

"Currently UHL utilises the terms 'woman' and 'women' within their obstetric and maternity guidelines but these recommendations will also apply to people who do not identify as women but are pregnant or have given birth."

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1. Introduction and who this guideline applies to

The Disability Discrimination Act (1995) states that women with a learning disability have a right to be provided with information about their care in a form that is accessible. This guideline aims to assist midwives to consider and plan with the woman on how her particular needs can be accommodated, working with other professionals and agencies where appropriate.

Accessible discrimination Act 2015 (AIS) – requirement that we identify and provide information.

Related UHL documents:

- [Safeguarding Adults UHL](#)
- [The Mental Capacity Act Policy Trust reference B23/2007](#)
- [The mental Capacity Act Code of Practice;](#)
- [The UHL Deprivation of Liberty Safeguards Policy and Procedure Trust reference B15/2009](#)
- [The UHL Deprivation of Liberty Safeguards Code of Practice;](#)

- [The Safeguarding Adults Policy and Procedure reference B26/2011 – only if the woman is being abused or neglected by a 3rd party.](#)

Definition of 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, Valuing People 2001)

In addition, please note any reference to a child includes a person under the age of 21 who has a learning disability (Children’s Act 2004).

2. Management of care for pregnant women with a learning disability

2.1 Issues in pregnancy, antenatal care, communication and education

- One third of pregnant woman with a learning disability report moderate to severe levels of stress, anxiety and depression.
- The babies of mothers with learning disabilities are at increased risk of poor birth outcomes, including:
 - Premature birth (28%)
 - Low birthweight (22%)
- 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 leaflets, 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.
- Comments made by health professionals can be taken at a literal level and therefore the tone may be misunderstood: it is important to avoid medical jargon.
- Parents with learning disabilities may be too shy to ask questions or say 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.

2.2 Antenatal Care:

Follow the NICE 2021 [www.nice.org.uk antenatal-care](http://www.nice.org.uk/antenatal-care) guidelines and in addition:

- The booking appointment should be completed by the community midwife. If the woman is under the age of 19 years old refer the woman to the Specialist Midwives for vulnerable people (Phoenix Team) for the attention of the Specialist midwife for teenagers.
- Women with recognisable learning disabilities should be referred to the Specialist Midwives for vulnerable people (Phoenix Team).
- Assess the partner’s capacity to provide effective support.

- Inform the health visitor and GP during the antenatal period that you are caring for a woman with a learning disability. HV form to be completed and sent and task/discuss with the GP. Document that this has been completed on the electronic patient records system/E3.
- Give more time at this appointment and consider a booking at home in their familiar surroundings. Establish the level of their learning disability and try to arrange a person/advocate whom they trust at the appointment. It is good practice to establish a term for their disability with which they feel comfortable and use in future acknowledgement and documentation. Use easy read documents (available in additional resources) and use language such as; can you read and write?
- Discuss your concerns with the learning disability team either by email or phone on learningdisabilities@uhl-tr.nhs.uk or 01162502809.
- Complete a multi-agency safeguarding referral form (A form) only if you have concerns that the learning disability will impact on the woman's ability to care for her baby and safeguard her baby from risk or potential risk. Discuss with the safeguarding team and consider a referral for support, with the consent of the woman.
- Consider referral to adult safeguarding
- An individualised plan of care should be devised and documented (appendix 3), a copy should be uploaded onto E3 and placed in the handheld records.
- More frequent antenatal visits may be required with continuity of carer if resource availability (caseholding), possibly being at their home to support the woman. Additional antenatal visits can be completed by the specialist Support Worker.
- Attend any Child protection meetings relating to the unborn and inform the Safe guarding Midwife of the outcome and document this action.
- Plan appointments for a one to one birth plan and parenting education involving those close to the woman to increase her support.
- Arrange parent education and complete a birth plan on a one to one level.
- Document a support plan in handheld notes, trust notes and E3 including contact details of any involved support workers.

Where possible give continuity of care and involve a trusted family member or friend of the woman.

