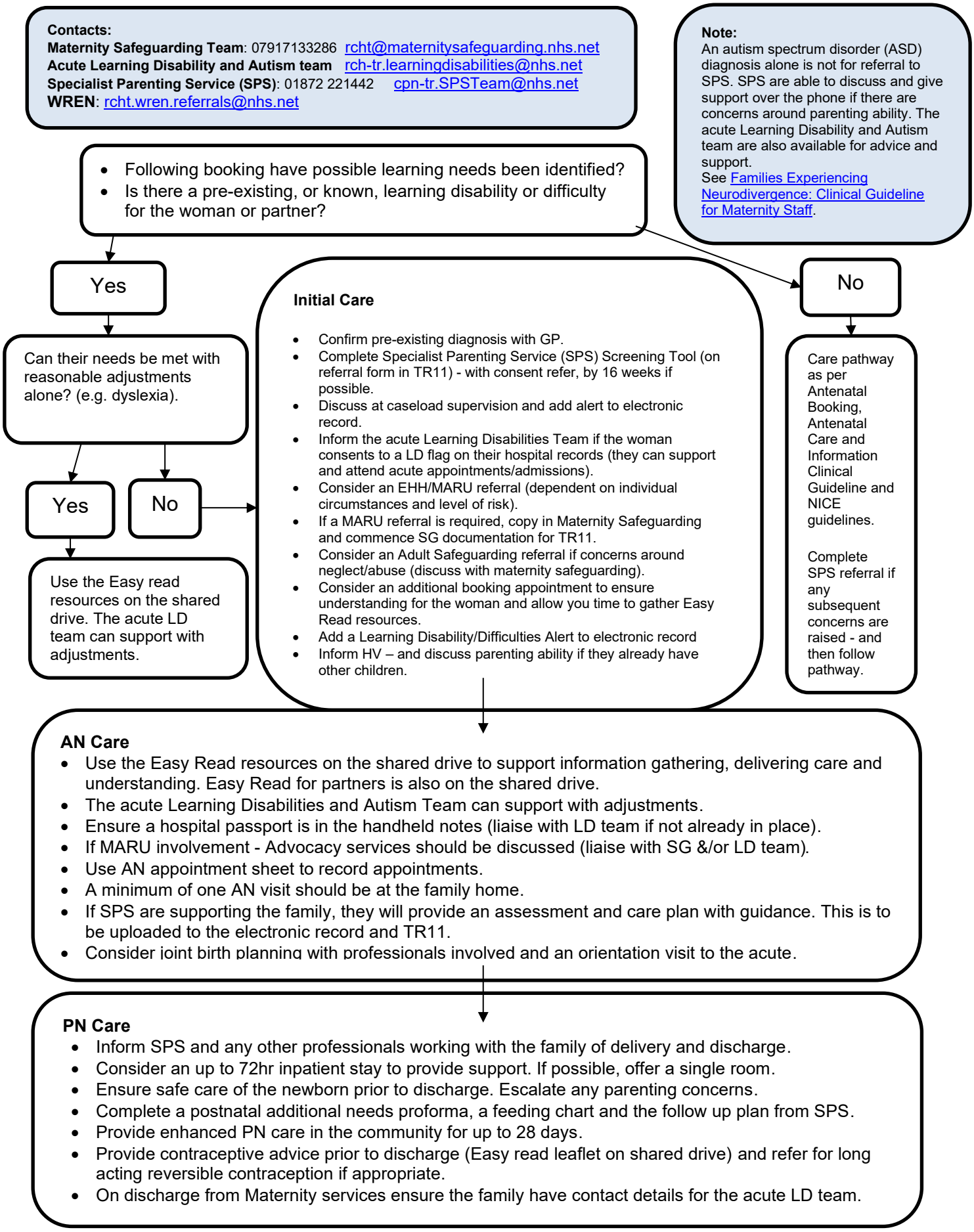
Royal Cornwall Hospitals
NHS Trust

Maternity Care for Expectant Parents with a Learning Disability Clinical Guideline

V4.0

September 2025

Summary. Learning Disability Pathway for Midwives



1. Aim/Purpose of this Guideline

1.1. This aim of this guideline is to improve maternal and neonatal health outcomes by meeting the individual needs of parents who have a learning disability, and to safeguard both adults and their children. This can be achieved by early identification, improved intervention and collaborative working as per Joint agency protocol for Cornwall and the Isles of Scilly (2023).

