



North East and Cumbria Learning Disability Network Impact Statement 23/24

Contents

Introduction	3
The Learning Disability Network has moved into the ICB	4
Tackling health inequalities	5
Cancer and digital workstreams	10
Long term conditions and physical health	13
Learning from the lives and deaths of people with learning disability and autistic people - (LeDeR)	16
Workforce transformation	18
Positive Behavioural Support (PBS)	19
Supporting family carers	24
So, what is next for the Learning Disability Network?	27
National PENNA Awards 2023	30

Introduction

Welcome to the Learning Disability Network Impact Statement 2023/24. My name is Judith Thompson and I've had the pleasure of managing the Network since it was formed in 2010. Having survived several NHS reorganisations, the Network has never been in a stronger position as it is today to drive up improvements in the lives of people with learning disability and family carers in the North East and North Cumbria.

I am honoured to lead an incredible and inspiring team of individuals, each who bring their unique gifts, talents and support each other and me on a daily basis, and work with undying energy, compassion, knowledge & insight each day to reduce the health inequalities that affect the lives of people with learning disability.

We hope you enjoy reading our new impact statement and look forward to what else is to come in 24/25. To keep in touch with our work please see our regular bulletins & website Learning Disability Network neclidnetwork.co.uk



The Learning Disability Network has moved into the ICB



The North East & Cumbria Learning Disability Network has been part of another NHS reorganisation, the 5th in its lifetime! We are very pleased that we have now moved from being hosted by NHS England to NHS North East North Cumbria Integrated Care Board from April 2024.

We continue to work on behalf of the entire health and social care system in collaboration with brilliant expert leaders with learning disability and family carers, inspiring community & voluntary sector partners and wide-ranging stakeholders.

Ensuring the North East and North Cumbria is the best place in England to live if you have a learning disability, placing people with learning disability and families at the heart of everything we do and making every effort to reduce health inequalities and premature mortality continues to be the central focus of our work.

Being part of the ICB brings with it greater opportunities to lead, contribute, influence and drive improvement work that affect the lives of people with learning disability across all parts of the ICBs plans; we are part of the Nursing & People Directorate and couldn't be happier that the Deputy Chief Nurse, Ann Fox is our Network chair and Judith's line manager.

Tackling health inequalities

Primary care & women's health

Network Facilitator, Kirsty Greenwell



Kirsty joined the Network in 2013, she was the first new member after the Network was created in 2010. Kirsty's role was to provide business support but very soon it became clear she had a much bigger offer to make.

Kirsty is often referred to as 'the engine room' and is usually the 'go to' person for our stakeholders for any questions or queries. Kirsty now takes lead responsibility on a wide range of initiatives, most recently is now providing lead programme management for the implementation of the Oliver McGowan training.

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. The films were made by a local film company led by people with a learning disability.



Prevention of Adult Not Brought

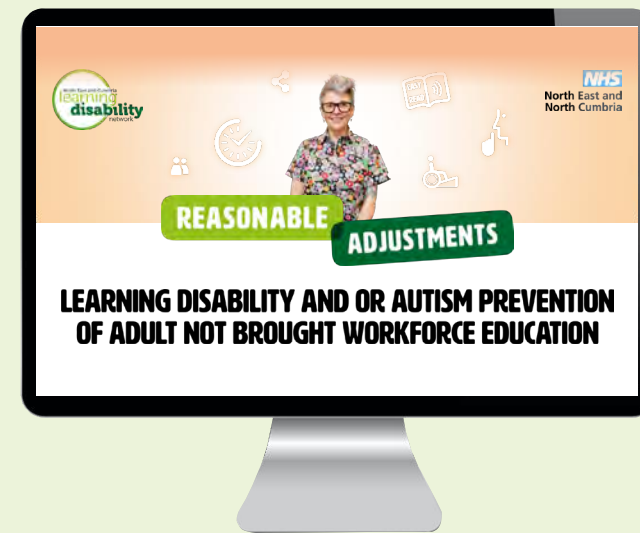
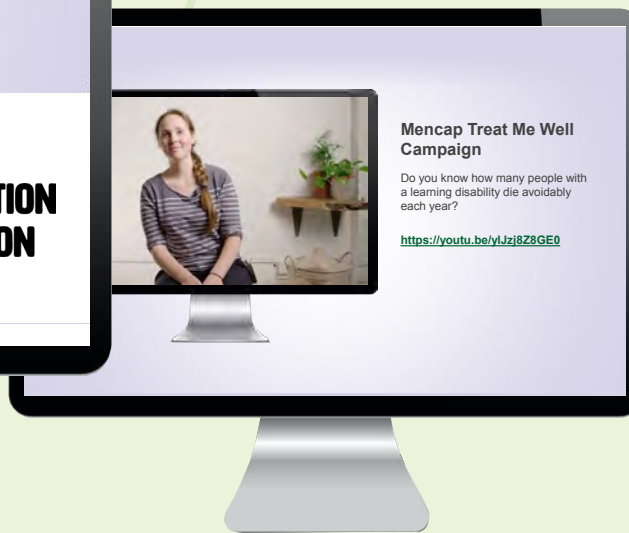
June 2023, we launched the Prevention of Adult Not Brought strategy and workforce education package.