2.3 Disability Teams

There are 5 learning disability teams identified for Leicester, and Leicestershire (establish if woman known to services)

- North West Leicestershire – team based at Coalville Community Resource Centre – Tel 01530 834422
- South West Leicestershire and Harborough – team based at Bassett Street – Tel 0116 2787111
- Charnwood – team based at Bridge Park Plaza – Tel 0116 2294048
- Melton – team based at The Mount – Tel 01664 561074
- Hinckley and Bosworth – team based at 27 Upper Bond Street – Tel- 01455 636964
- Learning Disability Acute Liaison Nurse Team on 0116 250 2809 or learningdisabilities@uhl-tr.nhs.uk if assistance or advice is required.

2.4 Assessing Capacity

- Following the establishment of a learning disability do not make assumptions about the woman's ability to understand and make decisions. If you have doubts about her mental capacity then consult the UHL Mental Capacity Act policy and refer to Appendix 1 'Mental Capacity Act Flowchart' for guidance (Insite Document number: 38513). The Act is supported by a code of Practice (<http://www.dca.gov.uk/legal-policy/mental-capacity/mca->

[cp.pdf](#)) which gives guidance for those who have duties and functions under the Act also adhere to the NMC code (2008).

- If you have doubts about the person's capacity to make decisions then you must complete the 2 stage test of capacity for each specific decision at the time it is needed. Refer to the Mental Capacity Act policy and the MCA WebPages on Insite for guidance: [Safeguarding Adults UHL](#)
- 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 can go on to make an informed decision. If the woman does not have the ability to understand consider the need for assessment and refer to trust reference [B23/2007 Mental Capacity Act Policy](#).
- Referral to the weekly Perinatal Mental Health Team clinic may be considered to assess mental capacity and consent.

2.5 Hospital based care:

- Staff caring for the woman in labour should refer to any plans made for the woman and ensure communication needs are met.
- An advocate must be present at all times if the woman is deemed to not have mental capacity.
- An advocate must be present at all times if the woman is under the age of 18.
- A longer stay in hospital must be considered to facilitate learning of parenting skills with a parenting skills log for documentation of care given and for review of any problems.
- If there are any parenting concerns discuss with the woman but also inform the safeguarding Midwife and document.
- If the woman wishes to self-discharge against medical advice you should first discuss with the woman and her advocate, ascertaining the reason why she wants to self-discharge. The person in charge of her 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'. (Insite Document Number:52278) and the DoLS WebPages on Insite for immediate advice and guidance: [Safeguarding Adults UHL](#)
- Notify the safeguarding midwife if the woman is deemed not to have mental capacity.

2.6 Postnatal care:

- The frequency and length of postnatal visits by the community midwife must be tailored to the woman's needs. 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 reported to the social care team and documented.

Additional Resources (Easy Read Guides)

[Screening for hepatitis B, HIV and syphilis](#)

[Screening for sickle cell disease and thalassaemia](#)

[Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome](#)

[Screening your baby's body](#)

[Eye screening for women with diabetes](#)

[Looking at your baby's heart, eyes, hips and testicles \(balls\)](#)

[Looking at your baby's hearing](#)

[Blood spot tests](#)

3. Education and Training

None

4. Monitoring Compliance

None

5. References:

1. The Disability Discrimination Act (1995)
2. The Children's Act (2004)
3. The NMC (2008). The code: Standards of conduct, performance and ethics for nurses and midwives.
4. NICE 2021 [www.nice.org.uk antenatal-care](http://www.nice.org.uk/antenatal-care) National Institute for Health and Clinical Excellence, Antenatal care. DOH.
5. <https://www.gov.uk/government/publications/antenatal-and-newborn-screening-identifying-and-reducing-inequalities> (accessed 22/02/23)
6. <https://www.gov.uk/government/publications/pharmacy-and-people-with-learning-disabilities/pharmacy-and-people-with-learning-disabilities-making-reasonable-adjustments-to-services> (accessed 22/02/23)
7. <https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-making-reasonable-adjustments-guidance> (accessed 22/02/23)
8. NICE 2015 ng11: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. <https://www.nice.org.uk/guidance/ng11>

