

Antenatal Pathway for Individuals with Learning Disabilities

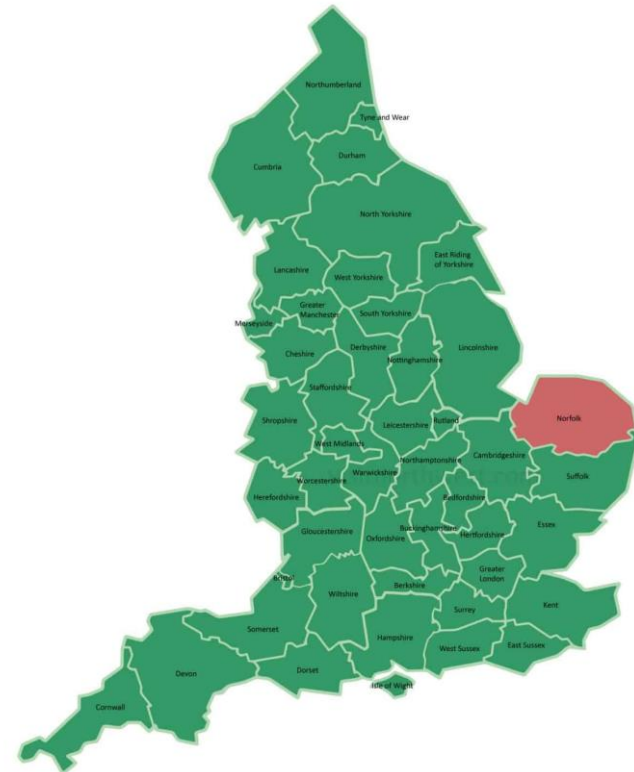
By Anca Manea

NICHE Research Fellow; MSc Adv Prof Prac.,
Community Learning Disabilities Nurse

Email: anca.manea2@nchc.nhs.uk

X (Twitter): @anca_ld_nurse

Where we are based



LOOKING AFTER YOU LOCALLY

Intellectual disabilities



Learning Disabilities and Pregnancy

Birth parents with learning disabilities are likely to have difficulty accessing good quality antenatal care that meets their needs, including:

- **extra time and support for appointments**
- **the opportunity to have information repeated**
- **information about pregnancy and birth choices, and about parenting, that is presented in a form they can understand and is empowering**
- **involvement of family carers and advocates**
- **understanding the complexity of consent issues**
- **liaison with other agencies involved**

