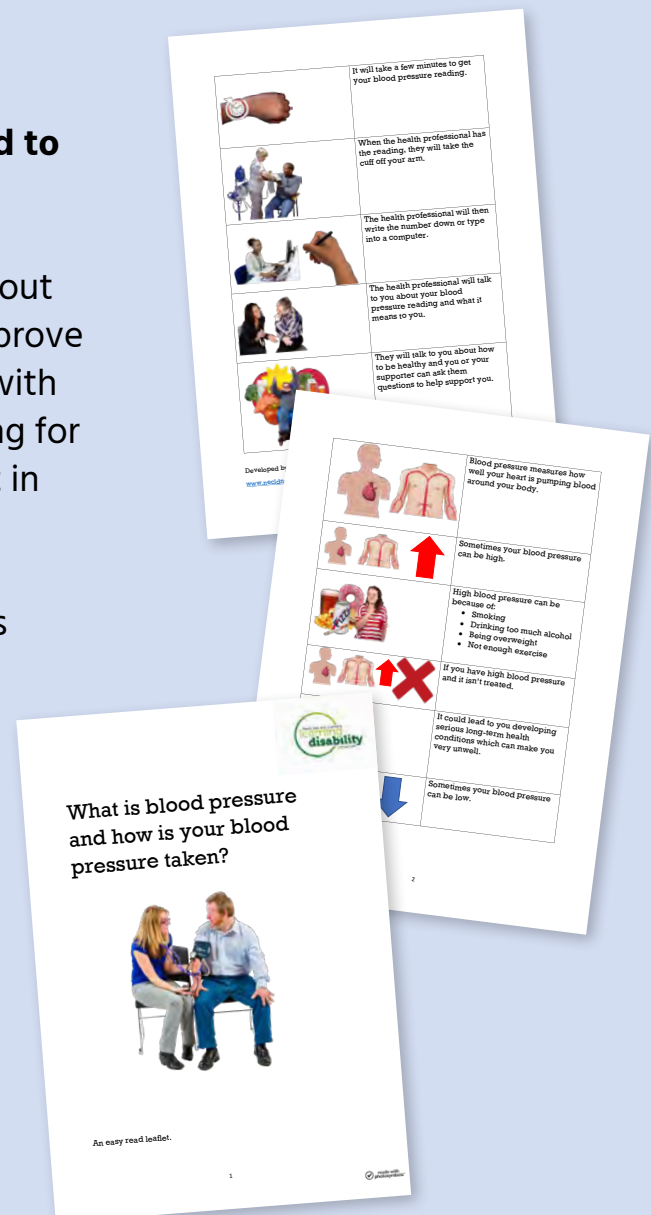


## Hypertension case finding

**20% of avoidable deaths were linked to hypertension (LeDeR, 2022).**

Linked to the ICB Core20plus5 carried out small scale scoping with 2 PCNS to improve hypertension case finding in patients with a learning disability. Plan to use learning for wider awareness raising/improvement in detection and management.

A [hypertension easy-read leaflet](#) was developed.



## Section 2 - The blue part

What we learned, what we did, what happened?

We learned **18** people died from cancer.



## Cancer

The LeDeR report tells us there are still challenges for people with a learning disability accessing preventative health care (screening and vaccinations) and in some cases challenged due to a lack of reasonable adjustments.

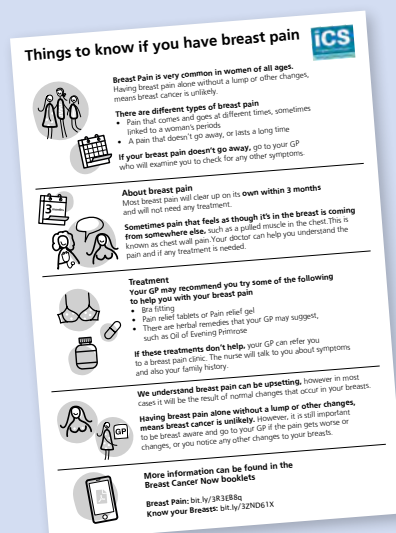
We continue to run in partnership with our community partners [Be Cancer Aware](#) and [Be Screening Aware](#) peer education courses and awareness campaigns to support the community to understand and ask questions about cancer and screening.

