

# MAKING CHOICES KEEPING SAFE

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## **Section 1- Introduction**

#### **1.1 BACKGROUND**

These guidelines have been produced as a response to the sexual health needs of adults (16 & over) with learning disabilities. It has been written in wide consultation with, and with input from, people with learning disabilities, their families and carers. It is supported by the Scottish Government's Sexual Health and Blood Borne Virus Framework 2015-2020 Update<sup>1</sup>. (See appendix 7 for references)

Much of the information is transferable, but for guidance specifically where young people are involved in sexual activity under the age of 16, follow the link below to the Underage Sexual Activity Guidance http://www.healthyrespect.co.uk/ Professionals/YoungPeopleSexLaw/Pages/ChildProtection.aspx

A multi-agency pan-Lothian group developed and adopted these guidelines in 2004 and they have since been reviewed in 2013-15 as part of the follow up work from the Justice Denied Report (MWCS 2008)2. Workers and staff must be supported and have guidance through organisational policy and procedures to enable them to feel confident and competent to assist People with Learning Disability with sexual health, relationships and wellbeing.

## **1.1.1 Learning disability, sexual health, relationships and wellbeing**

There is more recognition today of the human right of people with a learning disability to form relationships and express their sexuality, as stipulated in Article 8 of the Human Rights Act 4

(Liberty, 2009)

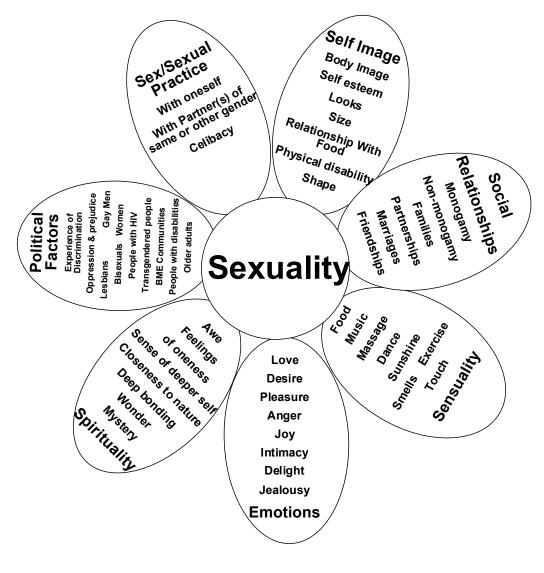
They have the right to choose their friends and have choice and control in relationship situations.

Sexuality is a subject that some often find difficult to discuss but it is a part of everyone's life. People who have learning disabilities have a right to be treated as adults and to have their sexuality recognised and respected.



It is recognised that some people with learning disabilities will need support to meet others and build relationships.

Relationships take many forms. Each relationship is important to the sense of belonging, social inclusion of people with learning disabilities and important in realising the potential of people with learning disabilities (The Keys to Life, 2013) 3



These all add up to how we define ourselves as sexual beings Sexuality = sexual selfhood Sexuality involves our relationships with ourselves, those around us and the society in which we live - whether we identify as gay, heterosexual, lesbian, bisexual or celibate

Sexuality is a natural and healthy part of being human. People are entitled to express their sexuality in different ways, showing respect for self and others. People with learning disabilities should be supported to make informed choices, and exercise their rights and responsibilities in regards to sexual health and personal relationships, which are an integral part of their lives.

#### **1.1.2 Overarching purpose and aims**

The purpose of the document is to allow workers, whether in statutory, private or voluntary sectors, to use this as a reference and guide for their practice. It will help workers understand how to approach the subject of sexuality and how to respond to difficult situations with the sexual behaviours of their clients.

The aims of the guidance are to:

- provide a set of principles and values to support work in the area of sexual health and relationships
- increase confidence and competence in managing situations at work relating to sexual health and relationships
- promote understanding of how to approach the subject of sexual health, relationships and wellbeing
- provide information about how to respond to challenging situations
- signpost useful links and resources
- consolidate learning beyond initial training for staff
- provide an accessible source of information for staff.

#### **1.2 INTRODUCTION**

Many people with learning disabilities will not need intervention, or a response in their sexual lives, from workers. However, the pan-Lothian working group believes that all people with learning disabilities will benefit from guidelines that describe and explain workers' roles and responsibilities.

Some people with learning disabilities need help and guidance to ensure wellbeing in relation to their sexuality and sexual behaviours. Similarly, some workers need support and guidance in this sensitive area to ensure that consistency and best practice are pursued. This document is designed to:

- provide workers with relevant information
- increase workers' confidence and competence in dealing with situations at work relating to sexual health, relationships and wellbeing
- give clear guidance on how to respond in specific situations.

People with learning disabilities need to receive consistent information and messages. This is why the document needs to be used by workers across all disciplines involved in the lives of people with learning disabilities.

Parents, carers, volunteers, friends and relatives, as well as people with learning disabilities themselves, also need to know what is in these guidelines. Although these guidelines are written specifically for workers, the guidance and the principles on which they are based are relevant to everyone involved in service provision. The guidelines described in the following pages have been agreed by the partners listed in appendix 8 and subsequently reviewed in 2013-15 by the multi-agency review group also listed in appendix 8.

#### 1.3 VALUES UNDERPINNING GUIDELINES FOR GOOD PRACTICE

These guidelines adhere to values that are firmly rooted within the United Nations Declaration on Human Rights 6 and the philosophy underpinning Harm Reduction 7. It supports the rights of all people with learning disabilities to access health information and services in a safe and supportive environment. The following principles, written by Anne Craft (1987), 8 describe these rights:

- the right to grow up, that is, to be treated with the respect and dignity accorded to adults
- the right to know, that is, to have access and assimilate information about themselves, their bodies and those of other people, their emotions, and appropriate social behaviour
- the right to be sexual and to make and break relationships
- the right not to be at the mercy of the individual sexual attitudes of different caregivers
- the right not to be sexually harmed or abused
- the right to humane and dignified environments.

These guidelines would also add the following to the above principles:

• the right to explore and express sexuality and sexual orientation / gender.

#### **1.4 DEFINITIONS**

The following definition was taken from 'The same as you?' 9

#### Learning disability

'People with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to:

- understand information:
- · learn skills; and
- cope independently.'

This definition was revisited and maintained in the Scottish Government's Learning Disability strategy, Keys to life (2013)3, but is acknowledged as only part of a description. It does not capture the whole person who can be much more – a friend, a family member, a community activist, a student, a parent, an employee or employer, to name just a few roles. It is essential that we keep in mind all of these possibilities. The term learning disabilities is now used throughout the UK, particularly in health and social care settings. We are aware there are some mixed views about this, and consistent with 'The same as you?' We can review the use of this term at some point in the future.

#### Incapacity

The definition of 'incapacity' outlined in the Adults with Incapacity (Scotland) Act 2000 10 is that someone is 'incapable' of making a specific decision when he or she cannot:

- act; or
- make decisions; or
- communicate decisions; or
- understand decisions; or
- keep a memory of decisions

because of mental disorder or inability to communicate that cannot be rectified by human or mechanical means.

This does not include people whose only problem is that they are unable to communicate if this can be overcome in some way using either human or mechanical help. This definition is 'decision-specific' so a person with learning disabilities may not have any degree of incapacity.

## **Section 2 – The Guidelines**

Sexuality is a subject that people often find difficult to discuss but it is a part of everyone's life. People who have learning disabilities have a right to be treated as adults and to have their sexuality recognised and respected.

Sexuality is a natural and healthy part of being human. People are entitled to express their sexuality in different ways, showing respect for self and others. People with learning disabilities should be supported to make informed choices, and exercise their rights and responsibilities in regards to sexual health and personal relationships, which are an integral part of their lives. All people with learning disabilities have the right to enjoy a full range of relationships and to choose to express their sexuality at a variety of levels.

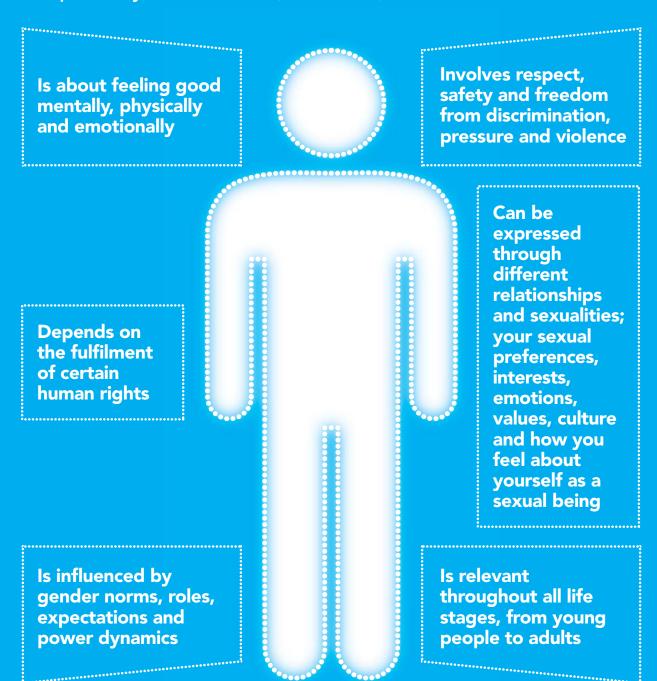
## Sexuality encompasses sexual health, so what do we mean by sexual health?

It is important that we don't limit our thinking about sexual health to pregnancy and sexually transmitted infections. Sexual health should be considered in its broadest sense to ensure that people's physical, mental and emotional needs are met adequately. Care providers need to understand and promote the potentially positive role that sexuality and good relationships can play in people's lives.

### What do we mean by sexual health?

We are thinking about sexual health in its broadest sense. The key elements of sexual health, when viewed holistically and positively, are as follows (WHO 2010). Sexual health...





Sexual health needs to be understood within specific social, economic and political contexts and in particular the inequalities linked to poverty and gender inequality. It's not just about an individual's behaviour but the context in which the behaviour is taking place or the reasons underpinning the behaviour.

#### 2.1 RELATIONSHIPS AND SEXUAL WELLBEING

All people with learning disabilities have the right to enjoy a full range of relationships and to choose to express their sexuality at a variety of levels. Having the chance to make and sustain friendships and relationships is something that improves their wellbeing and quality of life. Many people with learning disabilities want that chance to have a romantic, sexual and long-term relationship (The Keys to Life - Improving Quality of Life for People with Learning Disabilities, 2013) 3.

In practice this means that workers should ensure a range of opportunities such as:

- help with understanding and expressing feelings, for example pleasure, anger, happiness, loss, joy, love, desire, intimacy
- giving the opportunity to have a variety of sensory experiences, for example, massage, food, music, dance, exercise, warm baths, sunshine, rain, colour, smell
- giving the opportunity to develop a sense of spirituality, for example, closeness to nature, feelings of oneness, religious beliefs
- encouraging a positive self-image, for example, developing self-esteem, healthy lifestyle, looking good
- providing information and education on how people's bodies develop and work, for example, naming body parts, differences between genders, children and adults, puberty, growing older, sexual feelings and functions, pregnancy
- providing support to develop and maintain friendships, family and social relationships
- providing information on different means of sexual expression, for example, touch, masturbation, making love, same sex relationships, celibacy, use of sexually explicit materials
- supporting people to enjoy healthy non-abusive relationships through, for example, ensuring privacy, consent (see section 4.2 and appendix 1) and safety, including access to contraception and negotiating the use of contraception
- encouraging a sense of one's self in relation to society by, for example, providing information on, and access to, support for disabled people (or people with disability if you are using the social model), people from minority ethnic groups, older adults, gay men, lesbians, transgender, gypsy travellers.