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





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.

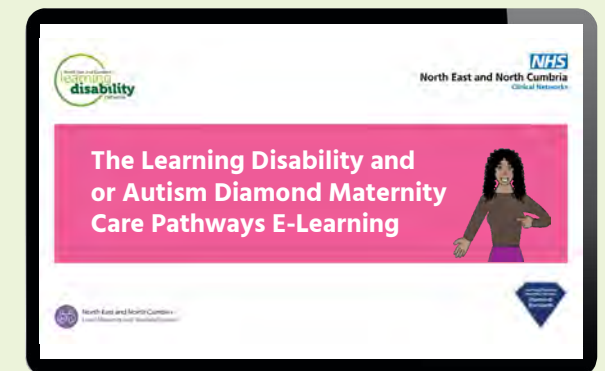
2024 we have commissioned The Lawnmowers Theatre Company led by people with a learning disability to develop **6 mini films** to be utilised as a training resource for health and care staff.



Learning Disability Maternity Diamond Standards

- Launched in February 2024
- Co-produced with Geordie Mums, the NENC Local Maternity Neonatal System and the Northern Maternity Network
- Co-produced set of core values and principles
- Delivered 3 reasonably adjusted care pathways antenatal, labour and post-natal up to 10 days
- Delivered a mandated education package aimed at the maternity workforce
- Delivered an easy read maternity health & care passport
- Delivered 2 one-page profiles, one for expectant mum, one for midwife
- Delivered an easy read birth plan
- Delivered an easy read post-natal plan
- Delivered an easy read 6-8 week GP post-natal check-up pre-questionnaire
- Delivered 15 easy read patient information leaflets

All 8 acute trusts across NENC have adopted the Learning Disability Maternity Diamond Standards.



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%

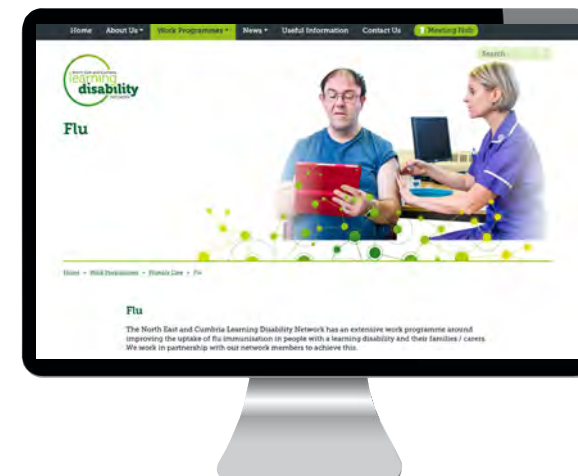


Flu

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
- Top tips for parents and carers



Cancer and digital workstreams

Project Manager, Julie Tucker



Julie Tucker, Project Manager with lead responsibility for the Network's cancer, end of life & palliative care and digital work has been part of the Network since 2015.

