



Capturing the voice of people with
a learning disability or autism living
in Humber Coast & Vale

Summary report of research and
feedback

Inclusion North
September 2019

Introduction

In 2018 NHS England provided some funding to Inclusion North to support the Yorkshire and Humber region to develop co-production skills and practice. The aim was to increase the amount and quality of co-production in the region in support of the Transforming Care programme.

The proposal was co-produced with a small group of family carers supported by Inclusion North who were keen to get involved in the Transforming Care programme locally. This group expanded to involve people with lived experience and the work has been co-produced by this group since.

There is remaining budget for this work to enable the region to access 10 further days of facilitated co-production. These days have been split across the 6 Transforming Care Partnerships across Yorkshire and Humber to support the involvement of local people in the development of local 5-year plans.

Humber Coast and Vale Sustainability and Transformation Partnership (STP) have been allocated 3 of these days supported by Inclusion North.

Aim of this work

The aim of the piece of work is to help Humber Coast and Vale STP capture the voice of people with a learning disability or autism both nationally and locally to feed into specific priority areas of their local 5-year plan which is due to be published in the Autumn 2019.

The clinical priority areas for Humber Coast and Vale STP are:

- Cancer
- Mental Health
- Primary Care (GP services)
- Urgent and Emergency Care
- Elective (Planned) Care
- Maternity Services

Inclusion North have been tasked with looking at specific priorities in relation to people with a learning disability or autism, these are:

- Respiratory and cardio (pneumonia, aspiration pneumonia and heart disease - from LeDer annual report)
<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>
- Maternity – women and families with a learning disability
- Mental health – children and young people with a learning disability or autism

Our approach

The most challenging aspect of this work was the timescales allowed to carry it out. During conversations with key people in Humber Coast and Vale Sustainability and Transformation Partnership to agree the remit of the work, it was acknowledged that

the minimal time available would limit what could be achieved. One thing that is universal about co production with people with lived experience is that it takes time to do well.

To maximise the time available, Inclusion North researched nationally in each of the 3 priority areas to bring together all the intelligence already shared on the subjects by people with lived experience. We then tried to capture the voices of local people in and around the area of Humber Coast and Vale, to add a local perspective to what has already been discovered nationally.

As part of this research, we have captured various resources and links to website information throughout this summary of findings. We have also created a further resource with other links to information which you can find in Appendix 1.

In carrying out this work, we took the approach that in terms of co production, this is just the beginning of involvement of local people in the development and delivery of the 5 year plan. To build trust and real partnership with people, this work has to be the start of a commitment to ongoing involvement.

What did we find out?

Pneumonia, Aspiration Pneumonia, and ischaemic heart disease

The Learning Disabilities Mortality Review (LeDeR) Programme's 2018 annual report produced by the University of Bristol shows the ongoing concerns about the premature deaths of people with a learning disability.

There are 12 recommendations in the report including key findings one of which is:

- *Pneumonia, or aspiration pneumonia, were identified as causes of death in 41% of reviews - conditions which are potentially treatable, if caught in time*

The work of LeDeR has highlighted where in some regions specific work has taken place to promote the awareness of pneumonia, aspiration pneumonia and ischaemic heart disease in respect to people with a learning disability.

There is though currently very little information available to highlight where people with a learning disability, autism or their families have been engaged in discussions around pneumonia, aspiration pneumonia and ischaemic heart disease.

Much of the work involving people with a learning disability, autism and their families has been around general health checks, such as annual health checks or some screening programmes.

As part of the NHS Long Term Plan Healthwatch organisations have recently been funded to engage with their local communities and people <https://bit.ly/2TzJtEg>. Some reports are already published on Healthwatch websites. There is evidence where some Healthwatch organisations have specifically targeted groups of people with a learning disability around general health issues.

Below are example of some of the areas where work is being carried out nationally in different ways. Inclusion North has also captured some local feedback from family members of people with a learning disability in relation to pneumonia, aspiration pneumonia, and ischaemic heart disease.