1.2. A learning disability includes the presence of 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 and functioning (Joint Agency Protocol, 2023).

1.3. The purpose of this guideline is to raise awareness of the significance of a learning disability ensuring early detection and use of the care pathway (See Summary), and to provide individualised care and enhanced support.

1.4. This guideline makes recommendations for women and people who are pregnant. For simplicity of language the guideline uses the term women throughout, but this should be taken to also include people who do not identify as women but who are pregnant, in labour and in the postnatal period. When discussing with a person who does not identify as a woman, please ask them their preferred pronouns and then ensure this is clearly documented in their notes to inform all health care professionals.

1.5. This version supersedes any previous versions of this document.

Data Protection Act 2018 (UK General Data Protection Regulation – GDPR) Legislation.

The Trust has a duty under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 to ensure that there is a valid legal basis to process personal and sensitive data. The legal basis for processing must be identified and documented before the processing begins. In many cases we may need consent; this must be explicit, informed, and documented. We cannot rely on opt out, it must be opt in.

Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 is applicable to all staff; this includes those working as contractors and providers of services.

For more information about your obligations under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 please see the Information Use Framework Policy or contact the Information Governance Team.

Royal Cornwall Hospital Trust rch-tr.infogov@nhs.net

2. The Guidance

2.1. Women with a learning disability may be extremely vulnerable and face significant barriers accessing services. They are more likely to book their pregnancy late and are at increased risk, as they may be unable to follow advice on prevention and safe care. They also have higher rates of co-morbidities.

2.2. The law requires us to make reasonable adjustments in the care we provide, to ensure women with learning needs receive equal standards, access and quality of care. It may be beneficial to use easy read leaflets, larger text, and make additional time for appointments.

2.3. If there are any safeguarding concerns for the unborn/newborn a referral to the Multi-Agency Referral Unit is required. Further guidance can be found in the Maternity Safeguarding Guideline and on TR11 shared drive.

2.4. Role of the Midwife

2.4.1. At booking, enquire about any learning needs for the mother and partner. If identified or suspected, for either parent, discuss what additional support may be available. These include the Specialist Parenting Service (SPS), Acute Learning Disabilities Team, Early Health Hub, and WILD young parents.

2.4.2. A safeguarding Children's referral to the Multi Agency Referral Unit (MARU) should be considered where there is concern that the parents may not be able to meet the needs of the baby due to their disability/difficulties. A Safeguarding adult referral should also be considered where there is a safeguarding concern, and the parent has care and support needs. Discuss with the Maternity Safeguarding team if you require further advice or support.

2.4.3. When a children's MARU or adult safeguarding referral is completed ensure the Maternity Safeguarding team are emailed a copy of the referrals. The person making the referral must also upload this to the electronic maternity record.

2.4.4. When a Children's MARU or adult safeguarding referral is completed, also complete the Maternity Safeguarding documentation for TR11 as per the Standard Operating Procedure for Safeguarding Documentation stored within the Shared TR11 Drive.

2.4.5. Contact the woman's GP through Accurex, with consent, to confirm what diagnosis, if any, has been made. Midwives may be the first to identify a learning disability.

2.4.6. Gain consent to refer to the Specialist Parenting Service (SPS) who will undertake a learning and parenting assessment. If there is no diagnosis in place, the SPS team can undertake a full cognitive assessment, however this needs to be completed prior to 25/40. Therefore, early referral to SPS, preferably by 16/40 is required where possible.

2.4.7. Discuss with Community Team Leader at case loading supervision. If needs can be met with reasonable adjustments alone, use the resources on the shared drive and contact the acute Learning Disability and Autism team for further support.

2.4.8. Pregnant people with a learning disability experience increased health inequality. Therefore, consider referral for a Continuity of Carer Community Midwife.

2.4.9. Consider a second appointment to complete the booking. This will enable the woman and her partner to comprehend manageable amounts of information.

2.4.10. Ask the parents how they prefer information to be given and what helps them remember important information. Utilise the Easy Read resources on shared drive TR11.

2.4.11. Remember to treat with respect. A woman with a learning disability may book late as they may be experiencing denial, confusion in understanding or acknowledging that they are pregnant.

2.4.12. As available, provide continuity of care, to ensure consistency.

2.4.13. Refer to the Health Visitor for the Family Health Plus team ensuring details of referrals and agencies involved. If the parents have other children discuss their parenting abilities with the Health Visitor.

