

Document Control

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Care of women with additional learning needs in Maternity			
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CONTENTS

Document Control	1
1. Purpose	3
2. Definitions (Only if Required)	3
Learning Disability	Error! Bookmark not defined.
Learning Difficulty	
Autistic Spectrum Disorders	
Hidden learning disability	Error! Bookmark not defined.
3. Responsibilities	4
Role of the Complex Care Midwife	4
Role of the Learning Disability Service.....	Error! Bookmark not defined.
4. Screening for additional learning needs	Error! Bookmark not defined.
5. Learning need identified (or suspected)	4
6. Care planning and ongoing support	5
7. Suggested supportive resources	7
8. Monitoring compliance with and effectiveness of the guideline	7
9. References	8
10. Associated Documentation	8

1. Purpose

- 1.1. The purpose of this document is to detail the process for ensuring that women with additional learning needs receive maternity care in a way that is equitable, in that it aims to mitigate against the disadvantage, and associated risks, that women with learning needs face when accessing maternity services (Homeyard *et al* 2015). This is in accordance with the NHS' long term plan (2019) to drive down health inequalities, and the principles of inclusivity enshrined in the Human Rights Act (Working Together with Parents Network (WTPN) 2016) and the Equality Act (2010)
- 1.2. The guideline applies to all maternity staff
- 1.3. Implementation of this guideline will ensure that:
 - Midwives and maternity staff feel confident in meeting additional learning needs, including the use of referral pathways and adjunct services
 - Care provided to women with additional learning needs is auditable and in accordance with national guidelines and recommendations
 - Women with additional learning needs are supported to feel involved in their care

2. Definitions

Definition of “learning needs” in the context of this guideline:

- 2.1. **Learning disability:** 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, with a lasting effect on development' (Department of Health, 2001, p.14).
- 2.2. **Learning difficulty:** this term encompasses conditions such as dyslexia and ADHD which do not affect IQ, but impact on a person's ability to understand or process information (MENCAP 2020). This may also apply to women with an acquired brain injury which affects cognitive ability, particularly thinking, memory and reasoning

- 2.3. Autistic spectrum disorders (including Asperger's syndrome):** This condition affects how people interact and communicate with others, and is associated with finding new environments and situations very stressful or uncomfortable. People with the condition may take longer to understand new information, particularly if feeling overwhelmed with bright lights, noise, or an unfamiliar environment. They may also report over- or under-sensitivity to physical sensations including pain (National Autistic Society 2020). It is thought that many women with ASD are less likely to display the behavioural characteristics traditionally associated with the condition, which leads to the hypothesis that women are generally under-diagnosed (Nasen 2016)
- 2.4. Hidden learning disability:** This refers to women whose learning needs or disability has not been formally diagnosed prior to the pregnancy- this may be because their learning need or disability is mild. It is estimated that less than a quarter of people with a learning disability in England are known to health services (ie undiagnosed) Professionals' suspicion that someone has a hidden learning disability should lead to further exploration and care delivered according to the principles of this document
- 2.5.** The term **learning need** will be used throughout this document to encompass all of the above definitions

3. Responsibilities

- 3.1.** It is the responsibility of all maternity staff to adhere to this guideline unless there is a clear reason for deviation from its recommendations- this should be clearly documented.

Role of the Complex Care Midwife:

- 3.2.** The Complex care midwife is responsible for:
- Facilitating the implementation of this guideline
 - Supporting maternity staff in meeting the recommendations

Role of the Learning Disability Service:

- 3.3** The Learning Disability Service is responsible for supporting maternity services in their care of women with additional needs, through referral and also ad-hoc advice and consultancy

4. Screening for additional learning needs

- 4.1.** Any additional learning needs should be screened for *at the start* of the maternity booking appointment, before any additional information is recorded (other than name, date of birth, address etc. If additional needs are identified they should be met before continuing with the booking

4.2. Screening should be completed by asking questions such as:

“Do you have any additional learning needs? Do you require any help or support with reading, writing, or understanding new information”

Additional questions which may help assess:

“Did you attend a mainstream school? Did you need any additional help at school? Were you statemented? Have you ever been tested for ADHD, dyslexia or autism?”

If a woman lives in supported accommodation and/or has a carer or social worker, then this suggests a learning need and should be explored.

- 4.3. If a learning need is suspected but not confirmed by the woman, the GP should be contacted for further information, and the hospital notes reviewed. Care should be delivered in accordance with the principles of this document

