



Guidelines for practitioners working with pregnant women and mothers with learning disabilities

Maternity Services NHS North Highland/Care and Learning Highland Council

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Policy e library Reference No:	Date of Issue: February 2021
Prepared by: Midwifery Development Officer Claire MacPhee	Date of Review: February 2024
Lead Reviewer/Owner: Claire MacPhee Midwifery Development Officer	Version: 4
Ratified by: MNSSCC/HC Clinical Governance Group	Date Ratified: April 2016
EQIA For Fairness: Yes	Date EQIA: March 2016 http://intranet.nhsh.scot.nhs.uk/Staff/EqualityAndDiversity/EqualityImpactAssessment/Pages/Default.aspx

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<http://www.nhshighland.scot.nhs.uk/Pages/YourRights.aspx>

Date	Author	Change
May 2021	C MacPhee	Review with expert group from LD teams to update email addresses and improve language taking a more person-centred rights based approach.

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1. Introduction

People with learning disabilities are an integral part of all our communities and may require additional support to access services when embarking on parenthood.

A diagnosis of learning disability is made when an individual has an IQ score below 70 with significant deficits in daily living and coping skills, acquired by the age of 16 years.

There may be a considerable number of people who may have difficulties managing with day-to-day life and the associated health and social inequalities of living with a degree of disability, who do not have any formal support in place.

It is often only when individuals meet services, such as during pregnancy, that barriers to accessing health advice and systems of care becomes apparent. This may alert practitioners of the need to consider the potential ability of the prospective parent to care for and nurture their new-born child.

The Keys to life implementation framework (SG 2019-2021) outlines the need to include people with learning disabilities in mainstream services and its strategic outcomes for a Healthy life, choice and control, independence and active citizenship are relevant to care delivered by services throughout parents care.

Having a learning disability is not in itself an indicator of limited parenting abilities however, research shows that robust early assessment and effective early interventions and supports creates positive outcomes and protective factors for families.

All staff supporting pregnant women and mothers with learning difficulties should follow their professional assessment frameworks as with any other client group. This includes the Highland practice model, Vulnerable Pregnancy pathway and the Universal Health Visiting Pathway. SHANARI wellbeing, my world triangle and resilience matrix assessments will ensure a person-centred individualised plan of care can be made in partnership with women and ensure that both the needs of the mother and the unborn/child are fully considered. If required any multiagency referrals and partnership working should take place as per child protection guidance within the specified timeframes.

The Children (Scotland) Act 1995 clearly states that the needs of the child must come first and is further strengthened by The Children (Equal Protection from Assault) Act 2019. It was recommended that by 2014 parents with learning disabilities have access to local supported parenting services based on the principles detailed in Scottish Good Practice Guidelines for supporting parents with Learning Disabilities (SCLD, 2015)

Joint working between the maternity team, integrated children’s services, learning disabilities teams and children and adult social work teams will help staff to consider the needs of parents whilst fulfilling their roles and responsibilities to babies and children (Tarleton et al, 2006).

1.1 Adult support and protection

Any concerns practitioners have around risk of significant harm or welfare of the woman then appropriate referral to adult support and protection should be made via an Adult Concern Form to nhshighland.adultprotection@nhs.scot (HHSCP, North Highland). Or phone **01546 605517** in A&B. These forms along with the relevant legislation, further guidance and contacts for North Highland and Argyll and Bute can be accessed via the links below:

[North Highland Adult Support and Protection Internet Page](#)
[Argyll and Bute Adult Support and Protection Internet page](#)

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2. Aim

The aim of these guidelines is to offer practitioners within maternity and early years services good practice reference points to consider when working with people with learning disabilities who are to become parents. This will help to ensure a more appropriate response to their needs thereby ensuring effective plans are in place at an early stage. This should facilitate a more positive experience of integrated services for parents and their children during pregnancy and the early years following birth.

