

North East and North Cumbria
Integrated Care Board

LeDeR Learning into Action Report 2024

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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 2024.

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 North East North Cumbria 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 North East North Cumbria.



Section 2 - The yellow part

Introduction

I am delighted to introduce this year's "LeDeR: Learning into Action" report for the North East and North Cumbria Integrated Care Board. This report is more than a record of our work, it demonstrates our shared commitment to listening, learning, and acting together to improve the lives of people with learning disability and autistic people across our region.

This report gives us a valuable chance to reflect on what we have achieved, celebrate the dedication of our teams, and recognise the voices of people with lived experience. The progress highlighted here shows how learning from LeDeR reviews and direct feedback has already led to meaningful changes, improving care, reducing inequalities, and supporting people to live longer, healthier lives.

Yet, there is always more to do. The insights from this report help us identify where further improvements are needed, ensuring our commissioning and service developments remain relevant and evidence based.

The NHS 10 Year Plan gives us a real opportunity to commission services that are fairer and more inclusive for people

with learning disabilities and autistic people, as well as the wider population. As we transition to a new role as Strategic Commissioners we can take practical steps, analyse local data to identify gaps to co-produce services with people who have lived experience. In doing so we can ensure accessibility and reasonable adjustments are made and clear targets set to reduce health inequalities, monitor outcomes, and work closely with partners across health, social care, and the voluntary sector to achieve this.

But our work is far from finished. The health inequalities faced by people with learning disabilities and autistic people are urgent. Every day, your actions, no matter how small, can help close this gap. Please take what you learn from this report and put it into practice, challenge the status quo, and champion change in your teams and services. Together, let's act now and make sure everyone in our communities receives the care, respect, and opportunities they deserve and without delay.

Thank you for your ongoing commitment and partnership.

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



Section 3 - The blue part

What we learned, what we did, what happened?

The most common cause of death in North East North Cumbria in 2024 was pneumonia and respiratory conditions.

We learned 38 people died from pneumonia and 13 from respiratory problems.



Winter Planning / Flu

Over the last 5 years, the uptake of flu vaccinations among people with learning disabilities has declined by more than 10% in NENC despite the continuation of a lot of communication resources in previous years.

In Winter 25/26 we've implemented a new 'Local Links' flu vaccination model bringing together Primary Care Networks, community pharmacies and learning disability day services (social care) across NENC.

The idea is for flu vaccinations to be offered to people with learning disability and the social care workforce in their neighbourhood in day services by local community pharmacies.

A huge amount of planning and promotional work has been done during recent months for implementation from October 2025.



Section 3 - The blue part

What we learned, what we did, what happened?

To support the delivery of the 'Local Links' project an extensive set of tools and resources has been made widely available and circulated across NENC.

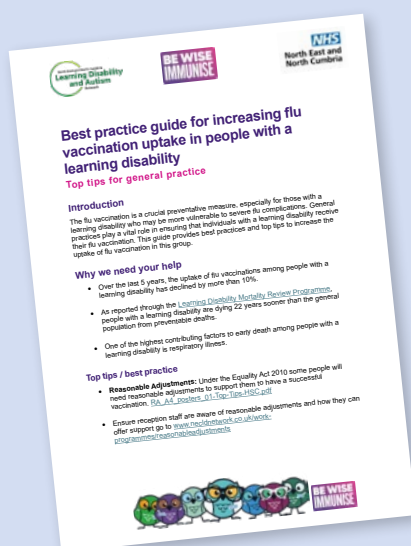
These include:

- 2 comprehensive strategic NENC wide communication plans, 1 for adults and 1 for children and young people.
- New lived experience promotional films explaining why the flu vaccination is important for people with learning disability.

All the Winter 2025 learning disability flu resources can be found [HERE](#)

Established a respiratory and learning Disability Community of Practice in March 2025

This brings together colleagues from North East and Yorkshire. The main purpose of the group is best practice sharing, sharing of practical tools, ideas, and useful resources. Each meeting has a focus on work happening to reduce the health inequalities associated with respiratory illness in people with a learning disability. For example, [Bradford's Keeping My Chest Healthy Project](#).



