

Guidelines for the Care of Women with Learning Disabilities and/ or Difficulties Accessing Maternity Services

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People who need to know about this document in detail	All staff working within maternity and neonatal services
People who need to have a broad understanding of this document	As above
People who need to know that this document exists	As above

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Disclaimer:

If the review date of this document has passed please ensure that the version you are using is the most up to date version by checking on WISDOM

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1. Purpose

The purpose of this guideline is to offer healthcare professionals working within perinatal services good practice reference points to consider when working with people with learning disabilities during pregnancy, labour and the postnatal period. This will help to ensure their needs and wants are identified and effective plans are put in place to meet them. This should facilitate achieving more positive experience and outcomes for parents and families. These guidelines may also be useful for other services who support adults with learning disabilities who are or will become parents.

2. Introduction

The numbers of women with severe learning disabilities who will become mothers is low however, as more people with mild to moderate learning disabilities are supported to lead more independent lives, it is expected that more will become parents. People with learning disabilities experience poorer health outcomes and shorter life expectancy than the wider population (Baines 2010) and mothers with learning disabilities and their babies are at higher risk of adverse outcomes during pregnancy and afterwards (Redshaw et al 2013).

Having a degree of learning disability is not in itself an indicator of a person's potential parenting abilities, however, when there is a lack of adequate early assessment and effective intervention and support for parents, then family breakdown becomes a significant risk. Fifty percent of children whose parents have a learning disability of some degree are taken into care, usually as a result of concerns for their wellbeing and/or the absence of appropriate support. Additionally, one third of pregnant woman with a learning disability report moderate to severe levels of stress, anxiety and depression.

Some women with learning disabilities may avoid maternity care because of lack of confidence, negative staff attitudes, lack of clear explanations of what is going on, inaccessible information, and fear of the involvement of social services.

Many parents with a learning disability live under conditions that may contribute to poorer parenting, including poverty, low literacy, poor health, poor mental health, domestic abuse, having grown up in care, and social isolation. Limited access to appropriate additional support can affect parents with learning disabilities in many ways (Matijasevich et al 2012). They may have already experienced a lack of practical and emotional help which might have resulted in poverty, unemployment, inadequate housing, homelessness or housing support and debt. They may have been subjected to harassment, bullying, domestic violence or exploitation and may have additional needs due to physical or mental health issues.

Ensuring that maternity services fully meet the specific and individual needs of women with learning disabilities is paramount in optimising outcomes and experience for the woman, baby and family. This guideline aims to assist healthcare professionals to consider and plan with the woman and family with how her individual needs can be met, working with other professionals and agencies where appropriate.

3. Definitions

A learning disability is defined by the Department of Health and Social Care ((DHSC) (2001) as 'a significantly 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. The degree of disability can vary greatly, being classified as mild, moderate, severe or profound. In all cases, a learning disability is a lifelong condition and cannot be treated or cured.

A learning disability is different to a learning difficulty, which is a reduced intellectual ability for a specific form of learning and includes conditions such as dyslexia (reading), dyspraxia (affecting physical co-ordination) and attention deficit hyperactivity disorder (ADHD). A person with a learning disability may also have one or more learning difficulties. Additionally, there are a number of conditions and neurological disorders that often involve or cause some type of learning disability, including Down's syndrome, autism, meningitis, epilepsy or cerebral palsy.

It is estimated that approximately 1.5 million people in the UK today have a learning disability, which equates to around 2.2% of the population. This can vary from mild to profound. Approximately 6.7% of the population may fall within the borderline of possibly having a learning disability without any formal diagnosis (NHS Digital). Therefore, around 20 people in every 1000 will have a mild to moderate learning disability with 3-4 in every 1000 with a severe or profound learning disability. A diagnosis of learning disability is made when an individual has an IQ below 70 with significant deficits in daily living and coping skills, acquired by the age of 16 years.

It is often only when individuals come into contact with services, such as during pregnancy, that an inability to fully engage with health advice and systems of care becomes apparent. This may alert healthcare professionals of the need to consider the potential capacity of the prospective parent(s) to care for their newborn child.

4. The Equality Act

The Equality Act (2010) states that a person (A) discriminates against a disabled person (B) if—

- A treats B unfavorably because of something arising in consequence of B's disability, and
- A cannot show that the treatment is a proportionate means of achieving a legitimate aim.

NB. The above does not apply if A shows that A did not know, and could not reasonably have been expected to know, that B had the disability.