2.4.14. Refer to the Obstetrician if clinically indicated, communicating the required reasonable adjustments.

2.4.15. Record clearly onto the electronic health record and add an alert.

2.4.16. With consent the acute Learning disability (LD) and Autism team can be informed and asked to place an LD flag on the hospital records. This will ensure the LD team are informed of any future admissions or appointments to provide additional support.

2.4.17. Women with a diagnosed Learning Disability should have a Hospital Passport, for use during admissions. If they do not already have one in place, liaise with the acute LD team who can support to create one. A copy is also on the shared drive. This is an NHS tool used to record reasonable adjustments for all staff to follow to ensure effective communication.

2.4.18. Utilise the Antenatal Appointment Sheet, Appendix 5, to record appointments.

2.4.19. An autism spectrum disorder (ASD) diagnosis alone is not for referral to the Special Parenting Services (SPS). They are able to discuss and give support over the phone if there are concerns around parenting ability. The acute LD team are also available for advice and support. Consider a hospital passport depending on needs. The National Autistic Society Hospital Passport can be used if more suitable and refer to the Family Units Experiencing Neurodivergence Guideline.

2.5. Ongoing Care

2.5.1. Home appointments should be considered for the provision of the woman's care, at least one antenatally is required.

2.5.2. The acute Learning Disabilities and Autism Team can support women whilst in the acute setting, they are notified through alerts on PAS when admitted to ward areas. With prior arrangement they can also support at consultant clinics and scans.

2.5.3. Encourage the woman to identify either a close family member or suitable professional to accompany them to their appointments for support if they require this.

2.5.4. Utilise Easy Read documents available on TR11 resources. Enable the parents to access and understand all the standard health and parenting information including breast feeding, to enable them to give consent and make informed choices. Personalised Easy Read can be created in specific situations. Liaise with the acute LD team.

2.5.5. The SPS provide a detailed letter describing their initial assessment of the parents and recommendations for support. This is saved to the electronic maternity record.

2.5.6. Those parents with a learning disability may receive intensive support from the SPS, often with multi-agency support from both Adult and Children's and Families Services, to prepare for the birth of their baby and the parenting role. Other parents with less significant learning needs will be discharged back to other universal and targeted services with recommendations for support.

2.5.7. It can be beneficial for the woman to attend an orientation visit to the unit with her midwife or this can be discussed with the WREN team on an individual basis, with support from the acute learning disabilities team where required.

2.5.8. Advocacy services should be discussed where there is Children and Families Service involvement and court proceedings. See The Advocacy People and Liaise with Maternity Safeguarding, SPS and the allocated Social Worker/s.

2.6. **Post Natal**

2.6.1. Notify the Specialist Parenting Service and/or Social Worker of the delivery.

2.6.2. Consider an inpatient stay up to 72 hours to support with the development of parenting skills. A relaxed environment with additional demonstrations, support and repetition of practical skills is less intimidating if they are in a single room. Accommodate as able.

2.6.3. Feedback is required to ascertain the level of understanding. Maintain contemporaneous documentation of parenting observations during this time.

2.6.4. If possible, allocate the same midwives during the postnatal period. The Maternity Safeguarding and Wren Team, along with the acute Learning Disabilities and Autism team can be contacted for advice and support.

2.6.5. Women may need to observe a skill and repeat it several times to reinforce their learning. Use reflective statements by the woman/partner to assess their comprehension.

2.6.6. Complete Post Natal Proforma (See Appendix 3) as a means of evidencing her attainment of skills and to identify which skills require additional support. This can also be used to aid effective communication between staff involved with her care. Ensure this is retained with her notes on discharge from the hospital for the Community Midwife.

2.6.7. Easy Read information on Safe Sleeping and ICON to be provided.

2.6.8. Maintain contemporaneous and thorough documentation on the Safeguarding documentation located on the shared drive (TR11). This must include details of parenting skills observed, undertaken and the displayed competence. Use this documentation to provide details around positive observations as well as any concerns.

2.6.9. If there are any concerns about the individual's ability to parent safely and independently it is crucial to consider making an urgent MARU referral to safeguard the infant. Even if a previous antenatal referral has not been actioned by MARU.

2.6.10. Provide Feeding Charts (See Appendix 4) to record and remember feeding routines. Some parents may need support to use these or need another method of remembering when they last fed their baby. Assess if they are able to tell and record the time. Support to breastfeed if that is their chosen method of feeding and adapt feeding records accordingly.