5. Learning need identified (or suspected in the case of non-disclosure):

- 5.1. A disclosure of any learning disability or identified need means that you must consider how this will affect the woman’s capacity to understand and retain relevant information, and may impact on her capacity to consent to any intervention, including routine maternity care. Consider whether capacity assessments are necessary and refer to the Mental Capacity Act policy: <https://www.northdevonhealth.nhs.uk/wp-content/uploads/2013/07/Mental-Capacity-Act-Policy-v2-0.pdf>
- 5.2. Aim for face-to-face appointments, and avoid phone appointments. Facial expressions and body language help us to assess someone’s understanding of the subject being discussed- this is not possible over the telephone. Also- people with learning needs often develop compensatory behaviours that will suggest understanding as they may feel uncomfortable about telling the truth (ie that they have not understood what is being said) (Homeyard 2015). It is a legal requirement (relating to “reasonable adjustments” Equality Act, 2010) that extra time is given for appointments, if necessary, to achieve understanding- it may be that another appointment needs to be arranged for the next available opportunity. **Aim to use video calling for any consultation if not seen face to face.**
- 5.3. Explore and gather as much information as possible about the nature of the learning need– ask about schooling-was she in mainstream education? Does she currently receive any support or are there unmet support needs?
- 5.4. Ask the woman what her information needs are (ie does she prefer large text, easy read, pictures etc). This information should guide your maternity care planning and needs should be met (NICE 2010)

- 5.5. Allow extra time in appointments to discuss her maternity care - offer a follow up appointment if short on time at initial booking or disclosure.
- 5.6. Discuss with GP who will provide further information including any historical diagnoses and needs identified
- 5.7. Hospital notes should be reviewed at the earliest possible opportunity by the named midwife or a member of the team, as this may detail previous assessments and diagnoses
- 5.8. If a significant learning need is suspected or identified, offer referral to the learning disability (LD) service, who can offer advice and support as appropriate and in response to need. In the absence of a LD diagnosis, the LD service's input may be limited to ad- hoc advice to the professional only.
- 5.9. Women should be reassured that it is not unusual to require additional support with parenting, and that information that is accessible to them will be provided (WTPY 2016)
- 5.10. Ensure information and plan of care is clearly documented

6. Care planning and ongoing support

- 6.1. The woman's learning needs must be documented in her handheld and hospital notes, alongside a plan for meeting these needs.
- 6.2. Ensure relevant information is shared with all professionals- information about learning needs should be shared on the booking form, and a CANI (Complex or Additional Needs Identified) form completed to be sent to the Complex Care specialist midwife who will support with a coordinated response, including the involvement of the LD service if necessary .
- 6.3. It is the responsibility of the woman's named midwife to ensure that the booking hospital (where the woman plans to give birth) is made aware of identified needs- this information should be shared prior to her first appointment at the hospital
- 6.4. Parents with learning disabilities may be scared to share if they do not understand something or have any concerns- this may be related to fear that they will have their children removed (WTPN 2015). Continuity of carer may help to develop a trusting relationship and reassure the woman that it is safe to share any concerns she may have. Familiarity with the woman and her individual needs will mean that a fair assessment can be made drawing on identified strengths as well as needs, and might increase the efficacy of interventions
- 6.5. Learning needs should be considered at every appointment and capacity confirmed for every decision.

- 6.6. When imparting vital information (such as the importance of the understanding of serious symptoms such as those of pre-eclampsia or reduced fetal movements), consider that discussion (as opposed to unilateral information giving) of the relevant factors is more likely to facilitate understanding (Homeyard 2015). Instead of asking “do you understand”, ask instead “what do you understand from what I have told you?”. Ensure that your documentation evidences the steps you have taken to confirm understanding – eg asking a woman to repeat back what you have told her. Revisit this frequently.
- 6.7. Ensure a plan is written for admission and birth – particularly if you feel a woman may lack capacity at times. The complex care midwife, learning disability specialist nurse or perinatal mental health service can support with this
- 6.8. Devon’s Children’s centres can support our service by contributing towards a thorough assessment of the woman’s circumstances, and can deliver benefits/financial advice, parenting skills and preparation, and provision of items for baby if the woman is affected by poverty/deprivation. This service should be promoted to women as early as possible so that the assessment and support package can be commenced in good time.
- 6.9. Progress and any additional support needs identified will be shared at the vulnerable pregnancy meeting and at Team around the Family (TAF) meetings, or Child in Need/Child protection meetings if Unborn is open to Children’s social care
- 6.10. If it is felt that the woman’s circumstances would lead to her baby being at risk of harm, then a MASH enquiry should be submitted, as always, with the woman’s knowledge (unless this information may put her at risk of harm such as in cases where domestic abuse is suspected). It is the expectation that this information will be shared sensitively with the awareness that this is likely to cause a great deal of anxiety to the woman who may fear that she will have her baby removed from her care. As much information as possible should be sought from relevant agencies prior to submitting a MASH enquiry.
- 6.11. Consideration should be given to the role of Adult Social Care for women for whom their learning need is impacting on their ability to remain safe. Consider raising a safeguarding concern with Care Direct (via Adult Safeguarding on BOB) if the woman has care and support needs and is at risk of or experiencing abuse or neglect, and as a result of her care and support needs is unable to protect herself. This will require consent unless the woman lacks capacity to consent, in which case a best interest decision should be made.
- 6.12. If the woman already has professionals working with her in a supportive role, they must be contacted as part of the coordinated process
- 6.13. The woman’s named midwife, or member of the team, is responsible for contributing to any multi-disciplinary response or care planning, including attendance at meetings, and documentation and dissemination of updated information to relevant professionals