National work identified

1. Derbyshire

Derbyshire Healthcare NHS Foundation Trust have a Good Health Group which meets to discuss health issues for people with a learning disability. The members of the group include health professional, local authority people with a learning disability, family members and local organisations. Recent minutes can be found here: [Recent Minutes - Good Health Group](#)

Inclusion North contacted Jackie Fleeman Jackie.fleeman@nhs.net to find out more, this is what Jackie told us:

- *At a recent meeting of the Good Health Group we talked about Pneumonia, aspiration pneumonia and ischaemic heart disease. This information is then shared with our County Learning Disability Partnership Boards (there are 4), who share it with local services, families and people with learning disabilities. We are raising awareness and encouraging prevention*
- *We are going to have a dedicated session about safe eating and drinking (Aspiration pneumonia) as this generated a lot of discussion yesterday*
- *We also offer Health Action Plan training which includes information about these conditions, this is aimed at carers (paid and families)*
- *We have been to children's parent meetings also*
- *We also cover lots of health topics with our local Advocacy services and Day service, helping people with learning disabilities to understand health conditions that affect them*
- *The team have been attending Social Worker meeting to raise their awareness of the causes of early death in people with learning disabilities.*
- *Derbyshire County Council are updating their contracts with care providers, these will include much more detailed requirements for health promotion and prevention. They have drafted a document which we are commenting upon this month which will be finalised in September. This will form part of the contract*
- *The team also offer GP training for the Learning Disability Annual Health checks and the information for LeDeR is included. This includes trainee GPs and Medical Students*

2. NHS North Somerset and North Somerset Council

Easy Read leaflet produced on Dysphagia, to help people to understand this condition and how it can lead to aspiration pneumonia. Available here:

<http://www.easyhealth.org.uk/sites/default/files/dysphagia.pdf>

3. North Cumbria Health & Care

A project called Stop And Watch, which was used firstly in America and modified for use in North Cumbria, has now been launched across the county and the North East to help people to spot the signs that vulnerable patients' conditions, including those with a learning disability or the elderly, are deteriorating.

The simple tool is designed to raise awareness of twelve signs of deterioration and supports carers, along with families and relatives, to seek appropriate assistance when needed. It is hoped the project will support people to be confident to raise concerns and could lead to preventing patients becoming unnecessarily unwell.

You can view a short animation that highlights the Early Warning Signs here:

<https://youtu.be/yJn9XR-cBI>

A poster that was designed to be displayed in healthcare settings is also available here: <http://www.northcumbriaccg.nhs.uk/about-us/safeguarding/stop-and-watch-poster.pdf>

Further information about the project is available online, here:

<http://www.northcumbriaccg.nhs.uk/about-us/safeguarding/stop-and-watch.aspx>

4. Learning Disabilities Mortality Review (LeDeR)

The LeDer website has various resources in relation to the health of people with a learning disability and produces an online newsletter called Learning in to Action; this includes various information <https://bit.ly/2Hc1K5A>. In particular the July 2018 version: [Learning into Action newsletter - aspiration pneumonia \(PDF, 386kB\)](#) details information about aspiration pneumonia and provides some examples from around the country of best practice actions taking place to reduce aspiration pneumonia deaths.

This includes an information brief written for carers <https://bit.ly/2Oe1K9W>

5. NHS Ealing Speech and Language Therapy Service – adults

Speech and Language Therapists (SLTs) specialise in assessing, diagnosing and treating people if they have a communication or swallowing disorder.

<https://www.westlondon.nhs.uk/ecp-adult-speech-language-therapy/>

6. Lincolnshire Talking Books scheme

This is a project set up by the Learning Disability Healthy Lifestyles Working Group. It's based on the Human Library, an international equalities movement that challenges prejudice and discrimination through social contact. Here in Lincolnshire individuals with learning disabilities visit GP Surgeries and talk to staff to increase awareness and understanding of disability issues.

<https://www.lincslmc.co.uk/healthylifestylesnewsletter>

7. Lancaster University and Voluntary Organisations Disability Group (VODG)

VODG (Voluntary Organisations Disability Group) and Lancaster University have been working with a group of organisations to explore how social care providers can support disabled people to maintain healthy levels of nutrition and hydration. Held an event that brought VODG members together to explore progress and this report brings together some of the key learning. It also includes examples of good practice, links to useful organisations and resources. <https://www.vodg.org.uk/wp-content/uploads/2019-VODG-Good-Food-Matters.pdf>

Page 10 of the resource has specific information in relation to supporting people with dysphagia.

