

Norfolk Antenatal Pathway for Women and Birthing People with Learning Disabilities

By Anca Manea

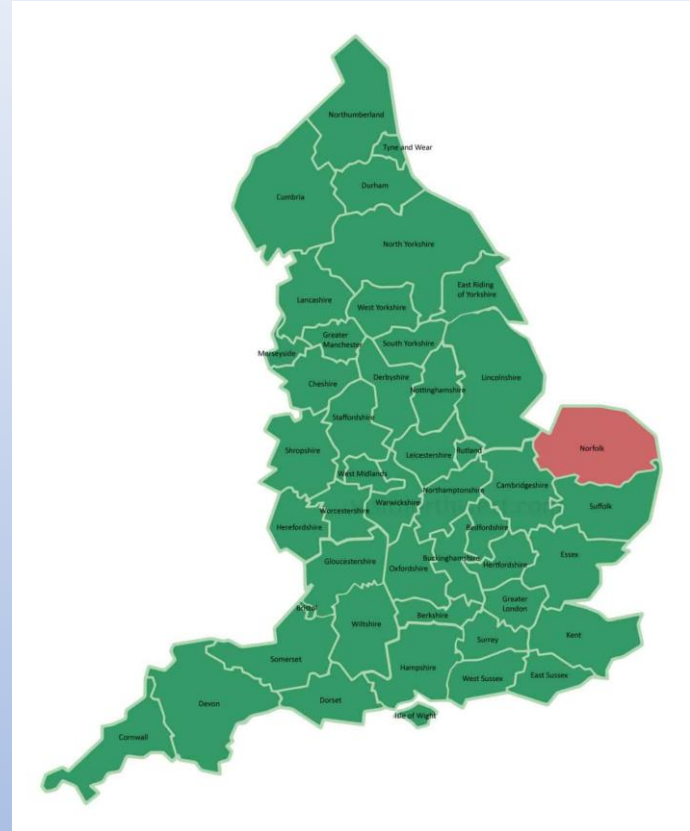
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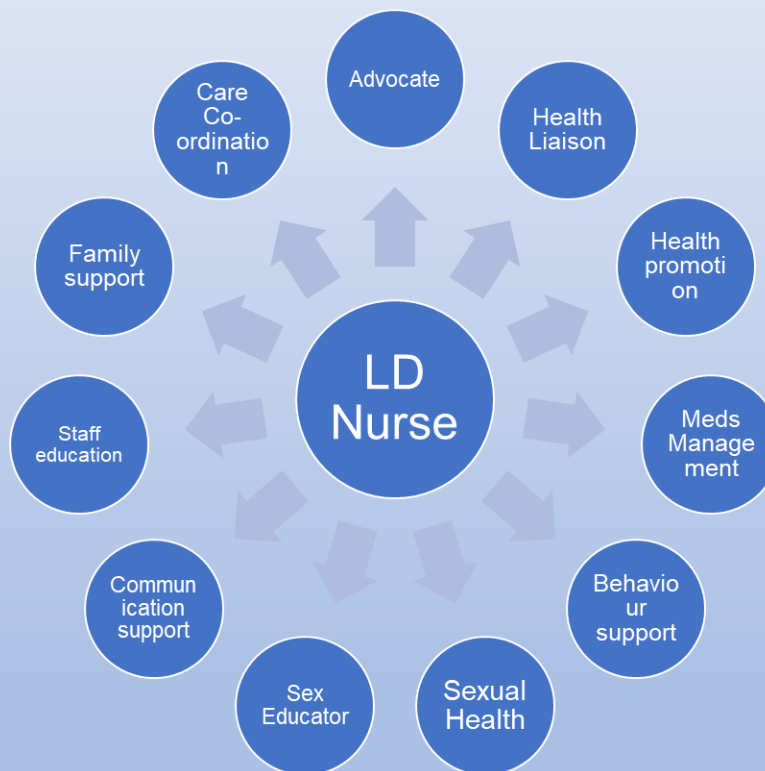
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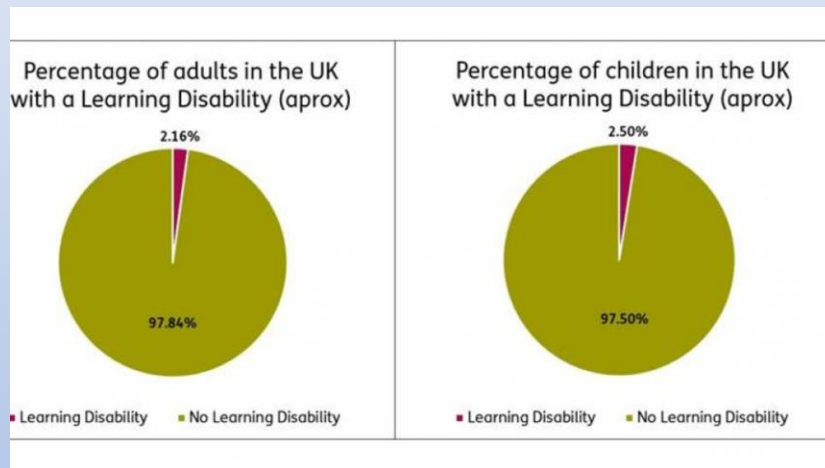
LOOKING AFTER YOU LOCALLY