Section 3 - The blue part

What we learned, what we did, what happened?

We learned 31 people died of aspiration pneumonia.



Learning Disability Dysphagia Diamond Standards

These were co-produced and designed by a wide range of stakeholders including colleagues from acute and primary care, social care, speech and language therapy, specialist learning disability and mental health trusts and people with learning disability and their families.

The Learning Disability Dysphagia Diamond Standards aim to:

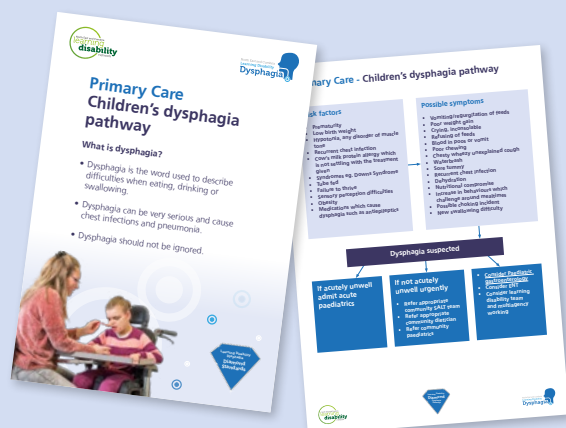
- Upskill both the workforce and family carers
- Provide adjusted pathways
- Signpost to workforce education option(s)
- Provide resources and information to support and provide high quality care for people with dysphagia
- Reduce the number of avoidable deaths from aspiration pneumonia in our region

Included are:

- A set of reasonably adjusted pathways for primary care, secondary care, families, carers and social care for both adults and children
- Workforce education
- An extensive library of resources and films

Screening tools

The resources can be found [HERE](#).



Section 3 - The blue part

What we learned, what we did, what happened?

We learned **28** people died from issues relating to their heart.



We learned **14** people died from issues relating to their organs.



Skills for Living with Type 2 Diabetes

We have reviewed and redesigned skills for living to include people with pre-diabetes with aim to prevent people developing type 2 diabetes.

Diabetes and hypertension often occur together, significantly increasing the risk of cardiovascular diseases and other complications.

Ongoing delivery in South Tyneside and **2** new courses being delivered in North Cumbria late 2025/26.



Section 3 - The blue part

What we learned, what we did, what happened?

We learned 20 people died from Cancer.



Learning Disability Cancer Workers

We employed 2 experts by experience to support the cancer work programme.

They have already made an impact working on Urgent cancer referral documentation, the National Cancer Patient Experience Survey and the Lung Cancer Screening Programme.



Section 3 - The blue part

What we learned, what we did, what happened?

Be Cancer Aware and Be Screening Aware

Our peer education programmes continue to be delivered across the North East and North Cumbria.

We have delivered **36 courses** which have shown an increase in understanding for participants.

Lung Cancer Screening Programme

Lung cancer screening is reducing the stage lung cancer is found, this enables many more lung cancers to be successfully treated.

We produced an easy read lung cancer screening booklet. This is now being used throughout the country for people with a learning disability invited for screening.



Section 3 - The blue part

What we learned, what we did, what happened?

We learned 6 people died from epilepsy or seizures.



We learned 6 people died from neurological conditions, related to the brain.



Be Epilepsy Aware

As shown within LeDeR Epilepsy continues to be the long-term condition that is most strongly associated with dying at a younger age nationally.

Working with **Epilepsy Action**, experts with lived experience, expert healthcare professionals across NENC to co-develop and design an accessible Epilepsy Awareness Course.

In 2024 the face-to-face course was piloted, **49** people attended. Online Training was launched in February 2025. **96%** attendees that attended the face-to-face course reported learning something new. recommend the course.

The course is a hybrid model and is can be accessed free of charge.