Local opportunities and feedback provided by family carers

We know from the Leder Annual Report that pneumonia, aspiration pneumonia and ischaemic heart disease are some of the most common causes of death for people with a learning disability, and that these deaths are often premature.

We managed to speak to one family carer whose adult child has profound and multiple learning disabilities. We know that people with profound and multiple learning disabilities are especially susceptible to pneumonia and aspiration pneumonia, due to postural issues and difficulties with swallowing that others may not experience.

This was the family carers' feedback:

"The problems that we face as family carers in relation to premature deaths of people with learning disabilities is that we cannot find out the information about premature deaths of people with learning disabilities in this area, when they occur and why they occur. We have been told that premature deaths in this area do not follow the national pattern, but no other explanation is provided. As family carers we are not involved in the local steering group but attend the regional steering group.

Locally there has been work to train community nurses regarding Sepsis in people with learning disabilities. We are also aware of the number of children with learning disabilities with bowel problems, impacted bowels. There are no proactive steps being taken to prevent these health conditions arising. Abrasive medications are being administered rather than teaching parent's bowel massage.

As a group of family carers, we have managed to secure the co-ordinator from LeDeR to share information about premature deaths of people with learning disabilities.

It is really important that we are included locally and regionally, without family carers the emotional component is missing, staff simply don't have that, it is that emotional component and the lived experience that we bring to the table."

This would reinforce our recommendation that people with a learning disability or autism and family carers need to be proactive partners in the long term plan, and in associated programmes that will support its delivery, such as Leder.

Maternity services and support offered to women with a learning disability and their family

This study <https://bmjopen.bmj.com/content/bmjopen/7/3/e015526.full.pdf> by BMJ Open explores *the lived experiences of pregnancy, childbirth, prenatal and postnatal care and services received by women with a learning disability in the UK, including their expressed information and support needs relating to maternity care.*

The conclusion of this study found that: *With support from family and services, learning disabled women can become confident and successful parents. Maternity services should make reasonable adjustments when providing care to this group, including adapting to their individual communication and learning needs: allowing sufficient time in appointments, offering clear explanations of each aspect of care and sensitive support for autonomy and fully informed choice.*

Mothers who will be subject to a social care assessment of their parenting skills need clear information about the process, their choices and the level of skill they must demonstrate, as well as access to sufficient antenatal and postnatal support to give them the best possible chance of passing the assessment.

Earlier research called Hidden Voices of Maternity in August 2015

<https://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/Hidden%20voices%20of%20maternity.pdf> states that:

Many parents with learning disabilities face stereotyped beliefs that:

- *they could never be good enough parents*
- *that any parenting difficulties are automatically linked to their learning disability without considering other environmental or social factors*

National work identified

1. Maternity Strategy for Leeds 2015-2020

Priority seven of the Maternity Strategy in Leeds focuses on targeted support:

Health services sometimes find it harder to identify and reach families in some communities or with specific needs and these families are therefore less likely to be able to get maternity care early in pregnancy and receive the information, advice and support to help them to have a healthy pregnancy. They can be at higher risk of poorer outcomes for both mother and baby. Antenatal education will often be harder for them to access and not meet their needs.

<https://www.leedsccg.nhs.uk/content/uploads/2015/06/Maternity-strategy-for-Leeds-2015-2020.pdf>

2. Leeds maternity care – easy read guides

- <https://www.cddft.nhs.uk/media/653337/an%20easy%20read%20guide%20to%20pregnancy.pdf>
- <https://www.cddft.nhs.uk/media/653331/my%20birth%20plan%20-%20easy%20read.pdf>

3. West Yorkshire & Harrogate Health and Care Partnership

Maternity services engagement and consultation mapping 2017: *The purpose of this report is to present the findings from all maternity engagement and consultation activity which has taken place during April 2013 to June 2017, across West Yorkshire and Harrogate Sustainability and Transformation Partnership (STP). The report captures intelligence collected from engagement and consultation activities.*

Key themes identified around learning disabilities include:

