

Supporting women with Disabilities and Special Needs through pregnancy

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Guideline to be followed by (target staff):

To be read in conjunction with the following documents:

- Milton Keynes University Hospital NHS Foundation Trust. *Anaesthetic involvement in maternity care*. MIDW/GL/105. Version 6, 2019.
- Milton Keynes University Hospital NHS Foundation Trust. *Antenatal care pathway*. MIDW/GL/137. Version 9, 2020.
- Milton Keynes University Hospital NHS Foundation Trust. *Baby alert*. MIDW/FM/26. Undated.
- Milton Keynes University Hospital NHS Foundation Trust. *Maternity multidisciplinary confidential communiqué*. MIDW/GL/116. Version 7, 2017.
- Milton Keynes University Hospital NHS Foundation Trust. *Perinatal mental health*. MIDW/GL/103. Version 6, 2019.
- Milton Keynes University Hospital NHS Foundation Trust. *Vulnerable team operational guidelines*. MIDW/GL/149. Version 3, 2019.
- Milton Keynes University Hospital NHS Foundation Trust. *Standardised management plans for common conditions in pregnancy* MIDW/GL/176. Version 3, 2017.
- Milton Keynes University Hospital NHS Foundation Trust. *Postnatal care pathway*. MIDW/GL/136. Version 4, 2020.
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Are there any eCARE implications? **No**

CQC Fundamental standards:

- Regulation 9 – person centred care
- Regulation 10 – dignity and respect
- Regulation 11 – Need for consent
- Regulation 12 – Safe care and treatment
- Regulation 13 – Safeguarding service users from abuse and improper treatment
- Regulation 17 – Good governance

Disclaimer –

Since every patient's history is different, and even the most exhaustive sources of information cannot cover every possible eventuality, you should be aware that all information is provided in this document on the basis that the healthcare professionals responsible for patient care will retain full and sole responsibility for decisions relating to patient care; the document is intended to supplement, not substitute for, the expertise and judgment of physicians, pharmacists or other healthcare professionals and should not be taken as an indication of suitability of a particular treatment for a particular individual. The ultimate responsibility for the use of the guideline, dosage of drugs and correct following of instructions as well as the interpretation of the published material **lies solely with you** as the medical practitioner.

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Guideline Statement

The Equality Act 2010 defines a disabled person with a physical or mental impairment which has substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities (Equality Act 2010, Section 6(1)).

In line with the Act, the maternity unit and services must be accessible to disabled women, and innovative and flexible in meeting the needs of women with communication and other disabilities. This may involve ensuring the appropriate reasonable adjustments have been put in place to meet these needs.

A disability can arise from a wide range of impairments which can be:

- Sensory impairments, such as those affecting sight or hearing
- Impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgia encephalitis (ME)/chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy
- Progressive, such as motor neurone disease, muscular dystrophy, forms of dementia and lupus (SLE)
- Organ specific, including respiratory conditions, such as asthma, and cardiovascular diseases, including thrombosis, stroke and heart disease
- Developmental, such as autistic spectrum disorders (ASD), Asperger's syndrome, Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) Learning difficulties including dyslexia, dysgraphia, Dyscalculia and dyspraxia
- Learning disabilities, this is determined by IQ. A Person may have a borderline (IQ of 71 – 84) mild (IQ of 50-70), moderate (IQ of 35-49), severe (IQ or 34-20) or profound learning disability (IQ of 20 or less) (WHO, ICD-10, 2019, Sections F70-79)
- Mental health conditions and mental illnesses, such as bipolar affective disorders, obsessive compulsive disorders, as well as personality disorders and some self-harming behaviour
- Produced by injury to the body or brain

Executive Summary

- To reduce clinical risk and meet the standard identified within the National Service Framework (NSF) for Children, Young People and Maternity Services, that:

Women have easy access to supportive, high quality maternity services, designed around their individual needs and those of their babies. (Department of Health, 2004, p.4)

- Not all disabilities/impairments are readily identifiable
- Women should be booked for Consultant Led Care
- A plan of care should be made in conjunction with the woman, consultant and midwife.