These guidelines will also be useful for other services who support adults with learning disabilities who are or will become parents

3. Principles of Good Practice

3.1 An early response

- Women are generally much more likely to accept professional support during pregnancy or following birth than at any other time.
- Early contact with maternity services by a woman with any of learning disabilities will enable early multidisciplinary or multiagency assessment to identify additional support required during pregnancy and following birth.
- Having a named (primary) midwife who is available for women from the beginning of pregnancy and following birth is essential to ensure consistent support and advice in line The Best Start A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland (SG 2017). The named community midwife will work closely with members of the multidisciplinary team, the named obstetrician will manage care for women with complex needs
- Within the context and principles of The Highland Practice Model (GIRFEC) and the Pathway of Care for Vulnerable Families: Conception – 3 years (Scottish Government 2011) the primary midwife will coordinate care for the mother and unborn baby and undertake information sharing role in collaborating with a lead professional where necessary .
- This child centred approach to early intervention in a pregnancy context, recognises that when additional needs are identified, support must be put in place to ensure that the mother is able to meet those needs until birth takes place. The promotion of attachment and bonding are particularly important to be discussed in pregnancy and further advice and recommendations should be sought from the Infant Mental Health (Prebirth – 3 years) Best Practice Guidelines (NHS Highland/Highland Council 2020)
- The named person for the child from birth will be the named health visitor or Family Nurse (HV/FNP). With the introduction of the revised Health Visiting Pathway, the HV will carry an antenatal visit for all women between 32-34 weeks of pregnancy. However, for women with learning disabilities contact must be made at an earlier stage. The HV must also be included in any assessments made by the midwifery team during pregnancy and good practice would support a joint antenatal visit with the midwife. Seamless support through transition between maternity and health visiting services is of utmost importance. The midwife will continue to provide midwifery care to the mother

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and her new baby as described in the Standards of Proficiency for midwives (NMC 2019).

- The HV will continue to support the mother and baby following birth to ensure that the child's needs are assessed, and on-going co-ordinated care provided by working closely with the Learning Disabilities Teams and the woman's GP. Following delivery, mother and baby should have their needs reassessed independently which may require additional input and a co-ordinated response between children and adult services. However, the focus must be on the woman's ability to parent her baby and any support available from her family and/or partner/baby's father considered.
- Where required a multiagency Lead Professional must be identified and they will ensure co-ordination of care across agencies, disciplines and teams.
- Early assessment and intervention is essential to ensure support is in place well before birth with the immediate and long term impact on the woman and child considered as their needs change.
- Women must be offered information in a format they understand and be informed of the reasons why information about her pregnancy and on-going care of her and her baby may need to be shared with other agencies or professionals. If the woman has an advocate they must be included in all discussions.

3.2 Needs led support

- Women must be fully engaged and consulted about the way in which services will be provided throughout their pregnancy, labour and following birth. These discussions should be documented within her Electronic Maternity notes (Badgernet). An HPI Wellbeing assessment and Antenatal Plan should be included as detailed in the Vulnerable Pregnancy Pathway (NHS/HC 2020). This takes a trauma informed approach to care and helps identify strengths and pressures for the woman, what support is in place or required and what the desired outcomes are.
- Women should have access to resources available in pregnancy that include the CHANGE resources and others recommended in Appendix 2. Scottish Governments Parent Club and Best beginnings are useful online platforms to help women understand the changes that are taking place during pregnancy and assist with the process of bonding by focusing on their growing baby.
- A full joint assessment of the needs and the support required for the woman to undertake parental responsibilities must be commenced early in pregnancy.
- Even if women believe they have no need for support, when they are involved in the assessment process it should be possible to negotiate a creative package of care which will be acceptable to them, their partner/family and practitioners.
- Assessment must consider any child protection issues for the woman and her child.
- A woman's right to confidentiality must be respected and she should be asked if she is happy to involve her partner or family in any discussions.

