



Impact Statement 2016/17 of the North East and Cumbria Learning Disability Network

*The North East and Cumbria will be the best place
in England to live if you have a learning disability*



From left to right
Julie Tucker, Improving
Access to Cancer Services;
Kirsty Bell, Admin Support;
Judith Thompson, Learning
Disability Network Manager;
Dominic Slowie, Learning
Disability Network Chair;

Supporting people with learning disabilities through flagging within the Bowel Cancer Screening Programme

- Tested in South Tyneside from May 2016
- Being rolled out across North East and Cumbria
- Full roll out expected by Autumn 2017
- Development of a pathway that flags people with learning disabilities
- Flag identifies people so support can be offered prior of invite for faecal occult blood test (FOBt) screening
- This enables individually tailored work to support informed decision making by the person with learning disabilities



All GPs in South Tyneside returned information to bowel screening hub for people with learning disabilities who consented to share information



7

people with a learning disability known prior to the project



209

people now identified and known



64

people passed to the community teams for additional support

Good Bowel Health and Screening Train the Trainer Programme



The Good Bowel Health and Screening Train the Trainer programme trains trainers who pass on information to colleagues, families, carers and people with a learning disability.

'A good interactive day and good resources. I feel confident in going to deliver to others.'



train the trainer courses delivered across the North East and Cumbria

'Very informative, interesting course which was delivered in a professional and interactive way. Resources shared will be able to help me deliver course to patients, colleagues, thank you.'



people trained as trainers across health and social care

Evaluation:

- 24 trainers responded to the 3 month evaluation
- 318 people have been spoken to about good bowel health and screening
- Most of these people were families and carers who support people with learning disabilities
- This equals **each trainer has spoken to 13 people** about good bowel health and screening within the first 3 months of roll out

Breast screening CQUIN

- A CQUIN to encourage breast screening centres to improve the offer and access of eligible women with learning disabilities in 2015/16
- This included flagging women on the breast screening system and making reasonable adjustments including extended appointments and easy read materials
- Gateshead Breast Screening Programme now have **84 women flagged as having a learning disability** so can now reasonably adjust the breast screening service to meet their needs



'The lady at the appointment explained what would happen and talked to me all the way through the appointment – it made me feel better about having it done.' Quote from lady with learning disability supported to attend breast screening:

Cervical screening support materials, for sample takers

- Task and finish group reviewed cervical screening support materials for sample takers and redistributed.
- We involved families, carers and people with learning disabilities in this work
- The pack includes information on best interest, decision making and capacity and consent, easy read letters and top tips for administration staff
- www.necn.nhs.uk/networks/cancer-network/supporting-primary-care/cervical-screening-with-learning-disability-support-materials-for-sample-takers/

'The ACE Programme would like to commend the work led by the North East and Cumbria Learning Disability Network to improve cancer screening for people with a recognised learning disability. The work has provided a rich evidence base of resources to inform the application of reasonable adjustments to the various screening pathways, in reducing the inequality in accessing healthcare, often experienced by people with a learning disability. The network has been effective in working collaboratively with a number of key stakeholders to ensure the recommended improvements are embedded as part of 'everyday business' and can be sustained as future-proof. As such, the outputs from the work have been able to influence healthcare policy at a national level as well as improving service provision at a more local operational level.'
Brian Knowles – Programme Lead ACE Programme

Breast screening easy read materials

- In collaboration with Inclusion North a series of easy read letters and facts books have been produced to support breast screening centres.
- This work was **co-produced with 41 women with learning disabilities**
- The letters and booklet and a series of standard operating procedures showing how to flag and distribute have been shared with all the breast screening units in the North East and Cumbria.



NHS Breast Screening
Helping you decide



Tackling health inequalities for people with learning disabilities

RAIDR learning disability primary care data dashboard

In collaboration with the North of England Commissioning Support Unit the network has developed a learning disability primary care data dashboard which is now available in every GP practice, CCG and commissioning support unit across the North East and Cumbria. The dashboard **supports service improvement and enables targeted activity to reduce health inequality and meet identified health needs.**



Learning Disability Primary Care Annual Health Checks

The Good Access Primary Services (GAPS) network, a sub group of the North East and Cumbria learning disability network carried out an audit of annual health checks for people with learning disabilities in order to reduce variation and improve quality. A 10% sample of annual health checks carried out in each CCG were audited against agreed quantitative and qualitative standards.



40%

of people with learning disabilities had new health problems identified



60%

of annual health checks had a GP involved



60%

of annual health checks carried out a heart and chest examinations



1 in 5

people with learning disabilities had blood tests at their annual health check

Most annual health checks took between

20-40 mins

During 2016 / 17 the North East and Cumbria had the largest annual health check uptake for people with learning disabilities anywhere in England



Improving uptake of flu immunisation in people with learning disabilities

As at winter 2016 / 17...



