

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

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Version: 1	Date of Issue: September 2011
Page: 1	Date of Review: September 2013

Contents	Page no
1. Introduction	3
2. Aim	4
3. Principles of Good Practice	5
3.1 An early response	5
3.2 Needs led support	5
3.3 Assets led model rather than deficit led	6
3.4 Time	6
3.5 Effective support involves a wide range of strategies	6
3.6 Capacity development	7
3.7 Parenting with support	7
3.8 Involving the extended family	8
4. Information for practitioners	8
5. Working together to support families	9
6. Conclusion	10
7. References and Bibliography	11
Appendices	
Appendix 1 Checklist for promoting best practice	12
Appendix 2 Resources	13
Appendix 3 Contacts	15
Appendix 4 Community Nursing Learning Disabilities Teams	16
Appendix 5 Contributions	19

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 2	Date of Review: September 2013

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. The Mental Health Care and Treatment Act (Section 311) states that it is an offence for anyone to have sexual intercourse with a person who is unable to fully consent due to any mental health issues or disorder (Scottish Parliament, 2003). Therefore if practitioners have any concerns about the woman's ability to consent then advice should be sought from the learning disabilities team and an adult support and protection referral should be considered.

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 to consider the potential capacity of the prospective parent to have the ability to care for and nurture their newborn child.

Having a learning disability is not in itself an indicator of limited parenting abilities however, when there is inadequate early and effective support for families then family breakdown is a real possibility. 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).

Not having 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 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 ongoing 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.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 3	Date of Review: September 2013

For practitioners, finding the balance between protecting children whilst maintaining the rights of parents can be difficult. However, by ensuring training to work with adults with learning disabilities and following child protection procedures is prioritised for any staff who work with this client group ought to help determine any level of risk. Integrated working between maternity, early years and learning disabilities teams and children and adult social work teams will also help staff to understand the needs of parents whilst fulfilling their roles and responsibilities to any children (Tarleton et al, 2006).

2. Aim

The aim of this guidance is to offer practitioners within maternity and early years services good practice reference points to consider when working with parents 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.

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.

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.sclد.org.uk/library-publications/scottish-good-practice-guidelines-supporting-parents-with-learning-disabilities>

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 4	Date of Review: September 2013

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 national Keeping Childbirth Natural and Dynamic (KCND) 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 Getting it Right for Every Child (GIRFEC) the midwife will also be the named person for the baby and when additional needs are identified in pregnancy support may be put in place to ensure that mum is able to meet those needs until birth takes place. Following delivery, mum and baby should have their needs assessed independently which may require additional input and a co-ordinated response between children and adult services.
- The named person for the child on handover from maternity care will be the named public health nurse/health visitor (PHN/HV). The PHN/HV will continue to support mum and ensure her needs are assessed and ongoing co-ordinated care provided by working closely with the Learning Disabilities Teams and her GP.
- Where required a multiagency Lead Professional must be identified for the woman and her child, 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 needs change.
- Women must be offered information in a format they understand and be informed of the reasons why information about her pregnancy and ongoing care of her and her baby may need to be shared with other agencies or professionals.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 5	Date of Review: September 2013

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) and the completion of an Antenatal Plan should be included where additional support from other agencies is identified during pregnancy.
- A full assessment of the needs and the support required for the woman to undertake parental responsibilities must be carried out, together with considering the needs of her children, born or unborn.
- 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 should 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.

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 (2006) 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 and effective care.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 6	Date of Review: September 2013

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 family must work closely together to ensure the needs of the whole family are considered and assessed.
- Universal services should make 'reasonable adjustments' to ensure they are accessible for people with learning disabilities including times and settings for appointments.
- Flexible support to meet an individual's needs should include consideration of assessments that occur in the woman's own home where possible, not an unfamiliar community setting.
- The planning of care between midwives and PHN/HVs is really important and must begin early in pregnancy as per NHS Highland handover procedure (2010).
- Joint appointments and care planning with partners providing additional support should be facilitated.
- 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 resources library or through the Accessible Information Officer in the Learning Disabilities Team (see Appendix 2 and 3).
- 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 and opportunities to meet the staff will help allay concerns.
- Although the 'Pink box' 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 or benefits and parenting may be offered through partner agencies and should be included in any assessment of needs and care plans.
- Understanding of individual and changing needs and helping parents to engage with children and family services will require a multiagency approach. The role of the Integrated Services Officers (ISO) in supporting frontline NHS staff should be considered, particularly for accessing social work early intervention staff (Children's service workers – early years, or support 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.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 7	Date of Review: September 2013

3.6 Capacity development

- Professionals working in services for adults with learning disabilities require training in child protection issues and should ensure they access this training available to all staff in Highland.
- Practitioners involved in children's or generic services require training and information about adults with learning difficulties 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.