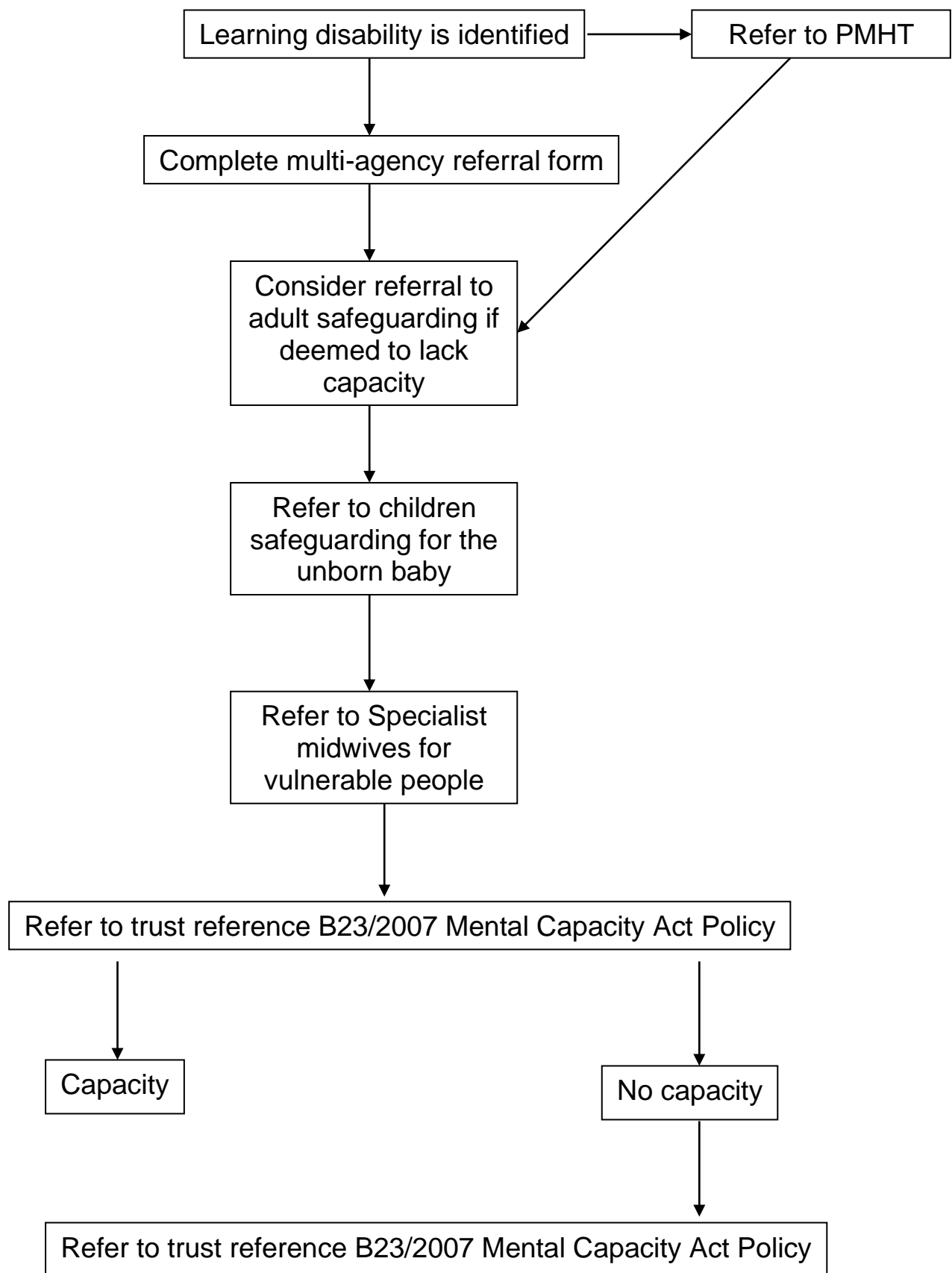
6. Key Words

Autism, Safeguarding, Mental capacity, Advocate

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

CONTACT AND REVIEW DETAILS			
Guideline Lead (Name and Title)		Executive Lead	
Details of Changes made during review:			
Date	Issue Number	Reviewed By	Description Of Changes (If Any)
2011	1		Author: Clare Robinson
March 2014	2	Clare Robinson. Reviewed by: C Robinson, L Robinson, M Duffy	Minimal changes
March 2017	2	Clare Robinson. Reviewed by: C Robinson, L Robinson, M Duffy	No change to practice
January 2021	3	C Robinson, L Robinson, M Duffy & H Archer	Hyperlinks added. Definition updated. Issues in pregnancy, antenatal care, communication and education added. Contact details for learning disability team updated. Additional resources added. Care pathway updated. Plan of care template updated. Maternity pathway added. Learning disability screening tool added.
February 2023	4	Gina Twist LTaylor	Now includes; <ul style="list-style-type: none"> • Consider referral to adult safeguarding • Parents with a learning disability should be accompanied by an advocate at all times • Women with recognisable learning disabilities should be referred to the Specialist Midwives for vulnerable people (Phoenix Team) • Referral to the weekly Perinatal Mental Health Team clinic may be considered to assess mental capacity and consent. • An advocate must be present at all times if the woman is under the age of 18

Appendix 1 - CARE PATHWAY FOR PROFESSIONALS



Appendix 2 - Care Pathway for women with a learning Disability

	Confirmation of Pregnancy	<ul style="list-style-type: none"> • Arrange booking appointment • Refer to specialist midwife for teenagers if <19 years old • Consider booking at home with more time