2.6.11. Contact all professionals involved in her care of delivery and/or discharge, a discharge planning meeting may be required, liaise with Maternity Safeguarding.

2.6.12. Upon discharge from Maternity Services ensure the woman has accessible contact details for the acute Learning Disability and Autism team. If they OR their baby, need any further hospital treatment or admission, the team will provide support.

2.6.13. A first day home visit is advised and provide enhanced postnatal care in the community for up to 28 days.

2.6.14. Provide thorough contraception advice before discharge. Easy Read information is available for this on the shared drive. If requiring long-acting reversible contraception (LARC), see Long Acting Reversible Contraception (LARC) in the Maternity Setting Standard Operating Procedure.

3. Monitoring compliance and effectiveness

Information Category	Detail of process and methodology for monitoring compliance
Element to be monitored	Correct Maternity Pathway has been followed.
Lead	Safeguarding Midwife.
Tool	• When appropriate a timely referral to SPS has been completed. • A Hospital Passport is completed. • The Post Natal Proforma has been completed. • Reasonable adjustments where required. • Enhanced Postnatal Care.
Frequency	3 yearly.
Reporting arrangements	• Maternity and Obstetric Business and Governance. Safeguarding Operational Group.
Acting on recommendations and Lead(s)	• The Named Midwife for Safeguarding. • Maternity Matrons.
Change in practice and lessons to be shared	• Lessons learned will be shared with all the relevant stakeholders. • Perinatal Newsletter. • Level 3 Maternity Safeguarding Training.

4. Equality and Diversity

4.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the Equality Diversity And Inclusion Policy or the Equality and Diversity website.

4.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.

Appendix 1. Governance Information

Information Category	Detailed Information
Document Title:	Maternity Care for Expectant Parents with a Learning Disability Clinical Guideline V4.0
This document replaces (exact title of previous version):	Learning Disability Guidance for Expectant Parents - Clinical Guideline V3.0
Date Issued/Approved:	September 2025
Date Valid From:	September 2025
Date Valid To:	September 2028
Directorate/Department responsible (author/owner):	Suzie Williams, Named Midwife for Safeguarding
Contact details:	01872 255741
Brief summary of contents:	The aim of this guideline is to improve maternal and neonatal health outcomes by meeting the individual needs of parents who have a learning disability.
Suggested Keywords:	Disability, safeguarding, needs, appointments, screening, learning, MARU.
Target Audience:	**RCHT:** Yes **CFT:** No **CIOS ICB:** No
Executive Director responsible for Policy:	Chief Medical Officer
Approval route for consultation and ratification:	Maternity Guidelines Group. Safeguarding Operational Group.
Manager confirming approval processes:	Caroline Chappell
Name of Governance Lead confirming consultation and ratification:	Michael Cross
Links to key external standards:	None
Related Documents:	• MBRRACE-UK (Maternal, Newborn and Infant Clinical Outcome Review Programme), Saving Lives, Improving Mothers' Care 2024 – Lessons Learned to inform maternity care from the UK and Ireland Confidential

Information Category	Detailed Information
	Enquiries into Maternal Deaths and Morbidity 2020-22 (2024). • Cornwall Partnership NHS Trust (2023) Working together to support parents with a learning disability. Joint agency protocol for Cornwall and The Isles of Scilly. • D.O.H and NHS Commissioning Board (2012) Compassion in Practice, Nursing, Midwifery and care staff: Our vision and Strategy • Birthrights (2021) Disability and long-term health conditions and maternity care. • Mencap (2012) Death by Indifference, 74 and counting. A progress report five years on. 2006.423 report. • Malouf, M., McLeish, J., Ryan, S., Gra, R. & Redshaw, M. (2017) We both just wanted to be normal parents: a qualitative study of the experience of maternity care for women with a learning disability. British Medical Journal. doi:10.1136/bmjopen-2016-015526. • Cox, A., Ip, A., Watkin, S., Matuska, G., Bunford, S., Gallagher, A & Taylor, C. (2024). Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England. Midwifery: 133. https://doi.org/10.1016/j.midw.2024.104019. • Livingstone, C (2025) Improving maternity care and support for pregnant women with disabilities. Royal College of Midwives. Online. Improving maternity care and support for pregnant women with disabilities - Royal College of Midwives • Images copyright of LYPFT (Leeds and York Partnership NHS Foundation Trust).
Training Need Identified?	No
Publication Location (refer to Policy on Policies – Approvals and Ratification):	Internet and Intranet
Document Library Folder/Sub Folder:	Clinical / Midwifery and Obstetrics

