

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

Revised April 2016

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1. Introduction

The numbers of women with severe learning disabilities who will become mothers is low however, as more people with mild to moderate learning disabilities are supported to lead more independent lives in the community it is expected that more of them will become parents.

It is estimated that 2.2% of the population has a recognised diagnosis of learning disability which can vary from mild to profound. Approximately 6.7% of the population may fall within the borderline of possibly having a learning disability without any formal diagnosis (Morris & Wates, 2006). Therefore, around 20 people in every 1000 will have a mild to moderate learning disability with 3-4 in every 1000 with a severe or profound learning disability. In Scotland, this equates to around 120,000 people with a learning disability (NHS QIS, 2004). A diagnosis of learning disability is made when an individual has an IQ below 70 with significant deficits in daily living and coping skills, acquired by the age of 16 years.

In Highland there are approximately 1500 people with a diagnosed learning disability that are known to specialist services with an estimated 6000 – 7500 more individuals with a degree of learning disability that has not been formally diagnosed. Therefore, 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 come into contact with services, such as during pregnancy, that an inability to fully engage with health advice and systems of care becomes apparent. This may alert practitioners of the need to consider the potential capacity of the prospective parent to care for and nurture their newborn child.

Having a degree of learning disability is not in itself an indicator of limited parenting abilities however, when there is inadequate early assessment and effective intervention and support for parents then family breakdown is a real possibility. Moreover, fifty per cent of children whose parents have a learning disability of some degree are taken into care usually as a result of concerns for their wellbeing and/or the absence of appropriate support (Scottish Consortium for Learning Disability, (SCLD)2009).

Limited access to appropriate additional support can affect parents with learning disabilities in many ways. They may have already experienced a lack of practical and emotional help which might have resulted in poverty, unemployment, inadequate housing, homelessness or housing support and debt. They may have been subjected to harassment, bullying, domestic violence or exploitation and may have additional needs due to physical or mental health issues. Potentially they may require on-going long term support to enable them to care for their children, particularly as their children grow and their needs change (SCLD, 2009). If their child is born with any additional needs such as those associated with prematurity or disability, this will put further pressure on their potential parenting capacity.

Finding the balance between protecting children whilst maintaining the rights of parents can be difficult for practitioners. Children's social workers have a primary duty to ensure the welfare of the child and this needs to be understood by all professionals. Ensuring that all staff that support this client group understand the need to consider parenting capacity through robust risk assessment, work within a multiagency approach through the use of the Highland Practice Model (GIRFEC) and follow child protection procedures, should ensure any risks are identified early and acted on appropriately.

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The Children (Scotland) Act 1995 clearly states that the needs of the child must come first and evidence has shown that in many cases children's needs can be met well by parents with learning disabilities with support (Scottish Government, 2013). It is 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, 2009)

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).

Equality and Diversity

The planning for fairness process has been applied to these guidelines to ensure that they address equality and diversity considerations.

If practitioners have any concerns about the woman's ability to consent to sexual intercourse then advice should be sought from the learning disabilities team and an adult support and protection referral must be considered. The Consenting Adults Guidance produced by the Mental Welfare Commission for Scotland, 2011 provides easily understood information to support staff

Another source of information is the Sexual Offences (Scotland) Act 2009 (Section 17) which states that it is an offence for anyone to have sexual intercourse with someone who is unable to consent due to a mental disorder (including learning disabilities). The Act also introduced the offence of sexual abuse of trust of someone with a mental disorder (including learning disabilities) by anyone responsible for the care and support of someone with a mental disorder regardless of whether the person can consent or not to sexual activity.

Those in primary care who will be supporting women in making choices around pre-conceptual care or pregnancy planning will need to consider capacity issues for each individual woman which will be determined by the degree of learning disability. If a woman has an advocate which may be a support worker, family member, independent advocate or other practitioner, they should be involved in any discussions to ensure that she clearly understands what is being discussed with her. More detailed information around legislative responsibilities and national policy around working with families can be accessed through the 'Scottish Good Practice Guidelines for supporting parents with learning disabilities' (SCLD, 2009) which can be obtained from:

<http://www.sclld.org.uk/library-publications/scottish-good-practice-guidelines-supporting-parents-with-learning-disabilities>

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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. However, for women with a learning disability there may be elements of denial or confusion which may lead to a delay in understanding or acknowledging that they are pregnant.
- Early contact with maternity services by a woman with any degree of learning disabilities will enable early multidisciplinary or multiagency assessment to identify additional support required during pregnancy and following birth.
- Having a named midwife who is available for women from the beginning of pregnancy and following birth is essential to ensure consistent support and advice in line with the recommendations of the Pathways for Maternity Care (NHS QIS 2009). The named community midwife will work closely with members of the multidisciplinary team and for women with complex needs the obstetrician will manage her care.
- 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 midwife will also be the named person for the mother and unborn baby.
- 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 <http://www.forhighlandschildren.org/4-icspublication>
- The named person for the child from birth will be the named health visitor (HV). With the introduction of the revised Health Visiting Pathway, the HV will be undertaking 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. The midwife will continue to provide midwifery care to the mother and her new baby as described in the Midwives rules and standards (NMC 2012).