8-10 weeks	<p>Booking Appointment</p> <p>Multidisciplinary Assessment</p>	<ul style="list-style-type: none"> • Establish learning disability (contact the GP if uncertainty regarding this). • Complete AForm – send to maternity safeguarding mailbox and Pregnancy bookings mailbox. • Inform the GP and complete HV form. • Email learning disability acute liaison team with details of pregnant women for information. • Discuss and confirm advocate • Refer to mental capacity act policy (B23/2007) if any doubts about the woman's mental capacity. • Assess social circumstances and risk included on AForm • Provide information on benefits, healthy start, health in pregnancy grant and sure start maternity grant • Provide additional resources • Refer to vulnerable midwives teams – consider caseloading/shared care. Referral to specialist Support Worker.
15 – 16 weeks	<p>Antenatal Check (With Midwife and specialist Support Worker if referral accepted)</p> <p>Implement Care Plan</p>	<ul style="list-style-type: none"> • Send HV form • Refer to mental capacity act policy (B23/2007) if any doubts about the woman's mental capacity. • Document 15/40 results on E3 and in handheld records. • Risk assessment
21 weeks	Antenatal Contact (With Midwife)	<ul style="list-style-type: none"> • Ensure woman understands findings from 20 weeks scan.
25 weeks	Antenatal Appointment (With Midwife)	<ul style="list-style-type: none"> • Monitor progress • Routine antenatal check • Discuss feeding
28 weeks	Antenatal Appointment (With Midwife)	<ul style="list-style-type: none"> • Review care plan • Routine Antenatal Check • Reassess social circumstances/risk
30 weeks	Support Visit (Specialist Support Worker)	<ul style="list-style-type: none"> • Discuss getting ready for baby • Discuss benefits, finances, housing etc