3.7 Parenting with support

- Parents need additional time to understand the choices available to them together with early contact with relevant services, co-ordinated by their Named Person and/or Lead Professional.
- 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 difficulties.
- 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 service 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 and PHN/HV can be accessed through the GP surgery or via the community midwifery or community nurse bases.
- 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 PHN/HV who will take over her care following handover from the midwife (usually around 10 days postnatal).

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 8	Date of Review: September 2013

- 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.
- Ongoing assessment will include discharge planning and support that is to be provided following handover of care to the PHN/HV including a Childs Plan for the baby if required.
- The PHN/HV will continue to offer support based on assessment of risks and needs of mother and baby.
- 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 professional working with the woman such as speech and language therapy, psychology. Support must be tailored to meet their 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. Discussions should also include sexual health and future pregnancy planning advice.
- 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 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 PHN/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 need assistance when considering 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.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 9	Date of Review: September 2013

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.
- 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 ongoing 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 and homelessness may be an issue for women and facilitating links to housing support organisations are very important for this client group.
- Assistance when 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.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 10	Date of Review: September 2013

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 'good enough' 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 good enough parents, 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).

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 11	Date of Review: September 2013

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<http://www.baringfoundation.org.uk/FRsupportSummary.pdf>

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 12	Date of Review: September 2013

Appendix 1

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 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 contact services (e.g. ability to dial numbers) Is this documented in her handheld notes?	
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 interaction, 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 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 as required?	
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 plan of care been communicated between midwifery and public health nursing/health visiting (PHN/HV) services and the woman’s GP and obstetrician?	
Does the woman know who her named PHN/HV is and how to contact her/him? Has she met her PHN/HV prior to her baby’s birth and is she clear about who to contact for help and advice?	
Has ongoing assessment considered parenting capacity, parent-child interaction and attachment and support available from partner/family/carers?	

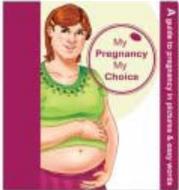
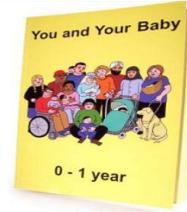
Warning – Document uncontrolled when printed

Version: 1	Date of Issue: September 2011
Page: 13	Date of Review: September 2013

Appendix 2

Resources

The Health Information and Resources Service library based at Assynt House offers a wide range of health related materials for loan. Visit the website at <http://www.nhshighland.scot.nhs.uk/hirs> or telephone: 01463 704647

<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>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. Picture disks are located in each CHP.</p>

Warning – Document uncontrolled when printed

Version: 1

Date of Issue: September 2011

Page: 14

Date of Review: September 2013

	<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>
<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 PHN bases have copies of the DVD and it is also in the HIRS library for loan. Most PHN/HVs and community midwives have been trained in baby massage.</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. PHN/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>

For staff working in Argyll and Bute leaflets and resources can be accessed through the Public Education Resources Library based at Gartnavel Royal Hospital campus, Glasgow. Contact perl@ggc.scot.nhs or telephone: 0141 201 4915/4540

Websites

Highland Council social work services for people with learning disabilities have accessible information on their website which can be accessed at:

<http://www.highland.gov.uk/socialwork/learningdisabilityservices/>

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/>

<p>Warning – Document uncontrolled when printed</p>	
<p>Version: 1</p>	<p>Date of Issue: September 2011</p>
<p>Page: 15</p>	<p>Date of Review: September 2013</p>

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 Craigs Hospital.
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 Craigs
Hospital. david.hughes6@nhs.net
- For information about supporting adults with learning disability whilst in acute
services:
Val Watson - Acute Adult Learning Disability Liaison Nurse,
Ward 5B 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.

Warning – Document uncontrolled when printed	
Version: 1	Date of Issue: September 2011
Page: 16	Date of Review: September 2013

Appendix 4

Community Nursing Learning Disabilities Teams

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Version: 1	Date of Issue: September 2011
Page: 17	Date of Review: September 2013

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Version: 1	Date of Issue: September 2011
Page: 19	Date of Review: September 2013

Appendix 5

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Version: 1	Date of Issue: September 2011
Page: 20	Date of Review: September 2013