

NICHE Fellowship Report

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This report will present the findings of piloting an integrated antenatal pathway for people with learning disabilities within an East of England region. Further, the report will discuss the findings and their potential impact on the wider health and social care system.

The learning disabilities demographic is more likely to be exposed to health and social inequalities, to include, poorer physical health, poorer mental health, less likely to be working, more likely to live in poverty, more likely to experience loneliness and more likely to be bullied and discriminated against (Department of Health, 2025). It is important to note that Indices of deprivation are used in the United Kingdom to measure components of social disadvantage, capturing the deprivation as an aggregate. However, there is the potential for inaccurate reporting of rural deprivation present in small pockets of an area, leading to these areas being overlooked. (Burke and Jones, 2019). In this context, Mencap (2023) highlights some of the health inequalities that people with learning disabilities are experiencing, such as a lack of accessible transport links, patients not being identified as having a learning disability, staff having little understanding about learning disability, failure to recognise that a person with a learning disability is unwell, failure to make a correct diagnosis, anxiety or lack of confidence for people with a learning disability, lack of joint working from different care providers, not enough involvement allowed from carers, and inadequate aftercare or follow-up care.

It is important to understand what a learning disability is, for the purpose of this report but also in relation to the findings presented later in the text. In United Kingdom (UK), the Department of Health (2025) defines learning disabilities as a 'significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'. Intellectual Disability is part of the International Classification of Disease and related Health Problems 11' (ICD-11). (WHO,2018) umbrella term of Disorders of Intellectual Development.

Classification of Intellectual Disability:

- mild (with IQ range between 50-69)
- moderate (with IQ range between 35-49)
- severe (with IQ range between 20-34)
- profound (with an IQ below 20), (WHO, 2018).

Within an international context, United Kingdom is the only country referring to the intellectual disability using the term 'learning disability'. Internationally, the 'learning disability' terminology is used to refer to those with an educational learning difficulty, like Dyslexia and Dyscalculia.

Prospective parents with Learning Disabilities (LD) are more likely to have difficulties accessing antenatal care that meet their needs (Best beginnings, 2022). Some prospective parents with LD may require extra time for appointments, along with the

opportunity to have information repeated; information in accessible format about pregnancy and birth choices; opportunities to have support from family, carers and advocates. Anecdotal evidence in one of the East of England regions indicates existing delays in addressing the needs of some pregnant women with LD. The prospective parents were referred very late in their pregnancy journey to the Specialist Community Learning Disabilities Team, resulting in a stressful journey for the pregnant individuals. Department of Health's (2007, 2025) clear guidance about the care of parents with LD, recommends responsive and co-ordinated referral and assessment procedures and processes to be in place across services.

The above promoters led to a focus group inclusive of significant stakeholders working with pregnant individuals with LD. The aim of the focus group was to find ways to improve antenatal care for the LD demographic within the County. Using the driver diagram (NHS England, 2010), the focus group identified primary, and secondary drivers, along with specific change ideas. The key outcome was creating an integrated antenatal pathway for people with learning disabilities, to ensure this demographic's care needs are met appropriately during their antenatal journey. Table 1 and Table 2 show the main primary and secondary drivers identified within the focus group, that led to the creation of the pathway.

Table 1

Aim	Primary driver	Secondary driver	Specific change idea	Measure
For people 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 pregnant people identified early during their antenatal journey

Table 2

Aim	Primary driver	Secondary driver	Specific change idea	Measure
For clients with learning disabilities to receive appropriate antenatal care	Education	Increase midwives' awareness about learning disabilities related issues	Targeted teaching sessions with midwives provided by the Community LD Clinicians	Baseline and follow-up knowledge survey

The Antenatal pathway for women and birthing people with learning disabilities is a coproduction project between several NHS Trusts and Adult Social Services within Norfolk and Waveney, in partnership with individuals with learning disabilities. The success of this project relied on the collaboration, involvement, and participation of the stakeholders. The changes required for practice identified under the Antenatal Pathway are 1) introducing a validated tool to help midwives with early identification of women and birthing people with learning disabilities, as a robust system to allow for patient identification and 2) targeted teaching sessions for midwives, to increase their awareness about learning disabilities.

The number of parents with learning disabilities within UK is an unknown figure, however there is an estimation that in England alone, there are over 53000 parents with LD. Additionally, in UK, 9% of women with Learning Disabilities has a child.

