Impact Statement 2017/2018 of the North East and Cumbria Learning Disability Network

"Over the last few years we have made significant progress in raising awareness of learning disabilities with health care professionals across Cumbria and the North East. In reflection of the progress made to date, our providers and commissioners have reaffirmed their commitment to supporting the work of the Network to ensure we can continue to achieve meaningful and sustained change. We look forward to supporting the Network programme in delivery better health, care and quality of life for this important group of people.

Professor Chris Gray Medical Director NHS England Cumbria North East

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Improving GP registers of people with learning disabilities

Too many people with a learning disability aren't getting support and access to annual health checks because they aren't on the GP registers. The network has developed some tools and is working with partners to improve the GP registers.

- Promoted importance of GP registers with a range of partners using the Mencap 'Don't Miss Out Campaign': [https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-annual-health-checks](https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-annual-health-checks) with a particular focus on children and young people
- Supported CCG's to implement new annual health check template

Improving uptake of flu immunisation in people with learning disabilities

As at winter 2017/18 47.5% of people with a learning disability known were immunised against flu, this is up from the 2016/17 data.

The network provides strategic leadership across Cumbria North East to widely promote flu immunisation.

A pragmatic plan has been developed for 2018/19 aimed at:

- Children and young people
- Frontline healthcare practitioners and providers
- Social care providers, people with learning disabilities and families
- Senior leaders and decision makers
- CCG commissioners
- NECS

Almost a third of all deaths reviewed by LeDeR programme had an underlying cause related to respiratory illness.

Implemented general anaesthetic and diagnostics pathway across Cumbria & North East

Worked collaboratively to design, develop and implement a reasonable adjusted care pathway for people with learning disabilities who require a general anaesthetic for diagnostic testing under the 2 week cancer wait referral.

Revised acute hospital reasonably adjusted care pathways

In 2011 the Learning Disability Network worked with the A2A Network to develop a set of reasonably adjusted care pathways for use in acute hospitals that are well embedded across North East & Cumbria.

We have refreshed the pathways to ensure they support acute hospitals to:

- Reduce premature mortality
- Reduce poor experiences of health care
- Improve quality of life
- Improve communication for people with learning disabilities across settings
- Promote seamless care & disparity of service

Given the changed landscape we have refreshed the pathways and have condensed them into 4 themes:

- Core values & principles
- Planned admission pathway
- Emergency admission pathway
- Discharge pathway

We are finalising the pathways after consulting with people with learning disabilities about the care they expect to receive when using an acute hospital and will launch the revised 'Learning Disability Diamond Standard Acute Care Pathways' across all acute trusts by April 2019.

Campaign and roll out by end of April 2019

Established a joint A2A and GAPS best practice and opportunities to collaborate network with our initial priorities being tackling sepsis and children and young people with learning disabilities.
Expectant mothers with a learning disability

Co-led with Mary Campbell, a graduate from the Tomorrows Leaders programme. We have developed 3 new maternity pathways for women with a learning disability:

- Antenatal
- Labour
- Post-natal

These are being incorporated in Local maternity system transformations across Cumbria North East.

In the region we are also piloting the CHANGE maternity books and developing a maternity hospital passport chapter.

Promoting healthy lifestyles

We are working in collaboration with the Northern Clinical Diabetes Network and Your Voice Counts on a project to tackle diabetes for people with a learning disability. Collaboratively mapped our priorities to include:

- Children and young people
- Training and education
- Linking services
- Workforce
- Reasonably adjusted pathways and services
- Identification and flagging

This work will make a lot of progress in the coming months and will be reported in our next impact statement.

Tackling inequalities for children and young people with learning disabilities

Children and young people with learning disabilities often have different needs and will likely need reasonably adjusted services and support. The Network is working with multiple stakeholders including parents and carers to develop a WebApp to enable parents and carers receive straightforward, pragmatic, realistic information that is aimed to help them day to day, know where to go for further help and understand what they are entitled to.