Julie has made enormous contribution to making huge improvements not only across NENC but nationally about cancer services and people with learning disability. She has more recently also taken lead responsibility for our digital work and is continuing to provide brilliant leadership regionally in the roll out of the Reasonable Adjustment Digital Flag.

Last year the Northern Cancer Alliance awarded Julie with an award 'Recognising commitment and innovation across cancer services' - we couldn't be prouder of her!

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



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.

Things to know if you have breast pain ICS

Breast Pain is very common in women of all ages. Having breast pain alone without a lump or other changes, means breast cancer is unlikely.

There are different types of breast pain

- Pain that comes and goes at different times, sometimes linked to a woman's periods
- A pain that doesn't go away, or lasts a long time

If your breast pain doesn't go away, go to your GP who will examine you to check for any other symptoms.

About breast pain
Most breast pain will clear up on its own within 3 months and will not need any treatment.

Sometimes pain that feels as though it's in the breast is coming from somewhere else, such as a pulled muscle in the chest. This is known as chest wall pain. Your doctor can help you understand the pain and if any treatment is needed.

Treatment
Your GP may recommend you try some of the following to help you with your breast pain

- Bra fitting
- Pain relief tablets or Pain relief gel
- There are herbal remedies that your GP may suggest, such as Oil of Evening Primrose.

If these treatments don't help, your GP can refer you to a breast pain clinic. The nurse will talk to you about symptoms and also your family history.

We understand breast pain can be upsetting, however in most cases it will be the result of normal changes that occur in your breasts. **Having breast pain alone without a lump or other changes, means breast cancer is unlikely.** However, it is still important to be breast aware and go to your GP if the pain gets worse or changes, or you notice any other changes to your breasts.

More information can be found in the Breast Cancer Now booklets
Breast Pain: bc-hy/3KJ889
Know your Breast: bh-hy/3ND61X

Staying safe in the sun

Be Cancer Aware

learning disability

Cover up with a hat and long sleeves.

Be Cancer Aware

Staying safe in the sun

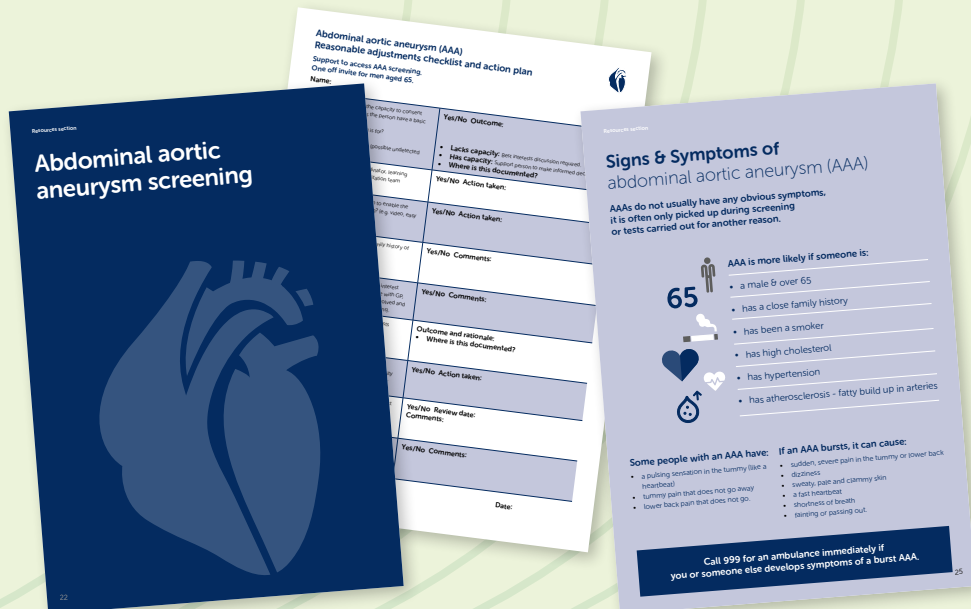
Be Cancer Aware

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.



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**.