1.0 Roles and Responsibilities:

Midwives – identifying, assessing, planning, implementing and evaluation care for women with special needs. Referring onto Multi-Disciplinary Team services (e.g. Occupational Therapy speech and language therapy and Physiotherapy) for holistic and safe care

Maternity Care Assistants and Nursery Nurses – implementing and evaluating care.

Obstetricians – responsible in planning and providing care appropriate for individual needs.
Referring onto Multi-Disciplinary Team services (e.g. Occupational Therapy speech and language therapy and physiotherapy) for holistic and safe care

Obstetric Physiotherapist responsible for meeting individual patient needs in an appropriate setting (e.g. group or 1:1) in an appropriate timeframe

2.0 Implementation and dissemination of document

This Guideline is available on the Intranet and has followed the Guideline process review prior to publication

3.0 Processes and procedures

3.1 Antenatal Care

Within the NSF it is stated that disabled women, and those requiring specific services, report that current services are not always responsive to their need; also, that their own knowledge as to what will suit them best is overlooked. (Department of Health, 2004, p.10)

The Better Births document states that women and their families can be powerful agents for change. They can help to shape their own care by making well-informed choices to ensure safe, personalised care is built around them and recognises that vulnerable women may need extra support to do this. (National Maternity Review, 2016, p.84)

- 3.1.1** Women should be booked for consultant led care to enable discussion on how particular disabilities or medical conditions may affect pregnancy, this includes medication information. A multidisciplinary approach and plan of care must be clearly documented in a management plan on eCare
- 3.1.2** Consider whether referral to Anaesthetics is required. Consider whether a Baby Alert is required
- 3.1.3** A Confidential Communiqué can be completed following discussion with and in agreement with the woman. Any identified safeguarding concerns should be discussed with the Named Midwife for Safeguarding and relevant referrals made following the Milton Keynes University Hospital NHS Foundation Trust Vulnerable team operational guidelines.
- 3.1.4** A risk assessment should be facilitated, if indicated by the relevant healthcare professional for the antenatal period, labour and postnatal period, using the mobility and assessment forms (Appendix 2)
- 3.1.5** Following the risk assessment the need for any equipment or aids may be identified and liaison with the Equipment Library or Trust Back Care Adviser should be initiated.
- 3.1.6** Information regarding support and benefits is available and may be accessed from the Citizens Advice website at <https://www.citizensadvice.org.uk/benefits>

3.1.7 Further information and support for disabled parents is available from Disability, Pregnancy and Parenthood at <https://www.disabledparent.org.uk/> and the Disabled Parents' Network at <http://disabledparentsnetwork.org.uk/>

3.2 Intrapartum Care

3.2.1 Admission

On admission, a discussion of the plan of care with the woman, her birth partner and the Multi-disciplinary Team.

3.2.2 Birth partners

The women's wishes with regards to additional birth partners should be respected

3.3 Postnatal Care

- If a side room is available and beneficial logistically then it should be offered.
- Liaison with the multidisciplinary team for discharge co-ordination, including community midwife, GP and Health Visitor if appropriate.

3.4 Learning Disabilities support

Although 7% of people with learning disabilities become parents (Best Beginnings) the Equality Act 2010 obligates responsibility to service providers to ensure that reasonable adjustments are put into place to ensure the holistic needs of people with learning disabilities are met to the highest standards.

Remember to think VALUE ME! (Appendix 1)

1. Early intervention strategies should be considered. Ensure that the community midwife is involved and if they are under 20 consider discussion with the specialist teenage pregnancy midwife for additional support.
2. Professionals should ensure that adequate time is provided for consultations, appointments and formal discussions. Taking time to allow the woman to understand the information in order to make an informed decision.
3. Professionals should ensure that reasonable adjustments are put into place to aid with understanding. Including: easy read, pictorials, large font, visual and hearing aids.
4. Abilities led practice rather than inabilities led practice. Professionals should avoid making assumptions based on a diagnosis of a learning disability as often mothers will have their own anxieties, fears and worries regarding motherhood.
5. Avoid assuming that mothers are being difficult. Consider other possible reasons such as the environment, loud noises, bright lights (especially if they have a dual diagnosis of learning disability and ASD), sensory needs, stress and anxiety. Provide a side room if possible.

4.0 Statement of evidence/references

Statement of evidence:

References:

Best Beginnings. Parents with learning disabilities. *Best Beginnings* [Online].