Best beginnings.org.uk

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

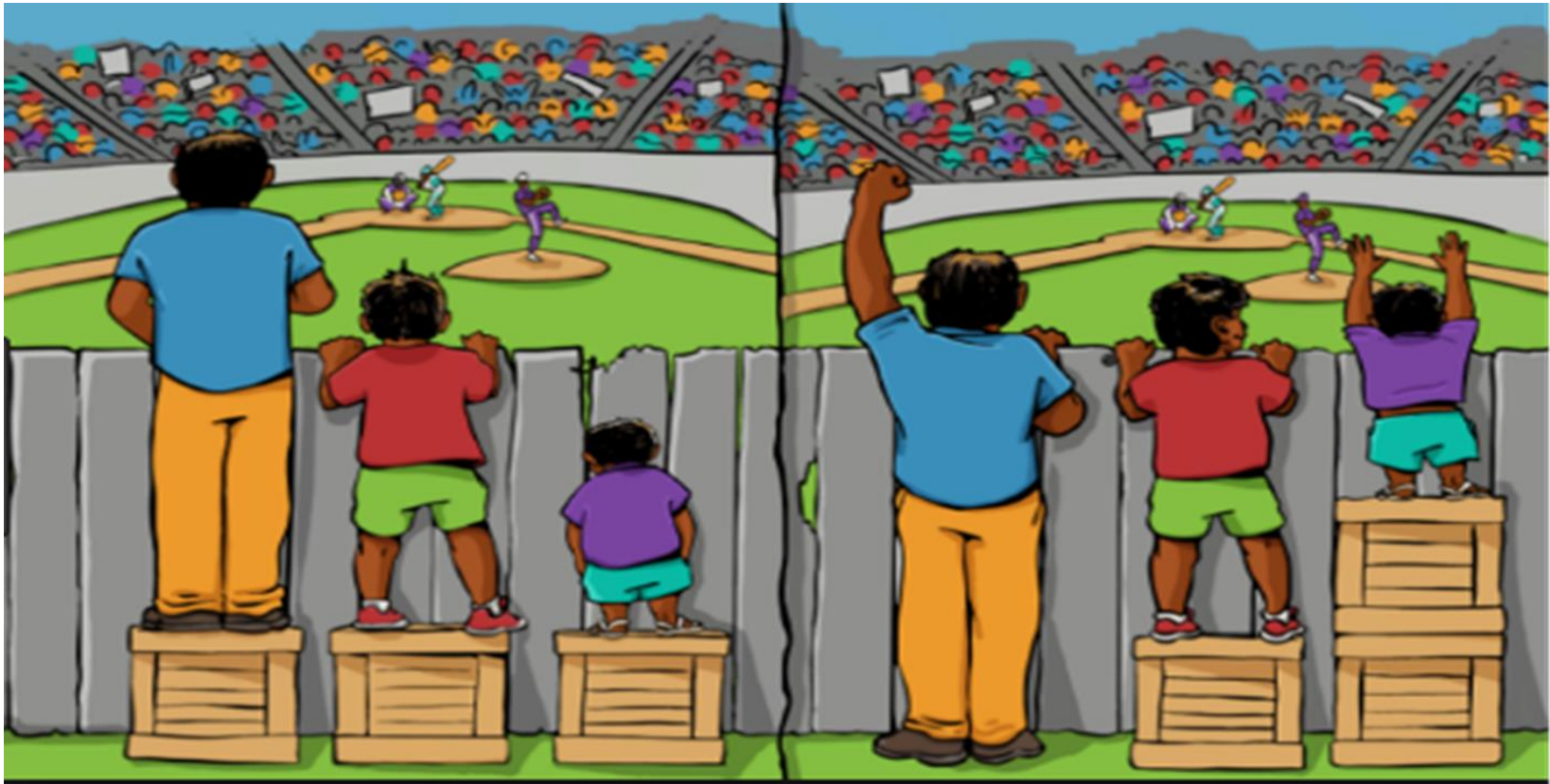
Access to
independent
advocacy

Learning Disabilities - Communication

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

Burke *et al.* (2022)

Learning disabilities



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

Project Aim

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
For clients with learning disabilities to receive appropriate prenatal 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 prenatal 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

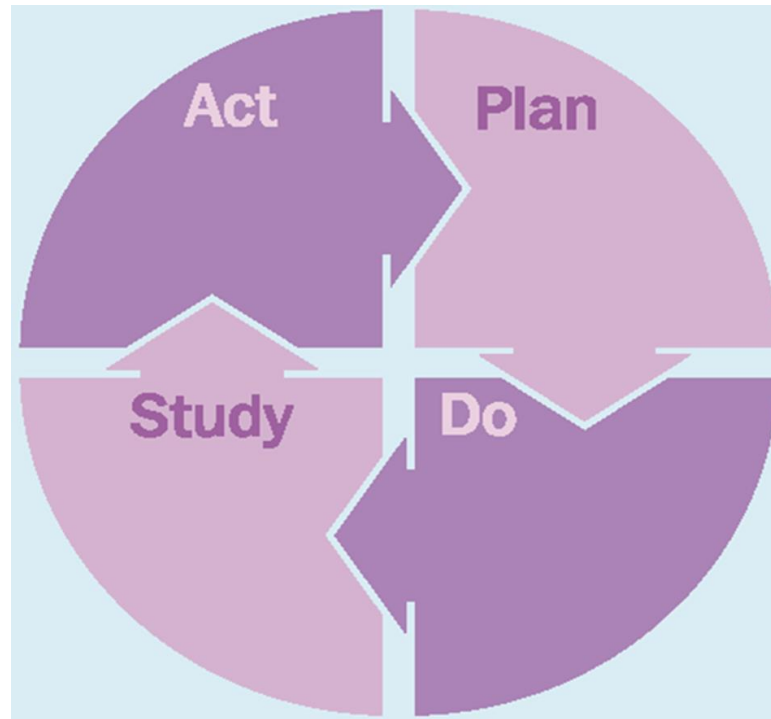
Project Aim

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
For clients with learning disabilities to receive appropriate prenatal care	Education	Increase midwives' awareness about learning disabilities related issues	<ul style="list-style-type: none"> Targeted teaching sessions with midwives provided by the Community LD Clinicians Provide midwives teams with the appropriate contact details for the LD Service Create a folder for the Community LD Service with useful resources 	Baseline and follow-up knowledge survey

Project Aim

Aim	Primary drivers	Secondary drivers	Specific change ideas	Measures
For clients with learning disabilities to receive appropriate prenatal care	Appropriate referrals to the Community LD Team	Referrals made in a timely manner	Clients to be allocated as high priority	<p>Waiting times since referral to initial contact</p> <p>Friend and Family tests results</p>

PDSA



This project will have multiple PDSA cycles reflecting its complexity. This will promote the identification of changes that work within the pathway

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



Perinatal 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!

What next?

- **Developing work around perinatal mental health within the Learning Disabilities population**
- **Presenting in September at the European Congress of Mental Health in Intellectual Disabilities (EAMHID) in Helsinki-Finland**
- **Collaborating with professionals in developing resources for the Family Hub and Start for Life programme in Norfolk, to ensure that parents with Learning Disabilities' needs are addressed**

Thank you for listening! Any Questions?



References

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