As at September 2025, 2203, have enrolled on the online version with **98%** of people saying they would recommend the course.

You can find the work **HERE**.



Section 3 - The blue part

What we learned, what we did, what happened?

NHS England Epilepsy Benchmarking

Delivered a systemwide benchmarking review between October 2024 and January 2025. This included 'Stakeholder Mapping' to ensure full representation of the entire system, followed by specific engagement with identified organisations and individuals.

The report can be found [HERE](#).

This will be used to influence improvement work in the care for people with epilepsy and a learning disability across North East and North Cumbria.

Sodium Valproate Medication

We have developed two easy read leaflets around the use of Sodium Valproate for pregnant women and men.

You can find the resources [HERE](#).



Section 3 - The blue part

What we learned, what we did, what happened?

We learned 105 people died in an acute setting.



Learning Disability and Autism Acute Diamond Standards

Alongside the acute learning disability liaison leads in every acute trust in NENC, we have fully refreshed the Learning Disability Acute Care Standards and Pathways.

These are a set of reasonably adjusted pathways for people with a learning disability around planned admission, emergency admission and discharge. They are underpinned by a core set of values and principles which were co-developed with experts with lived experience. These have been adopted by all **8** acute trusts in NENC to improve health outcomes and experiences for people with a learning disability and reduce variation.

This year has also seen us develop the Autism Acute Diamond Standards. Which are a set of reasonably acute care pathways focusing on the needs of autistic people.

The resources can be found [HERE](#).



Section 3 - The blue part

What we learned, what we did, what happened?

Health and Care Passport

We have refreshed the NENC health and care passport.

This can be localised by each acute trust in NENC. This is a patient held document to support people with a learning disability when coming into hospital. It documents their communication needs, reasonable adjustments and support requirements. They are designed to support health and care staff to be able to provide the best support to patients with learning disability and their family carers.

It can be downloaded [HERE](#).

The image displays two pages of the Health and Care Passport. The top page is the 'Contents' page, which lists the following sections and their page numbers: My Details (3), Communication (4), Home Environment (5), Living Support (6), Supporting pain or distress in Hospital (10), Sight and Hearing (13), Food and Drink (14), Keeping Safe (15), Resources Page (17), and Learning Disability Team (19). The bottom page is the 'My Details' form, which includes a consent section and a form for personal information. The consent section states: 'This Health and Care Passport should be completed by you and the person that know you best. By filling it in, you are giving permission for your information to be shared with health and care staff who are caring for you. This is called consent.' Below this is a checkbox for 'Tick yes if you agree to this.' The form for personal information includes fields for: My name is..., I like to be called..., My pronouns are: (he/his, she/her, or other), NHS number..., Date of birth..., Address..., Mobile number..., and Landline number... The NHS logo is visible on the form.

What to do when you're coming into hospital pack

We have refreshed the NENC 'What to Do When You Are Coming into Hospital Pack'.

This can be localised by each acute trust in NENC. It is an easy read information pack to support people when using hospital services. It can be downloaded [HERE](#).

Deteriorating Health

We have relaunched the STOP and WATCH resources across NENC. We have also ensured that 'Martha's Rule' has been promoted and referenced throughout our refresh of materials.

The STOP and WATCH resources can be found [HERE](#).

Section 3 - The blue part

What we learned, what we did, what happened?

In all the work we do it's important to raise awareness and understanding of learning disability and autism.

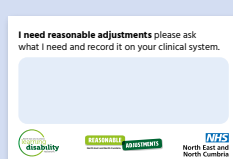
Reasonable Adjustment Campaign

In June 2023 we successfully co-produced and launched the Reasonable Adjustment Campaign and supporting resources.

The campaign has continued to expand throughout 2024/25. 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

All the Reasonable Adjustment Campaign resources are [HERE](#).



Reasonable Adjustment Digital Flag

We continue to lead the rollout of the reasonable adjustments digital flag for the North East and North Cumbria Integrated Care Board.