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- 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 Maternity notes (Scottish Woman Held Maternity Record – SWHMR). An Antenatal Plan should be included which will indicate any 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. The GIRFEC pregnancy wheel which is given to all women at booking in Highland can be used to remind women of the changes that are taking place during pregnancy and help them begin 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 safeguarding issues for the woman and her child.
- Women should have issues such as domestic abuse, substance misuse and mental health discussed with them as with any other pregnant woman.
- 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.

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3.3 Assets led model rather than deficit led

- The concept of assessing parental capacity within the assessment framework of GIRFEC, as detailed in the Highland Practice Guidance (2015) 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 child care, 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 Appendix 2.
- 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 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 are responsible for registering their baby's birth and this should be discussed with them. In the case of a parent who is unable to register due to capacity issues 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 or through the Accessible Information Officer in the Learning Disabilities Team (see Appendix 2 and 3).
- The 'Pink Box' scheme provides resources for clients with learning disabilities and although the scheme does not include material relevant to pregnancy and is therefore not distributed to maternity units, the Accessible Information Officer may be able to offer advice around accessing specific material.
- 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.
- Adaptation of services to ensure that they are appropriate to support families over an extended period of time to accommodate age and stage developmental needs will be required. Helping parents to engage most effectively with children and family services will require a multiagency approach that recognises the need for on-going assessment and support is essential.

3.6 Capacity development

- Professionals working in services for adults with learning disabilities require training in child protection issues and The Highland Practice Model (GIRFEC) and staff should ensure they access this training available to all in Highland.
- Practitioners involved in children's or generic services require training and information about adults with learning disabilities and their support needs. This includes training on adult support and protection issues and adults with incapacity legislation which is available locally (see Appendix 3).
- Professionals working in universal services providing support to women should seek assistance with communication issues associated with learning disabilities and their particular needs through specialist services. This can in the first instance be through a phone call to the local Learning Disabilities Team for advice.

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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 Person 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 understand 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 parents with learning disabilities and accessing specialist expertise to facilitate this. Useful contacts can be found in Appendix 3 and 4.

3.8 Involving the extended family

- It is essential to include 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 in control. 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 assessment using the Antenatal 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.

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- Parents with moderate learning disabilities must have their needs assessed by an appropriately qualified practitioner with experience of working with this client group. This can be accessed through the Community Nursing Learning Disabilities Team or other professionals working with the woman such as speech and language therapy, psychology, autism services or other adult supports working with the woman across agencies. Support must be tailored to meet their individual needs and assessments should not be based on assumptions of capacity.
- 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 advice. Long acting contraception is the most effective choice for women with additional support needs, lessening the likelihood of unplanned pregnancy.
- If the woman is currently taking any medication or undertaking treatment regimes 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, can get additional advice through the appropriate Speech and Language Therapist and/or the Accessible Information Officer (see Appendix 3).
- The checklist for best practice (Appendix 1) can be downloaded separately and used to inform part of the woman's Maternity Record Summary (SWHMR) held at base, 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 ensure that they fully understand the information that is being given.

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- Parents should be involved in assessments and formation of care plans and they should be supported to ensure understanding. This may require support from an advocate to help with this.
- Partners/fathers should be included in planning care and assessing support requirements where possible, and their needs considered.
- Although most of the research and literature around parenting and learning disability focuses on the mother, fathers with a learning disability are heavily involved in parenting their children and their needs should be considered and assessed.
- 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.
- Women with learning disabilities may be vulnerable to mental health issues, behavioural problems, relationship issues, abuse and exploitation and staff working with them must be mindful of this and the risks to them 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 Healthy Start 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.
- If a baby of a mother with learning disabilities is admitted to SCBU, the Antenatal Plan must be available for SCBU staff.
- There must be clarity about which member of the SCBU staff will contribute to the wider family assessment. SCBU staff will be assessing and observing family dynamics and often practical tasks such as feeding or baby care.
- A Child's Plan should be developed for the baby with an identified Lead Professional.