#### **2.2 CONFIDENTIALITY**

People with learning disabilities have the right to confidentiality. They have the right to have their confidentiality acknowledged and respected, and to have clear boundaries to that confidentiality explained. People with learning disabilities have the right to know whether any of their information will be shared and with whom, and the right to decide whether the information should be

People with learning disabilities have the right to confidentiality, unless there is concern about abuse or risk of harm shared at all. If people with learning disabilities feel their confidentiality has been breached, they have a right to complain.

In practice, this means that workers have a responsibility to:

- know the content of these guidelines when working with people with learning disabilities
- ensure you keep up-to-date with relevant training
- ensure each person with a learning disability using the service/resource is aware of the guidelines regarding confidentiality of information
- inform each person with a learning disability that they are allowed and encouraged to talk about aspects of relationships/sexual wellbeing if they need to. If they do choose to, their privacy will be respected at all times, and they will be advised by workers of times and places where it would be appropriate to have these discussions
- agree clear boundaries to confidentiality with each person, ensure they are aware of who has access to their information and which events would impede their right to confidentiality, for example, if the worker has concerns that the individual or another is in a situation of risk
- work towards building an appropriate relationship with each person so that the client feels confident to share personal information with their worker
- refer concerns/anxieties/disclosure of harm or abuse to the relevant agency, whilst making sure each person is aware of the process
- be familiar with guidelines and procedures on legal constraints to maintaining or breaking confidentiality - see appendix 1. In particular circumstances of public protection, care staff have a duty to breach confidentiality. Where someone suspects there may be an adult or child at risk of harm they must follow the NHS Lothian Child Protection / Adult Support & Protection Procedures http:// intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/ Pages/default.aspx
- In all cases where you deliberately release information, even if you believe it to be in the best interests of the public, you must be able to justify your decision
- Inform people with learning disabilities about complaints policies and procedures and support them to use these as appropriate. It is recommended that support from an independent advocate is considered
- If the person has a Power Of Attorney/ Guardian under the Adults with Incapacity Act, they still have the right to confidentiality although the Power Of Attorney/ Guardian might have powers to allow access to such information.

#### 2.3 SUPPORT FOR WORKERS

People with learning disabilities have the right to be supported by workers with relevant knowledge, skills and resources in relationship and sexual wellbeing.

In practice, this means that workers should:

- be familiar with relevant policy and guidelines and be trained in their use
- have access to support from their line
   manager

All workers should be trained on how to work with service users on relationship and sexual wellbeing issues to increase confidence and competence to do so.

- have access to specialist and peer support where required
- have access to and complete relevant and appropriate training on an ongoing basis
- have access to appropriate information and resources, both for their own use and for use with people with learning disabilities
- work to their own level of competence however, this should never diminish the service offered to the person seeking support
- have the right to hold their own values and beliefs however, this does not mean that workers may refuse to support the person's individual choice
- have the right to contribute to the assessment of the person's needs and wants.

#### **2.4 PROTECTION**

People with learning disabilities have the right to be protected from any situation where they are vulnerable to exploitation and at risk of physical, sexual or emotional harm.

In practice this means that workers have a responsibility to ensure people with learning disabilities know that:

- they have the absolute right to feel safe and to be supported to learn the skills to keep themselves safe
- in a situation where they do not feel safe, if they talk to someone they trust they will be listened to
- they have the power to decide how to express their sexuality in a way that is protective of themselves and others.

In order to facilitate the above three objectives, it is essential that personal social education programmes include elements of personal safety and protective behaviour training (organisations that can offer training in this area are listed in appendix 2).

The person with a learning disability should be taught to:

- recognise the signs when personal safety is compromised
- · learn strategies on how to feel safe and protect oneself
- negotiate saying 'yes' and saying 'no'.

It is essential that:

- workers and carers have formal training and support to work with each person, to ensure that however sexuality is expressed, it is consensual for all parties
- the relevant training and support is provided so that workers know how to facilitate an effective protective behaviours programme and how to deal with disclosure of harm or abuse
- in the event of a person disclosing a situation of harm or abuse, the person is listened to and the appropriate organisational policies and procedures are invoked to ensure the protection of that individual and any other people who may be at risk. Care staff must follow the NHS Lothian Child Protection / Adult Support & Protection Procedures – for more information, click on this link:

http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/ Pages/default.aspx

#### 2.5 MULTI-AGENCY WORKING

All people with learning disabilities have the right to planned and coordinated support and services from agencies with a common value base.

This means keeping the person with learning disabilities as the focus whilst:

- working together
- using consistent approaches
- sharing information (see Confidentiality in section 2.2)
- having knowledge of appropriate specialist services, or where to get that information
- agreeing roles
- joint planning
- joint training
- being aware of different agencies' roles and practices
- working to agreed protocols
- use of the Care Programme Approach, in particular complex cases involving a variety of carers and services.

#### 2.6 WORKING WITH FAMILIES AND CARERS

Families and carers can be key influencers in the lives of people with learning disabilities. It is important to work in partnership with families, whilst keeping the person with a learning disability as the focus. In practice this means that workers have a responsibility to:

- ensure good communication with families and carers exists, and make sure their views are listened to and treated with respect. However, the rights of the person with learning disabilities need to be of primary importance
- take seriously any issues raised by families relating to personal safety of the person with a learning disability by undertaking appropriate risk assessment

- consider the need to consult about any decisions in relation to the person with learning disabilities if a Power of Attorney/ Guardian under Adults with Incapacity (Scotland) Act (2000) 10 has been appointed
- share information on appropriate resources with the person's family. This should always be done with the knowledge and, where possible, the agreement of the person with learning disabilities
- ensure that families and carers have access to support, training and education. There should be opportunities for carers to meet other carers to find out about and discuss issues relating to relationships and sexual wellbeing
- ensure that families and carers have access to the appropriate complaint procedure.

#### 2.7 INFORMATION GIVING

All people with learning disabilities have the right to access any information that they need about relationships and sexual wellbeing.

In practice this means that workers should ensure that:

- an agreed person provides this information, at an agreed time and place, discussed with the person with learning disabilities. The choice of who provides information will depend on a number of factors, e.g. preference for a specific worker, the level of knowledge or expertise required, professional relationships, gender or sexuality issues. If a worker recognises that he/she is not the most appropriate person, they should refer on to someone else
- information gives a balanced view and is free of value judgements
- recognition is given that sexuality may be a difficult issue for the person
- information given or gained considers issues of confidentiality
- shared information, e.g. with a parent or relative, is agreed by the person with a learning disability who has the capacity to consent
- information is provided in the most accessible format related to the understanding of the individual. It should be available in a range of formats including written material, audiotapes, DVD, pictures, symbols and/or multimedia
- they obtain relevant information from a range of resources and organisations, for example, F.A.I.R, FPA Scotland (Family Planning Association), BILD (British Institute for Learning Disabilities), LGBT Centre, Respond, Community Learning Disability Teams (see appendix 2)
- people with learning disabilities, workers and families and informal carers all have information about how to disclose abuse or suspected harm
- people with learning disabilities have information on how to complain about services or individuals. They should be given support by a worker in making a complaint if they wish or require it
- people with learning disabilities have information about local independent advocacy organisations. They should be referred with their consent wherever possible.

#### 2.8 SEXUAL HEALTH

People with learning disabilities have the same right as others to have a healthy sexual life. They have the right to choose or refuse sexual health care. They have the right to be made aware of all choices. They have a right to confidentiality. All of the above is based on assessment of their capacity to do so.

In order to adequately promote sexual health, workers need to be:

- confident and competent to discuss relationships and sexual wellbeing with the person with learning disabilities
- confident to discuss condom use and contraception
- able to inform and support the service user in recognition of safer sex practice
- able to facilitate access to condoms and relevant sexual health services.

The following issues could come up in a discussion about sexual health. Some of these issues are expanded on throughout this resource or other resources are recommended (see section 4):

- relationships / friendships
- periods
- condoms
- sexually transmitted infections (STI) and HIV
- sexual activity
- masturbation
- pregnancy
- contraception
- emergency contraception
- sexuality
- sexual harm or abuse
- smear tests
- testicular awareness
- breast awareness
- premenstrual tension / syndrome
- sexual problems
- sterilisation
- abortion
- impact of alcohol and substance use.

## **Section 3 – Good Practice Guidelines**

#### **PRACTICE GUIDANCE FOR WORKERS**

Note: This document should be read in conjunction with the NHS Lothian Child Protection / Adult Support & Protection Procedures http://intranet.lothian.scot. nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/Pages/default.aspx and individual agencies' policies and Confidentiality Guidelines.

Workers should be aware of the National Care Standards 12 and the Scottish Social Services Council Employer and Employee Codes of Practice 13 and other Professional Codes of Practice, e.g. NMC, GMC.

Some of the sections contained in this document are procedural and require action from workers, while others are simply information giving. Workers are therefore strongly advised to read all sections and familiarise themselves with the contents.

It is important for workers to be aware of the legal context. These guidelines will not under any circumstances permit, encourage, or condone any activity which is illegal. Throughout the guidelines it is indicated that the law is particularly important. Appendix 1 gives further information on sexuality and the law as it applies to people with learning disabilities.

The relationships and sexual wellbeing of people with learning disabilities is bound to raise questions and sometimes dilemmas; on the one hand we wish to secure freedom and choice for our clients; but at the same time we have a duty to protect them from exploitation or harm. Any attempts to strike a balance must inevitably be imperfect, but there is a legal duty to report concerns if there are suspicions of harm.

Supporting people with learning disabilities in the area of relationships and sexual wellbeing will involve workers having a positive attitude and sensitive approach when offering help and advice.

Workers should not impose their own beliefs on clients or other workers and should be aware of and respect others' cultural and religious beliefs and practices.

Senior staff and managers have a responsibility to create a climate whereby workers who feel worried or distressed about any situation in their place of work are able to approach a senior member of staff to discuss their anxieties.

People with learning disabilities are entitled to confidentiality – see guidance on confidentiality, individual agency policies and National Care Standards 12.

However, workers do have an overriding responsibility to report disclosures of abuse, harm or illegal acts to their line manager immediately (see NHS Lothian Child Protection / Adult Support & Protection Procedures http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/Pages/default.aspx).

It is important for workers to strive towards a climate of privacy for the personal lives of people with learning disabilities. Gossip and minor sensationalism must not

take place at the expense of the dignity of people with learning disabilities.

Some people with learning disabilities may use street slang for body parts and sexual practices, and workers should be prepared to use language which can be understood by the person with learning disabilities. However, workers should also support people with learning disabilities to understand other terms and in particular develop adult-appropriate language.

Workers should try to feel comfortable when they are required to discuss sexual practices with people with learning disabilities. If they are embarrassed or furtive in their approach, the person with learning disabilities may mirror this. Training may offer workers an opportunity to develop confidence in talking about these issues.

#### **3.1 INTIMATE CARE**

When working with people with profound learning disabilities or those with certain physical disabilities, it may be necessary for workers to undertake personal hygiene and intimate care tasks.