32 weeks	Antenatal Appointment (With Midwife)	<ul style="list-style-type: none"> • Routine Antenatal Check • Risk Assessment
34 weeks	Antenatal Appointment (With Midwife)	<ul style="list-style-type: none"> • Routine Antenatal Check • Risk Assessment
36 weeks	Antenatal Appointment (With Midwife)	<ul style="list-style-type: none"> • Routine Antenatal Check • Risk Assessment • Discuss birth plan. • Complete a plan for labour with the woman. Document a support plan in the handheld records and on E3, and include details of support workers. • Liaise with Delivery Suite Co-Ordinator/Manager to arrange any additional adjustments • Liaise with Antenatal/Postnatal Manager to arrange any additional adjustments
38 weeks	Antenatal Appointment (With Midwife and specialist Support Worker if referral accepted)	<ul style="list-style-type: none"> • Routine Antenatal Check • Further preparations for parenthood
40 & 41 weeks	Antenatal Appointment (With Midwife and specialist Support Worker if referral accepted)	<ul style="list-style-type: none"> • Discuss discharge plan • Discuss membrane sweep and IOL and gain consent if able to do so. • Discuss SIDS advice. • Discuss feeding. • Discuss birth plan
	Birth	<ul style="list-style-type: none"> • Staff caring for the woman in labour should refer to any plans made for the woman and ensure communication needs are met. • If the woman is going to be an inpatient for >72hours and lacks capacity, consider DoLs referral. • A longer stay in hospital should be considered to facilitate learning of parenting skills with a parenting log for documentation of care given and for review of any problems. • If any problems are identified discuss with the woman but also inform safeguarding midwife and document.
0 day to 28 days Post delivery	Postnatal Care (With Midwife and specialist Support Worker if referral accepted)	<ul style="list-style-type: none"> • Postnatal visits as required. • Ensure woman has support and contact numbers. • Continue multidisciplinary Support/Postnatal Care Plan

Appendix 3: Plan of care template:

My Pregnancy Support Plan

For women who may benefit from reasonable adjustments during their pregnancy

Personal Information

My name is -

I like to be called -

My date of birth -

If I am admitted to hospital on my own, please call -

About me

My medical conditions that you should be aware of –

How I like to communicate and how you can support me with this –

e.g. pictures, symbols, hearing difficulties

Sensory difficulties and how you can support me –

e.g. smells, lights, taste, hypersensitivity to touch

Things that may cause me to become upset –

E.g. lots of people talking, pain, stress, loud noises, bright lights, being touched

How you can help and support me –

How to support me during my pregnancy

E.g. arrange my appointments for quieter times, show me pictures of the wards to help familiarise myself, prepare me for my visits by giving me a list of what I need to bring, give me prior notice if you need to take blood or touch me

My Birth Plan

Who will be with me whilst I am in hospital –

Things I would like to try in labour and how you can support me –

E.g. personal items, not touching me, lowlighting, using water/bath, music

How I will communicate my pain –

Other things to consider –

I am happy to have students involved with my care

I am happy to have male health care professionals involved with my care

I would like to wear my own clothes in labour

I would like to wear a hospital gown in labour

After birth i would like to have skin to skin with my baby

I would like to have delayed cord clamping

I would like my baby to have the vitamin K injection

I have discussed the delivery of my placenta with my midwife and I would like to have -

Physiological

Active Management

How I would like to feed my baby and how you can support me -

My postnatal Care

Things I would like support with if I go to the postnatal ward –

E.g. ward orientation, when meal times are, when drinks will be offered, if I would like a side room, dim lights, curtains around my bed