The WebApp will include:

- Tools to help identify a learning disability where there is concern the child or young person might have one.
- Films that explain what a learning disability is and what it isn’t.
- Films of families of children and young people with learning disabilities sharing their experiences and giving helpful advice, positive examples and practical information of where to go for further help.
- Health conditions to look out for and advice about what to do.
- Make sure parents and carers know their rights about reasonable adjustments to services.
- Examples of what voluntary sector organisations are able to do to support families.
- Provide advice and guidance about the sorts of services that can be helpful.
- Information about the importance of children and young people being on the G.P. learning disability register.
- Why it is important for children and young people to be immunised against flu.
- Explanation of the GP Annual Health Check that children and young people aged 14+ are entitled to, why it is important, what happens and how to get it.

The WebApp will be launched early 2019 and we hope
Information and Support

Ensuring people with a learning disability have access to information, advice, and support is crucial. In collaboration with Macmillan, Northern Cancer Alliance & North East & Cumbria Learning Disability Network, we have developed a system to provide support and information to professionals to enable effective support for women with a learning disability in accessing cervical screening.

The two-week wait easy read patient information leaflet supports people with a learning disability being referred for further tests with a suspicion of cancer. We have developed a two-week wait patient information leaflet which is accessible via a hyper link on the GP online referral form. It is accessible to everyone being referred through a two-week wait who would benefit from easy read materials.

Access to cancer screening in patients aims to ensure all people with a learning disability or mental health condition receive inpatient and outpatient appointments. The project is supported by partners from PHE, NHS digital, health and social care to develop and pilot pathways enabling ‘call and recall’ and workforce training.

Communications

Communicating effectively is essential to ensure information is shared during each stage of a person’s journey, as well as sharing good practice with others.

Bowel cancer screening flagging project

A pathway that allows the bowel screening hub to flag a person has a learning disability and offer additional support through the community learning disability team, to enable informed choice and support completing bowel screening. Bowel flagging is now available across the whole North East and Cumbria and being replicated in areas across England.

Sharing challenges through film four films of individual stories discuss the challenges of supporting people with learning disabilities through the cancer journey.

Conference – Working together to improve cancer services and experiences for people with a learning disability

27th November 2017

120 people from health and social care and people with learning disabilities came together to share learning and work out what we’ll do next. Here is the key note speech describing reasonable adjustments and staff commitments to support cancer diagnostic tests.


Education and training

Identify need and provide appropriate education and training to improve cancer services and experiences.

Primary care workforce development: We have provided training to 970 social care providers in Hartlepool, 150 GP practice staff in North Tees, Durham, South Tees and Gateshead. Information has also been shared through the Cancer Research UK primary care facilitators, CCG cancer leads and CCG learning disability leads.

20 trainee GP practice nurses attended learning disability awareness training looking at cancer pathway and screening case studies. We are working with Health Education England to include learning disability/cancer in the nursing undergraduate programmes.

BCUK train the trainer model in partnership with Bowel Cancer UK. The Train the Trainer course and resource pack has been produced and delivered across the North East and Cumbria. We have 64 trainers who deliver courses to people with learning disabilities, families and carers. The training pack is available at the Bowel Cancer UK website.

The Macmillan cancer learning disability project is improving the experiences of people with learning disabilities and reducing inequalities throughout the cancer journey. It is working on the things that matter most to people and families. There are four key themes of work:

1. National issues
   - Our work is improving & influencing cancer services and experiences for people with learning disabilities at a national level.

2. National screening and immunisations literature review
   - With the support from Gateshead People & Public Health England we have attended a number of workshops to support the development of materials. Completed materials are now available through gov.uk


3. National Screening Inequalities Strategy
   - We have supported development of Public Health England’s strategy ‘Supporting the health system to reduce inequalities in screening’. It is available now to raise the awareness of inequalities and the requirements of all screening providers.

Crispin Hebron, Consultant Learning Disability Nurse, NHS England

The project has been an excellent partner in such work with representation from patients, carers, commissioners and clinicians from a full range of services – such co-production and involvement is essential for such work to be meaningful and yet extremely difficult to do well – the project has excelled in this area of work.
Transforming the Learning Disability Workforce

The network has continued to lead the workforce transformation on behalf of the Transforming Care Partnership.

Developing our leaders ...