Long term conditions and physical health

Project Manager, Emma Cheetham



Emma joined the Network in 2021 as a Project Manager with lead responsibility for long term conditions

& physical health. We were thrilled to welcome Emma to the team in this new role; it has given us great opportunity to focus on this huge agenda that we know massively impacts the lives & deaths of people with learning disability. Emma's leadership, knowledge & energy goes from strength to strength in working collaboratively across NENC to co-design & delivery a widely diverse work plan.

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.



Introduction

This toolkit demonstrates a reasonably adjusted clinic. It was developed to support healthcare professionals to embed reasonable adjustments in their working practice. This also includes anyone organising or managing services for people with a learning disability.

This toolkit will provide you with practical resources, guidance and information to change your working practice and better support patients with a learning disability. Although focused on adults with asthma, the learning and materials can be adapted for use across other long term condition areas (Equality Act, 2010).

REASONABLE ADJUSTMENTS

A Reasonably Adjusted Clinic for Patients with a Learning Disability - Toolkit

North East and North Cumbria Learning Disability Network and North East and North Cumbria Respiratory Clinical Network

Health literacy

43% of UK adults do not understand health materials containing text. This means they will struggle to understand communication media like information leaflets or appointment letters. (Rowlands et al, 2015).

61% of UK adults do not understand health materials containing numbers as well as text. This means they may struggle to understand charts and graphs or instructions on how and when to take their medication. (Rowlands et al, 2015).

Poor health literacy uses up between 3-5% of the annual health budget in Europe. 2015

How do we measure health inequalities?

How do we measure health inequalities?

What can we do to reduce health inequalities?

Health inequalities can be seen and measured through differences in prevalence of conditions and mortality, behavioural risks to health such as smoking, the wider determinants of health such as housing and employment, access to care, the quality and experience of healthcare services (NICE, 2023).

- Reasonable adjustments
- Personalised care
- Shared decision making
- Co-production

Data from the Sunderland clinic over a 6-month period

Category	Pre project	Post project
Prevalence of asthma	~10	~5
Cost of asthma	~10	~5
Self-management	~10	~5

Key: Pre project (dark green), Post project (light green)

Total cost 6 months pre project: Total Cost: £5,519

Total cost in 6 months post project: Total Cost: £3,233

Total savings over 6 month period: £2,286 or £81.64 per patient

Other Useful Tools - Respiratory Focus

Other tools:

- Easy read asthma management plans
- Ensure spacers are used with metered dose inhalers (**Bright breathe** is an excellent resource for helping choose the right inhaler)
- Mid Yorkshire have produced a **YouTube** channel full of Asthma Self Management resource in multiple languages
- West Yorkshire have produced **guides** to help manage your asthma in multiple languages
- Keeping my chest healthy** - Bradford District Care NHS Foundation Trust. (bdcf.nhs.uk)

Reasonably adjusted respiratory clinic and toolkit

24% of avoidable deaths were due to respiratory conditions excluding covid (LeDeR 2022). One 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**.



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."

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.

Coming Autumn 2024.



Learning from the lives and deaths of people with learning disability and autistic people - (LeDeR)

LeDeR Network Facilitator, Amy Hocking



Amy first joined the Network in 2019 when Kirsty was going off to have her first baby.

Amy quickly became 'at home' in the Network and provided much needed support to our work and the team. She must've enjoyed the experience as she came back again in 2020 whilst Kirsty welcomed her second baby and has remained ever since!

Amy's focus is LeDeR and provides business intelligence, co-ordination & strategic leadership in delivering this national mortality programme. She continues to provide much needed insight into understanding learning from the lives and deaths of people with learning disability and autistic people making sure it is widely shared with all our stakeholders.

"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."

Sam Allen, Chief Executive, NENC ICB, LeDeR annual report 22/23



LeDeR, a national service improvement programme, continues to make sure that every death of a person with learning disability or autistic person is reviewed in a timely way, learning is taken from the review and turned into improvement action across NENC.

On behalf of the ICB, the Network published the first NENC LeDeR annual report last year for 22/23. It provides detailed commentary on learning from the lives and deaths of people and a range of improvement activity in response to the learning, [find it here](#).