5. Principles of Good Practice

Being honest and clear about expectations is important for parents, as are coordinated assessment processes based on competency and communication that take account of comprehension levels. It is not always the case that both parents will have a learning disability and assessment should take account of the whole family set up.

The role of perinatal services is crucial in ensuring an integrated and full assessment of needs and strengths from the start of pregnancy is undertaken, ensuring parents are offered the emotional and practical support that they require. Parenting can be difficult but a parent with a learning disability can often be a very competent parent when well supported by their partner, family and services working together.

A strengths-based approach should be adopted, acknowledging the person's individual needs, but keeping the focus on the potential of the individual to parent their child rather than a focus on limitations. Details of what additional support may be required should be recorded in the maternity notes, using the [together-project-toolkit.pdf](#) [maternity-passport.pdf](#).

Access to advocacy is important for people with a learning disability, and healthcare professionals who work in learning disabilities teams are often the mediators between parents, and children and family services. The main issue will be how parents are supported to develop parenting skills and overcome any issues in their lives that may negatively impact on their ability to be a good parent, whilst retaining a focus on the needs of the child and reporting any concerns to children and family services where there may be issues of potential risk.

All healthcare professionals within perinatal services require an awareness of what a learning disability is and the differences between learning disabilities, neurological conditions, autism, mental health conditions and learning difficulties but recognising the need for reasonable adjustments could be similar across these groups.

All services should promote good practice when undertaking assessment of risks and needs around parenting by using appropriate assessment materials and resources for parents with learning disabilities and accessing specialist expertise to facilitate this.

Women must be fully engaged and consulted about the way in which services will be provided throughout their pregnancy, labour and following birth. These discussions should be documented within the Maternity notes.

Even if women believe they have no need for support, when they are involved in the assessment process it should be possible to negotiate a creative package of care which will be acceptable to them, their partner/family and practitioners.

Women should have issues such as domestic abuse, substance misuse and mental health discussed with them as with any other pregnant woman.

A woman's right to confidentiality must be respected and she should be asked if she is happy to involve her partner or family in any discussions.

Treatment, care and information that is given to women with additional support requirements should be appropriate to their needs and accessible for them.

All health and social care professionals who are involved in supporting the woman or child must work closely together to ensure the needs of the whole family are considered and assessed. This must also ensure that the statutory duty of care to the child is fulfilled.

Parents should be involved in assessments and formation of care plans and they should be supported to ensure understanding. This may require support from an advocate.

Partners/fathers should be included in planning care and assessing support requirements where possible, and their needs considered.

The protection of children is paramount and any concerns around risk of potential neglect or harm and child protection procedures must be followed.

If the baby is admitted to the Neonatal Unit (NNU), there must be clarity about which member of the NNU staff will contribute to the wider family assessment. NNU staff will be assessing and observing family dynamics and often practical tasks such as feeding or baby care.

5.1. Safeguarding

Complete a multi-agency safeguarding referral form only if you have concerns that the learning disability will impact on the woman's ability to care for her baby and is required to safeguard her baby from risk or potential risk. Discuss with the Safeguarding Lead Midwife and consider a referral for support, with the consent of the woman. A referral to Adult Safeguarding should also be considered if required, but should not be completed as a routine. Referral to Flying Start or Resilient Families should also be made.

Attend any Child protection meetings relating to the unborn child and inform the Safeguarding Midwife of the outcome and document this action.

If you have doubts about the person's capacity to make decisions then you must complete a Mental Capacity Assessment, documenting this on a Mental Capacity Assessment form. Capacity may change throughout the period of care and may be reassessed at any time if deemed appropriate. A Capacity Assessment would only be required when an individual has a confirmed Learning 'Disability' (i.e. a proven impairment of the mind or brain- notably an impaired IQ, secondary to learning disability. Refer to the Mental Capacity Act policy and the MCA information on SharePoint.

Capacity means that the woman is capable of giving consent for treatment or care. This means that the woman understands information given to her and is able to make an informed decision.

5.2. Communication

There are many challenges that a woman with a learning disability may face but ensuring that

services and information for pregnant woman and new parents is accessible will help to ensure that they are engaged throughout every part of their perinatal care.

Information should be provided in short, non-complex chunks, providing one piece of information at time. Verbal information should be supplemented by easy read information, wherever possible. Photos and pictures are generally easier to understand than symbols, to support both understanding and choice making, and should be used if possible. Both spoken and written information should generally be pitched at the age of a 7–8-year-old recipient (a link to how to make information accessible can be found on the [bild](#) website). A pause to promote processing time, before a response, is encouraged. If repetition is then needed, health professionals should remain consistent. Too many varieties of the same information can become confusing.