We are now able to see the progress in uptake of the flag within Primary Care thanks to the support of the ICB Insight Team. We are focusing support on enabling full engagement with the flag and compliance with the Information Standard Notice.



Section 3 - The blue part

What we learned, what we did, what happened?

All Behaviour Happens for a Reason Campaign

In September 2025 we have launched the 'All Behaviour Happens for a Reason' campaign.

This is a campaign to raise awareness amongst mainstream health and care services to enable the workforce to:

- Understand that 'all behaviour happens for a reason' and instead of trying to stop it, try to understand the reasons why the behaviour is happening to enable you to address it.
- Tools and resources to support the workforce in their understanding

The campaign can be found [HERE](#).



Section 3 - The blue part

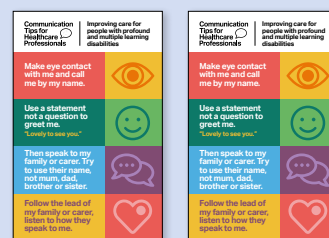
What we learned, what we did, what happened?

Communication tips for people with a profound and multiple learning disability

Working in partnership with the Involving Everyone Group (family carers of people with profound and multiple learning disability), this has led the creation of '[Communication Tips for Healthcare Professionals](#)' now rolled out across NENC as part of the Reasonable Adjustment campaign.

These important tools provide health professionals who do not often meet people with profound and multiple learning disability with education to ensure their contact is positive, respectful and meaningful.

The resources can be found [HERE](#).



Section 3 - The blue part

What we learned, what we did, what happened?

Population Health Management

To commission improvement, work effectively, we use detailed population health management profiles to understand the needs of people with learning disability and autistic people across North East and North Cumbria. The Learning Disability and Autism Network is supported by the ICB Insights team with this.

Our dashboards provide up-to-date information that supports evidence-based commissioning and service improvement.

By identifying where needs are greatest, we can help local services plan and deliver the right care, reducing health inequalities and improving lives. This approach is central to our ongoing work with health and social care partners across the region



Section 3 - The blue part

What we learned, what we did, what happened?

Workforce Transformation

GP Training Programme

During last year, the North East and North Cumbria Learning Disability & Autism Network Team alongside GP learning disability clinical leads, was invited to deliver training to GP Speciality Registrars across NENC as part of their mandated training programme. Working closely with the Programme Directors, we designed a training programme specifically designed to meet the needs of the doctors including LeDeR, importance of flagging 'learning disability status in primary care', reasonable adjustments, long term condition groups most common in people with learning disability.

Mandatory Learning Disability and Autism Awareness Training

In July 2022 it became law for all CQC registered health and care services to make sure their workforce has mandatory learning disability and autism awareness training appropriate to their role.

Oliver McGowan Training

Working alongside the [Good Life Collaborative](#) as our delivery partners. We have made available the [Oliver McGowan Training](#) across NENC. Much further implementation work will continue to ensure the entire health and care workforce have access to the training.



Section 3 - The blue part

What we learned, what we did, what happened?

Learning Disability and Autism Ambulance Diamond Workforce Education

We have worked with the North East Ambulance Service and experts with lived experience to co-develop an education package for the ambulance sector. This has been delivered to **90%** of their North East Ambulance Service workforce and a model for sustainability is in place.

Positive Behavioural Support

Positive Behavioural Support (PBS) is the NENC system vehicle of delivering all quality and safe care and support for people with learning disability across NHS and care. Learning from all the 'abuse' scandals requires cultural change; the NENC PBS programme safeguards people with learning disability and drives cultural change to prevent abuse. The NENC PBS programme is leading the way in eliminating abusive, aversive, and restrictive practice. The NENC PBS programme, as recommended by NICE, DoHSC, CQC & Building the Right Support recommends PBS as best practice.



Section 3 - The blue part

What we learned, what we did, what happened?