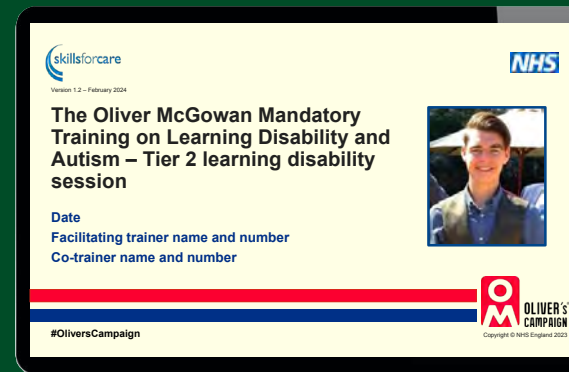
As part of NENC ICB 2.0 LeDeR is undergoing significant transformation with the Network taking a lead & strategic role operationally, improvement initiatives and assurance. Central to our transformed plans is the inclusion in every part of the programme of experts with lived experience from the Stop People Dying Too Soon and Cumbria Confirm & Challenge groups. We're looking forward to moving towards more streamlined, efficient and effective delivery of LeDeR in NENC that will influence commissioning and service improvement

Workforce transformation Oliver McGowan training Programme Manager, Kirsty Greenwell



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](#).

Positive Behavioural Support (PBS)

Strategic Workforce Development
Manager, Melissa Sherring

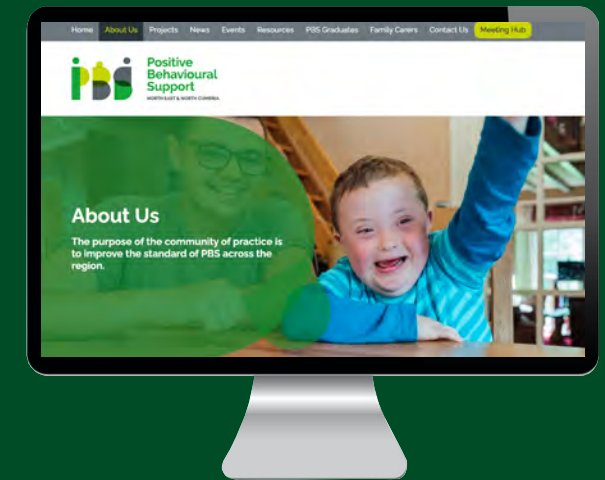


Melissa joined the Network in 2018 bringing a breadth of knowledge and experience in PBS to build, from scratch, our NENC workforce transformation programme across health and social care as part of NENC response to [national strategy building the right support.](#)

Melissa brings enormous energy, attention to detail and expertise to our team overseeing workforce transformation in collaboration with universities & colleges for professionals, family carers & experts with lived experience in PBS.

Relaunched pbsnec.co.uk

We have relaunched our PBSNEC website based on consultation with others. The aim is to offer a centre for up-to-date information and resource and the host of our virtual community of practice hub. This will enable local information to be held in one place. Positive Behavioural Support pbsnec.co.uk



Level 6/7 leading PBS in organisation programmes

We have now offered four cohorts of leading PBS in organisation at Level 6/7 with Northumbria University. This includes the initial pilot focusing on social care providers in 2018.

Since then, we opened the programme to the entire workforce and have delivered to Social Care, NHS staff, education, and a family carer. Roughly around 110 people have completed the programme. We are currently planning another cohort for 2024/25.

[Find out more about the regional workforce approach to PBS here.](#)

“The people that we support lives’ have changed incredibly. They’ve got more independence, they’re happier, it actually works.”

Student feedback

Level 4 facilitating PBS in teams programme

We piloted the level 4 facilitating PBS in teams with Northumbria University in 2018. More recently we’ve started to work with Sunderland College to develop a sustainable method to deliver this programme. An initial pilot cohort was delivered by Sunderland College in 2023/24 to around 10 students. Following this we are now running a second pilot 2024/25 to a larger cohort of students and aim to explore the method of teaching further.