- *Women were often unaware that they were pregnant until quite late on in their pregnancy which led to delays in accessing services*
- *Women tended to attend appointments alone as they were unaware that they could bring family / friend / support worker with them*
- *When they attended their appointments they were not asked if they needed any additional support with communication / information needs. Many were unable to understand the information they were provided with*
- *Provision of support from VCS organisations made a huge difference to those women that accessed these services*
- *Staff should be trained to support women with learning disabilities, and be able to support them to make their own decisions and explain their options*
- *Should be offered ante-natal classes and parenting classes*

<https://bit.ly/2Z525SJ>

4. Healthtalk.org

Healthtalk.org provides free information about health issues, by sharing people's real-life experiences, including women with a learning disability about their experiences of pregnancy <https://bit.ly/2N7jiDV>

Local opportunities for involvement

Maternity Voices Partnerships

Better Births describes how maternity services should be co-produced with Maternity Voices Partnerships (MVPs). MVP's bring together women and their families,

commissioners, maternity teams including midwives and obstetricians, and other providers, to work as a team to develop local maternity care.

In Hull, our MVP is made up of over 40 members, including local mums, CCG commissioners, GPs, midwives and obstetricians, Local Authority leads, mental health specialists, doulas, peer supporters and representatives from the community and voluntary sector.

- Maternity Voices Partnership – Hull <https://www.hullccg.nhs.uk/have-your-say/maternity-voices-partnership/>
- Maternity Voices Partnership – East Riding <https://www.eastridingofyorkshireccg.nhs.uk/MVP>

HEY Baby Parent Education and Antenatal Classes

<https://www.hey.nhs.uk/heybaby/>

Inclusion North spoke with Melanie Lee a Midwife Childbirth Educator at Hull Women's and Children's Hospital, Hull and East Yorkshire Hospitals NHS Trust.

Hey Baby Hull offers free Antenatal classes to help parents get ready for their baby's birth which provides confidence and information. These classes are also available to women and families with a learning disability.

They also offer Hey Baby Hull carousel events <https://www.hey.nhs.uk/heybaby/carousel/> which take place once a month for 2 hours from 6pm-8pm next door to the Women and Children's Hospital.

Although this service is not just specifically for women and families with a learning disability as it is person centred it focuses on the best outcomes for mother and baby. On average 140 people access the Hey Baby Carousel per month. They support and offer education to all groups which might include teenage pregnancy, mental health, vulnerable families, dads only and people with a learning disability.

These events are facilitated to be stress free; no appointments are required. If for example a person with a learning disability requires more input, they can receive this from the Hey Baby Carousel; they will spend time with people on a 1-1 basis around their specific needs to build confidence and knowledge.

5. York Teaching Hospital

Learning Disabilities – Maternity Multi Professional Pathway <https://bit.ly/2NgVXzI>

Mental health – children and young people with a learning disability or autism

To support the ambitions identified in the NHS Long Term Plan children's and young people's mental health plans must also align with other plans for people a learning disability or autism. This is highlighted in the NHS Mental Health Implementation Plan 2019/20 – 2023/24. <https://bit.ly/2M7QpH9>

Learning Disabilities and Autism	Mental health plans must align with the ambitions outlined in the NHS Long Term Plan for people with learning disabilities and autism; this is especially relevant for the planning and provision of children and young people's mental health services. All appropriate specialised learning disability and autism services will be managed through NHS-led Provider Collaboratives over the next five years.
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National work identified

1. Mental Health Foundation (Children and young people with learning disabilities and their mental health)

This information pack is intended to provide a basic introduction to mental wellbeing and mental health problems before considering mental health problems in children and young people with learning disabilities in more depth. Download here:

<https://bit.ly/31K8lwc>

2. The Anna Freud National Centre for Children and Families

On My Mind online resource

On My Mind aims to empower young people to make informed choices about the mental health support they want, the treatments they receive and the outcomes they desire.

It contains information, advice and resources to help young people support their own mental health, including signposting to sources of support in times of crisis and tools to help young people manage their own wellbeing.

The free digital resources are designed for use by children and young people between the ages of 10 – 25. These may be young people who are thinking about looking for support, who may be receiving or waiting to receive support or for those the traditional offer does not appeal to or has not worked for and who want help and information about self-managing their own mental health and wellbeing.