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6. Conclusion

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

Being honest and clear about expectations is important for parents as are co-ordinated assessment processes based on competency, communication that takes account of comprehension levels and flexible responsive services. It is not always the case that both parents will have a learning disability and assessment should take account of the family structure.

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. Parenting can be difficult but a parent with a learning disability can often be a very competent parent when well supported by their partner, family and services working together.

Access to advocacy is important for people with a learning disability and professionals who work in learning disabilities teams are often the mediators between parents, and children and family services. The main issue will be how parents are supported to develop parenting skills and overcome any issues in their lives that may negatively impact on their ability to be a good parent, whilst retaining a focus on the needs of the child and reporting any concerns to children and family services where there may be issues of potential risk.

It is often the lack of support that is the problem for families particularly with the changing needs of the child. Providing an integrated service for parents with learning disabilities will go some way to facilitating this by ensuring a dynamic assessment process using the Highland Practice Model (GIRFEC).

References and Bibliography

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Highland Children's Services, March 2016. *Child Protection Inter-agency Guidelines*
http://www.forhighlandschildren.org/2-childprotection/publications_112_2964544787.pdf

Highland Children's Service, June 2015. *Highland Practice Guidance: Getting it Right for Every Child*.
<http://www.forhighlandschildren.org/5-practiceguidance/high-pract-model.pdf>

Highland Learning Disabilities Relationships Group (HLDRG), 2012. *Touch me touch me not – protocol for clients, carers and staff*. Highland: HLDRG.

Mental Welfare Commission for Scotland, November 2011. *Consenting Adults? Guidance for professionals and carers when considering rights and risks in sexual relationships involving people with a mental disorder*. Edinburgh: MWCScot
<http://www.mwscot.org.uk/media/51782/Consenting%20Adults.pdf>

Morris, J. and Wates, M., 2006. *Supporting disabled parents and parents with additional support needs*. London: Scottish Care Institute for Excellence.

NMC, 2012. *Midwives rule and standards*.

NHS Highland, 2010. *Revised Procedure for the Communication and Handover of Health and Social Information Between Midwife and Health Visitor*. Inverness: NHS Highland.

NHS Highland, 2010. *Guidelines for Maternity Services Getting it Right for Every Mother and Child*. Inverness: NHS Highland.

NHS QIS, 2004. *Quality Indicators: Learning Disabilities*. Edinburgh: NHS Quality Improvement Scotland.

NHS QIS, 2006. *Promoting access to healthcare for people with a learning disability – a guide for frontline staff*, Edinburgh: NHS QIS.

NHS QIS, 2009. *Pathways for Maternity Care*. Edinburgh: NHS QIS.

NHS QIS, 2009. *Tackling indifference: healthcare services and people with learning disabilities*. Edinburgh: NHS QIS

NICE Clinical guideline 10, 2010. *Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors*. London: NICE.

Scottish Consortium for Learning Disability, 2009. *Scottish Good Practice Guidelines for supporting Parents with Learning Disabilities*. Glasgow: SCLD.

Scottish Executive, 2002. *Promoting health, supporting inclusion: the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities*. Edinburgh: Scottish Executive.

Scottish Government, 2013. *The keys to life: Improving the quality of life for people with learning disabilities*. Edinburgh: Scottish Government
<http://www.scotland.gov.uk/Resource/0042/00424389.pdf>

Scottish Parliament, 2000. *Adults with Incapacity (Scotland) Act 2000*. Edinburgh: HMSO.

Scottish Parliament, 2009. *Sexual Offences (Scotland) Act 2009*. Edinburgh: HMSO.

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Tarleton, B. Ward, L. and Howard, J., 2006. *Finding the Right Support: A review of issues and positive practice in supporting parents with learning difficulties and their children*. London: The Baring Foundation.