3.3 Assets led model rather than deficit led

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- The concept of assessing parental capacity within the assessment framework of GIRFEC, as detailed in the Highland Practice Guidance (2017) considers the strengths as well as pressures for the woman and her partner/family through exploring the use of a solution focused approach.
- Assessment should be undertaken in consultation with practitioners who are experienced in working with this client group such as nurses or social workers who work in learning disabilities teams.
- Risk is dynamic and may change and assessments should always consider the impact of any parental issues on the baby which will change following delivery and as the child grows.

3.4 Time

- To enable parents to assimilate knowledge and understanding of concepts such as changes in pregnancy, labour or 'good enough' parenting and childcare, practitioners working together across disciplines with families will need to spend adequate time with them to ensure this occurs.
- Resources that should be considered to assist with imparting knowledge can be found in the Highland Information Trail which is updated annually.
- Time to listen is important and should be seen as time well invested to facilitate good quality and effective care.

3.5 Effective support involves a wide range of strategies

- Treatment, care and information that is given to women with additional support requirements should be appropriate to their needs and accessible for them.
- Adult and children's services practitioners who are involved in supporting the woman or child must work closely together to ensure the needs of the whole family are considered and assessed. This must also ensure that the statutory duty of care to the child (and vulnerable adult) is fulfilled.
- Universal services should make 'reasonable adjustments' to ensure they are accessible for people with learning disabilities including times and settings for appointments.
- Parents should be supported to register their baby's birth and this should be discussed with them. In the case of a parent who is unable to register grandparents can also register the birth.
- Flexible support to meet an individual's needs should include consideration of assessments that occur in the woman's own home where possible, not in an unfamiliar community setting.
- The planning of care between midwives and HVs is really important and must begin early in pregnancy.

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- Joint appointments with HVs and other partners providing additional support should be facilitated as early as possible.
- Giving women with learning disabilities an opportunity to talk to other mums who have recently had babies may be invaluable to them. Also, visits to the unit and wards where they will have their babies with opportunities to meet the staff will help allay concerns.
- Practitioners should consider a range of teaching and support techniques available to them such as posters, photographs, drawings, diagrams, online video clips, audio tapes and DVDs, tailored to the woman’s ability. Many of these are available in the HIRS resources library, the learning disability service will support with person centred accessible information. (see Appendix 2 and 3).
- Opportunities for parents-to-be around skills training, help at home, finance, budgeting, benefits and parenting may be offered through partner agencies and should be facilitated in any assessment of needs and detailed in any care plans.
- Early assessment and intervention for additional support needs can be provided through a variety of practitioners including Children’s Service Workers – early years.
- Person centred outcome plans should be developed to ensure that parents and children are supported to meet their own individual needs.

3.6 Maternity Staff Skills, knowledge and confidence

- Practitioners involved in children’s or universal services require training and skills development about adults with learning disabilities and their support needs. This will also include training on adult support and protection issues and adults with incapacity legislation which is available locally.
- Professionals working in universal services providing support to women should seek assistance with communication issues associated with learning disabilities and their particular needs through a phone call to the local Learning Disabilities Team for advice.

3.7 Parenting with support

Parents-to-be will need additional time to understand the choices available to them through early contact with relevant services, co-ordinated by their named midwife

- and/or Lead Professional. The agreed plan for pregnancy should be detailed in their Antenatal Plan and shared with all relevant partners to the Plan.
- The HV as the named person for the child should ensure that maternal/parental wellbeing and parenting are considered during all assessments and contacts.
- Staff providing universal services (maternity and health visiting) must work in partnership with GPs, learning disabilities teams and allied health professionals in order to support the needs of individual prospective parents with learning disabilities.
- All services should promote good practice when undertaking assessment of risks and needs around parenting by using appropriate assessment materials and resources for

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parents with learning disabilities and accessing specialist expertise to facilitate this. Useful contacts can be found in Appendix 2 and 3.