Tomorrows Leaders for people with learning disability delivered by Inclusion North

Sharing the Knowledge for family carers delivered by In Control

Learning Disability Leaders Development programme delivered by Teesside University

https://vimeo.com/273667349
https://vimeo.com/273674976
https://vimeo.com/273661987

39 improvement projects implemented
64 people graduated from programmes

“A having the opportunity to lift my head, think and learn has been immensely helpful to me. As a leader I spend a great deal of time thinking about how to develop my staff and provide learning opportunities to those we support. The Leading Transformational Change in Health and Care Services programme with Teesside University allowed me to invest in myself and in turn in my organisation. It helped me to think about how I approach tasks, how I collaborate and include people at every level of our organisation. I’m grateful to the North East and Cumbria Learning Disability Network for creating such a positive and growth full experience for me.”

David Blacklock, Chief Executive
People First Independent Advocacy.

A region wide approach to Positive Behavioural Support (PBS)

In order to enable transition of people with behaviour that challenges from hospital into community settings an appropriately prepared workforce is required, able to reflect the patient-centred value base and competencies required to use a Positive Behavioural Support approach in practice.

In the last 12 months we have:

Made the case for, secured funding and appointed 3 strategic learning disability workforce development managers each aligned to a collaborative commissioning hub

PBS programmes in collaboration with Northumbria University being developed for roll out September 2018:

135 & 548 at level 4
31 practice leaders at level 6/7
31 practice facilitators
support workers
service users
For completion by summer 2020

781 PBS awareness sessions delivered to 781 people from community & voluntary sector, local authorities, NHS, police, CQC, universities & colleges

Northumbria University

Dr Anne McNall, Associate Professor Workforce Development, Northumbria University

"PBS is a way of life"

Shona Chambers Family Carer.

We developed a film for GPs to help them understand what PBS is about and how to use care support.

https://vimeo.com/266074956
Early intervention & prevention programme (pilot) in Cumbria

In collaboration with Carlisle Mencap, Challenging Behaviour Foundation, Tizard Centre, North Cumbria CCG 4 strands to the programme are being implemented:

- Early Positive Approaches to Support (EPaTS) for children aged 0–5 years; 9 families are participating, co-facilitated by parents and the Tizard Centre.
- Positive Behaviour Support workshops to schools and parents of children. 3 special schools in Cumbria taking part.
- Mindfulness Based Stress Reduction programme for all parents of children taking part building resilience.
- Develop a strategy for early intervention & prevention support in Cumbria.
- Full evaluation being undertaken to be completed in 2019.

The network has supported and enabled important early intervention work with children and families to be developed and implemented in Cumbria. Local partners, national charities and research centres are working together with families to pilot and evaluate a range of new early support for families focused on good outcomes for children and young people.'

Viv Cooper, OBE, Chief Executive, The Challenging Behaviour Foundation

Total Attachment

Building upon the success of previous Total Attachment Theory training leading services towards compassionate care, a framework for developing advocacy & inclusion in care services for people with learning disabilities we have successfully secured additional resource and are implementing roll out of the first of its type 'Train the Trainer' programme.

50 places have been allocated from 24 social care organisations

The North East and Cumbria Learning Disabilities Network have commissioned and supported the ongoing development of Total Attachment with a train the trainer programme which is being rolled out across the area. Built on the success of the initial roll out of Total Attachment training, the network looked at ways to make the benefits of the learning more sustainable across the sector. The train the trainer programme emerged from this to support personnel in services to guide their teams to consistently implement the model in services. Total Attachment has a proven record in contributing to Outstanding service provision in the area (CQC 2018) and the network has been pivotal in the support of this development to the clear benefit of those who use care services.'

Dr. Celia Harbottle, freelance lecturer/trainer working in the field of Social Care and Health

How the network works...

National directive, policy, strategy links

- NHS Syr Forward View
- NHS GP 5yr Forward View
- Building the Right Support
- NHS Improvement learning disability standards
- CQC Registering me right support
- NHS cancer strategy
- Better Births
- NHS Diabetes Prevention Programme
- NHS Diabetes treatment and care programme
- NHS learning disability employment strategy
- LeDeR programme
- NICE PBS standards
- PBS competency frameworks
- NHS Children & Young People Programme
- PHE Screening inequalities strategy
- HEE Learning Disability Programme

11 CCGs, 13 Local Authorities, 3 specialist trusts, 10 acute trusts, 1 ambulance trust, HEE NE, PHE, NECS, CQC, NHS Improvement, Macmillan, People with Learning Disabilities & families, Inclusion North, Self Advocacy organisations, 13 provider forums