44.87% of people with learning disabilities across the North East and Cumbria have been immunised against flu



72.38% of general population 65+ have been immunised against flu

There is a significant health inequalities gap for people with learning disabilities at 27.51% (4681 people with learning disabilities) to equal the 65+ general population rate.

The network will continue to work closely with learning disability primary care facilitators across the region to support local primary care flu plans to tackle this gap.

Transforming the learning disability workforce

The Learning Disability Network is leading the workforce transformation work on behalf of the Transforming Care Partnership across Cumbria and the North East.

"As the workforce partner of Transforming Care, we at Health Education England, working across the North East, recognise the immense value that the Learning Disability Network has in our region. The network has the ability to bring together a wide range of stakeholder organisations to advance work around the Learning Disability workforce. We have been able to lead the field across Health Education England in support of the transforming care agenda by working with the Network to use their ready-developed, multi-organisational, cross-sector relationships to develop regional work at scale and at pace." Alex Glover Local Director - North East Health Education England.



Reducing premature mortality in people with learning disabilities

Do you want to be a learning disability nurse?

A short film and briefing developed by the GAPS network - <https://www.healthcareers.nhs.uk/explore-roles/nursing/learning-disability-nurse>



"North East and Cumbria Learning Disability Network has brought together learning disability nurses from across their region to produce a fantastic film that gets to the heart of why it is such a worthwhile and rewarding career. We are proud to be promoting it through the Health Careers service and are confident it will inspire many to consider learning disability nursing as a future career option" Darren Aldrich Strategy and Communications Lead for Health Careers at Health Education England



The learning disability mortality review programme aims to drive improvement in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality in this population through mortality case review.

The network was the first pilot site in England and early implementer of the programme.



Acute Hospital Pilot



"I worked with the Learning Disability Network to develop and pilot the local mortality review process, in advance of the national body being established. The project aimed to deliver a system that would enable us to learn lessons from the deaths of people with learning disability in order to improve outcomes for them in the future. We worked very closely with the local Trusts in developing our model. The National Mortality Review Programme (LeDeR) acknowledged the importance of the work done in the North East as they developed their approach." Gerald Tompkins Acting Consultant in Public Health Gateshead Council

"We value the ability to work collaboratively across and through the Network which helps to develop robust regional work which supports patients who go across providers, some of the development work has enabled efficiencies and better value for money both as developments but also on an ongoing basis as it has enabled more joined up care. The network is a very good way to share learning and to network across NHS, social care, and the voluntary sector and work in a partnership way. Without the Network we would not have access to these relationships." Frances Blackburn Deputy Director of Nursing and Patient Services The Newcastle Upon Tyne Hospitals NHS Foundation Trust

The Positive Behavioural Support Community of Practice;

is a network of people who are passionate about developing Positive Behavioural Support in our region to ensure people with learning disabilities and or autism, who are at risk of behaviour that challenges, have the best possible quality of life. www.pbsnec.co.uk



Total Attachment Training leading services towards compassionate care is a framework for developing advocacy and inclusion in care services for people with learning disabilities.



546 health and social care staff trained across North East and Cumbria

Leadership Programmes Developed and delivered:

- Three learning disability leadership programmes:
- Tomorrows leaders for people with learning disabilities
- Sharing the knowledge for family carers
- Learning disability leaders programme for commissioners and providers

*"NELA was commissioned by the Network to help develop an innovative, improvement and future focussed leadership development intervention to support leaders in the commissioning functions in health and care to enable the transformational improvements required in the Learning Disability system. The fully inclusive nature of the Network is ever present, as you'd expect, and this culminated in a leadership programme across health and care for commissioning leaders which runs in parallel with programmes for family members and citizens with learning disabilities. This innovative and challenging design brings together all members of these communities to share learning and navigate the changing landscapes of an integrated service. Members of the Network fully appreciate the need to be agile within a transforming system and have skills and behaviours which model those needed of our future system leaders within learning disability services. We look forward to evolving and supporting more development opportunities and demonstrating the service impact through longitudinal evaluation and continuous service improvement."*relationships to develop regional work at scale and at pace." Clive Spencer Director North East Leadership Academy

Learning and the influence of LeDeR



Learning and sharing conference films
<https://vimeo.com/183758017/eb77c2f077>
<https://vimeo.com/184005377/8936c0664bo>

"Cumbria and the North East (CNE) contributed to the development of the methodology for the national Learning Disabilities Mortality Review (LeDeR) programme, through learning from the work already taking place in the region, and their role as the first pilot site for the programme. As the main pilot site, CNE helped the national team to identify facilitators and challenges to the delivery of mortality reviews of people with learning disabilities, learning that has been generously shared across England as the work has progressed. A number of challenges still remain, particularly in terms of identifying dedicated time for reviewers to lead reviews, and as a result, mortality reviews are not yet embedded in existing systems. Continued support and resources for the LeDeR programme would be beneficial in order for the work to be fully aligned with the expectations of the new Learning from Deaths programme." Dr Pauline Heslop Programme Lead Learning Disabilities Mortality Review Programme