The physical comfort of people with learning disabilities should be prioritised by workers as being of primary importance in the care of individuals. Work relating to intimate care should take precedence over all other tasks, e.g. if a client is incontinent during meal time then the physical comfort of the client must be given priority. The physical comfort and dignity of people with learning disabilities should be prioritised by workers as being of primary importance

The dignity of people with learning disabilities must be upheld by workers at all times. Considerations should include:

- gender issues
- closing toilet / bathroom / bedroom doors
- consulting and communicating with people with learning disabilities about their intimate care
- sensitivity, for example, being aware of appropriate use of language when talking to people with learning disabilities
- awareness of religious and cultural beliefs and practices
- people with learning disabilities have a right to choose who assists them when they need help or support with their personal care where practicable, whilst respecting the rights of both parties
- a risk assessment.

Negative comments and disapproval expressed through word or body language by workers is always unacceptable practice. Intimate care should be undertaken ideally by workers whom the client is familiar with and trusts. This has implications for managers in the recruitment of workers and forward planning of rotas. Minimising the number of workers working with a client should be seen as a priority to ensure consistency in care and maintaining the dignity and privacy of the client.

#### Intimate care should be undertaken in private.

The emotional and physical safety of people with learning disabilities should be considered by workers at all times, e.g. paying strict attention to Health and Safety matters. A risk assessment should be carried out to ensure both the emotional and physical safety of workers and clients, paying close attention to workplace policies and health and safety matters.

#### **3.2 RELATIONSHIPS**

It is important for people to have the opportunity to develop a range and variety of relationships. Some people with learning disabilities are able to do this without help; some will need workers' support and assistance. This may include actively seeking out places where couples can have private space alone together, and facilities for an overnight stay.

Relationships that develop may or may not have a sexual element. Refer to National Care standards 12 on rights to privacy.

#### **Sexual activity**

Sexual activity refers to the way in which humans experience and express their sexuality. Every person has a right to engage in sexual activities that are lawful, wanted and understood, without being exposed to exploitation or sexual violence.

Sexual desires and activities will vary depending on the individual. Some people may choose not to be sexually active and some have fewer opportunities to be sexually active, especially with a partner. The term sexual activity is wide ranging and can include anything from stroking, cuddling, masturbation and self stimulation to vaginal intercourse, anal intercourse or oral sex. People with a learning disability have a right to express emotions and sexuality in ways that suit them and are legally accepted for all adults

Staff should be confident and open to discussing different types of sexual activity, including pleasure and how to stay safe with the people they are working with and where appropriate as part of a person's care. Training should be provided by workplaces to help staff feel prepared to do so and increase knowledge of sexual health and wellbeing issues for people with learning disabilities.

All sexual activity with another person should be consenting. The Sexual Offences Act (Scotland) 2009 14 defines consent and allows one party to withdraw it at any stage, whether they initially gave consent or not. It also highlights circumstances where it is deemed consent cannot be given. See the following link to brief explanatory notes http://www.article12.org/pdf/Sexual\_Offences\_Scotland\_2009.pdf

Sexual activity between workers and an adult at risk of harm is exploitative, abusive and is forbidden by law.

Any allegation of harm or abuse made against a worker will be investigated. See NHS Lothian Child Protection / Adult Support & Protection Procedures

http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/ Pages/default.aspx

#### **3.3 SAME SEX RELATIONSHIPS**

People with learning disabilities have the right to conduct consenting sexual relationships. This applies equally to all adults and does not differ for people in or seeking relationships with someone of the same gender. Around 10% of the general population are estimated to be lesbian, gay or bisexual (LGB). There is no reason to believe that a smaller proportion of people with learning disabilities are lesbian, gay or bisexual. There may be additional barriers to people talking about or acting on feelings of same-sex attraction over and above those experienced by people with learning disabilities who only have feelings of mixedsex attraction (i.e. heterosexual).

Workers need to be aware of their own values around same sex relationships on ethical, moral or religious grounds. The interests and needs of people who are being supported or cared for remain the focus. Workers must not impose their own beliefs on people with learning disabilities. Any discomfort in supporting people to pursue or express interest in relationships with people of the same gender can be an opportunity for workers to reflect on their own practice and to learn more about local social opportunities and support organisations. It may also be useful to organise some training, so that workers can discuss issues and their awareness. People with learning disabilities have the right to conduct a consenting sexual relationship with someone of the same gender.



Any discrimination must be challenged, whether this is among workers or people who are being supported. Even if nobody has expressed thoughts that they are or may be lesbian, gay or bisexual, challenging discrimination will contribute to a supportive atmosphere where people are reassured that it is safe to discuss these issues if or when they choose to. Leaving discrimination unaddressed can have long term negative effects on people's mental health, self-esteem and personal development. It can also reduce the level of trust a person may have in the worker. A zero tolerance approach to discrimination against any individual or group of people (e.g. on the basis of a personal characteristic such as race, sexual orientation or appearance) can be an effective way of approaching this, rather than only addressing the issue of sexual orientation.

If a person with learning disabilities thinks they may be lesbian, gay, or bisexual (LGB), they should be offered full support by workers to help them discover and express their sexuality. This could perhaps involve contacting agencies to meet other LGB people, or to access specific support or counselling (see appendix 3). Some people who have feelings of same-sex attraction decide not to use the labels gay, lesbian or bisexual for themselves. People should be supported to understand commonly understood meanings of these labels, while not being pressured to take on a label they have not chosen. This is different from feeling confused about being attracted to people of the same gender. Sometimes people have conflicting feelings if they are used to hearing negative comments about being LGB, while also feeling same-sex attraction and this can be confusing. Equally, other people are sure that they are LGB and are not confused. The most useful support may be in making contact with other LGB people whether for friendship, sexual or romantic relationships, or finding out about having healthy relationships. As for people of any sexual orientation, accessing relevant safer sex information is one part of this. People with learning disabilities who are LGB or have feelings of same-sex attraction but have been assessed to lack capacity to have sexual relationships can still be supported by workers to attend social spaces to meet other LGB people and to build friendships, just as anyone else may be supported to be socially active.

During any group or individual discussions about relationships, workers should not make assumptions about sexual orientation. Same-sex and mixed-sex relationships should be spoken about equally in an ordinary, supportive way. Using words that are not connected to an assumption about sexual orientation can also help (e.g. talking about a 'partner' rather than boyfriend or girlfriend) or giving examples that include same-sex attraction or bisexual people.

#### **3.4 GENDER DIVERSITY**

Gender identity is about how someone feels inside about whether they are a man, woman or something else. It is separate from someone's biological sex (including hormones, chromosomes, genitals, testes / ovaries). It is also different from sexual orientation. Everyone express their gender in different ways (e.g. through clothing, using a different name or having physical treatment to change their body). People who change their body or express their gender in a non-traditional way are sometimes known as transgender people. Transgender people can be any sexual orientation (e.g. lesbian, gay, bisexual or heterosexual). There are many reasons for people choosing to express their gender in a particular way. Reasons include feeling more comfortable, wanting to express how they feel inside, feeling freer to express particular emotions or for sexual expression. There are no official figures for the number of transgender people in Scotland. Only people who have attended a gender specialist service or have applied for legal recognition of their new gender will be counted. Since legal recognition of someone's new gender was introduced in 2005, there has been an average of 456 applications per year<sup>15</sup>. This does not include people who feel inside that their gender is different or people who make changes in their life such as wearing different clothing, without accessing a gender specialist service.

People should not be pressured to use the label transgender or to say why they want to express their gender in a particular way, if they don't want to. People with learning disabilities have the right to express themselves without having to explain or justify themselves, the same as for people without learning disabilities. On the other hand, workers should be open, accepting a person as they are and being available to speak about feelings. People with learning disabilities may need workers to provide practical support for someone to express themselves. This could be through creating opportunities to cross-dress, going shopping for clothing, helping someone to change their name legally or supporting referral to a specialist service (see appendix 3).

As for any aspects of diversity, workers need to be aware of their own values around diverse gender expression or transgender identities on ethical, moral or religious grounds. The interests and needs of people who are being supported or cared for remain the focus. Workers must not impose their own beliefs on people with learning disabilities. Any discomfort in supporting people to explore or express their gender in a non-traditional way should be acknowledged by workers. It may be useful for workers to gather more information about gender diversity or to arrange training on the topic. Learning more about local social opportunities and support organisations can also be shared with people who may be interested in attending other groups of services. Any discrimination must be challenged, whether this is among workers or people who are being supported. Challenging discrimination will contribute to a supportive atmosphere where people are reassured that it is safe to discuss these issues if or when they choose to. This applies even if nobody is known to be thinking about their gender identity or expression. Leaving discrimination unaddressed can have long term negative effects on people's mental health, self-esteem and personal development. It can also reduce the level of trust a person may have in the worker. A zero tolerance approach to discrimination against any individual or group of people on the basis of a personal characteristic (e.g. race, sexual orientation, wearing glasses, hair style) can be an effective way of approaching this, rather than only addressing the issue of gender diversity.

It is not acceptable to deny someone the right to express their gender in their preferred way because other people are uncomfortable. In single-sex settings, services may need to be adapted to ensure that an equivalent service continues to be offered. People who want to permanently change their gender must be supported to live full time in their chosen gender. This is part of the assessment and treatment process 15.

#### **3.4.1 Domestic abuse/Gender-based violence**

'Domestic abuse (as gender-based abuse) can be perpetrated by partners / expartners and can include physical abuse (assault and physical attack involving a range of behaviour), sexual abuse (acts which degrade and humiliate women and are perpetrated against their will, including rape) and mental and emotional abuse such as threats, verbal abuse, racial abuse, withholding money and other types of controlling behaviour such as isolation from family and friends.' (Scottish Executive, 2000)

#### What is gender-based violence?

'Violence that is directed against a woman because she is a woman, or violence that affects women disproportionately. It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty' (United Nations, 1992) 16.

For more information visit http://www.gbv.scot.nhs.uk/

#### 3.5 SEXUALLY EXPLICIT MATERIALS AND SEX TOYS

For legal, professional, moral and ethical reasons, these guidelines cannot support the use or display at work of sexually explicit material (sometimes referred to as pornography) by employees, for whatever purpose.

Sexually explicit materials and sex toys are readily available to members of the public at the legal age of 18. Providing that the material is only viewed or read in private, this is generally legal. It follows that this material is available to any person with learning disabilities in the same way as any other person.

An interest in such material can be seen as sexual development, especially where the opportunity of sexual discussion is limited or suppressed.

People with learning disabilities should not be reprimanded if found in possession of sexually explicit material. However, those who wish to use these materials should not infringe the rights of other people who do not wish to view or use such materials. Nor should they break the law in what material they have and how they use or view that material.

If a client, who is living in supported accommodation, requests assistance to obtain sexually explicit materials, including those available through the internet, this must be discussed with the manager and the outcome recorded. When the agreement is made to assist the service user to buy or view sexually explicit materials, it is imperative that only legal materials are purchased.

Workers should feel able to initiate discussion and / or respond to service user questions around the use of sexually explicit materials. For example, it would be possible to point out to the service user that some people believe such material is offensive, that it can give a distorted image of sexuality and that it can be degrading.

People with learning disabilities can be supported in exploring various images of sex, which may be sexually explicit, as part of an educational programme. However, the use of pornography within a teaching programme is not appropriate and must not be used.