Intellectual Disabilities/Learning Disabilities



Learning Disabilities statistics



Mencap, 2020

Number of parents with a Learning Disability in UK:

- ❖ In England only, over 53000 parents with LD
- ❖ 60% of parents with LD were not living with their children

Working Together with Parents network (2008)



Prevalence of mothers with learning disabilities and risks associated with the diagnosis

In UK, 9% of women with Learning Disabilities has a child.

Research shows that women with learning disabilities have poorer outcomes:

- **increased rates of pre-eclampsia**
- **venous thromboembolism**
- **pre-term birth**
- **delivery by caesarean section**
- **low birth weight**
- **low Apgar scores**
- **greater rate of stillbirths**

Public Health of England, 2019



Learning disabilities - good practice

The five key features of good practice in working with parents with learning disabilities:

1

Accessible information and communication

2

Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways

3

Support designed to meet the needs of parents and children based on assessments of their needs and strengths

4

Long-term support where necessary

5

Access to independent advocacy

Learning Disabilities and the Antenatal pathway

The beginnings

1. The parenting pathway for people with learning disabilities work group was already established.
2. Prospective mothers with Learning Disabilities were still referred to the Learning Disabilities Service too late in their pregnancy journey.

What changed

- **Discussions with relevant partner agencies to include midwives and Social Services; agreement to develop a County wide pathway**
- **Agreement to split the parenting pathway into two pathways: antenatal and postnatal pathways**
- **Inclusive pathway: the terminology used in the pathway should be gender neutral**
The AIM of the project

For clients with learning disabilities to receive appropriate antenatal care

Focus group

Stakeholders involved in the project

Role	Team Member
Day to day lead	Community LD Nurse jointly with a Lead nurse/Team manager
Clinical champions	Clinicians across the Learning Disabilities Service, representing each discipline
Expert by experience	Clients feeding back via clinicians
External champions	Clinicians working in external NHS agencies Professionals working within Social Services



Project

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
For clients with learning disabilities to receive appropriate antenatal care	Patient identification	Implement robust systems to recognise birth parents with learning disabilities	Introducing a tool to help midwives with early identification of the learning disabilities	Increased number of birth parents identified early during their antenatal journey

Definition of a learning disability: A significantly reduced ability to understand new or complex information, to learn new skills (Significantly impaired intelligence)
AND A reduced ability to cope independently, (Impaired social / adaptive functioning)
AND Which started before adulthood (onset before aged 18) with a lasting effect on development

*Consider the following for reasons why a person cannot achieve these things at the time of the assessment:
 - sensory impairment (hearing or sight impairment), English is not their first language

Rectangular Snip

Questions to consider	yes ✓	no ✗
Did person attend any special schools or were they statemented in mainstream school? Do they have an educational health care plan		
Is there a diagnosis of a learning disability/mental handicap in any notes? IQ under 70 (please refer to read code list of definite and potential diagnosis of a learning disability)		
Is the person known to the Learning Disability Service?		
Is the person under the care of a consultant psychiatrist for learning disabilities?		
Has anyone ever told the person that they have a learning disability?		
Did the person achieve qualifications at school?(GCSE at low grades could indicate LD but high grade GCSE, A Levels or university education then LD is not likely)		
How does the person function in society? Does the person need support with activities of daily living? Tell me what you do during the day. Does this indicate that they require support to undertake daily living activities?		
Does the person need help to read i.e. appointment letters or other official letters?		
Does the person have problems with simple numerical calculations? (i.e. "If I gave you £5 to buy milk. Milk costs £1.50 – how much change would you have left?)		
Does the person need assistance with transport? (unable to get around independently?)		