<https://www.bestbeginnings.org.uk/parents-with-learning-disabilities> [Accessed 20 July 2020]

Citizens' Advice. Benefits. *Citizens' Advice* [Online]. <https://www.citizensadvice.org.uk/benefits/> [Accessed 20 July 2020]

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 code of practice*. [Online]. Available from: <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice> [Accessed 20 July 2020]

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: maternity services*. [Online]. Available from: <https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services> [Accessed 20 July 2020]

Disability, Pregnancy & Parenthood. <https://www.disabledparent.org.uk/> [Accessed 20 July 2020]

Disabled Parents' Network. <http://disabledparentsnetwork.org.uk/> [Accessed 20 July 2020]

Equality Act 2010 (c.15). [Online]. Available from: <https://www.legislation.gov.uk/ukpga/2010/15/contents> [Accessed 20 July 2020]

Government Equalities Office (2010) *Equality Act 2010: what do I need to know? Disability quick start guide*. [Online]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/85011/disability.pdf [Accessed 21 July 2020]

National Institute for Health and Care Excellence (2016) *Mental health problems in people with learning disabilities: prevention, assessment and management*. NICE guideline [NG54] [Online]. Available from: <https://www.nice.org.uk/guidance/ng54> [Accessed 20 July 2020]

National Maternity Review (2016) *Better births: Improving outcomes of maternity services in England. A five year forward view for maternity care*. [Online]. Available from: <https://www.england.nhs.uk/publication/better-births-improving-outcomes-of-maternity-services-in-england-a-five-year-forward-view-for-maternity-care/> [Accessed 20 July 2020]

Mental Capacity Act 2005 (c.9) [Online]. Available from: <https://www.legislation.gov.uk/ukpga/2005/9/contents> [Accessed 20 July 2020]

World Health Organization (2019) *International Statistical Classification of Diseases and Related Health Problems*. 10th Revision (ICD-10). [Online]. Available from: <https://www.who.int/classifications/icd/icdonlineversions/en/> [Accessed 23 July 2020]

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5.0 Governance

5.1 Document review history

Version number	Review date	Reviewed by	Changes made
4.0	06/2020	Louise Romeo	Full review and update
3.0	06/2017	Vulnerable team	Reviewed and updated

5.2 Consultation History

Stakeholders Name/Board	Area of Expertise	Date Sent	Date Received	Comments	Endorsed Yes/No
Elizabeth Maushe	Student Nurse	06/2020	06/2020	Incorporated	Yes
Christina Edley	Physiotherapy	06/2020	06/2020	Incorporated	Yes
Natalie Lucas	Audit and Guidelines Midwife	23/06/2020	23/06/2020	Incorporated	Yes
Cath Hudson	Lead Midwife for risk and QI	23/06/2020	02/07/2020	Formatting	Yes
Julie Cooper	Head of Midwifery	23/06/2020	27/06/2020	Incorporated	Yes
Jayne Plant	Library and e-learning services manager	02/04/2020	23/07/2020	Reference check and suggestions	Yes

5.3 Audit and monitoring

Audit/Monitoring Criteria	Tool	Audit Lead	Frequency of Audit	Responsible Committee/Board
Non-adherence to any care plans will be reported and investigated	Datix	Vulnerable team Midwives	After each incident	WH CIG

5.4 Equality Impact Assessment

As part of its development, this Guideline and its impact on equality has been reviewed. The purpose of the assessment is to minimise and if possible remove any disproportionate impact on the grounds of race, gender, disability, age, sexual orientation, religion or belief, pregnancy and maternity, gender reassignment or marriage and civil partnership. No detriment was identified. Equality Impact assessments will show any future actions required to overcome any identified barriers or discriminatory practice.