Requests for assistance to purchase sex toys should be considered in the same way as sexually explicit materials.

The Mental Welfare Commission for Scotland has printed 'Consenting Adults? Guidance for professionals and carers' (December 2012) 17

http://www.mwcscot.org.uk/media/51782/updated\_consenting\_adults.pdf

#### **3.6 PRIVACY**

In our society, sexual activities are expected to be conducted in a private place, and it is important to respect the rights of people with learning disabilities around relationships, sexuality and privacy.

People with learning disabilities should have the opportunity to develop a range and variety of relationships. Relationships that develop may or may not have a sexual element. Residential establishments need to cater for privacy and the following principles should apply. It is important to respect the rights of people with learning disabilities around relationships, sexuality and privacy.

In residential establishments:

- people with learning disabilities should be able to lock their bedroom doors
- workers should not go into a client's room without seeking their permission and having very good cause. However, there may be times when permission is not required, for example, landlords' entry rights
- workers should assist in helping the client to make the room a comfortable environment
- workers should support people with learning disabilities to entertain friends in private.

All sexual acts should take place in private. Sexual behaviour in public may be offensive to others and could lead to prosecution of those involved. Public places are not acceptable venues for any sexual behaviour which can cause offence to others.

In providing privacy for residents, workers will need to remain aware that some people with learning disabilities are vulnerable to harm by others and may need support so that their rights and wishes are protected. Some people with learning disabilities will require help in making informed decisions (see appendix 1 for more information on the Scottish Legal Framework).

#### 3.7 MASTURBATION OR SELF STIMULATION

#### Masturbation

Self-stimulation or masturbation is a normal physical sexual activity and can be a valid outlet of sexual feelings for everyone. For some people with learning disabilities it may be the only way they can achieve orgasm. The knowledge of and familiarity and comfort of our body is an important part of positive self-esteem. Masturbation can relieve frustration and tension, provide pleasure and relaxation.

Self stimulation or masturbation is a normal physical, sexual activity for everyone.

People touch their genitalia for different reasons: it can be a comfort, sensory reason or sexual. We need to understand this in the context of the person's presentation. It is important that people we work with are supported and not prevented from experiencing or made to feel guilty about masturbation.

Masturbation is legal as long as it is carried out in a private and not in a public place. If it takes place in a public space, care must be taken to ensure individuals know it is the space and not the behaviour that is inappropriate.

#### Potential problems with masturbation

- lack of understanding of the process
- physical difficulties there may be a practical issue is if a person is not able to remove clothing or continence products
- psychological issues
- some people can find it difficult to have erections and ejaculate
- some known side-effects of anti-convulsant and psychotropic drugs can cause problems with erections and ejaculation
- recreational drugs.

#### Other things to consider

- is the person bored and in need of alternative stimulation/activities?
- is the person able to masturbate effectively?
- is an appropriate private environment available?
- are there relationship issues?
- is there a concern about abuse?
- is there any health-related issue?

#### What happens if we choose to ignore these issues?

- potential for physical and emotional distress demonstrated through behaviour
- sexually inappropriate behaviour in public
- stigma and isolation
- potential for frequency and intensity of issues to further develop becoming a major management problem.

#### What do people with learning disabilities need?

- 1. Assessment of sexual behaviour(s) taking into account cognition, processing of information and communication needs.
- 2. Accessible information, i.e. visual sequencing strip, social story or easy-read booklet on:
  - what is masturbation
  - how to masturbate
  - what happens to them when they masturbate
  - what is public and private and what may be offensive to others
  - health and hygiene relating to masturbation
- 3. Sensitive empathic carers who can promote:
  - positive sexual expression and sexual health
  - access to GP and / or specialist services (if required).

#### What do staff need?

Awareness of:

- sexual health policy and guidance
- how to be responsible increasing knowledge, skills and confidence
- how to access training and support
- how to complete a risk assessment, developing a multi-professional / multiagency shared care plan identifying issues, supports and positive interventions required and by whom.

#### Please note: Workers are strictly forbidden to perform any sexual relief or other acts with a service user. Any contravention of this would be a disciplinary matter and in addition workers could be charged with indecent assault.

(See appendix 1 for the Scottish Legal Framework on this issue).

#### 3.8 MARRIAGE, CIVIL PARTNERSHIPS, LIVING TOGETHER OR CO-HABITING AND DIVORCE

People with learning disabilities have the same rights in law as anyone else to marry or live together. Providing the person is over 16 years and has a general understanding of what it means to get married, he or she has the legal capacity to consent to marriage. No one else's consent is ever required. The District Registrar can refuse to authorise a marriage taking place if he or she believes one of the parties does not have the mental capacity to consent, but the level of learning disability has to be very high before the District Registrar will do so.



The Forced Marriage (Protection and Jurisdiction) (Scotland) Act 2011<sup>18</sup> has been introduced to protect the human rights of people living in Scotland. The legislation will ensure that anyone in Scotland is protected from the threat, harassment or pressure to marry or enter into a civil partnership which they have not consented to or to which they are not capable of consenting. In addition, forcing someone into marriage was made a criminal offence in Scotland under the Anti-social Behaviour, Crime and Policing Act 2014.

If people with learning disabilities express a desire to marry, co-habit or enter a civil partnership, workers should be willing to discuss this option with them sensitively and seriously – whatever their sexuality. Only if the couple agree, can workers involve families and carers. However, the benefit of family/carer support should be emphasised. Workers should be aware of the subtle distinction between offering guidance and influencing people's decision-making. The professional's responsibility is to clarify the implications of various actions and to assess practical support needed by the couple.

Living together / marriage will mean that the person's financial and legal obligations will change. Workers may need to help the person with learning disabilities to access appropriate information and advice (see Benefits Helpline, Citizens Advice Scotland, Enable legal advice in Appendix 3).

There are many successful marriages, civil partnerships and relationships involving people with varying degrees of learning disability. However, as with other couples, there are examples of unsuccessful marriages and relationships, some of which may end in separation and divorce. It is important that workers and/or families do not demand guarantees that a marriage/living together between two people with learning disabilities will work.

The law relating to divorce is the same for a couple with learning disabilities as for others. Workers should be aware of the support services on offer, e.g. counselling with Relationship Scotland. Again, the professional's role would be to offer guidance on the implications of any action.

Couples who separate may need additional support, including seeking help from other agencies, such as housing and solicitors, as well as emotional support. Couples who live in residential care homes may need practical provision made to allow them to separate.

#### **3.9 DIVERSE COMMUNITY VIEWS**

The Lothians benefit from a wide range of diverse communities with their own distinctive cultural and religious beliefs and practices. Increasingly, many people with learning disabilities, workers, and parents will come from these minority communities, some of which will have very clear views about the place of sexuality in people's lives. Workers and relatives from particular communities may have strong views on matters such as sexual orientation, masturbation, pornography and sexual relationships outside of marriage. Contraception, for example, may be unacceptable or controversial for Roman Catholics and Muslims.

It is important for workers to understand that cultural and religious perspectives need to be taken into account when making decisions about learning disabled people's lives. However, this in itself can be complex, as it is not always clear what is in fact a religious belief and what is a cultural norm. Any queries about this type of situation should be referred to the line manager who can then seek further guidance.

This document has been written from a perspective which looks to the rights of the individual, whilst placing this in a context of protection, where appropriate. It has also been written with reference to Scottish law. In many communities the rights of the individual are subservient to what is seen as the greater good of the community. Scottish law puts the rights of the individual first. These two sets of values can conflict with each other and difficulties may arise as a result. Homosexuality is one of the areas where the rights and preferences of the individual may clash with their community's beliefs. It is important to understand that people with learning disabilities all come from different communities and that sexuality will be just one part of their lives, albeit an integral part. In making decisions and judgements about any individual's sexual behaviour, it is important to make reference not just to the situation in question, but to the wider context of that person's life, including the religious/cultural context.

It is also important that, just like anybody else, the person has the right to step, or be aided to step, outside the values of their community, as long as they remain within the limits of the law. However, the consequences for the person of doing so will often have far-reaching effects in terms of their place within their family and the larger community. At times like this, workers have a duty to act sensitively to the family's needs, therefore decisions which may have long-term consequences must not be taken lightly, and should be part of the care planning process. Particularly sensitive issues should be discussed with the line manager.

## **Section 4 Sexual health**

Section 2 outlined what is meant by sexual health. Having clear and consistent information and a good understanding of the information can help people to make healthy choices.

Sexual health is about feeling good mentally, physically and emotionally.

#### 4.1 ELEMENTS OF A SEXUAL HEALTH, RELATIONSHIPS AND WELLBEING EDUCATION PROGRAMME

It is important that everyone has information and education about relationships and sexual wellbeing so that they can make informed choices, so provision of education and information is an essential part of sexual health and wellbeing.

The aim of these programmes should be to help people with learning disabilities to develop the self and social awareness needed to make personal relationships with others, and an appropriate awareness of sex and sexuality. It should not only increase their knowledge but also enhance their skills to do so.Not all individuals will have an ability to understand all the areas listed and facilitators will have to exercise care and skill in tailoring such input to individual needs.

During the planning stage, workers should give consideration to family concerns. Families may wish to have the opportunity to discuss the programme and view materials with the consent of the person with learning disabilities. It is important that families and carers should be helped to understand that talking about sexual health does not encourage sexual activity.

Openness to discuss sexual health with both parents and service users means that a proactive and supportive approach can be taken which should also be clear that: The provision of education and information is an essential part of sexual health and wellbeing.

- everything done will comply with the current law
- the information and education provided will be tailored to the ability and level of need for each person
- the individual's confidentiality, privacy and right to make informed choices will be respected
- any potential risks will always be assessed as part of the work around sexual health and wellbeing as part of our duty of care.

The following list is not exhaustive and should be referred to as a basis for planning relationship and sexual wellbeing education. Specialist workers are available to offer practical help and support to workers who lack the experience or confidence in this work (see Appendix 3 for specialist workers in the area of sexual health and relationship education). All workers should be encouraged to seek support if in doubt.

Research has shown that relationship and sexual wellbeing education offered to small groups of people with learning disabilities is beneficial. For this reason, initial work on the following areas will be needed:

#### 4.1.1 Social Skills

- establishing rules and boundaries to create a safe atmosphere for discussion about sexual health
- forming a group and supportive behaviours for effective group work
- awareness of self in relation to others
- providing support to form and maintain relationships with family, friends and relationships
- societal and cultural attitudes
- increasing the ability to communicate about relationship and sexual and emotional issues, including the use of appropriate vocabulary.

#### 4.1.2 Body awareness and basic information about sex

- appropriate education about the human body which includes sexuality and sensuality
- developing a positive self image and increasing self-esteem
- helping them to understand and express feelings and emotions
- reproduction
- puberty and hygiene
- masturbation and self stimulation
- ejaculation
- menstruation
- conception and signs of pregnancy, needs of a baby; reality of parenthood
- sexually transmitted infections and HIV (transmission, symptoms and prevention)
- safer sex and how to prevent STIs and unwanted pregnancy.

#### 4.1.3 Personal health and contraceptive advice

 how to access a range of sexual health and reproductive health services including services within Primary Care, for example, family doctor and practice nurse.