PBS family carer workshops (children)

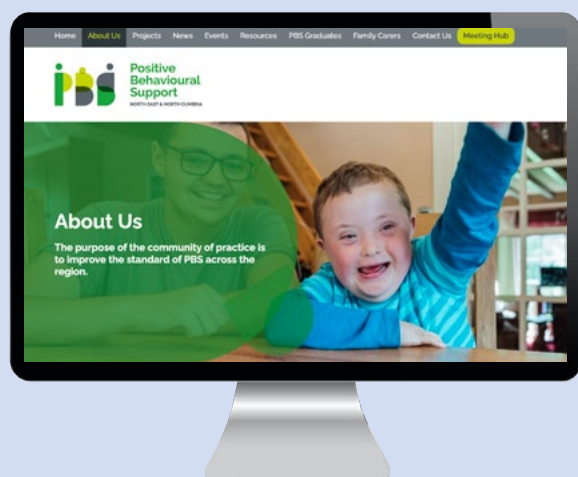
Delivered **22** workshops in collaboration with Skills for People – **19** face-to-face and **3** online. Delivered to **128** family carers attended as part of the Keyworker and Together for Children projects.

We have further increased family carer facilitators so will be able to expand the offer for families to access the training.

A refresh and review of the training materials and delivery has happened based on feedback from families.

2 films have been made to highlight the benefits of the training and workshops from a family carer perspective.

These can be found [HERE](#) and [HERE](#).



PBS family carer workshops (adults)

We have worked with our partners Durham Care Academy, Durham County Carers and TEWV to co-deliver workshops to family carers across Durham.

Post Graduate Level 6/7 Leading PBS in organisations

With Northumbria University we successfully recruited over 30 students for the level 6/7 programme which started Sept 24. A new cohort has started in September 2025.

Information for interested students and providers is found [HERE](#).

Level 4 Diploma in facilitating PBS in teams

In collaboration with Sunderland College, we successfully recruited 35 students for the level 4 Diploma in facilitating PBS in teams in September 2024. A new cohort has started in September 25.

Key Learning into Action Initiatives



Respiratory and Learning Disability Community of Practice:

Established to share best practice and improve respiratory health outcomes.



Learning Disability Dysphagia Diamond Standards: Co-produced standards and resources to upskill staff and carers, aiming to reduce deaths from aspiration pneumonia.



Skills for Living with Type 2 Diabetes: Redesigned to include people with pre-diabetes, focusing on prevention and better management of diabetes and hypertension.



Be Epilepsy Aware: Developed accessible epilepsy education for people with learning disabilities, their families, and carers, with positive feedback and high uptake.



Acute Diamond Standards: Refreshed care pathways for people with learning disabilities and autistic people in acute settings, adopted by all local trusts.



Reasonable Adjustment Campaign: Co-produced resources to raise awareness of legal rights and obligations, supporting both people and services.



Population Health Management Dashboards: Developed and maintained detailed profiles to inform evidence-based commissioning and service improvement.



Workforce Transformation: Delivered targeted training for GPs, ambulance staff, and commissioners, and expanded Positive Behavioural Support (PBS) training for families and professionals.

Next Steps for Further Improvement

1. **Expand Co-Production:** Involve more people with lived experience in designing and evaluating services.
2. **Strengthen Data Use:** Continue to update and use population health management dashboards to identify gaps and monitor progress.
3. **Targeted Interventions:** Focus on areas with the greatest health inequalities, using local data to tailor interventions.
4. **Sustain and Scale Training:** Ensure all staff receive mandatory learning disability and autism training and expand PBS training to more sectors.
5. **Monitor and Share Impact:** Regularly review outcomes of initiatives, share learning across the system, and adapt approaches based on what works.
6. **Enhance Partnership Working:** Deepen collaboration with social care, voluntary sector, and community groups to address wider determinants of health.
7. **Promote Reasonable Adjustments:** Ensure all services consistently make reasonable adjustments and raise awareness among staff and the public.

By building on these initiatives and focusing on these next steps, the ICB can continue to reduce health inequalities and improve the lives of people with learning disabilities and autistic people across North East and North Cumbria

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