Health Quality Check reports were completed for [breast](#) and [bowel cancer screening](#) and recommendations shared at programme boards.

Coproduced accessible breast pain resources to support the new breast pain pathway.



In 23-24 we delivered **15** courses to **129** people.





## Section 2 - The blue part

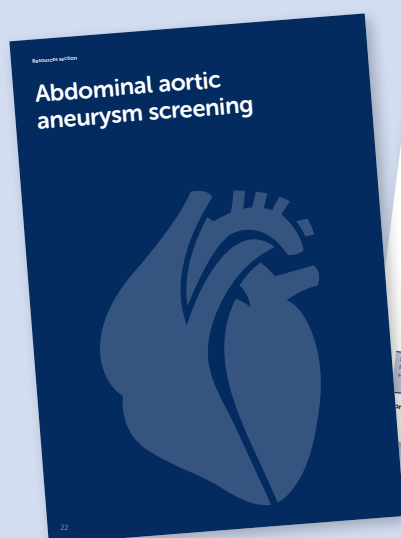
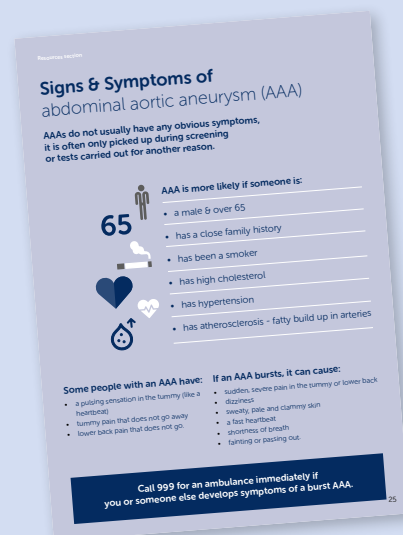
What we learned, what we did, what happened?

# AAA screening

Abdominal aortic aneurysm screening is offered to men in the year they turn 65. It is an effective screening programme helping to identify potential life-threatening aneurysms. We have worked on a number of projects to improve access for People with a learning disability.

Produced accessible results letter for use across NENC and Lancashire and South Cumbria AAA screening programmes.

[Health Quality Checks](#) completed and recommendations shared at programme board.

This is a screenshot of a checklist form titled 'Abdominal aortic aneurysm (AAA) Reasonable adjustments checklist and action plan'. The form is designed to help healthcare providers identify and address barriers to AAA screening for people with learning disabilities. It includes sections for 'Name', 'Does the person have the capacity to consent to AAA screening?', 'Can the person be contacted?', 'Does the person have a known family history of AAA?', 'Does the person lack capacity?', 'What are the barriers to the person's attendance?', 'What adjustments can be made?', 'What support can be provided?', and 'What information can be provided?'. Each section has a 'Yes/No' column and a 'Comments' column. The form is numbered 22 in the bottom left corner.

## Section 2 - The blue part

What we learned, what we did, what happened?

We learned that **69** people died from conditions that Annual Health Checks can help identify and prevent premature deaths.

We know that Reasonable Adjustments are key to support people access good quality and effective healthcare.

# Reasonable Adjustments Digital Flag

The [Reasonable Adjustment Digital Flag](#) is a locally and nationally available record which indicates the reasonable adjustments required for an individual to access health and social care.

Work continues to support the ICB to be compliant with the information standard notice, we provide regular update sessions and engagement through [reasonable adjustments campaign](#).



## Section 2 - The blue part

What we learned, what we did, what happened?

### Annual Health Check prompt sheets

In Spring 2024 we successfully co-produced and launched the [Annual Health Check prompt sheets](#) and [easy read invitation letter](#) across Primary Care in NENC. North Cumbria place have successfully integrated this as part of their clinical systems.

2023/2024 AHC NENC uptake **78.2%** exceeding the NHS England national target of **75%**.



### Children and young people EHCP & GP register film

September 2023 successfully developed and launched 2 films.

Aimed at promoting:

- [Educational Health & Care Plans from the voice of the young person](#)
- [GP Learning Disability Registers & Annual Health Checks](#)

These were co-produced with a local youth forum and family carers.



## Section 2 - The blue part

What we learned, what we did, what happened?