Equality Impact Assessment			
Division	Women's and children's	Department	Maternity
Person completing the EqIA	Louise Romeo	Contact No.	
Others involved:		Date of assessment:	06/2020
Existing policy/service	Yes	New policy/service	No
Will patients, carers, the public or staff be affected by the policy/service?		Yes	
If staff, how many/which groups will be affected?		All staff working within the maternity department	
Protected characteristic	Any impact?	Comments	
Age	NO	Positive impact as the policy aims to recognise diversity, promote inclusion and fair treatment for patients and staff	
Disability	NO		
Gender reassignment	NO		
Marriage and civil partnership	NO		
Pregnancy and maternity	NO		
Race	NO		
Religion or belief	NO		
Sex	NO		
Sexual orientation	NO		
What consultation method(s) have you carried out?			
<i>Circulation vis email/ MS Teams. Discussion at guidelines meeting and CIG</i>			
How are the changes/amendments to the policies/services communicated?			
<i>Circulation vis email/ MS Teams. Discussion at guidelines meeting and CIG</i>			
What future actions need to be taken to overcome any barriers or discrimination?			
What?	Who will lead this?	Date of completion	Resources needed
Review date of EqIA			

Appendix 1: MOTHERS WITH LEARNING DISABILITIES GUIDANCE TOOL

V *Value family* – Involve individuals who best know the woman with learning disabilities as they can provide additional information that may be helpful to the decision-making process

A *Avoid making assumptions* – Do not assume that because someone has a diagnosis of a learning disability that they cannot be good enough parents

L *Look for support* – Professionals should not work in isolation and should involve learning disability services for further support and guidance

U *Understand emotions* – Take into consideration that many mothers with learning disabilities have their own anxieties and worries about motherhood and fear of judgment. Do not assume they are being difficult.

E *Establish reasonable adjustments* – Professionals should put reasonable adjustments into place to ensure women with learning disabilities can comprehend and understand information to give informed consent. I.E. easy read, pictorials, large font, visual and hearing aids.

M *Mental Capacity* – Do not assume capacity. In liaison with the Mental Capacity Act 2005, professionals should consider completing a Mental Capacity Assessment (MCA) to establish whether the women can give informed consent. Professionals should also consider best interest, Deprivation of Liberty Safeguards (DoLS) and involving an Independent Mental Capacity Advocate (IMCA).

E *Efficient discharge* – Professionals should consider possible support that can be put into place to ensure a person-centered discharge is consolidated. Consider, access to health and additional services, transport, financial support and accommodation.

THINK... VALUE ME

Appendix 2: Mobility and communication planning assessment form

Appendix 2: Mobility and Communication Planning Assessment Form

Assessment No: _____

Parity: _____ EDD: _____

Midwife Led Care/ Consultant Led Care (please circle)

Disability e.g. MS, Deaf, _____

Telephone No: _____

GP Name: _____ GP Telephone No: _____

Patient Sticker

Communication

To communicate effectively I need to use:

- An induction loop
- Minicom/ Text phone
- British sign language interpreter
- Lip reading
- Community language interpreter
Language: _____
- Braille
- Large print
- British sign language interpreter
- Please support me in writing
- Other (please state below)

Mobility

To help me get around, I use:

- A frame
- Walking stick
- Crutches
- Wheelchair
- Slide sheet
- Banana Board
- Hoist
- A rotunda
- Other (please state below)

- My partner has a disability: **Yes/ No**
(Please circle)
If yes, please state: _____
- No. of assistants required: _____
- Would benefit from physiotherapy
assessment: **Yes/ No** (please circle)

Documentation (tick as appropriate)

- Copy to EDM – Date completed: _____
- eCare alert – Date completed: _____
- Copy to hospital notes
- Confidential Communique (CC) updated

Communication sent to:

- Clinical leads
- Consultant
- Risk Manager

Form completed by: _____ Date: _____

Mobility and communication planning assessment form

During a hospital stay, I will need the following:

- Single room
- Single room with ensuite toilet and shower
- Disable access room with level access shower
- Specialised bed (please specify below)

- Shower chair
- Hydraulic cot
- Text phone in main entrance
- Minicom from patientline
- Minicom in antenatal reception/ PALS
- Television with subtitles
- Hoist
- Does an assistant need to stay overnight?
- Other (please state below)



Summary of woman's/ carer's needs:

Form completed by: _____ Date: _____



Mobility and Communication Planning Assessment Form (Postnatal support)



Has this woman been referred to any of the following and what support is in place?

Health Visitor:

Physiotherapist:

Occupational Therapist:

Social Services- Adult:

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Social Services- Child:

General Practitioner:

Specialist Nurse:

Other:

Form completed by: _____ Date: _____