#### 4.1.4 Appropriate behaviour

- time and place
- body language
- private and public behaviour
- difference between child and adult behaviour
- appropriate expression of feelings and emotions
- advice and guidance on what is culturally and legally acceptable
- use of sexually explicit materials, including safe internet use and other forms of social media e.g. email, texting, twitter, etc
- providing information, advice and skills training about abuse and sexual exploitation to help them to be aware of situations when they are at risk of abuse or of exploiting others and about what to do in such situations.

#### 4.1.5 Assertion: Protection against harm

- how to make choices
- how to say 'Yes' and 'No' assertively, and how to insist it is acted upon
- rights and responsibilities of increased independence
- good touch and bad touch
- protective behaviours
- identifying harm if it happens and reporting it.

#### 4.1.6 The Law

Responsibilities of the individual, workers and parents in line with the new Sexual Offences (Scotland) Act 2009 (see appendix 1 for brief information on the above Act) 14.

#### 4.1.7 Awareness of media influence

Media is an increasingly accessible way for people to learn about and see sexual behaviour. This increasing accessibility comes with both advantages and disadvantages that individuals, parents and carers should be aware of, such as:

- issues around possible devaluation and exploitation of people through pornography and stereotyping
- how media can affect awareness of, beliefs about and possibly sexual behaviour
- security and safety issues, e.g. access to personal details and opportunities to meet up with people who are unfamiliar.

#### 4.1.8 Technology and safety

- including the safe use of internet and mobile phones
- sexting
- where to go for help
- how to identify the risks.

#### 4.1.9 Consent

Consent should always be discussed in relation to any sexual relationship or sexual activity. The Sexual Offences Act (Scotland) 2009 14 defines consent as the ability to enter into a "free agreement" and that there is "reasonable belief" that the other person has the ability or capacity to enter into that free agreement. It is important to discuss:

- what does consent mean
- the right to withdraw consent at any point even if a person has given consent at the start
- the legal implications of sexual activity where consent is not given
- circumstances where a person is unable to give consent.



#### 4.2 CONSENT

Consent is a crucial factor in deciding whether a particular sexual relationship or act is consensual or harmful or abusive.

The Adults with Incapacity (Scotland) Act (2000) 10 states a person may lack capacity, in relation to a specific decision, if they are incapable of:

- acting on; or
- making decisions; or
- communicating decisions; or
- understanding decisions; or
- retaining the memory of decisions; or
- because they are affected by mental disorder or inability to communicate because of physical disability (that cannot be rectified by human or mechanical means).

Under current law, to establish that someone has the capacity to consent to a sexual relationship, the following criteria have to be satisfied:

- the person must understand what is proposed
- the person must understand the implications of this
- the person must be able to exercise choice.<sup>20</sup>

Ultimately what needs to be decided is:

- whether consent was able to be freely given
- whether it was given by the individual.

There are some individuals with a learning disability who would be considered as being unable to make an informed choice about having sexual relationships. This is a complex decision and workers should seek guidance.

The Adults with Incapacity (Scotland) Act 2000 (AWI)<sup>10</sup> and Adult Support & Protection (Scotland) Act 2007<sup>11</sup> are two of the most significant pieces of legislation for adults at risk of harm.

These laws are written to protect people from harm and abuse. Only the courts can make a definite judgement about this.

In practical terms, undoubtedly many individuals with a learning disability could be considered to have a severe impairment of intelligence. Assessing the degree to which this is significant in terms of meaningful consent in a person's life should be done by those who know them well. It must also be remembered that, whilst a person may be incapable of making certain decisions in their life, they may be capable of making and retaining other decisions. An assessment of capacity for the purposes of sexual relationships requires to be specifically about the adult's abilities to understand sexual and personal relationships. Clearly, professional intervention and assessment is not necessary in every situation. In areas where there is any doubt, workers should ask for a professional assessment of the person's intellectual functioning, communication skills and current level of knowledge and understanding of sexual and personal relationships.

Evidence of mutuality should be looked for by those assessing consent, to show that the relationship is not harmful or abusive. This is reflected in previous or current behaviours such as:

- both parties seeking each other out
- spending spare time together
- shared resources
- shared leisure activities
- restriction of activities with other potential partners.

There are clear situations in which any consent given would be considered invalid. Factors which might make a person's consent to sex invalid include:

- If a person does not really understand what is being asked
- If a person does not know they have the right to refuse sex
- If a person does not know how to refuse sex
- If a person is afraid to refuse sex or is being coerced to have sex
- If a person does not know that sex is not meant to be painful or uncomfortable
- If a person does not know that he or she is being exploited when a reward / incentive or payment for sex is used
- If a person does not know that some relationships are illegal, such as those within families, or between workers and clients.

Consent can only be said to be valid if the person knows what they are consenting to, and has a real option of saying yes or no – i.e. there is free agreement to having sex.

Workers should bear in mind that the law stipulates that consent is not valid if the individual is under the influence of drugs or alcohol (Sexual Offences (Scotland) Act 2009<sup>14</sup>.

There are situations where people may be engaging in activities which other people view as morally wrong or not in the best interests of the individual. Some examples are same sex relationships, not using condoms, having multiple partners, or being in a violent relationship. The individual could be very aware of what they are doing, and aware of the implications, positive or negative, and may still wish to continue to engage with this activity.

Workers are not expected to make a value judgement about the rightness of any sexual activity which is taking place. However, they are expected to be sensitive to the possibility of harm or abuse. If workers are unsure, they must bring any observations or concerns to the attention of their line manager.

If at any time workers become aware of a particular situation or act taking place which, in their opinion, is abusive, they should take immediate action to intervene.

(See NHS Lothian Child Protection / Adult Support & Protection Procedures)

http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/PublicProtection/ Pages/default.aspx

The welfare and wellbeing of those in their care are of prime importance and not to act quickly would be to have neglected their duty of care.

#### 4.3 CONTRACEPTION

People with learning disabilities have the same right to information and help with contraception as non-disabled people; this should be discussed sensitively as part of the overall care plan (but may not necessarily be discussed at a review meeting). In making their own decisions about contraception methods, individuals should be supported through referral to the mainstream medical community resources and specialist agencies. This must include considerations of the person's cultural and religious values, which may forbid the use of some forms of contraception.

Bear in mind that consenting or otherwise to using contraception is separate from consenting or otherwise to sexual activity.

Contraception should be seen in terms of the needs of the person rather than in terms of relieving the anxieties of workers and relatives.

Every effort must be made to ensure that the person understands any contraceptive method advised and the person's wish to inform relatives or not must be respected.

Where a person with a learning disability is unable to understand and take responsibility for contraception, involved parties, including carers, should meet to address issues around the apparent need for contraception and to establish programmes for future work in support of that person. It may be necessary to consider the appointment of a welfare guardian under the Adults with Incapacity (Scotland) Act 2000<sup>10</sup> (see Appendix 1 to get further information).

Strict attention should be given to limit the number of involved people to an absolute minimum, i.e. essential parties only, people who need to know.

Workers must be clear that their role is to identify the need, ensure the service user has all the necessary information and then to refer on to the relevant services.

## 4.3.1 Longer lasting contraception (sometimes referred to as long acting and reversible contraception or LARC)

Contraception is an individual choice and it may change from time to time dependent on people's lifestyles. LLC is contraception that lasts a long time where the person doesn't need to remember or think about it every day.

Longer-lasting contraception starts working very quickly but stops within days after it is removed and won't affect future fertility. It is very safe and most people can use it up until the menopause. As with any contraceptive, occasionally there are some side-effects.

The three main types of longer lasting contraception include:

- the intrauterine device (IUD) (lasts 5-10 years)
- the intrauterine system (IUS) (lasts up to 5 years)
- the implant (Can last for 3 years).

A medical professional will discuss the range of methods available to help the service user to decide.

All forms of LLC are suitable for any age, irrespective of whether or not the person has had a child. It is important to note that, as with other forms of contraception, LLC only provides protection from pregnancy and does not protect against sexually transmitted infections, unless used with condoms.

(See appendix 3 for more information and useful links).

(See also 4.11 Condoms)

#### 4.3.2 Emergency contraception

Remember: if someone has not used contraception or the contraception has failed, e.g. they have had a burst condom, they can access emergency contraception from the GP, a pharmacy or a sexual health service (see Appendix 2 for contact details). Emergency contraception is available for free from most pharmacists.

There are two types of emergency oral pills (sometimes known as 'the morningafter pill') available from doctors, community pharmacies and sexual health services.

Or an intrauterine device (IUD) is a small, plastic and copper device that can be fitted into the womb. It can be fitted up to five days after having unprotected sex.

Both types of emergency contraception (pill or IUD) offer **no** protection against sexually transmitted infections.

Information on the methods of contraception is available from a number of online sources in easy-read versions and other leaflets are also available free from Family Planning Association (Scotland) FPA, and from sexual health services. (See useful contact details in Appendix 2). Emergency contraception is free from all pharmacies in Lothian.

#### 4.3.3 Sterilisation

Sterilisation is an effective, irreversible, method of contraception. It is a medical procedure with known complications and side-effects. Normally all other acceptable alternative methods of birth control should be considered first, in particular the option of longer lasting reversible contraception which is comparably effective and less invasive.

A person with learning disabilities who chooses sterilisation must have the opportunity to receive appropriate counselling from a specialist medical advisor, to understand the emotional and permanent implications of sterilisation. Demands for sterilisation from families or relatives must not override the wellbeing of the individual and their right to choose.

Advice and counselling from a specialist outside agency would be appropriate in meeting the needs of the individual and also perhaps family members. It may be necessary to consider the appointment of a welfare guardian under the Adults with Incapacity (Scotland) Act 2000<sup>10</sup>.

Where a person is unable to give consent, sterilisation, on a non-emergency basis, can legally only be carried out as the result of a court application under the Adults with Incapacity (Scotland) Act 2000<sup>10</sup>. It should be noted that such treatment would not be covered by the powers given to medical practitioners under Part 5 of the Act.

Counselling for Female Sterilisation and Male Sterilisation (vasectomy) is available through referral to sexual health services, or referral to gynaecology or urology. Vasectomy is a less complicated procedure and more effective in the long term. (See Appendix 2)

#### 4.4 PREGNANCY

It is important that any sexual health, relationship and wellbeing education programme for people with learning disabilities includes information on:

- **reproductive health** including how to get pregnant and how to prevent pregnancy (see section 4.3 on contraception)
- **signs of pregnancy** (most common signs include feeling more tired or moody, nausea or sickness, breasts becoming larger or sore or missed periods. It is important to remember that these can also be associated with other things and not just pregnancy).

If a person becomes pregnant it is important that they are supported to access a midwife as early as possible.

- **pregnancy testing** (information and support on how to buy a home pregnancy testing kit from a pharmacy or supermarket, or going to the GP for a test.)
- **if the pregnancy test is positive** what to do if they are pregnant and where to go for help and choices when pregnant. If the person you are working with is unsure about continuing with the pregnancy, you should assist them to call or visit their GP or local sexual health clinic as soon as possible for advice and support. More information and advice can be found on the Lothian Sexual Health website. (Also see Appendices 3 and 4).

Upon phoning the Lothian Maternity Appointment line and providing some details (e.g. date of the first day of the last period) the person will be given:

- an appointment with a midwife for around 8-10 weeks into the pregnancy
- a scan appointment for 11-14 weeks

Once the person is in touch with a midwife, the midwife will ensure that the person gets the care and the resources that they require.