# Reasonable Adjustment campaign

June 2023 we successfully co-produced and launched the [Reasonable Adjustment campaign](#) and supporting resources.

The aims of the campaign are to:

- Help people to know their rights to reasonable adjustments
- Help health and care services to know their legal obligation to provide reasonable adjustments

Resources have been shared across the Integrated Care System with health and care providers and the public.

2024 we have commissioned The Lawnmowers Theatre Company led by people with a learning disability to develop [6 mini films](#) to be utilised as a training resource for health and care staff.



## Section 2 - The blue part

What we learned, what we did, what happened?

**We have learned that there are still people with learning disability 'not being brought' to healthcare appointments.**



# Prevention of Adult Not Brought

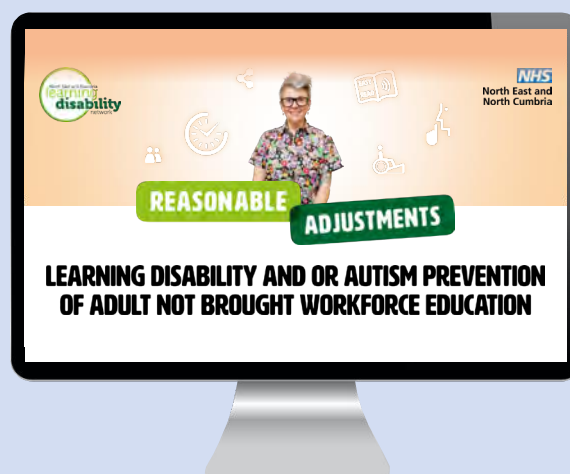
**June 2023, we launched the Prevention of Adult Not Brought strategy and workforce education package.**

The aim of this work is to:

- Support services to identify patients who are at risk of not being brought to appointments and how to mitigate those risks through early identification and reasonable adjustments
- Ensure adults who rely on others to bring them to appointments are correctly coded under the ANB code and not DNA
- Improve workforce education

This is what we did:

- Delivered a [Prevention of Adult Not Brought Strategy developed for primary care](#)
- Delivered a [Prevention of Adult Not Brought Strategy developed for secondary care](#)
- Delivered an [e-learning workforce education package](#)
- Delivered a range of [resources to support the health and care sector](#)
- Development of the reasonable adjustment campaign



## Section 2 - The blue part

What we learned, what we did, what happened?

# Learning Disability Acute Diamond Standards, pathways and workforce education



**We have fully rolled out in every acute hospital in the North East and North Cumbria the Learning Disability Acute Diamond Standards, Pathways and Workforce Education.**

The aim of the Acute Diamond Standards is to:

1. To improve communication for people with learning disability across settings
2. To improve experiences of health care for people with learning disability
3. Improve quality of life for people with learning disability
4. Promote seamless care and disparity of service
5. To reduce premature mortality

We have recently made a short animation to show how the Acute Diamond Standards work [www.youtube.com/watch?v=a0exDZFK204](https://www.youtube.com/watch?v=a0exDZFK204)

During 2023 most acute hospitals reported that there was very high uptake (between 80 – 90%) of clinical staff having completed the Diamond Workforce Education who are now using their learning in practice.

The ICB has also written to 5 hospital departments where all the clinical staff have completed the training and so are now awarded 'Learning Disability Diamond' status.

We are currently finishing work on Acute Diamond Standards for Autistic People and they will be rolled out soon.





## Section 2 - The blue part

What we learned, what we did, what happened?

**For the ICB to be able to be able to commission effectively based on population health management profiles, (that is very good and detailed information about people with learning disability and autistic people in every part of NENC), we have developed a set of 'dashboard' information that is extremely useful to support commissioning and service improvement.**

We will continue to keep this information up to date. We are using these profiles across our area with health and social care colleagues.



## What is population health management?

Using a 'population health management approach' is an important way of understanding the health of particular groups of people. In NENC we have used 'population health management approach' to understand the health conditions e.g. different diseases and long term conditions, that particularly affect people with learning disability and autistic people.

The information is very detailed and shows which parts of NENC there are higher or lower levels of people with learning disability and autistic people living there.