- 6.14. Extra time must be given to developing individualised admission/birth and postnatal plans, with the support of the learning disability service or perinatal mental health team (if open to them), complex care midwife, children's centre and health visiting team. These should be based on identified strengths and needs and must be made available to all staff providing care

7. Suggested supportive resources:

- 7.1. The learning disability service can be contacted on bleep 382, extension 4171; from outside the hospital call 01271 314171. Referral form can be found at: <https://ndht.ndevon.swest.nhs.uk/learning-disability-service/learning-disability-service-referral/>
- 7.2. Consider use of a "hospital passport" for women with significant learning need (the learning disability service can support with this)
- 7.3. If a woman is dyslexic, suggest overlaying a clear yellow (or alternative colour) plastic sheet over the notes to make it easier to read
- 7.4. Women with Autistic Spectrum Disorders (ASD- includes Asperger's) may have their capacity to process and retain information challenged if they are emotionally overwhelmed- aim for a calm and quiet environment and consider how a busier environment (eg Day Assessment Unit) might affect understanding or cause distress. A key principle of the Mental Capacity Act is that people are supported in their decision making- environmental factors must be considered to meet this requirement
- 7.5. The "Baby Buddy" app has been developed specifically for women with additional needs, including learning needs, and its use should be encouraged. It was developed to improve outcomes in women vulnerable to disadvantage. <https://www.bestbeginnings.org.uk/baby-buddy>
- 7.6. "My pregnancy, My choice" is an extensive, easy read resource which describes all aspects of pregnancy and birth, and is valuable to aid discussion. The resource is kept in the manager's office on Bassett ward; it may be borrowed but must be returned after use. Pages or sections may be photocopied if required .
- 7.7. Public Health England have produced easy read screening leaflets which should be used as an aide to understanding, alongside a verbal discussion (ie these leaflets should not replace discussion). Download and print (single sided and in colour) from <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides>

8. Monitoring Compliance with and the Effectiveness of the Guideline

Process for Implementation and Monitoring Compliance and Effectiveness

- 8.1. The Complex Care midwife is responsible for the dissemination of this guideline, monitoring its effectiveness, and delivering training to staff.
- 8.2. The guideline will be monitored through :
 - Reviews of relevant notes through audit and clinical incident reporting
 - Audit
 - Safeguarding supervision

9. References

Department of Health 2001 Valuing People: A New strategy for the 21st century, DoH, London

Homeyard C, Montgomery E, Chinn, D, and Patelarou, E 2015 Current evidence on antenatal care for women with intellectual disabilities: A systematic review *Midwifery* (2015)
<http://dx.doi.org/10.1016/j.midw.2015.10.002i>

MENCAP 2020 Learning Difficulties <https://www.mencap.org.uk/learning-disability-explained/learning-difficulties>

Nasen 2016 Girls and Autism: Flying under the radar Nasen, Staffordshire
Available from <https://nasen.org.uk/uploads/assets/c6c70871-4de8-410f-a444ef1efa0261a6/flying-under-the-radar.pdf>

National Institute for Health and Care Excellence (NICE) 2010 Pregnancy and Complex Social Factors: A Model for pregnant women with complex social factors NICE clinical guideline 110, London

NHS. The NHS long term plan. 2019. <https://www.longtermplan.nhs.uk/>

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 (2007),

10. Associated Documentation

- Managing the care of people with a learning disability in the acute hospital setting Standard Operating Procedure <https://www.northdevonhealth.nhs.uk/wp-content/uploads/2020/10/Learning-disability-SOP-V1.0.pdf>
- Mental health in maternity guideline (in development)
- Mental Capacity Act policy <https://www.northdevonhealth.nhs.uk/wp-content/uploads/2013/07/Mental-Capacity-Act-Policy-v2-0.pdf>
- Identification of a pregnant woman/family with additional or complex needs
- Date Completed:

Identification of a pregnant woman/family with additional or complex needs

Date Completed:

<p>Name: Date Of Birth: NHS number: Address: Phone number:</p> <p>EDD: Parity:</p> <p>Partner/FOB: Partner/FoB's DOB:</p> <p>Other children and DOBs:</p>	<p>Named Midwife: Health Visitor: GP surgery:</p> <hr/> <p>Other professionals (eg IDVA, Social worker, PMHT practitioner) and contact numbers:</p>
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<p>Needs relate to:</p> <p>Mental health <input type="checkbox"/></p> <p>Domestic abuse <input type="checkbox"/></p> <p>Drug or alcohol use <input type="checkbox"/></p> <p>Social work involvement <input type="checkbox"/></p> <p>Under 18 <input type="checkbox"/></p> <p>Learning disability <input type="checkbox"/></p> <p>Other <input type="checkbox"/></p>	<p>Further information:</p> <hr/> <p>Plan:</p>
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Please save form as **(name)CANI** and send to **Jess Harrison** (Complex care midwife) Jessica.harrison13@nhs.net, cc **Angela Whitfield** angela.whitfield1@nhs.net