The Pregnancy Support Pack<sup>®</sup> "My pregnancy, my choice" <sup>21</sup> is an accessible resource used by midwives in Lothian. It provides information given at each stage of a typical pregnancy in an easyto-read and visual format, that aims to support parents with a learning disability to engage in their experience of pregnancy.

The resources have been used and positively evaluated by prospective mothers with a learning disability as being both acceptable and accessible. Midwives report that they support engagement in the antenatal process, are time efficient, provide a clear structure for sessions and enable informed consent for medical procedures. Two examples of information included in the resource pack are the blood test consent form and coping with your labour pains.



## 4.5 PARENTHOOD

The number of parents with learning disabilities becoming known to services has increased over the years and will continue to do so. Many value the parenting role, and choose to become parents.

Studies have shown no direct link between learning disability and inadequate parenting, in that intellectual impairment alone does not mean an individual will be a poor parent. As a group, parents with learning disabilities share many characteristics with other 'at risk' parents, such as inadequate housing, debt, social isolation, and stress, but they may lack robust coping mechanisms or appropriate support to deal with these. Research indicates that the presence or absence of social support is more important than having a learning disability in relation to positive outcomes for families. Findings indicate that support should be competence-promoting rather than competence-inhibiting, offered by a worker who both likes and is liked by the family, who is non judgemental, and who includes the parent in the decision-making.

We know that parents with learning disabilities are more likely than any other group of parents to have their children removed. These families rarely commit acts of neglect or abuse; however their own upbringing and vulnerability may place a child at risk of abuse from others. For example, many mothers have experienced a lack of appropriate parenting role models, including neglect and abuse, and their need for stability may override their children's needs. They may struggle to leave unhealthy situations, and so risk their children being removed. This is an extremely distressing time for families, and a challenging time for workers, who may feel caught between wishing to support their clients to have every chance to parent, and the long term welfare of the children, which must take priority.

## What works best for parents?

Workers should always consider what life is like within a particular household, is the child safe, and what can be done to improve the child's chances.

Positively, outcome studies of parent education programmes have demonstrated that parents with learning disabilities can be taught important parenting behaviours, providing teaching techniques are used which have proven effectiveness in prompting knowledge and skill with people with learning disabilities. Stories of positive practice (Norah Fry Research Centre 2009) describe families who can parent effectively when given support tailored to their specific learning styles and needs.

## Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities (SCLD 2009) outline 5 key features when working with families <sup>22</sup>:

#### Clear and co-ordinated referral and assessment procedures

Advice and specialist assessment from Community Learning Disability Teams (CLDT) should be sought when parental disability is considered, and assessment should start as early as possible during pregnancy. Multiple assessments by different agencies should be avoided. In families where children have been removed, parents can be disadvantaged by out of home assessments due to well documented difficulties with skill generalisation and maintenance on different settings.

#### • Accessible information

All services should provide information which is clear and easy to understand, as reinforced by Equalities legislation. Parents consistently complain about lack of clear information and practitioners not taking time to go over reports. Where possible, easy-read formats should be used, and there are several useful resources (e.g. CHANGE publications)

#### Needs-based support

Specific parental needs which may affect parenting should be assessed and addressed (e.g. tenancy or financial issues). Workers should be mindful of potential barriers to support, such as a distrust of professionals for fear of children being removed. Research describes a 'cloak of competence' where parents are keen to present as able to avoid drawing attention to a problem, which may lead to negative assumptions about their coping skills. As a result, many parents only come to the attention of services at times of crisis.

#### • Long term support

Support should be sensitive to the family's changing needs over time, and should be offered for as long as the family requires it.

#### Access to independent advocacy

People with intellectual impairment have a right to access independent advocacy under the Mental Health Care and Treatment (Scotland) Act (2003)<sup>23</sup>. This should always be provided where there is a child protection plan.

## 4.6 ABORTION

Abortion is regulated by statute and can only be authorised by appropriate medical practitioners.

A person with learning disabilities has the right to information, counselling and support to make a reasoned decision about whether to continue the pregnancy or to terminate it, regardless of the reason for the choice. The wellbeing of the person must always come first and they have the right to choose. It is unlikely that someone will be given a termination in Scotland in the later stages of pregnancy unless there is severe foetal abnormality or the individual's life is at risk.

If a termination is chosen, it is essential that help is provided to understand all implications and give consent freely. It may be necessary to consider the appointment of a welfare guardian under the Adults with Incapacity (Scotland) Act 2000 10 (see Appendix 1 to get further information).

Family or carer demands for a termination must not override the rights and wellbeing of the person concerned.

Judgements on the ability of the person to be a parent are not grounds for termination of pregnancy, just as this would not be considered sufficient grounds for anyone else. If an abortion is chosen, this must be carried out in a supportive atmosphere, with sufficient information available and on-going counselling if required.

When a person is deemed unable to give consent to an abortion, such treatment, on a non-emergency basis, can only be given as the result of an application under the Adults with Incapacity (Scotland) Act 2000<sup>10</sup>. Such an application should only be considered in the light of the principles of the Act, including the fact that an adult will not be deemed incapable if they have a communication difficulty that can be rectified by mechanical or human means.

The decision should involve professionals, family and the person's medical practitioner. In such cases the decision must be in the best interests of the individual, rather than for the convenience of others.

It is safer for the woman if the abortion is performed before or up to 12 weeks' gestation. Thus when a woman is faced with a dilemma as to whether to continue or terminate a pregnancy or consider adoption, she should access counselling and support immediately. Counselling and referral for termination is available from sexual health services, or via the GP (family doctor). Information about abortion is available free from the Lothian sexual health services and GPs. (See Appendix 2 for contact details).

It is hoped that they will attend for abortion before 9 weeks so that they do not require a surgical intervention. However, those with learning disabilities may be at risk of needing second trimester terminations of pregnancy because they are more at risk of missing the early signs of pregnancy due to lack of understanding or poor sex and relationship education. It is important that any relationships and sexual wellbeing education includes information about signs of pregnancy, especially if the woman is sexually active.

#### **4.7 SMEAR TESTS**

All women aged 20-60 across Scotland are invited to have a cervical screening test every three years. A set of leaflets is available to enable women to make an informed choice to attend their screening appointment.

A cervical screening test is currently the most effective way to screen for cervical cancer. This is a way of preventing cervical cancer by detecting and treating pre cancerous cell changes. If left untreated these abnormal cells could develop into cervical cancer. But there are circumstances where a screening test may not be the right thing to do.

If a woman has such severe learning disabilities and no language, then she is unlikely to be able to give consent to having the test. This can make it very difficult for the people caring for her to make a decision about what is best for her. It is strongly suggested that in this situation you ask each woman's GP for advice. Hopefully the doctor will have known her for some time and there will be a certain amount of trust between them. (www.cancerresearch.org)

It is well documented that having a smear test can be very distressing for people

with learning disabilities as they don't understand the reason for the test and can find it very frightening. They are much less likely to have the test than women in general. It can be very distressing for women with learning disabilities to have such an intimate test. If they do have one, they usually need a series of visits to the clinic or surgery before the test so that they can develop some trust in the people involved. Most health care staff will understand and be sensitive to this need.

You can access the following easy-read leaflets to support people with learning disabilities and their carers on the Health Scotland website (www.healthscotland. com):

#### Keep yourself healthy: do I need a smear test?

Keep yourself healthy: a guide to having a smear test is available to support people with learning disabilities and their carers

You may also find it useful to contact the NHS cervical screening programme for advice on this situation

## **4.8 SEXUALLY TRANSMITTED INFECTIONS (STI)**

STI is the term used to cover sexually transmitted infections. The most common ones include:

- Chlamydia
- Genital herpes
- Genital warts
- Gonorrhoea
- Pubic lice (crabs)
- Hepatitis B
- HIV
- Non specific-urethritis (NSU)
- Syphilis

STIs are a significant health risk for all parts of society. If left undiagnosed, they can result in pain, ill health, infertility and/or death.

People with learning disabilities need to know:

- how an STI is passed on
- the general signs and symptoms of STIs, and that some people often don't have symptoms
- where to go for diagnosis, testing and treatment
- how to access services (bus routes, opening times, etc.)
- who to talk to for advice and confidentiality
- how to avoid getting an STI.

People with learning disabilities who are sexually active are just as likely as other people to come into contact with STIs.

Workers and people with learning disabilities need to be aware that GPs can provide routine sexual healthcare and thereafter be aware of specialist sexual health services and local agencies offering advice/support and treatment of STIs if the GP cannot meet their needs (see appendix 2).

Workers should take an active role to encourage and promote the use of appropriate services. Part of a sexual health, relationship and wellbeing education programme could involve visits to Sexual Health services and others to assist in removing the anxiety about accessing when required.

When a person with learning disabilities complains of symptoms associated with STI, workers should agree a plan of action with the person, which would include seeking medical advice and treatment as appropriate. Symptoms associated with STI include:

- itchiness around the genitals
- lower abdominal pain
- pain during sex
- · blisters, sores or lumps, spots in or around the genitals
- unusual or smelly discharge from the penis or vagina
- pain when urinating (peeing)
- unusual or abnormal bleeding.

It is also important to know that some STIs may have no symptoms and screening is very important.

The best way to reduce the risk of getting an STI or passing one on is through safer sex and condom use.

The medical background and matters relating to the sexual health of a person with learning disabilities is strictly confidential. Information on STI would be restricted to essential (need to know) persons only.

Leaflets on a range of STIs are available from NHS Lothian Resource Centre, sexual health services, GPs (family doctors) or visit Lothian Sexual Health (See Appendices 3 / 4 for details).

#### **4.9 OTHER INFECTIONS**

Thrush, Cystitis and BV (Bacterial Vaginiosis) are other infections that have some of the symptoms of STIs, but are not necessarily sexually transmitted. They are very common and easily treated.

Symptoms can be similar to those of STIs and include strange discharge and smell, itchiness, soreness when urinating (peeing) (see appendix 3 for more information).

## 4.10 HIV (HUMAN IMMUNODEFICIENCY VIRUS)

As with other STIs, HIV poses a health risk to people with learning disabilities. People with learning disabilities are as likely to encounter HIV as people without learning disabilities.

People with learning disabilities should be offered education around HIV and how it can be transmitted and where to get tested as an essential part of their health education programme, in a way which is accessible to them.

This element of their education programme would include:

- what are HIV and AIDS?
- how people get HIV and how to prevent getting it or transmitting it
- how and where to test for it?
- how it is treated
- medical and social implications of being HIV positive
- rights to confidentiality.



It is important to distinguish the difference between HIV and AIDS, as often it is used interchangeably but they are not the same thing.

HIV is a virus that attacks the immune system and makes it difficult to fight off other illnesses.

AIDS stands for Acquired Immune Deficiency Syndrome. It's the name given to a collection of infections and diseases, such as tuberculosis, pneumonia and some cancers that, when present, indicate that the HIV virus has severely weakened someone's immune system.

You cannot catch AIDS. HIV causes AIDS. It is only HIV that can be passed on. (www.hivalwayshear.org).

There is no cure for HIV but there are drugs that can slow the progress of the condition. With recent developments in the treatment for HIV, people can live relatively well.