This is important information so local services and communities can plan and deliver health and care services most needed to improve the lives of people with learning disability and autistic people. Using a 'population health management approach' is a very important part of the NENC work to reduce health inequalities for people with learning disability and autistic people.

We will make sure our learning disability and autism population health management information is updated every year and used to improve health and care services across NENC.

## Section 2 - The blue part

What we learned, what we did, what happened?

**We know that our health and social care workforce need to have great knowledge and opportunities to learn about learning disability and autism. We have made a lot of progress in beginning to roll out the mandatory learning disability & autism awareness programme called 'Oliver McGowan Training'.**

# Workforce transformation Oliver McGowan training

**In July 2022 Learning Disability and Autism Awareness Training became mandatory for the entire health and care workforce.**

- Since 2023 across NENC, the North East & Cumbria Learning Disability Network has had strategic leadership, oversight and implementation across the Integrated Care System
- 2023 - A partnership was formed with the Good Life Collaborative, a collection of 6 self-advocacy organisations from NENC who are expert in working with people with a learning disability and autistic people
- 2023 - phase 1 pilot was successfully completed and evaluated with 11 health and care providers across the ICS
- 2024 - For the North East North Cumbria this applies to 150,000 FTE staff working across health and care
- 2024 - Successfully developed and implemented NENC augmentation of Tier 2 training

**You can find out more about the work we are doing [here](#).**





## Section 2 - The blue part

What we learned, what we did, what happened?

**What else is coming during 2024 to improve services and support of people with learning disability and autistic people live longer, healthier and more fulfilling lives?**

### Skills for Living

**17% of avoidable deaths were linked to diabetes. (LeDeR, 2021).**

Skills for Living with type 2 diabetes: Co-produced [accessible diabetes education](#) for people with learning disability with Type 2 diabetes. The standard NHS offer of diabetes education was not accessible or working for people with learning disability. The 6-week course is delivered by a specially trained facilitator and a peer facilitator(s) (person with a learning disability). It's also suitable for people with pre-diabetes.

#### What we've achieved so far...

- Delivered 5 courses across County Durham - 12 people with a learning disability attended and 6 co-learners
- Delivered 5 courses across South Tyneside - 23 people with a learning disability attended and 1 co-learner



**“I never expected to get on a course like this. I have learned about things I never knew before about diabetes. I have enjoyed coming. I don't think you could do better.”**



## Section 2 - The blue part

What we learned, what we did, what happened?

# Be Epilepsy Aware

**Epilepsy was the long-term condition that was most strongly associated with dying at a younger age (LeDeR, 2022).**

You are 22 times more likely to have epilepsy if you have a learning disability.

Working in Partnership with Epilepsy Action and experts with lived experience to coproduce and design an accessible 'Be Epilepsy Aware' course.

Delivered either online or face to face, it will empower people with a learning disability to better understand and live well with epilepsy.

Currently being co-designed with experts with lived experience for future implementation.



## Section 2 - The blue part

What we learned, what we did, what happened?



### Learning Disability Diamond Dysphagia Standards

**The NENC Learning Disability Diamond Dysphagia Standards will be launched during the winter of 2024/25.**

These will include a range of web-based resources and workforce education to upskill the health and social care workforce as well as providing very helpful information for families about dysphagia.



### Learning Disability Diamond Menopause Standards

**Later in 2024/25 we will be launching the Learning Disability Diamond Menopause Standards.**

Following the successful roll out of Learning Disability Acute and Learning Disability Maternity Diamond Standards the Menopause standards will be co-developed as a start of the NENC learning disability & autism women's health work. We will develop reasonably adjusted menopause standards, workforce education for health and care staff, peer education for women with learning disability and accessible information and resources.

We will launch this work with a major communication 'Think Menopause'.

**North East and North Cumbria Integrated Care Board**  
[northeastnorthcumbria.nhs.uk](https://northeastnorthcumbria.nhs.uk)

✕ [@NENC\\_NHS](https://twitter.com/NENC_NHS)

**North East and Cumbria Learning Disability Network**  
[neclidnetwork.co.uk](https://neclidnetwork.co.uk)

▶ [@neclidnetwork](https://www.youtube.com/@neclidnetwork)

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✉ [nencicb.learningdisabilitynetwork@nhs.net](mailto:nencicb.learningdisabilitynetwork@nhs.net)



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