Comments made by health professionals may be taken very literally and the tone may be misunderstood: it is important to avoid medical jargon.

It is important to be aware that parents with learning disabilities may be anxious about asking questions or saying when they don't understand, and may be afraid to ask for help with parenting in case that triggers the removal of the child.

Parents with learning disabilities may need the same information to be repeated several times.

Parents with a learning disability should be accompanied by an advocate at all times when having their or their baby's care plan/treatment discussed.

Midwives and HVs are the key providers of parent information during pregnancy and the early years. They should ensure that prospective and new parents are given information in a format that makes it easy for them to understand such as DVDs, audio, use of pictures, large print, accessible websites, verbal explanations and practical demonstrations. Parents should be given enough time to ensure that they fully understand the information that is being given.

5.3. Consent

If a healthcare professional has any concerns about the woman's ability to provide consent, then a Mental Capacity Assessment should be completed.

If a woman has an advocate which may be a support worker, family member, independent advocate or other practitioner, they should be involved in any discussions to ensure that she clearly understands what is being discussed.

Please also refer to the Health Board's Consent Policy for further guidance.

6. Antenatal Care

Women are generally much more likely to accept professional support during pregnancy or following birth than at any other time. However, for women with a learning disability there

may be elements of denial or confusion which may lead to a delay in understanding or acknowledging that they are pregnant.

Early contact with maternity services by a woman with any degree of learning disabilities will enable early multidisciplinary or multiagency assessment to identify additional support required during pregnancy and following birth.

Having a named midwife who is available for women from the beginning of pregnancy, throughout the antenatal period and following birth is essential to ensure consistent support and advice. The named community midwife will work closely with members of the multidisciplinary team. Recommendations for the appropriate pathway of care should be made as per usual, ensuring the woman understands the choices and decisions she is making (Sandall J et al 2016).

The booking appointment should be completed as usual by the community midwife. More time should be allowed for the booking and subsequent antenatal appointments. Flexible support should include offering appointments and/ or assessments that occur in the woman's own home where possible, not in an unfamiliar community setting.

The 'About Me' page should be completed with the woman to ensure any additional needs are identified and documented. It is good practice to establish a term for their disability with which they feel comfortable and use in future acknowledgement and documentation.

The University of Surrey's Together Toolkit Maternity Passport should be accessed via this link [maternity-passport.pdf](#) and completed, in collaboration with the woman and family.

The Maternity Disadvantage Assessment Toolkit should also be completed to help identify the level of support needed.

The need for reasonable adjustments and additional support should be identified at the booking in appointment utilising the documents described in this guideline. The process should be transparent and enable the woman and family to identify their needs.

Inform the health visitor and GP during the antenatal period that you are caring for a woman with a learning disability.

If an advocate is needed for antenatal appointments, this should be arranged accordingly.

When additional needs are identified, support must be put in place to ensure that the mother is able to meet those needs until birth takes place. The promotion of attachment and bonding are particularly important to be discussed in pregnancy.

The named person for the child from birth will be the named health visitor (HV). The HV will be undertaking an antenatal visit for all women between 32-34 weeks of pregnancy. However, for women with learning disabilities contact may be considered at an earlier stage. The HV must also be included in any assessments made by the midwifery team during pregnancy.

Giving women with learning disabilities an opportunity to talk to other mums who are

pregnant or have recently had babies may be invaluable to them (Malouf et al 2017). Also, visits to the unit and wards where they will have their babies with opportunities to meet the staff may help allay fears or concerns.

7. Care During Labour and Birth

Any healthcare professional caring for the woman in labour should refer to plans for labour and birth made during the antenatal period and ensure all needs and wishes are met.

An advocate must be present at all times if the woman has been assessed as not having mental capacity.

An appropriate advocate must be present at all times if the woman is under the age of 18.

The principles of good practice and communication which are outlined in this guideline should be followed at all times.

8. Postnatal care

A longer stay in hospital must be considered to facilitate the woman (and partner/ family) to develop parenting skills (Mitra M et al 2018).

Following birth, the woman and baby should have their needs reassessed. However, the focus must be on the woman's ability to parent her baby and any support available from her family and/or partner considered. If there are any parenting concerns, these should be discussed with the woman and her family. Advice may be required from the Safeguarding Lead Midwife. Any discussions, recommendations and plans should be clearly documented in the notes.