<https://www.annafreud.org/on-my-mind/>

3. Foundation for people with learning disabilities

Improving access to mental health services for people with learning disabilities

In line with the Government's 'No health without mental health' strategy, the Foundation for People with Learning Disabilities was funded to find out about the barriers that make it difficult for people with learning disabilities to access mental health services and resources.

Following this research, they produced various different resources, although not specifically aimed at young people they highlight some of the reasonable adjustments that are required to enable people with a learning disability to access services in relation to their mental health.

<https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/improving-access-mental-health>

4. The Challenging Behaviour Foundation

Valuing the Views of Children with a Learning Disability Report

All children and young people are able to tell us what they think and feel in many ways and have a right to be heard. A new report, "Valuing the Views of Children with a Learning Disability" developed by the Challenging Behaviour Foundation and Mencap gives examples of how organisations and have actively sought and responded to the views of children with severe or profound and multiple learning disabilities in ways that other people can replicate. It tackles misconceptions, signposts further useful information and is aimed at anyone involved in supporting children or young people with learning disabilities including schools, CAMHS and short breaks. It will be of interest to those consulting young people in order to shape future services (including commissioners in SEND and Transforming Care Partnerships.)

<https://www.challengingbehaviour.org.uk/cbf-articles/latest-news/valuingtheviews.html>

Local opportunities and feedback

Appendix 1



Research Information and further resources:

Pneumonia, Aspiration Pneumonia, and ischaemic heart disease

Organisation	Resource & description	Further information
LeDeR Learning Disability Mortality Review	Learning Into Action newsletters: including aspiration pneumonia.	https://bit.ly/2Hc1K5A
NESTA	The People Powered Results team <i>are pioneering new approaches to achieving change and innovation in complex systems that are smarter, faster, more collaborative and more inclusive of citizens and the front line.</i>	https://www.nesta.org.uk/project/people-powered-results/

Organisation	Resource & description	Further information
NICE guideline Published date: April 2018	Care and support of people growing older with learning disabilities	https://www.nice.org.uk/guidance/ng96/chapter/Context
NHS Ealing Community Partners	Speech and Language Therapy Service - adults	https://www.westlondon.nhs.uk/ecp-adult-speech-language-therapy/
Lincolnshire Learning Disability Partnership Board	Learning Disability - Healthy Lifestyles Newsletter	https://www.lincslmc.co.uk/healthylifestylesnewsletter
Healthwatch Sheffield Learning Disabilities Report 2017	My Health, My Say: the experiences of people with a learning disability using local health and social care services	https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/reports-library/Learning-Disability-Report-Final-PDF.pdf
Four Greater Manchester localities worked as part of an 'Innovation' programme.	"GLORIOUSLY ORDINARY LIVES" MAKING COMPLEX SYSTEMS WORK FOR ALL PEOPLE WITH LEARNING DISABILITIES	http://www.gmhsc.org.uk/wp-content/uploads/2019/06/gmhscp-gloriously-ordinary-lives-doc.pdf
Lancaster University and VODG (Voluntary Organisations Disability Group)	Good Food Matters – a practice resource	https://www.vodg.org.uk/wp-content/uploads/2019-VODG-Good-Food-Matters.pdf

Maternity

Organisation	Resource & description	Further information
Healthtalk.org	<i>Women we talked to with a learning disability described their maternity experiences that were sometimes different to other women.</i>	http://www.healthtalk.org/peoples-experiences/pregnancy-children/pregnancy/learning-disability-and-pregnancy

Organisation	Resource & description	Further information
Public Health England	Easy guides for pregnant women with a learning disability	https://bit.ly/2ZbRBjD
Research gate	Developing the pregnancy support pack for people who have a learning disability	https://bit.ly/2z4EDpq Download the PDF

Mental health – children and young people with a learning disability or autism

Organisation	Resource & description	Further information
Iriss	Mental health of young people with learning disabilities in transition	https://www.iriss.org.uk/resources/esss-outlines/mental-health-YP-LD-transition
Anna Freud National Centre for Children and families		https://www.annafreud.org/on-my-mind/
CORC for young people – Child Outcomes Research Consortium	Believe in improving support to children and young people around mental health by learning from feedback and other evidence	https://www.corc.uk.net/for-young-people/