Research (Public Health of England, 2019) shows that women with learning disabilities have poorer antenatal outcomes, to include:

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

- greater rate of stillbirths

Some of the risk associated with non-engaging with antenatal care have been identified as follows:

- Double the number of deaths in women who received a minimum level of antenatal care compared to the number of women received attending all their antenatal appointments
- Low weight at birth, intrauterine growth issues, premature births
- Non engagement associated with complex social factors, such child protection involvement, domestic abuse, substance misuse, communication issues
- Women declining investigations and treatment

The NICHE Anchor Institute Fellowship facilitated the work underpinning the antenatal pathway and the delivery of specific learning disabilities training to circa 300 midwives and obstetric staff in a part of the Norfolk County. The training provided learning disabilities awareness along with a delivery of a communication workshop and introduced the antenatal pathway for people with learning disabilities. The training was compacted in one hour session delivered during the NHS Trust existing mandatory sessions. Prior to these sessions, all staff have had mandatory yearly learning disabilities awareness training provided by the employing NHS Trust.

Quantitative data was obtained from a random sample of 50 participants, before the training session was delivered to gauge into the clinical staff's understanding of the learning disabilities demographic and their needs.

Findings

84% of the sample did not know that learning disabilities is linked to cognitive disability/impaired intelligence, 46% believed that Autism is a type of Learning Disability, 58% said that Dyslexia is a type of learning disability, while 92% understood that a learning disability and a learning difficulty, are not the same. 34% of the staff believed that Hyperactivity is a type of learning disability, and 30% of the staff sampled believed that all people have a degree of learning disability.

Conversely, 90 of the sample knew that people with learning disabilities have the same rights as the general population, while only 66% agreed with the statement that the law for people with learning disabilities is the same as for everyone. 86% identified correctly that the learning disabilities demographic is most likely to have communication problems.

The communication workshop included within the training, asked all participants to relay to their peers a medical/clinical term using lay language. A significant percentage of the participants struggled to explain in lay terms the clinical terminology.

Positively, following the implementation of the pathway, the number of referrals to request support from the Learning Disabilities Specialist Teams has increased significantly. Moreover, feedback from clinical practice indicated that midwives receiving the training tailored around antenatal care, felt more confident in practice.

People with learning disabilities receiving care under the pathway, feedback that their experience during antenatal journey has improved. Feedback included that the waiting times to be seen in the clinics has reduced, from 3-4 hours wait, to being seen within an hour. Other pregnant individuals and some of their family members and carers gave positive feedback about the easy read information made available by the learning disabilities nurse.

Discussion

Reducing inequalities that the learning disabilities demographic is exposed to, is encompassed in the 10 years NHS plan and draws data from the Lord Darzi report (2024), which acknowledges the multiple barriers that prevent people with learning disabilities from accessing the care that they require.

The findings from the sample surveyed are concerning, when considering that all staff have had learning disability mandatory training provided yearly by their employing Trust for a number of years. The learning disabilities nursing workforce has suffered a huge decline in recent years (RCN, 2024) and this report is adding to the existing evidence, highlighting the importance of training specialist learning disabilities nurses, able to support all clinicians working in mainstream healthcare to provide, specialist reasonable adjustments, when they are caring for people with learning disabilities.

Reasonable adjustments to those who need it, is a requirement of the Equality Act (2010). Explaining the care required to someone with a learning disability, in a way that promotes their understanding is a significant and basic reasonable adjustment. How are we going to get things right if the most simple and basic part of the care we provide – communication- is often missed for those with a learning disability. This raises a further question, how about those who's communication needs go beyond using a clear and lay language, those who may require visual aids to enhance their communication, are they are missed all together?

An unexpected outcome of the antenatal pathway was midwives' self-reported increased confidence in practice. There is strong evidence that clinical staff confidence in practice contributes to retention, particularly when supported by targeted strategies and funding (Department of Health, 2025).

The findings of the survey highlight the critical importance of an integrated approach within the Antenatal Pathway for individuals with learning disabilities. The data reinforces that meaningful collaboration—between learning disabilities nurses, service users, and other statutory services such as midwifery, social care, and primary health—is essential to effectively address and reduce antenatal care inequalities. This integrated model not only facilitates early identification and tailored

support but also ensures that care is person-centred and responsive to the unique needs of this demographic.

Moreover, the results contribute to the growing body of evidence that highlights the pivotal role of learning disabilities nurses in tackling systemic health disparities. Their expertise in communication, advocacy, and holistic care enables them to bridge gaps in understanding and access, particularly during critical life stages such as pregnancy. By working in partnership with families and professionals across sectors, learning disabilities nurses help ensure that individuals with learning disabilities receive equitable, dignified, and safe antenatal care—ultimately contributing to improved health outcomes and greater satisfaction for both people with learning disabilities and clinicians.

Recommendations:

All midwifery services within the UK, should prioritise working towards embedding an integrated antenatal pathway model of care for people with learning disabilities. All midwifery clinical staff should receive face to face learning disabilities awareness training along with a tailored communication workshop, to increase skills and knowledge.

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