[Find out more about this programme here.](#)

“Since we started using PBS in the workplace... restraint has reduced...and the use of chemical restraint has actually decreased also.”

Student feedback

STOMP/STAMP

We have created films to show people's powerful examples of alternatives to medication that people can relate to and apply to their own lives or practice. By sharing these stories and making clear the impact of alternatives to medication, we aim to give people the confidence to consider alternatives to medication and empower them with resources to act.

Four films were developed in collaboration with NHS England:

- [Supporting STOMP STAMP reviews](#)
- [Debbie & Lucy's story STOMP/STAMP](#)
- [Shane's Story STOMP/STAMP](#)
- [Ethan's Story STOMP/STAMP](#)

We made an additional film for NENC, [Social care organisational approach to the successful implementation of STOMP/STAMP.](#)



Family carer children's workshops

We partnered with Skills for People to co-develop and co-deliver the PBS family workshops across the region starting in 2019. Most recently we have worked with 'Keyworker Project' to deliver the workshops to families across Northeast and North Cumbria partnering with Skills for People and Daisy Chain. Hundreds of families have now attended these workshops.

Skills for People have led on the development of a support network for the families who complete the workshops. This was to enable ongoing support after the workshops, providing a space for families to come together for peer support and a chance to discuss and focus on topics of their choice.

"Having parents delivering the workshops means there's a recognition of our own personal needs and I could connect with them more easily. I feel they have a clearer understanding of my child's needs, and they have more empathy for my situation." Families feedback

Family carer of adult loved one's workshops

We also deliver a similar workshop to family carers of adult loved one's. We work in partnership with Tees Esk & Wear Valley NHS Trust, Durham County Carers & Durham Care Academy to deliver workshops for parents of adult loved ones. They have been delivering several workshops a year in the Durham area for around 3 years to roughly just under 50 families. Further workshops are planned this year.

We have developed a logo for the PBS family carer of a loved one workshops to include in the workshops and on all promotional materials.





PBS community of practices

We were privileged to hold a national webinar on the refreshed definition of PBS where our own Debbie Austin, Nick Gore and Susie Sapiets presented the refreshed definition paper. This was well attended locally and nationally.

- In Spring 2024 we held our initial consultation of the regional CofP, this was attended by around 60 people including people with lived experience, social care, health care & education. There were some thought provoking presentations, discussions and constructive feedback on the next steps.
- We continue to facilitate Tees PBS Community of Practice, it meets every 8 weeks where members present and discuss a range of topics around PBS.
- To represent our communities of practice we regularly attend the PBS alliance to represent our communities of practice across the region. [UK PBS Alliance | bild.](#)

60 people attended the Initial consultation of the regional CofP

Supporting family carers

Debbie Austin



Debbie Austin (mum of Lucy, her teenager with severe learning disability and autism) joined the Learning Disability

Network team in 2021 as a workforce development manager with focus on family carers. Debbie has had a huge impact influencing the massive role family carers play is well understood in helping their loved ones enjoy fulfilling lives in their homes & communities.

Debbie's passion for the work comes from a place of lived experience, this insight is gold dust in our work.

We are extremely proud of Debbie who was the winner of British Institute of Learning Disabilities - Outstanding Contribution to PBS 2024.

Spreading the word

A range of over 34 different presentations created and delivered multiple times regionally, nationally, and internationally.

Topics covered included Positive Behavioural Support, working with and Valuing Families, Healthcare by Hope (health inequalities and the challenges of being healthy when you have a learning disability), Diagnostic Overshadowing, STOMP and Stamp, The Down Syndrome Act, Early Intervention, The Cumbria Early Intervention Pilot.

"I will always remember the fantastic Debbie Austin saying 'not all kind things are PBS - but all PBS should be kind.'"

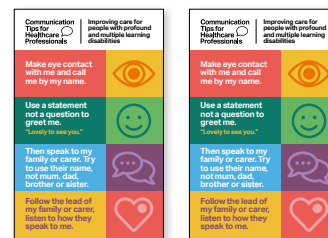
PBSUK June 2024



Supporting people with profound & multiple learning disability

In collaboration with families of people with profound & multiple learning disability a range of resources have been coproduced to support health and care professionals' initial interactions with people with profound & multiple learning disability.