Does person have difficulty with:		
Communicating needs	yes	no
Writing	yes	no
Self-Care	yes	no
Living independently	yes	no
Interpreting social cues	yes	no
Controlling their behaviour	yes	no
Co-ordinating movement	yes	no
Learning new skills	yes	no
Understanding new or complex information	yes	no
Do they have a sensory impairment?	yes	no
Is English their first language?	yes	no
Several 'yes' answers could indicate the presence of a Learning Disability*		

Factors which MAY indicate No learning disability	Factors that MAY indicate a learning disability
<ul style="list-style-type: none"> • Normal development until other factors impact (before 18). • Diagnosis of ADHD, dyslexia, dyspraxia or Asperger's • Successfully attended a mainstream education facility without support. • Gained qualifications (GCSE and/or A 'Levels) • Able to function socially without support • Independently manage their financial commitments • Able to drive a car. • Contact with mental health services • Recorded IQ above 70 • Communication difficulties due to English as a second language 	<ul style="list-style-type: none"> • Record of delayed development/difficulties with social functioning & daily living before the age of 18. • Requires significant assistance to undertake activities of daily living (eating & drinking, attending to personal hygiene, wears appropriate clothing) and/or with social/ community adaptation (e.g. Social problem solving/reasoning). NB need for assistance may be subtle. • Presence of all three criteria for LD i.e. Impairment of intellectual functioning/social adaptive functioning and age of onset. • Range of information presenting a picture of difficulties in a number of areas of function, not explainable by another 'label' • Contact with specialist Learning Disability consultant. • Attendance at specialist education facility for people with intellectual delay



Project

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
<p>For clients with learning disabilities to receive appropriate antenatal care</p>	<p>Education</p>	<p>Increase midwives' awareness about learning disabilities related issues</p>	<ul style="list-style-type: none"> Targeted teaching sessions with midwives provided by the Community LD Clinicians 	<p>Baseline and follow-up knowledge survey</p>



Project

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
For clients with learning disabilities to receive appropriate antenatal care	Appropriate referrals to the Community LD Team	Referrals made in a timely manner	Clients to be allocated as high priority	Waiting times since referral to initial contact

Antenatal pathway

The pathway won an NHS England and ICCHNR research award in December 2022.



Antenatal pathway



NICHE
Anchor Institute

NICHE Fellowship
Norfolk Initiative for Coastal
and Rural Health Equalities





Learning Disabilities antenatal journey recommendations

- Avoid long words or medical terms
- Check understanding – request feedback
- Repeat information where required
- Offer longer appointments
- Use **accessible information**

Burke *et al.* (2022)



Antenatal care and women and birthing people with LD:

DOs

- **Allow extra time for appointments**
- **Repeat information if necessary**
- **Request feedback to ensure the information is understood**
- **Provide information in alternative form in required**
- **Consider Mental Capacity Act (2005) principles**
- **Refer to Specialist Services- LD Teams and develop a multiagency care plan**

DON'Ts

- **Don't presume incapacity due to the learning disability**
- **Don't fall in the diagnosis overshadowing trap**
- **Don't forget, people with learning disabilities can be good parents too!**

Initial findings following the educational sessions provided to midwives and obstetrics staff at a local hospital

Learning Disabilities

- **Some staff mistake the Learning Disabilities terminology for Learning Difficulties, Autism, Cerebral Palsy**
- **Not many staff knew that the Learning Disabilities diagnosis is linked to the IQ**
- **Staff with relatives diagnosed with Autism, most likely to know the difference between Autism and Learning Disabilities**
- **Staff's understanding improved when LD explained in relation to IQ and rephrased as ID/Cognitive Disability**

Communication

- **Most staff had difficulties in explaining both lay terms and medical terms to their peers, while using a simple language**

Additional personal observations

Bristol chart

- **All staff asked to describe the term using lay terms, struggled with the task and appeared embarrassed in front of the other trained professionals**



How is staff going to recognise and talk about Constipation with people with Learning Disabilities, if they struggle to describe a chart in front of their trained peers?

Going forward

- **Gathering the data collated in relation to the educational component**
- **Roll out the pathway to the whole county**
- **Further research regarding client's experience with the pathway**

Thank you for listening!

References

Burke, E.,A., Fleming, S., Doyle, C. (2022) Using verbal and non-verbal communication to support people with learning disabilities. *Learning Disability Practice*.

NHS England and NHS Improvement (2010). Quality, Service Improvement and Redesign Tools: Driver diagrams. [link](#)

NHS England and NHS Improvement (2019) *Learning disability identification check-list* [link](#)

Working Together with Parents Network. (2016). *The Working Together with Parents Network update of the DoH/DfES Good Practice Guidance on working with parents with a learning disability*. [link](#)