"The network undertakes a vital function by raising awareness of the health needs of people who have a learning disability and by ensuring that there is strong clinical engagement across the region. The network has also undertaken work of national significance. Its early work to pilot reviews of deaths of people with a learning disability provided valuable learning which informed the design and commissioning of a national mortality review programme – the LeDeR programme." Matthew Fagg Programme Director Medical Directorate NHS England

"In Cumbria and the North East we are very fortunate in having had a learning disabilities network for several years. This provides a unique opportunity to bring together local clinicians and professionals across health and social care around the agenda of improving the lives of people with a learning disability. The work that has been done on a wide range of areas such as shaping the workforce, improving health and wellbeing and providing employment opportunities and is incredibly impressive and greatly appreciated by our local CCGs."
 Dr David Hambleton Chief Executive South Tyneside NHS Clinical Commissioning Group

"As a social care commissioner with a Local Authority I have attended the Learning Disability Network for over 5 years. In that time I have found it to be invaluable resource as it impartially offers the chance to share good practice and discuss and find solutions to some of the "wicked problems" we are working through in a complex world. The Network has also taken a lead role in jointly developing several programmes of work, most recently the refresh of the Self-Assessment Framework; the response to the workforce requirements of the Transforming Care Programme and how we can understand the role of family carers in the development of services and systems."
 Ang Jamson Commissioner Social Care Newcastle City Council

"Learning disability has for far too long been a neglected area of health and social care, which has now rightly, risen to the top of the national clinical agenda. The learning disability network brings both expertise and enthusiasm to implement meaningful transformation to improve the lives of people with learning disability."
 Dr Jonathan Slade Deputy Medical Director and Responsible Officer Cumbria North East NHS England

National Overview

- NHS England 5 Year Forward View
- NHS England Building the Right Support
- NHS England GP 5 Year Forward View

Regional Overview

- Sustainability Transformation Plans
- Transforming Care Partnerships

Aims and Objectives of the Network

To improve the health and wellbeing of people with a learning disability in the North East and Cumbria and eliminate avoidable premature deaths, injury and illness.

To lead improvements in quality and access to health and social care services delivered to people with a learning disability so that these services are equal and equitable to services delivered to the wider population in the North East and Cumbria.

To eliminate any experience of discrimination, abuse and neglect from the system towards people with a learning disability, their families and carers.

How do we deliver?

- Networking
- Building relationships
- Programme and project management
- Linking stakeholders together
- Learning and sharing nationally, regionally and locally
- Enabling and supporting our stakeholders

Our stakeholders

- PEOPLE WITH LEARNING DISABILITIES AND FAMILIES
- 11 CLINICAL COMMISSIONING GROUPS
- 13 LOCAL AUTHORITIES
- 10 ACUTE HOSPITAL TRUSTS
- 03 SPECIALIST HOSPITAL TRUST
- VOLUNTARY AND COMMUNITY SECTOR



What's next for the North East and Cumbria Learning Disability Network?



Increasing employment opportunities for people with learning disabilities

The Opportunity Café. We have established a community interest company café that employs 11 people with learning disabilities and 3 people without learning disabilities. We know that having a job is one of the most important things that has a positive impact on the health and wellbeing of people with learning disabilities. We are extremely proud the network has led this exciting initiative at Waterfront 4.

Our future aims for the café is to provide apprenticeships, work internships and Small Sparks grant fund to connect lots of people with learning disabilities from the North East and Cumbria with their local community.

"I am delighted to support the opening of the new café development at Waterfront 4. A new café and new colleagues will make our building a more interesting place to be. I am confident this initiative will be a great success and I am pleased that it will create meaningful employment opportunities for people with learning disabilities to use and develop their skills and abilities" Jim Mackey, Chief Executive NHS Improvement



the opportunity
café

Implementation of the general anaesthetic and diagnostics pathway

In collaboration with the Cancer Alliance have developed two pathways for acute hospital trusts when needing to offer patients with learning disabilities a general anaesthetic for diagnostic imaging.



Expectant mothers with a learning disability

In response to the NHS England Hidden Voices report and the NHS England Better Births Maternity Strategy we've started to tackle a piece of work on how best to support expectant mothers with a learning disability. We are developing a pathway to support pregnant women with learning disabilities through their maternity experience and ongoing parental support.



Addressing health inequalities in children and young people

The network is beginning a programme of work across the North East and Cumbria to reduce variation, improve quality and address inequalities for children with learning disabilities.



Tackling obesity in people with learning disabilities

The network is beginning a programme of work across the North East and Cumbria in collaboration with a number of stakeholders to identify and coordinate initiatives to tackle obesity and higher prevalence of diabetes in people with learning disabilities.



Contact us

If you are interested with what you have read or would like to find out about any of our other projects then you can contact us by:

🐦 @necldnetwork

✉ email.england.learningdisabilitynetwork@nhs.net



With thanks to Academic Health Science Network North East and North Cumbria