If the woman wishes to discharge against medical advice, the healthcare professional providing care must make a judgement about the woman's capacity to make the decision to self-discharge. If it is deemed that the woman lacks the mental capacity to self-discharge then you must act in her best interests and prevent her from leaving if the action is proportionate to the risk of harm. Refer to The Deprivation of Liberty Safeguards (DoLS) Policy and Procedures for immediate advice and guidance.

Plans for discharge home should be made with the woman and take into account her physical, practical and emotional leads.

The frequency and length of postnatal visits by the community midwife must be made to meet the woman and family's individual needs. This may mean additional visits are required.

Visits must include the ongoing assessment of the woman's understanding and capacity in relation to the care of the newborn.

Notify and liaise with the health visitor and other relevant known support agencies prior to the handover of care and document this action.

Any concerns should be discussed with the woman and her family and clearly documented in

the postnatal care pathway.

Parents are responsible for registering their baby's birth and this should be discussed with them. In the case of a parent who is unable to register due to capacity issues, grandparents can also register the birth.

Discussions with women must include sexual health and future pregnancy planning advice. Long-acting reversible contraception (LARC) is the most effective choice for women with additional support needs, lessening the likelihood of unplanned pregnancy.

References

Department of Health and Social Care (2001),
Malouf R et al (2017). 'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open*, 7(3) 16

Matijasevich, A et al (2012). Association of socioeconomic position with maternal pregnancy and infant health outcomes in birth cohort studies from Brazil and the UK. *Journal of Epidemiology and Community Health*, 66(2): p. 127-13

Mitra M et al (2018). Postpartum Hospital Utilisation among Women with Intellectual and Developmental Disabilities: A Retrospective Cohort Study. *Maternal and Child Health Journal*, 14

NHS Digital (2022) Health and care of people with learning disabilities, experimental statistics 2021 to 2022. NHS Digital.

Redshaw M and others. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy & Childbirth*, 2013. 13(1): p. 1-14 17

Sandall J et al (2016). Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No: CD004667. DOI: 10.1002/14651858.CD004667.pub5 21

Bibliography

Cox A, Parsons T, Watkin S, Gallagher A. (2021) Supporting the delivery of good maternity care for parents with learning disabilities. *Midwifery*.

Ip, A., Kendall, S., Jabeen, A., Watkin, S., & Cox, A. (2023). A measure to evaluate parenting interventions: Using inclusive research to modify a tool to measure change in parenting self-efficacy during the antenatal period. *British Journal of Learning Disabilities*, 1–9.

[Mental Capacity Act 2005](#)

NICE Clinical guideline 10, 2010. *Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors*. London: NICE

Tarleton, B. Ward, L. and Howard, J., 2006. *Finding the Right Support: A review of issues and positive practice in supporting parents with learning difficulties and their children*. London: The Baring Foundation

Appendix – Learning Disabilities Assessment Tool

Consider: -	Yes	No	How can you meet this need? -
Communication			
Is the woman able to communicate effectively?			
Can the woman read and or write?			
Does the woman understand information provided to her about her pregnancy? Birth? Care of baby?			
Mental Capacity			
Are there any concerns regarding mental capacity; to make the decisions needed?			
Behaviour			
Does the woman display any behaviour that may challenge or cause risk/harm? Are there any triggers such as noise, bright lights etc.?			
Psychological/Emotional			
Does the woman have any fears or anxieties e.g., medical interventions venepuncture?			
Personal Needs			
Are there any issues with mobility/personal hygiene/continence?			
Epilepsy			
Does the woman have epilepsy?			
Eating/Drinking/Swallowing			
Can the woman take medication independently any problems taking medication?			
Sleep Pattern			
Are there any problems sleeping?			
Preparation for birth			
Has there been discussions about labour and birth?			
Are there any issues regarding coping in labour and pain relief?			
Coping mechanisms calm music, quiet etc			
Consider: -	Yes	No	Comments: -
Does the woman know who to call if she is worried about any pregnancy issue?			

Labour			
Does the woman know signs of labour and what to do when it happens?			
Parenting Skills			
Are there preparations for the baby?			
Recognising babies needs Feeding etc.?			
Supportive partner/family			
Is there someone supporting her through the pregnancy, birth and post natally?			
Safeguarding Concerns			
Are there any concerns, is there involvement with Children Services? C1 referral. Pre-Birth plan in place			
Liaison			
Children Services			
Education			
Learning Disability Team			
Epilepsy Nurse			
Support worker /Flying Start, RFS, Home start, Team around the Family. Early help.			
Adult Services			
Summary of Needs and Plan of Care			
Assessment of need Referral to Children Services? Referral to Adult Services? Referral to Advocacy? Liaison with Multiagency Team			

Name
Signature
Date