Appendix 1

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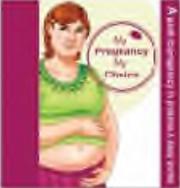
Checklist for promoting best practice	Yes /No - details
Has the woman been allocated a named community midwife who will be the main point of contact for her in her pregnancy? Is this clearly documented in her handheld maternity notes? (Scottish Woman Held Maternity Record – SWHMR).	
Does the woman have clear details about how to contact her midwife, GP, out-of-hours services or planned place of birth for advice and support at any stage during pregnancy? Does she have an awareness of the types of issues she should contact services for advice on?	
Has the woman demonstrated the ability to self-advocate and contact services (e.g. ability to dial numbers) Is this documented in her handheld notes? If not, are her advocate details in her health records held at base?	
Has the Lead Professional for this woman’s care been documented and does the woman know who will be managing her care?	
Does the woman have all the contact details she needs and are they contained within her handheld maternity notes in a format that she understands? Does the woman know she can use these numbers when required?	
Has the woman been advised of the importance of keeping her maternity notes with her and taking them to all contacts she has with health staff for any reason?	
If the woman is on any drug or treatment regimes, has she been referred to the specialist for review (e.g. epileptic medication).	
Has the woman been given enough practitioner time and contact to enable full explanations to her and ensure her understanding?	
Is the woman’s preferred means of communicating: telephone, mobile, text, email, use of pictures - recorded in her notes?	
Has the woman been given access to high quality information in a format she understands around her needs and support? This should include details about her pregnancy, her growing baby, the birth, infant feeding, parenting expectations, child-parent attachment and bonding, sexual health and pregnancy planning.	
Is the woman clear about the support package of care that has been planned for her dependent on her assessed needs and who else is involved? Is this clearly documented in her notes?	
Does the woman have support from her partner and wider family and are their details recorded in her notes, regularly checked and updated at each contact?	
Has the woman been given verbal explanations or demonstrations about aspects of her pregnancy and care using various resources matched to her ability level?	
Have any assessments and decisions about her plan of care been communicated between midwifery and health visiting services and the woman’s GP and obstetrician? Has she met her HV prior to her baby’s birth and is she clear about who to contact for help and advice?	
Does the woman know who her named HV is and how to contact her/him? Does she know who to contact for help and advice out-of-hours?	
Has on-going assessment considered parenting capacity, parent-child interaction and attachment and support available from partner/family/carers?	

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Resources

The Health Information and Resources Service (HIRS) library based at Assynt House offers a wide range of health related materials either for loan or to give to women. It is available to all practitioners across health, social care and the third sector. Visit the website at <http://healthyhighlanders.co.uk/HPAC> and complete and submit the online registration form. Once you have done that you will be free to order materials on line. Or telephone: 01463 704647 for more information.

<p>CHANGE resources</p>	<p>These resources are available from NHS Health Scotland to give to pregnant women or parents who have a learning disability. They can be used as an alternative to Ready, Steady, Baby@ and Ready Steady Toddler! They have been developed with users and contain pictures and simple language to help when imparting information around pregnancy and childcare. They were originally designed to be given to women but practice has often been to use sections of the books at different times and stages. Practitioners should make individual assessments as to the best use for each woman.</p> <p>They have recently been evaluated and will be updated to reflect current evidence and policy so at present it may be more useful to use sections of the resources as appropriate.</p>
<p>There are 3 CHANGE resources for different stages. Practitioners in children and families teams, adult learning disabilities teams, family centres and third sector (voluntary and private) should also be familiar with all 3 resources.</p>	
	<p>My Pregnancy My Choice is an alternative to Ready, Steady, Baby! (RSB) for women who have literacy problems. As with RSB there is an expectation that is used with women at an early stage in pregnancy by the midwife however other groups of staff working with parents with learning disabilities can access these resources.</p>
	<p>You and your baby 0-1 year contains useful pictures and text to help support the early days with a new baby up until one year.</p>
	<p>You and Your Little Child 1-5 years contains pictures and simple text around parenting skills, routines, play and many more issues that parents may need information on.</p>