Basic information on HIV can be found in leaflets held at Lothian NHS Resource Centre. Other good sources of information can be found online and provided by Waverley Care (www.waverleycare.org), PHACE Scotland, the AVERT website (www.avert.org), the NAM website (www.aidsmap.com), and the Terrence Higgins Trust website (www.tht.org.uk) (see useful contact details in Appendix 2).

There should also be information and support for HIV negative and untested people with learning disabilities who experience a disproportionate risk of exposure to HIV and subsequent transmission of the virus. This may include gay and bisexual men, men who have sex with men, younger people, and those who have high numbers of sexual partners. There should be provision of specific resources for people with learning disabilities, who are also HIV positive (see appendix 4 for more information).

Workers should familiarise themselves with local Information and Guidelines on HIV, particularly Training and Support and Guidelines on Hygiene and Infection Control (see Appendices 3 and 4 for organisations that can provide training). It is important that workers keep themselves up-to-date with information through training.

Parents and carers should be offered support and information on where to obtain advice and further information as appropriate (see Appendix 3).

## 4.11 CONDOMS

Condoms are useful in preventing the spread of sexually transmitted infections (STI) and HIV, as well as pregnancy. They are the only method of contraception that reduces risk of STIs as they act as a barrier to virus and bacteria. Safer sex practices means using a barrier method either as a main form of contraception or as well as another method.

People with learning disabilities need to know:

- why using condoms is important
- how to ensure the condom is not damaged
- how to put one on correctly, and how to dispose of it
- where to get free condoms and where to buy them
- the different names for condoms
- how to negotiate use of condoms with a partner
- the selection of condoms that are available with information about the use of lubrication
- what to do if a condom bursts.

Lothian has a service which provides free condoms called c:card. For more details about c:cards and the different types of condoms available in Lothian and where to get them please visit www.ccard.org.uk.

## 4.12 SEXUAL PROBLEMS

It is common for both men and women to experience sexual problems at some stage in their lives. Such problems can cause a great degree of distress. Sexual function depends on physical, psychological and emotional factors and can be

A selection of free condoms, lubrication and dams are available from c:card in Lothian.





affected by a number of things such as illness, medication, stress, relationship problems and substance misuse. Some problems resolve themselves, but may need professional help to improve or overcome them.

See Lothian sexual health (www.lothiansexualhealth.scot.nhs.uk/Sexual HealthWellbeing/SexualProblems/Pages/default.aspx) for further information on different types of sexual problems and how to access services for support.

A common problem for men can be Erectile Dysfunction (see appendix 5 for further information).

## 4.13 ALCOHOL

## 4.13.1 New alcohol guidelines

Following a two year expert review of the scientific evidence, the UK Chief Medical Officers published updated alcohol consumption guidelines in January 2016. Their guidance makes it clear that there is no completely 'safe' level of alcohol consumption, since cancer risk increases even at low levels of consumption. There is also no justification for recommending drinking on health grounds as previous evidence is likely to have over-estimated the protective effects of alcohol for the heart.

To keep health risks to a low level, both men and women are advised:

- not to regularly drink more than 14 units per week
- drinking should be spread over three days or more
- having several alcohol-free days a week is a good way to cut down.<sup>24</sup>

## 4.13.2 Advice on short term effects of alcohol

The Chief Medical Officers advise men and women who wish to keep their short term health risks from a single drinking occasion to a low level that they can reduce these risks by:

- limiting the total amount of alcohol you drink on any occasion
- drinking more slowly, drinking with food, and alternating with water
- avoiding risky places and activities, making sure you have people you know around, and ensuring you can get home safely.

The sorts of things that are more likely to happen if you don't judge the risks from how you drink correctly can include:

- accidents resulting in injury
- misjudging risky situations
- losing self-control.

These risks can arise for people drinking within the weekly guidelines for regular drinking, if they drink too much or too quickly on a single occasion; and for people who drink at higher levels, whether regularly or infrequently.<sup>24</sup>

## 4.13.3 Guideline of pregnancy and drinking

The 'no alcohol in pregnancy' message is now consistent across the UK previously only Scotland advised that avoiding alcohol when pregnant or trying to conceive is the safest choice. The Chief Medical Officers' guideline is that:

- if you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum
- drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk <sup>24</sup>

## 4.13.4 Importance of education

It is important that people with learning disabilities are educated about the effects of alcohol both physically and socially to ensure that they know how to enjoy alcohol safely and drink within safe limits for them.

If you are concerned by another person's alcohol use, you can seek help or support them to seek help, from various specialist services. (See appendix 6).

Further information can be sourced from the Health Promotion Resource Centre (see appendix 2 for contact details) or free training from the Health Promotion Service www.hpstraining@nhslothian.scot.nhs.uk.



## 4.14 SAFER INTERNET USE

Some information within this section has been extracted from the Mental Welfare Commission for Scotland, 'Consenting Adults?' Guidance: p19-21. www.mwcscot.org.uk/search/?keyword=consenting+adults <sup>17</sup>

The internet opens up a whole world of possibilities and opportunities but there are also risks, particularly for people with learning disabilities. People with learning disabilities should be encouraged to use the internet safely wherever possible and those working with them should feel confident in raising issues around sexual health and relationships that relate to internet use.

The New Media Education Project has developed training packages encouraging the safe and productive use of Social Media for young people with learning disabilities, parents and carers.

## 4.14.1 Social media

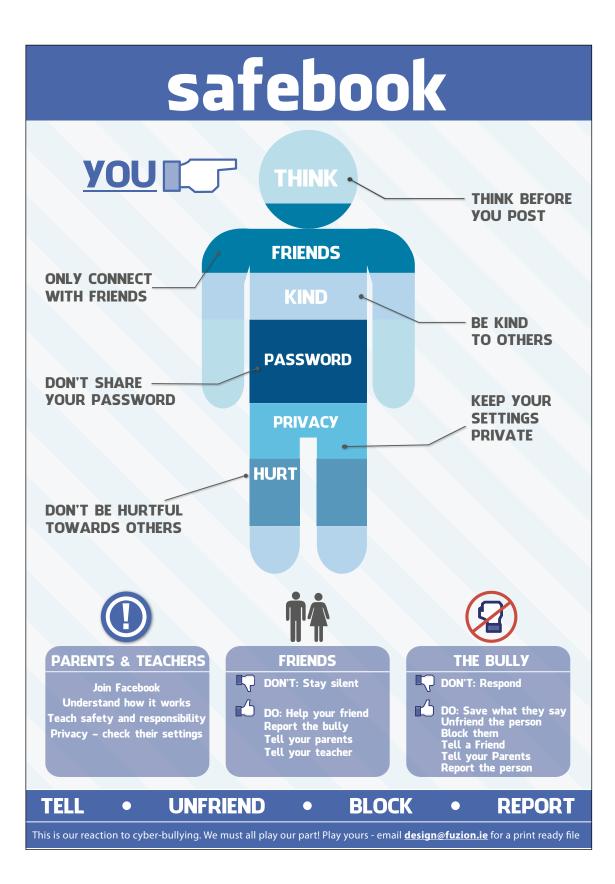
Staff may be asked to assist people in accessing social networking sites, dating or gaming sites, or chat rooms, and increasingly people are forming relationships online. Staff and people with learning disabilities should be aware of any age limits (e.g. over 18s only) and costs that may apply. Whilst the use of such sites can have positive benefits for people, staff need to be aware of the risks to adults, as well as children, of internet grooming.



## 4.14.2 Grooming

Groomers may try to establish relationships and gather more information on their potential victims and their vulnerability, assess the risk of going further with their plans, try to isolate victims from those around them (e.g. sabotaging relationships with family/friends/carers) and may use threats and blackmail to achieve compliance and control. Some are interested in the victim's social networks, targeting an index victim in order to access other people who may be vulnerable. They may expose victims to inappropriate and illegal sexual material, or material that is offensive and traumatising for some, or subject victims to cyber sexual abuse on line, e.g. using webcam/audio technology to observe or exhibit sexual behaviours.

Staff should encourage people with learning disabilities to ensure they never display their full name, address, phone number, passwords, bank details or where they are going to be at a specific time. Remember that people may not always be who they say there are, and that profile pictures may not always be true representations - and it is important staff remind people about this.



## 4.14.3 Cyberbullying

While for the majority of people social media is a positive experience, bullying exists online just as it has the potential to do so in any setting. The impacts can be devastating. Staff should feel confident in helping people with learning disabilities become aware of how to 'block' or 'unfriend' unwelcome 'friends', report abuse and ensure their privacy settings allow only genuine friends to access their pages or to send them messages.

Where a member of staff is suspicious or concerned about possible grooming or bullying, they should discuss it in the first instance with their line manager, who may consider involving the police and notifying the local authority under adult protection procedures. Education on the risks of social networking may increase awareness in people with learning disabilities of the potential dangers. Just as you wouldn't allow a stranger to walk around your bedroom and look through your things, nor should you disclose private or sensitive information online. Both the Child Exploitation Online Protection Centre (CEOP) 'thinkUknow' and the Childnet International 'Know IT All' websites have materials for young people, which may be useful in this regard.

It is important that staff remind people they work with that when communicating remotely via social media, they should treat others as they would wish to be treated themselves, and

if they become aware

of anyone being bullied they should seek advice from a trusted person. In short, if there's a problem, 'tell, unfriend, remove, block, report'.

People with disabilities should always be encouraged to think carefully before posting or commenting on anything that could be considered offensive to others.

## 4.14.4 Internet pornography

In residential settings, access to legal pornography on the internet will not be permissible on the organisation's computers and this will be covered by organisational policy. However, many people with learning disabilities will have their own computers, or other technologies which give internet access, with no filtering or blocking. Supporting people with learning disabilities to access legal internet pornography may pose more risks than assisting someone to purchase a pornographic magazine. The speed and ease of access increases the risk of people with learning disabilities entering sites with more hard core or potentially illegal material without necessarily understanding the consequences.

## 4.14.5 Mobile technology

As mobile phone technology continues to evolve into increasingly smaller and affordable hand-held devices, staff may be met with a situation where a large number of people with learning disabilities / adults with a learning disability have remote internet access on them where ever they may be. The same guidelines apply to that of a static computer (see also Social media) with regard to accessing social media and pornographic material. Staff should ensure people with learning disabilities are aware that they should not access explicit material in a public place. Additional concerns may include that 'roaming' data downloads may be much more expensive than a Wi-Fi connection, leading to increased bills, and that mobile devices have a digital camera attached.

Photographs of others should only be taken and /or shared with that person's consent; which must be given beforehand. The sharing of sensitive and intimate images (sometimes called 'sexting') with anyone other than the two consenting adults should be strongly discouraged. Public 'posting' of these images on social media sites (whether legitimate or not) should be actively prohibited as on-line photographs can be copied, saved, shared and very hard to remove.

Many new 'Smart' phone Apps encourage the swapping of images and staff should encourage that this happens only with known and trusted friends.

## 4.14.6 Meeting up with people who have been met online

As increasing amounts of socialising takes place via chat rooms and social media networks, staff may be asked to support individuals to meet up with someone new who they have met on the internet. People with learning disabilities should be encouraged to take someone trusted with them. Always prompt the individual to tell the person they are planning to meet that they are taking a friend along – what is their reaction? Do they still want to meet up?