3.8 Involving the extended family

- It is essential to consider other family members, carers or advocacy services who may provide a supportive role in assessments made but this must be on the woman's terms so that she can be heard and make informed choices. Not every woman will want her family to be involved.

4. Information for practitioners

- The woman's named midwife can be accessed through the GP surgery or via the community midwifery base. The HVs are based within the local Family Teams.
- Each woman will require an individual assessment but is likely to have additional needs that will require a co-ordinated response from the wider maternity care team including the GP, obstetrician and close liaison with the named HV who will take over care following handover from the midwife (usually around 10 days postnatal).
- The woman's named midwife should undertake wellbeing assessment using the Wellbeing HPI and A/N plan based on the Highland Practice Model (GIRFEC). This will include details of the planned actions required to meet the desired outcomes including the input from all partners, who is co-ordinating care and the likely impact on the woman, her baby and her family.
- On-going assessment will include discharge planning arrangements and support that is to be provided following handover of care to the HV and a Childs Plan for the baby.
- The HV will continue to offer support based on assessment of risks and needs of mother and baby. The child will be at the centre of the assessments but the family needs must be included in any assessment.
- Support must be tailored to meet their individual needs and assessments should not be based on assumptions of capacity. Parents that have learning disabilities must have their needs assessed therefor practitioners should consider referral for additional assessment and support to relevant adult health and social care partners. This includes local CLDN teams and adult social work.
- Any assessments must include details of the woman's understanding of her health and social needs in relation to her pregnancy, screening and surveillance tests, keeping herself healthy including diet and exercise, substance use, baby care and any potential parenting issues.
- Once baby is born a full assessment of parenting must be facilitated through the named person or lead professional using the Highland Practice Model.
- Discussions with women must include sexual health and future pregnancy planning and contraception advice.

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- If the woman is currently taking any medication or undertaking treatment for a pre-existing medical condition (e.g. diabetes, epilepsy, chronic illness), specialist referral/discussion must take place with the appropriate Medical Consultant or Specialist Nurse before any decisions to change treatment or medication are taken. These decisions must be clearly documented, and the woman's understanding ensured.
- Support (or not) available from the woman's wider family and partner should be included in assessments made.
- Midwives and HVs are the key providers of parent information during pregnancy and the early years. They should ensure that prospective and new parents are given information in a format that makes it easy for them to understand such as DVDs, audio, use of pictures, large print, accessible websites, verbal explanations and practical demonstrations.
- Practitioners who may require alternative resources tailored to an individual woman's needs, easy read formats are included in the Highland information trail [here](#).
- The checklist for best practice (Appendix 1) can be downloaded separately and used to inform part of the woman's A/N plan with details shared with the wider team as appropriate.

5. Working together to support families

- Services should work in a co-ordinated and integrated way to ensure early assessment, early support and early intervention that is appropriate to individual needs, is timely and occurs with less bureaucracy.
- Parents should be given enough time to process the information that is being given.
- Parents should be involved in assessments and formation of care plans and they should be supported to ensure they have processed and retained the information. This may require support from an advocate to help with this. This can be from a trusted support, a paid or voluntary advocate. Advocacy Highland can be accessed [here](#).
- Partners/fathers should be included in planning care and assessing support requirements where possible, and their needs considered.
- The protection of children is paramount and any concerns around risk of potential neglect or harm must be discussed with the local Child Protection Advisor (CPA) or social work team and child protection procedures must be followed.
- Although assessments should be child centred, the needs of the parents must be considered. Parents should be supported to undertake their parental duties with a focus on strengths as well as pressures.
- Assessment must be an on-going process as the needs of a child will change over time, as may a parent's capacity to cope with changing needs.