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<p>Pregnancy Support Pack © – CD-ROM</p>	<p>Produced by NHS Fife this CD has a bank of easy to read and visual resources designed to be used in the antenatal period that aims to support parents with a learning disability during pregnancy. It uses the 'Boardmaker' and CHANGE pictures.</p> <p>The resource was developed by the speech and language team in Fife and has been positively evaluated by mothers with learning disabilities. It can also be used for parents with literacy problems. Although some of the content is specific to Fife it contains useful pictures for generic use.</p> <p>A copy of the CD is available for staff to borrow from the HIRS library and a copy is also available in each midwifery team.</p>
<p>Play@home Baby DVD</p>	<p>Is a resource that can be used with women and their families. It shows many images of parents interacting with their babies and also contains a section on baby massage which can be taught to parents by a baby massage trainer to support attachment and bonding. All Health Visitor bases have copies of the DVD and it is also in the HIRS library for loan. Most HVs and community midwives have been trained in baby massage which can be taught to women to promote attachment and attunement to their baby.</p>
<p>Baby and Me DVD</p>	<p>This DVD has clips of positive interactions between parents and babies that may be useful for teaching purposes. HV bases have copies of this resource and it is also available in the HIRS library.</p>
<p>Me and Us</p>	<p>These publications provide picture images to enable discussion of personal, social and health education around sex and relationship issues. Although not specific to pregnancy, the resources may be useful for imparting information.</p>
<p>Breastfeeding Your Baby</p>	<p>This pictorial training book and DVD from UNICEF has been developed to support the needs of women who have difficulties with literacy and will be useful for this client group.</p>
<p>I'm only a baby but...</p>	<p>An introduction for new parents on how to keep their baby safe. This booklet covers falls, fire, burns, choking, feeding, bath time and travel. It covers essential child safety messages in pictures and simple text. Perfect for all parents and carers but especially those with low literacy and those for whom English is an additional language</p>
<p>Now I can crawl I can ...</p>	<p>Now I Can Crawl, I Can ... is an innovative and colourful picture-based safety booklet for all parents, particularly those with low literacy and those for whom English is an additional language. Essential safety advice covering the emerging risks to babies as they begin to crawl and stand up, this 48-page booklet is a perfect follow-on to <i>I'm only a baby, but ...</i></p>
<p>Child Development Pack</p>	<p>There are 3 elements to this pack produced by the Child Accident Prevention Trust</p> <p>Session Plan Pack which includes 15 flashcards illustrating an accident scenario on one side and a session plan on the reverse. Each one gives aims, learning outcomes, facts and advice to enable you to run a simple, effective discussion.</p> <p>Accidents and Child Development is an A4 book containing guidelines for practitioners.</p> <p>As I Grow and Change I Can... (40 copies) of pictorial booklet for parents, showing how risk is linked to their young child's physical development and learning about the world. Valued resource for all parents, but especially those with low literacy or for whom English is a second language.</p>

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Websites

NHS Highland adult social work and social care services for people with learning disabilities have information on their website which can be accessed at:
<http://www.nhshighland.scot.nhs.uk/Services/ASC/LearningDisability/Pages/welcome.aspx>

Specialist Learning Disability Health Service web page:
<http://www.nhshighland.scot.nhs.uk/Services/Pages/LearningDisabilityService.aspx>

Advocacy services in Highland <http://www.advocacy-highland.org.uk/>

Information about the Learning Disability health and social work staff in Argyll and Bute can be accessed at:
<http://www.argyll-bute.gov.uk/social-care-and-health/learning-disability-service>

Advocacy services in Argyll and Bute <http://www.laas.org.uk>

Health and Happiness <http://www.healthandhappiness.org.uk/>

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Appendix 3

Contacts

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

Jonathan Gray - Consultant Nurse for Learning Disabilities,
NHS Highland, Learning Disabilities Team, Drumossie Unit, New
CraigsHospital. jonathangray@nhs.net

Or for staff in Argyll and Bute

Anne-Lise Dickie – Professional Lead Learning Disability Service, Argyll and Bute
Hospital, Blarbuie Road, Lochgilphead, Argyll.
annelise.dickie@nhs.net

- For information about resources for people with learning disabilities:
David Hughes - Accessible Information Officer,
Learning Disabilities Team, Drumossie Unit, New
CraigsHospital. david.hughes6@nhs.net
- For information about supporting adults with learning disability whilst in acute
services:
Val Watson - Acute Adult Learning Disability Liaison Nurse,
Kyle Court, Raigmore Hospital Inverness Tel 01463 7060 Mobile 07920784063.
val.watson@nhs.net

Additional training is available to all staff on Equality and Diversity, Child Protection and Domestic Abuse and information on these courses can be found on the respective NHS Highland and Highland Council intranet sites.

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Appendix 4

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
East and Mid Ross Community Learning Disability Nursing Team for Adults	Isobel Rhind Centre Tomich Road Invergordon IV18 0AX Tel: 01349 854537

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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 709855 Tel: 01397 709866 Fax: 01397 705829
Skye &Lochalash Community Learning Disability Nursing Team for Adults, Children and Young People	Lochalsh Healthcare Centre Station Road Kyle of Lochalsh IV40 8AE Tel: 01599 530937 Fax: 01599 534451
Wester Ross Community Learning Disability Nurse for Adults, Children and Young People	The Nurse's Base Poolewe Wester Ross IV22 2JU Tel: 01445 781288
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 (answer phone) Tel: 01408 664084
Caithness Community Learning Disability Nursing Team for Adults, Children and Young People	Old Medical Unit Dunbar Hospital Thurso KW14 7XE Tel: 01847 893106 Fax: 01847 892263

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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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