Version Control Table

Date	Version Number	Summary of Changes	Changes Made by
January 2016	V1.0	Initial issue	Sandra Whitehall, Specialist midwife for Women with Complex Needs
April 2019	V2.0	Pathway and appendices updated. Definition included. Change in roles and services available.	Suzie Williams and Bernie Dolan Named Midwives for Safeguarding
May 2022	V3.0	Guideline reviewed and updated. Changes made to Pathway, appendix 1.	Suzie Williams Named Midwife for Safeguarding
September 2025	V4.0	Guideline reviewed and updated. Addition of Appendix 5.	Holly Streeter Safeguarding Specialist Midwife

All or part of this document can be released under the Freedom of Information Act 2000.

All Policies, Strategies and Operating Procedures, including Business Plans, are to be kept for the lifetime of the organisation plus 6 years.

This document is only valid on the day of printing.

Controlled Document.

This document has been created following the Royal Cornwall Hospitals NHS Trust The Policy on Policies (Development and Management of Knowledge Procedural and Web Documents Policy). It should not be altered in any way without the express permission of the author or their Line Manager.

Appendix 2. Equality Impact Assessment

Section 1: Equality Impact Assessment (EIA) Form

The EIA process allows the Trust to identify where a policy or service may have a negative impact on an individual or particular group of people.

For guidance please refer to the Equality Impact Assessment Policy (available from the document library) or contact the Equality, Diversity, and Inclusion Team rcht.inclusion@nhs.net

Information Category	Detailed Information
Name of the strategy/policy/proposal/service function to be assessed:	Learning Disability Guidance for Expectant Parents - Clinical Guideline V4.0
Directorate and service area:	Midwifery and Obstetrics
Is this a new or existing Policy?	Existing
Name of individual completing EIA (Should be completed by an individual with a good understanding of the Service/Policy):	Suzie Williams Named Midwife for Safeguarding
Contact details:	01872 255741

Information Category	Detailed Information
1. Policy Aim - Who is the Policy aimed at? (The Policy is the Strategy, Policy, Proposal or Service Change to be assessed)	The aim of this guideline is to improve maternal and neonatal health outcomes by meeting the individual needs of parents who have a learning disability.
2. Policy Objectives	To provide all staff with tools to enable early identification and facilitate provision of information that is tailored to parent's specific learning needs.
3. Policy Intended Outcomes	Improved patient experience by enabling parents to develop skills requisite to safely provide care for themselves and their new-born baby.
4. How will you measure each outcome?	Compliance Monitoring Tool.
5. Who is intended to benefit from the policy?	All pregnant women and their partners.

Information Category	Detailed Information
6a. Who did you consult with? (Please select Yes or No for each category)	• Workforce: Yes • Patients/visitors: No • Local groups/system partners: No • External organisations: No • Other: No
6b. Please list the individuals/groups who have been consulted about this policy.	**Please record specific names of individuals/ groups:** Maternity Guidelines Group. Adult Safeguarding Operational Group. Specialist Parenting Service.
6c. What was the outcome of the consultation?	Guideline Agreed.
6d. Have you used any of the following to assist your assessment?	**National or local statistics, audits, activity reports, process maps, complaints, staff or patient surveys:** No.

7. The Impact

Following consultation with key groups, has a negative impact been identified for any protected characteristic? Please note that a rationale is required for each one.

Where a negative impact is identified without rationale, the key groups will need to be consulted again.

Protected Characteristic	(Yes or No)	Rationale
Age	No	
Sex (male or female)	No	
Gender reassignment (Transgender, non-binary, gender fluid etc.)	No	
Race	No	
Disability (e.g. physical or cognitive impairment, mental health, long term conditions etc.)	No	
Religion or belief	No	

Protected Characteristic	(Yes or No)	Rationale
Marriage and civil partnership	No	
Pregnancy and maternity	No	
Sexual orientation (e.g. gay, straight, bisexual, lesbian etc.)	No	

A robust rationale must be in place for all protected characteristics. If a negative impact has been identified, please complete section 2. If no negative impact has been identified and if this is not a major service change, you can end the assessment here.

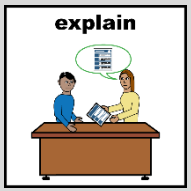
I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.