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- Amongst women with learning disabilities there is a greater incidence of mental illness, behaviour which is perceived to be challenging, developing and maintaining relationships, increased vulnerability to abuse and exploitation. Staff working with them should consider the risks of harm to the woman and their children, born or unborn.
- Inadequate housing, homelessness or home support requirements may be an issue for women and facilitating links to housing support organisations are very important for this client group.
- Assistance with applying for benefits and grants should be provided and advocating for a woman to ensure this occurs is important when planning her care.
- Parents should also receive support to apply for Best Star Food vouchers and vitamin supplements.
- Local family support services provided through social work and the third sector (voluntary and private) can help to support new parents, provide adapted parenting programmes and assist with assessments that focus on the practicalities of child care. Maternity staff can liaise with both child and adult social work services to gain information around availability of third sector support services.
- A Child's Plan may need to be developed for the baby with an identified Lead Professional.

6. Conclusion

There are many challenges that a mother with a learning disability may face but by ensuring that services and information for pregnant mothers and new parents is accessible and person centred to ensure that they are included and engaged at an early stage in planning care.

The role of maternity services is crucial in ensuring an integrated and full assessment of needs and strengths from the start of pregnancy is undertaken, ensuring parents are offered the emotional and practical support that they require.

A priority is that parents are supported to develop parenting skills and overcome any barriers or challenges in their lives that may impact on their ability to parent well, whilst retaining a focus on the needs of the child and reporting any concerns to children and family services where appropriate.

Ensuring ongoing appropriate support and guidance for families is vital particularly around the changing needs of the child. Providing an integrated service for parents with learning disabilities ongoing assessment and support of needs as outlined within the Highland Practice Model (GIRFEC).

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Appendix 1		Good Practice Checklist	
1 st Contact	Ensure continuity of carer by primary midwife, early introduction of buddy midwife and allocate additional time at all appointments. Consider if appts at home maybe more suitable.		
	Take time to build trust, parents with LD can face barriers such including poverty, discrimination, mental illness and poor self-esteem.		
	Ensure any information given is in an accessible such as easy read versions as detailed in Highland Information Trail.		
	Clear Communication is key: o Listen– to the parent and take time to understand how they communicate o Keep it simple - ordinary words, no ambiguity or jargon o Big – write everything in at least point 14 type o Write – a note of any advice or next meeting using an accessible method see https://www.easyhealth.org.uk/ o Don't assume – that parents have understood what you have said.....check o Don't overwhelm: don't give too much information all at once consider breaking up booking appointment		
	Refer to specialist for review as required eg epilepsy nurse, LD Nurse,		
	If any adult support and protection concerns consult ASP guidance in North Highland and WOS guidance in A & B		
By 16 Weeks	Carry out HPI <i>Wellbeing Assessment (SHANARI)</i> and allocate as Additional. Ensure full assessment of preferred methods of communication are documented within the assessment, consider advocacy support needs and referral to LD professionals		
	Communicate verbally with the named Health Visitor in addition to sending a copy of the HPI Wellbeing assessment, consider involvement of an Early Years Practitioner.		
	Refer to <i>Additional Services</i> and appropriate third sector agencies such as Advocacy Highland Lomond & Argyll Advocacy Service if appropriate, with consent.		
	If socially complex and the unborn baby is considered at risk of significant harm, follow Vulnerable pregnancy pathway. Ensure early liaison with SW if parenting capacity assessment required. Early identification of issues and early intervention is crucial to prevent crisis intervention.		
By 25 weeks	Plan a person centred package of care within the A/N plan that includes details of any family, friends or professional support that needs be in place.		
	Primary midwife considers convening an Antenatal Plan Meeting with parent/s and partner agencies involved in the plan. The CPA (Health) is available to support this meeting.		
	Ensure early access to any parenting programmes available and consider adapting to include additional 1:1 session tailored to specific needs of the woman and her family.		
By 28 weeks	Consider additional 1:1 preparation for what to expect going into labour alongside group formats .Communication needs should be clearly documented for any change of staff to accommodate.		
	Write birth plan in collaboration with women ensure any additional support that may be required in labour can be accommodated. Offer a visit to the unit where birth is planned to take place more than once if necessary.		
Birth	If possible, care in labour to be carried out by primary midwife or buddy, if not possible clear birth plan to be in place and accessible.		
Post Birth	Ensure any additional support for the immediate post birth period is in place including longer stay and additional support for feeding and care of baby as well as hands on parentcraft sessions.		
Discharge home	The mother's confidence and ability to care for her baby should be assessed and supported and any required additional support in place prior to discharge home. Follow any required Child Protection Procedures as detailed in VPP and any multidisciplinary discharge planning arrangements.		