This work was done in response to an obvious need and has been designed to build upon the Network's Reasonable Adjustment Campaign; it will be rolled out this summer.



PBS for family carers

Designed & delivered autobiographical PBS awareness training to over 80 families as a response to need expressed by a Parent Carer Forum. Supporting family carers is a critical part of enabling people with learning disability and autistic people live at home with their family and prevent them from needing care away from home after crisis, prevention is key and is the bedrock of this training. This training continues to be massively popular, and we hope to continue offer this across NENC.

Values based advocacy

Values based advocacy on behalf of family carers across ICB and nationally has been delivered.

“Dear Debbie, Have just finished listening to your talk at the ACAMH Camhs LD network conference and wanted to thank you – it was absolutely brilliant. I wish my whole team could have heard it. I’ve been in my role for 12 years but there were still tons of messages and important points I’ve taken from it. Thank you for educating me.” Consultant Child and Adolescent Psychiatrist

We have provided support to services to improve their communication with people with learning disability and their families. “I found the meeting extremely useful, insightful and motivating! It was particularly useful to not only hear of your experiences and advice from a professional stance (in your work with people with learning disability), but also from a personal viewpoint in terms of your own family. I believe what you shared and advised has enabled our service to develop a leaflet that aims to be compassionate and encouraging rather than something that could potentially distress our clients and their families/carers – I am extremely grateful for this.”

Evaluation of Health Education England Tier 1 Learning disability Awareness training. Primary research conducted, questionnaires, and focus groups. Thematic analysis undertaken and report written for HEE 2022. This was a pre-cursor to the Oliver McGowan Training.

British Institute of Learning Disability annual conferences

- Invited to be opening keynote speaker at BILD International PBS conference 2023, also was invited to chair day 2 of BILD international PBS conference 2023.
- Commissioned to write first draft of the national Plain English version of State of Nation Report 2022. Presented on this alongside Dr Nick Gore at BILD conference 2023.
- Invited to deliver a workshop for BILD international conference 2024.
- Invited to speak about annual health checks at the Royal College of GP’s One Day Essential.
- Work for Pharmacy Learning Disability project. “Many many thanks for your brilliant input to today’s meeting. Going by the chat you gave a really positive and powerful set of messages making it real around your lived experience with Lucy. I think everyone at the meeting got a real sense of the practical and important nature of the work, giving them plenty to think about”. -Health Improvement Pharmacy Lead, Learning Disability and Autism-NHS England materials.
- Presented at PBS good practice conference PBSUK-213 people signed up for “Partnership working with families, a parental perspective.”
- Invited to write a commentary for Roy Deveaux for his paper on practice leadership. Published Oct 2023. [Good Autism Practice.](#)

So, what is next for the Learning Disability Network?