Special dietary requirements –

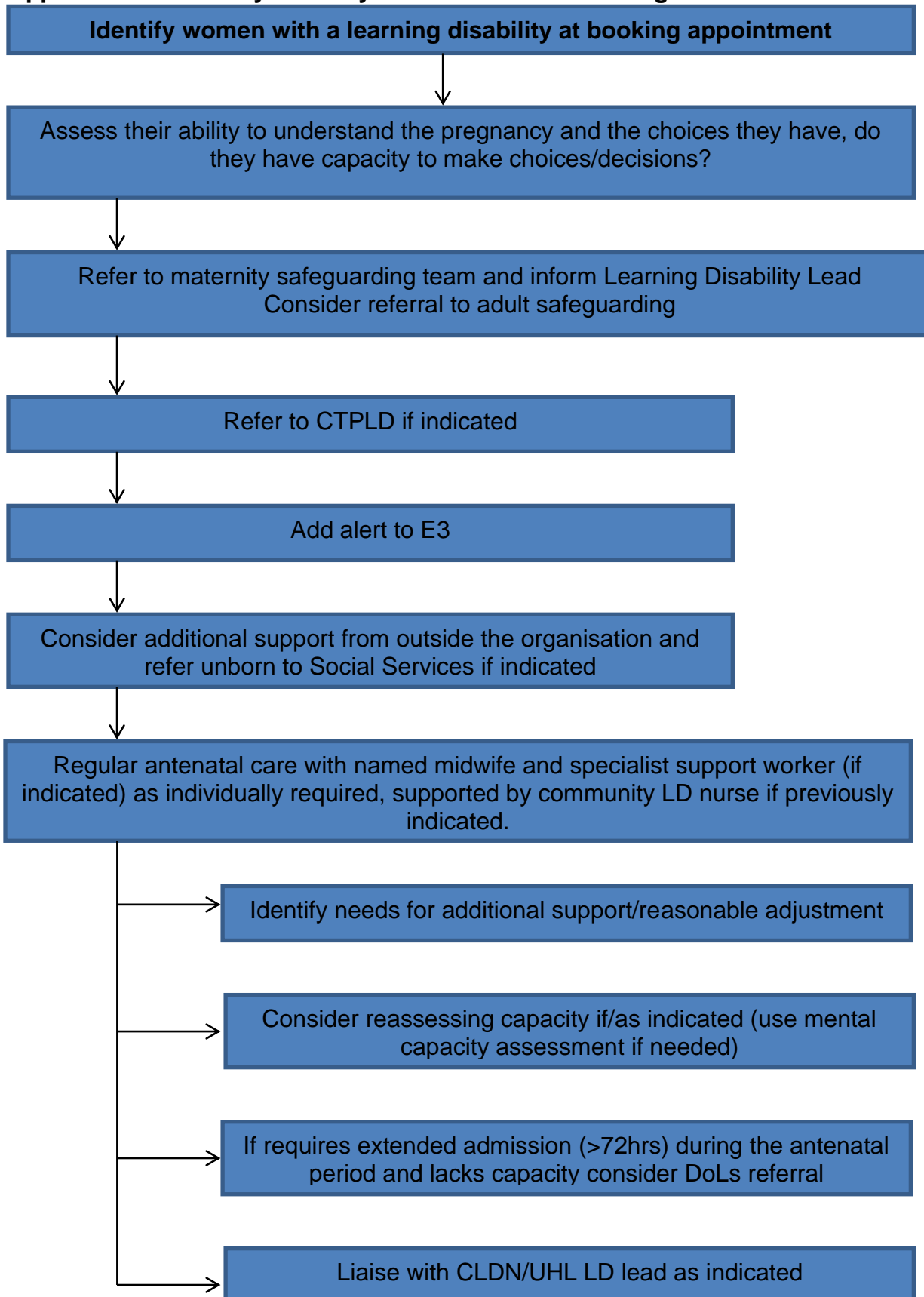
Who I would like to visit me –

Who will be with me when I go home –

What I would like support with –

Anything else I would like you to know about me

Appendix 4 - Maternity Pathway for Women with Learning Disabilities and their families



By 36/40 complete plan for Delivery and Postnatal Period

- Liaise with delivery suite Co-ordinator/Manager to arrange any additional adjustments that might be required
- Liaise with Antenatal/Postnatal manager and arrange additional adjustments that might be required.
- Ensure birth plan has been discussed and is completed

On Admission to Delivery Suite, Mental Capacity to be reassessed (if indicated)

- 36/40 to be followed and reasonable adjustments to be made where needed/appropriate. If going to be an inpatient for >72hours and lacks capacity may need to consider DOLS.

At Discharge

- Ensure all services are aware of discharge
- Give all information re postnatal care in a manner/format that the woman and her family understand
- Ensure woman and her family have all relevant contact details and services involved

Appendix 5 - Learning Disability Screening Tool

Please use this tool if you suspect that the lady may have a global learning disability requiring joint working between the midwife and a community learning disability nurse.

Name of person completing the form:	
Designation:	
Name of Patient:	
NHS Number / Date of Birth:	
Date of completion:	

Please circle appropriate answer.