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Appendix 2

Contacts

For information about learning disability services and training including Adult Support and Protection training and Adults with Incapacity training:

- Heather Carr – Lead Learning Disability Nurse
Heather.carr@nhs.scot

Staff in Argyll and Bute

- Anne-Lise – Professional Lead Learning Disability Service,
annelise.dickie@nhs.scot
07769932589

Appendix 3

Community Learning Disabilities Nursing Teams

Mid and South Operational Unit	
Inverness Community Learning Disability Nursing Team for Adults	Corbett Centre Coronation Road Inverness IV3 8AD Tel: 01463 711291 Fax: 01463 715993
Inverness Community Learning Disability Nurse for Children and Young People	Ness House Drummond Road Inverness IV2 4N2 Tel: 01463 668667
Nairn, Ardersier, Badenoch & Strathspey Community Learning Disability Nursing Team for Adults	Town and County Hospital Cawdor Road Nairn IV12 5EE Tel: 01667 422814
Nairn, Ardersier, Badenoch & Strathspey Community Learning Disability Nursing Team for Children and Young People	Town and County Hospital Cawdor Road Nairn IV12 5EE Tel: 01667 452914

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East and Mid Ross Community Learning Disability Nursing Team for Adults	Isobel Rhind Centre Tomich Road Invergordon IV18 0AX Tel: 01349 854537
North and West Operational Unit	
Lochaber Community Learning Disability Nursing Team for Adults, Children and Young People	Fort William Health Care Camaghael Fort William PH33 6AQ Tel: 01397 709866
Skye & Lochalsh Community Learning Disability Nursing Team for Adults, Children and Young People	Lochalsh Healthcare Centre Station Road Kyle of Lochalsh IV40 8AE Tel: 01599 530937 Tigh Na Drochaid Bridge Road Portree Isle of Skye IV51 9ER Tel: 01478 613113
Wester Ross Community Learning Disability Nurse for Adults, Children and Young People	Unit 2 Auchtercairn Gairloch IV21 2BH
Sutherland Community Learning Disability Nursing Team for Adults, Children and Young People	First Floor Offices The Lawson Memorial Hospital Golspie KW10 6SS Tel: 01408 664080
Caithness Community Learning Disability Nursing Team for Adults, Children and Young People	Community Learning Disabilities Nurse Caithness West William Smith Building Thurso Business Park KW14 7XW Community Learning Disabilities Nurse Caithness East Old Medical Centre Bankhead Road

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	Wick KW1 5LB Tel: 01955 604134
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Argyll & Bute Operational Unit	
Oban, Lorn and Isles Community Learning Disability Nurse for Adults	Learning Disability Network Lorne Resource Centre Soroba Road Oban PA34 4HY Tel: 01631 572964 Fax: 01631 572959
Mid-Argyll, Kintyre and Islay Community Learning Disability Nurse for Adults	Learning Disability Network Argyll and Bute Hospital Blarbuie Road Lochgilphead PA31 8LD Tel: 01546 605605 Fax: 01546 604915
Bute and Cowal Community Learning Disability Nurse for Adults	Learning Disability Network Dolphin Hall Annexe Manse Avenue Dunoon PA23 8DU Tel: 01369 707151 Fax: 01369 703420
Helensburgh and Lochside Community Learning Disability Nurse for Adults	Learning Disability Network Jeannie Deans Unit 93 East King Street Helensburgh G84 7BU Tel: 01436 655021 Fax: 01546 666035

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