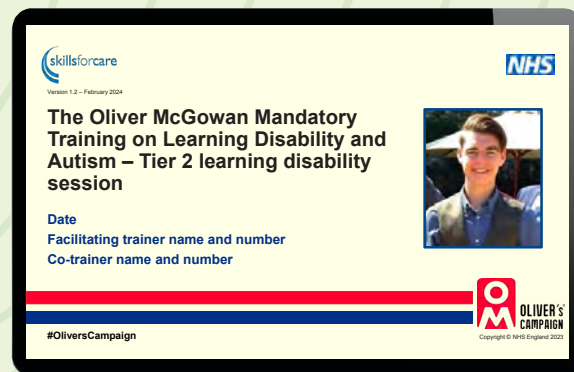
Health inequalities

- Developing interoperability with Learning Disability Maternity Diamond Standards and Budget Net
- Including Learning Disability Maternity Diamond Standards as part of undergraduate midwifery programmes
- Roll out of acute autism diamond standards, workforce education & resources
- Learning Disability Menopause Diamond Standards – coming Winter 2024/25
- Dysphagia website and resources launch - coming Autumn 2024
- Sleep Apnoea diamond standards will be co-developed and launched Winter 2024
- Launch and pilot of Be Epilepsy Aware (online and face to face) - coming Late Summer 2024
- Development of tier 2 accessible weight management using arts and theatre
- Wider rollout of Skills for Living
- Further roll out of Be Cancer Aware
- Further roll out of Be Screening Aware
- Wider promotion of all national screening & vaccination programmes
- Taking forward recommendations from the Health Quality Checker recommendations of breast screening services
- Implementation of General Anaesthetic & diagnostics revised pathway. Wide scale implementation of the reasonable adjustment digital flag & embedding it into clinical systems
- Centralised LeDeR systems, processes & assurance will be launched autumn 2024.
- We will hold our first Network Learning & Sharing event on 5th December 2024 in Newcastle including our first ever Learning Disability Network Awards

Workforce transformation

Mandatory Learning Disability Autism Awareness Training

- Continue roll out and implementation of Oliver McGowan Training across the ICS
- Development of a train the trainer programme
- Development of a digital platform where all learning disability and autism awareness training can be accessed and report in to multiple stakeholders
- Launch acute autism diamond standards



PBS

UKSBA News

The UK society of behaviour analysis (UKSBA) register has been accredited under the Professional Standards Authority Accredited Registers programme. This register is made up of qualified professionals working in behaviour analysis who have additional DBS and safeguarding checks. This means that those professionals on the register are now regulated and have agreed to the ethical and professional guidelines in place.

For further information visit PSA Accreditation - UK Society for Behaviour Analysis, uk-sba.org.

We will support the NENC workforce to gain this accreditation.



Digital Presence

Web

North East and Cumbria Learning Disability Network
necldnetwork.co.uk

Learning Disability Matters for Families
learningdisabilitymatters.co.uk

Positive Behavioural Support
pbsnec.co.uk

YouTube Channel

(2020 to present day)

111 films created

30,000 views

83 subscribers

470 hours watch time

Social Media

1220

followers on



And finally...

The Network team have, between them, **15** children (**4** of whom born during working in the Network age from **6** months to **25** years!), **5** dogs, **5** cats, **6** bikes, a cyclist who has just ridden solo **3000**km from Portugal through Spain, France and England, a keen women's competitive footballer, a tap dancer of **54** years' experience, a performing saxophonist, someone who actually likes spinning, **2** musical theatre fanatics & a keen walker - not a bad crowd!

We are a cohesive team with shared vision, passion and energy for our work and will continue to work together to make a difference to the lives of people with a learning disability and their families in the North East and North Cumbria.

National PENNA Awards 2023

(Patient Experience Network National Awards)



Runner up award in category

'Cancer Experience of Care' Breast & Bowel Cancer Screening for people with Learning Disability Health Quality Checkers Programme

'Success of the project has come from partnership working. Engagement with experts by experience, the flexibility to adapt and the inclusion of professional experts.'





Runner up award in categories

‘Working to Improve Experience’ & ‘Partnership Working to Improve Experience of Equality of Care’ - Skills for Living with Type 2 Diabetes

‘This initiative is unique as it was co-produced right from the start with appropriate input from clinicians to ensure that the right messages are delivered. The course is co-delivered by a person with a learning disability, something participants feel makes the course far more relatable and enjoyable meaning they get maximum benefits from attending and is a highly effective delivery model. The education fills a gap in nationally commissioned education.’

Runner up award in category

‘Strengthening the Foundation’ Learning Disability Diamond Standards Acute Care

‘This initiative stands out as is the first time all 8 acute trusts have come together to standardise the way people with learning disability access and use acute trust services. This has been a true collaborative effort of the A2A network and joined up working to reduce variation and improve health outcomes for people with a learning disability across the NENC.’



**North East and Cumbria
Learning Disability Network
Impact Statement 23/24**

www.neclidnetwork.co.uk

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

✕ [@neclidnetwork](https://twitter.com/neclidnetwork)

✉ nencicb.learningdisabilitynetwork@nhs.net