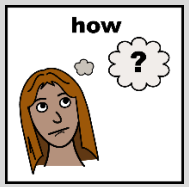
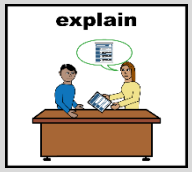
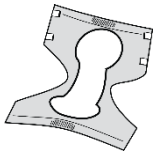
Name of person confirming result of initial impact assessment: Suzie Williams Named Midwife for Safeguarding.

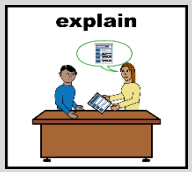
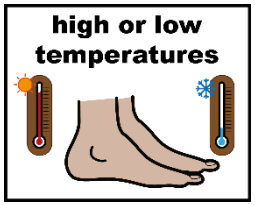
If a negative impact has been identified above OR this is a major service change, you will need to complete section 2 of the EIA form available here:
Section 2. Full Equality Analysis

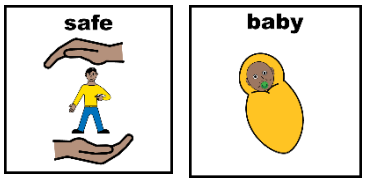
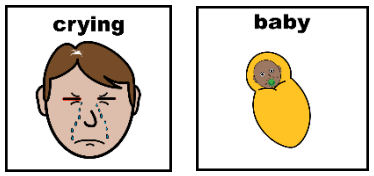
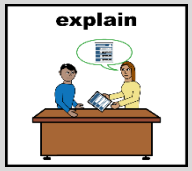
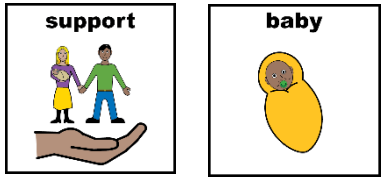
Appendix 3: Postnatal Additional Support Proforma (to be kept by the parent/s)

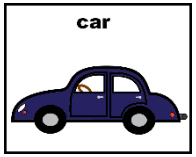
For parents use to evidence the level of support required to provide physical and emotional care for their newborn baby, also their own needs. Images with permission from Leeds and York Partnership NHS Foundation Trust (LYPFT).

		Objective **(Can I do this?)** 	**Discussed and Demonstrated** (If applicable) 	**Observed** 	**Requires support** 	**Can do Alone** 
1	 	**How to contact the midwife & get help**				
2		**Skin to Skin contact**				
3		**Safe Handling of baby**				

		Objective (Can I do this?) 	Discussed and Demonstrate 	Observed 	Requires support 	Can do Alone 
4	 	Nappy Changing				
5	 	Suitable Clothing for Baby				
6	 	Recognising Feeding Cues				

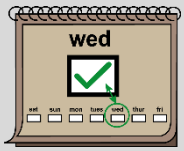
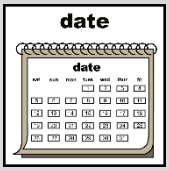
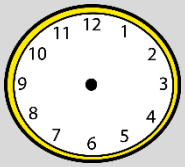
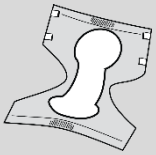
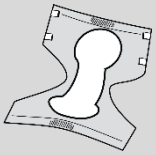
7		**Hand Hygiene**				
		Objective **(Can I do this?)** 	**Discussed and Demonstrate** 	**Observed** 	**Requires support** 	**Can do Alone** 
8	 	**Talking to Baby**				
9		**Appropriate Temperature of room and Baby**				

10		**Safe Sleeping** **SIDS** **Cot Death**				
11		**Coping with a Crying baby ICON**				
		Objective **(Can I do this?)** 	**Discussed and Demonstrate** 	**Observed** 	**Requires support** 	**Can do Alone** 
12		**Winding baby**				

13	 	**Car Safety Car Seat**				
14		**Personal Care**				
15		**Manage Emotional & Mental Health**				

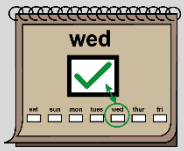
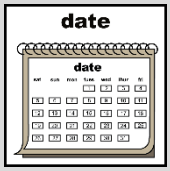
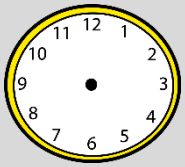
Appendix 4: Feeding Chart

For parents use, form to be kept by parent/s.

Day 	Date 	Time 	Feed  	Wet Napy 	Dirty Nappy 

Appendix 5: Appointment Record

For parents use, form to be kept by parent/s.

Day 	Date 	Time 	Place  	Person