1	<p>Has the person had a diagnosis of a learning disability in any paperwork? (Previous ICD10 Code (F70/71 or F72/73) or READ Code using Eu81z-1)</p> <p><i>Please refer to 'Definition of Learning Disability', page 2, and conditions that can be confused with learning disability, learning difficulties do not necessarily mean they have a learning disability.</i></p>	Yes	No
2	<p>Does the person have a clinical syndrome likely to be a cause of learning disability?</p> <p><i>For example: Down's syndrome, Fragile X etc</i></p>	Yes	No
3	<p>Do the person's medical records show results of formal assessments with an IQ Score below 70?</p> <p><i>For example: Wechsler Adult Intelligence Scale (WAIS) or Wechsler Intelligence Scale for Children (WISC).</i></p>	Yes	No
4	Has the person been known to Learning Disability Health Professionals:		
	Psychiatrist	Yes	No
	Learning Disability Community Nurse	Yes	No
	Speech Therapist	Yes	No
	Psychologist	Yes	No
	Physiotherapist	Yes	No
	Occupational Therapist	Yes	No
	Outreach	Yes	No
	CAMHS - LD	Yes	No
5	Have they attended any Learning Disability Health Services such as:		
	In-Patient (E.g The Agnes Unit)	Yes	No
	Short Break (respite care)	Yes	No

If you have answered yes to any of the above questions it is likely the person has a learning disability. Please make a referral to the community LD team (LDRMT), copying in the UHL Learning Disability Acute Liaison Team (learningdisabilities@uhl-tr.nhs.uk) and including a copy of this screening tool.

If you have answered no to all the above questions please continue from question 6.

6	Did the person have a significant delay in reaching the following developmental Milestones within the appropriate age range? <i>A significant delay in more than one area of development may indicate the person has a learning disability, unless there is another possible reason, for example cerebral palsy or physical disability.</i>			
	Sit up (unsupported)	Yes	No	
	Crawl	Yes	No	
	Walk	Yes	No	
	Speak in full sentences	Yes	No	
	Bowel & bladder control	Yes	No	
7	Did the person go to a special school or have additional support at a mainstream school? <i>It may be necessary to ask the relevant professionals for copies of reports.</i>		Yes No	
8	Has the person been statemented for child education as having a learning disability? <i>This does not include support for emotional / behavioural difficulties alone but for health difficulties affecting education</i>		Yes No	
9	Has the person passed any formal academic qualifications ('O' levels, CSE's, GCSE's, BTEC level 3 'A' Levels or higher)		Yes No	
10	Does the person hold a full UK driving licence?		Yes No	
Adaptive skills (also known as social competence or social skills functioning) <i>This must be completed when person is in a period of stable health, not when physically or mentally ill, under the influence of substances or post incident distress.</i> <i>Ask the person, family or carers for the 6 months prior to this screening being completed</i>				
Tick the most appropriate box		Fully independent (no help / prompting needed)	Some help and/or prompting needed	Fully dependent on others / carers.
(a) Communication				
(b) Self care (washing, etc.)				
(c) Home living (domestic skills, e.g. setting the table, cooking, cleaning, Hoovering)				
(d) Social skills (relationships, e.g. has good friends/ goes out independently with friends)				
(e) Use of community facilities (e.g. accesses library, leisure activities independently)				
(f) Self direction (e.g. structuring your day, setting goals)				
(g) Health and Safety (e.g. understanding of danger)				
(h) Reading and Writing				
(i) Uses public transport and can determine new routes to places.				
(j) Paid employment (kind of work)				
(k) Can they text or use the internet?				
(l) Can they understand the value of different coins?				

If you have answered 'Yes' to questions 7 and 8, No to questions 9 and 10, and there are more ticks in the 'some help/prompting needed and fully dependent' column of the adaptive skills table this may suggest that the person has a learning disability.

Please make a referral to the community LD team (LDRMT), copying in the UHL Learning Disability Acute Liaison Team (learningdisabilities@uhl-tr.co.uk) and including a copy of this screening tool.