For those who are not under guardianship and have capacity, and choose to meet someone without any staff present, the person should be strongly encouraged to take a friend. If the person still wishes to go unaccompanied, the following advice should be given:

- it is best to not meet someone that they know only from talking to on-line, even if they have seen pictures of them
- before they go they should always tell someone they trust who they are meeting, with their full name and phone number and where they are meeting

   always advise a public place, never a person's house for a first meeting, especially if this has been requested
- tell someone they trust what time they are meeting and what time they are due back, and to have their phone with them, charged up and switched on.

### 4.15 THE SEX INDUSTRY

Some information within this section has been extracted from the Mental Welfare Commission for Scotland, 'Consenting Adults?' Guidance: p19-21. www.mwcscot.org.uk/search/?keyword=consenting+adults <sup>17</sup>

To enable a person to have a fulfilling sex life, staff may be asked for assistance in sexual matters. This may be a request for assistance in accessing sex education or sexual health advice or contraception. It may also include requests relating to pornography, sex toys or hiring the services of a sex worker.

Education and counselling should be provided when individuals express a wish for this or display a need for such assistance, or may be considered when families and /or professionals request it. Where relatives object to education and advice being given on sexual matters, the question of the capacity of the adult needs to be assessed. Where the adult has capacity, his or her wishes should be adhered to. Where the adult does not have capacity to decide on these matters, there may still be a need for this and it may be necessary for the local authority to act under their "duty of care" or to consider guardianship.

Staff should feel able to initiate discussion and/or respond to service user questions around the use of sexually explicit materials. For example, it would be possible to point out to the service user that some people believe pornography is offensive, that it can give a distorted image of sexuality and that it can be degrading.

Requests for other kinds of assistance can raise issues for carers. Where an adult has capacity, staff may consider the degree of assistance requested following discussion with their manager or the support team. This should be recorded as part of the care plan. Staff should never assist an adult to engage in any unlawful activity.

## 4.15.1 Pornographic materials

Individuals might request assistance to access pornographic material, for example magazines, for the purposes of sexual arousal or entertainment. This is part of sexual activity for many adults. Whilst staff should not encourage the use of these materials, neither should they deny access to an individual who is able to make the choice, nor impose their own views on other people. See also the earlier paragraph on internet pornography for more information.

However, for some individuals there may be concerns about it leading to unhealthy sexual expression or increasing the potential for sexual offending. Staff may need to discuss this in the wider multidisciplinary team, in order to decide whether staff should assist with this in any way. Others will have restrictions imposed on them because they are in hospital settings where hospital policies, individual care plans and legislative restrictions may apply, or they may be in a community setting but still subject to legislative restrictions.

Legal pornography includes any materials that may be legally sold in the UK in a newsagent, a licensed sex shop, DVDs certificated by The British Board of Film Censors (BBFC)<sup>26</sup>, or material legally downloaded from the internet. Illegal pornography includes indecent photographs of children (s52 Civic Government (Scotland) Act1982)<sup>27</sup> and possession of 'extreme pornographic images' (Criminal Justice and Licensing (Scotland) Act 2010)<sup>28</sup>. Extreme images are those depicting rape or non consensual penetrative activity or act likely to result in a person's severe injury (s42). Information is also available on the BBFC website<sup>26</sup>. Where materials are being accessed that are believed to be illegal, staff should immediately seek advice from their line manager, who may report the matter to the police.

In residential and independent living settings people may depend on staff support and staff may be asked to assist in accessing pornographic material. Staff must never help people access illegal material but may assist access to legal material, after discussion and agreement with their line manager. Such decisions should be recorded. It should be made clear that the material should be used in private, should not be shared with other people and should not be displayed when staff are with the person. The storage and the visibility of such material may need to be discussed depending on the person's living situation, where the rights of coresidents may also need to be considered.

## 4.15.2 Sex toys

Requests for assistance to purchase sex toys should be considered in the same way as pornography – there should be discussion with the line manager or, where there are additional concerns, the wider multidisciplinary team. Decisions should be recorded in the care / support plan and staff should only assist after discussion with their line manager. Again the use of such toys needs to be in a private setting and staff should not be involved in this. The storage and visibility of such items needs to be considered. People with learning disabilities and staff also need to be aware that buying such items via the internet or by mail order may lead to a lot of unsolicited correspondence from companies selling similar products.

The exception to the above is the use of sex toys for educational or counselling purposes, rather than for sexual stimulation and pleasure. In such instances, staff would be using toys with people with learning disabilities as part of their care plan, for example, to enhance sexual understanding or assist with correct use of contraception.

## 4.15.3 Commercial sex venues

A person with learning disabilities may seek support to access, for example, a strip club. Strip clubs are legal and a part of normal sexual experience for some people, though felt by others to be exploitative and degrading. Requests for assistance to visit such a venue should be considered in the same way as pornography – the person should have capacity, their wish should be acknowledged, and there should be discussion with the line manager or, where there are more serious concerns, the wider multidisciplinary team. A risk assessment should be undertaken to ensure that all involved are not negatively impacted, whether the person themselves, the staff member, the other patrons in the venue, or indeed those working in the venue. All decisions should be recorded in care /support plan and the feelings of the worker considered.

## 4.15.4 Sex workers

A person with a learning disability may choose to seek the services of a sex worker and may request assistance from staff to do so. Staff may assist in maximising a service user's general ability to communicate independently, e.g. accessing assistive technology but staff should not make direct arrangements with a sex worker or agency. While prostitution itself (the exchange of sexual services for money) is not illegal in Scotland, there are a number of potential crimes around it, and any contact with a sex worker, either on the street or in a brothel or sauna, could leave staff open to a variety of allegations and potential criminal charges.

If the person has capacity their wish should be acknowledged but staff should point out the potential legal, emotional or financial implications of accessing sex workers. There are also potential impacts around loss of reputation, sexual health and experience of stigma. These should all be made clear to the person so they have as clear as possible an understanding of the potential risks.

## 4.16 INAPPROPRIATE SEXUAL BEHAVIOURS

Some people with learning disabilities may demonstrate inappropriate sexual behaviours towards other people with learning disability, young people or adults. Sexually inappropriate behaviours can range from masturbating in public, sexually aggressive language through to inappropriate touching and at the extreme end of the continuum, sexually offending behaviours.

People with learning disabilities should be encouraged towards healthier sexual attitudes and practices. They have the right to receive the same sexual health and relationship education as others.

# 4.16.1 What to do if you know a person who exhibits sexually inappropriate behaviours

- Seek referral to Community Learning Disability Team (CLDT)
- CLDT can complete specialist assessment and intervention, taking into account individualised care needs
- multi-agency risk assessment and support plans should be developed that identify the issue, triggers and positive management strategies
- should there be adult protection concerns, multi-agency risk assessment and care planning will be in place to support all parties.

## 4.16.2 Criminal justice

Should there be forensic concerns, specialist health and social work assessment and intervention will be arranged.

Easy-read information for people with learning disability can be accessed from the Scottish Government Website:

People with Learning Disabilities and the Scottish Criminal Justice System (2012) <sup>29</sup>



- introduction
- information about going to court
- information about Criminal Justice Social Work Services
- information about Health and Social Work
- information about the Police
- information about Prison.

## **Section 5 - Appendices**

## **Appendix 1**

## **LEGAL FRAMEWORK**

The purpose of the legal rules which are relevant to sexual relationships and people with learning disabilities is to protect people who do not have the capacity to consent, whilst preserving the rights of people who do.

There are two groups of legal rules which are relevant to sexual relationships and people with learning disabilities. The first group are those which apply to everybody and the second are the special provisions which are intended to give extra protection to people who are intellectually disabled and perceived as being more at risk of harm. These include:

- Human Rights Act (1998)
- Data Protection Act (1998)
- Adults with Incapacity (Scotland) Act 2000
- Mental Health (Care and Treatment) (Scotland) Act 2003
- Vulnerable Witnesses (Scotland) Act 2004
- Prohibition of Female Genital Mutilation (Scotland) Act 2005
- Adult Support and Protection (Scotland) Act 2007
- Sexual Offences (Scotland) Act 2009
- Equality Act (2010)
- Forced Marriage etc. (Protection and Jurisdiction) (Scotland) Act 2011
- Anti-social Behaviour, Crime and Policing Act 2014

For further information about Scottish legislation refer to the HMSO website www.legislation.gov.uk/browse/scotland

#### Summary of Provisions of the Sexual Offences (Scotland) Act

Part One of the Sexual Offences (Scotland) Act 2009 creates new statutory offences of rape, sexual assault by penetration, sexual assault, sexual coercion, coercing a person to be present during sexual activity, coercing a person to look at an image of sexual activity, communicating indecently, sexual exposure, voyeurism and administering a substance for a sexual purpose. These offences are committed when a person engages in any such conduct without the other person's consent, and without any reasonable belief that the other person consented.

Part Two of the Act provides for a statutory definition of consent as "free agreement", supplemented with a non-exhaustive list of circumstances in which consent can never be present. It further provides that consent to conduct does not in and of itself constitute consent to any other conduct, and that consent may be withdrawn at any time. Part Three of the Act makes provision regarding the capacity of persons with a mental disorder to consent to conduct. Part Four of the Act provides for "protective offences" which address predatory sexual behaviour towards children. The Bill maintains the age of consent at 16. It provides that sexual activity of any kind between adults and children under the age of 16 is unlawful. Separate 'protective' offences are provided for in respect of sexual activity with young children (under the age of 13) and older children (from age 13 to age 15). It further provides that sexual intercourse and oral sex between under-16s remains unlawful.

Part Five of the Act provides for offences concerning sexual abuse of trust. The Act provides that it shall be an offence for a person in a position of trust over a child under the age of 18 or a person with a mental disorder to engage in sexual activity with that child or person.

www.gov.scot/Topics/archive/law-order/8980/rape-sexual-offences-bill/bill-provisions

## **Appendix 2**

## **USEFUL CONTACT DETAILS**

## **Learning Disability**

#### Ann Craft Trust

Centre for Social Work University Park Nottingham NG7 2RD

Telephone: 0115 951 5400 Email: ann-craft-trust@nottingham.ac.uk Website: www.anncrafttrust.org

National organisation working with staff in the interest of people with learning disabilities who may be at risk from abuse.

#### British Institute of Learning Disabilities (BILD)

Campion House Kidderminster DY10 1JL

Telephone: 01562 723010 Email: enquiries@build.org.uk Website: www.bild.org.uk

BILD exists to improve the quality of life of all people with a learning disability. BILD provides information, publications and training and consultancy services for organisations and individuals.

#### Enable

National office Enable 2nd floor 146 Argyle Street Glasgow G2 8BL

Telephone: 0300 020 0101 Email: Enabledirect@enable.org.uk Website: www.enable.org.uk

Enable Scotland provides information on a wide range of topics related to learning disability.

#### FAIR (Family Advice and Information Resource)

95 Causewayside, Edinburgh, EH9 1QG

Telephone: 0131 662 1962 Email: fair@fairadvice.org.uk Website: www.fairadvice.org.uk

This is a local service for people with learning disabilities in Edinburgh and Midlothian. It gives advice and information for people with learning disabilities, their carers and professionals. It provides information on money and benefits, health, travel, leisure, housing, education, work, and holidays.

#### NHS Lothian Community Learning Disability Teams

Website: www.nhslothian.scot.nhs.uk/Services/A-Z/LearningDisabilities/ ClinicalServices/Pages/CommunityLearningDisabilityTeams.aspx

Community Learning Disability nurses carry out assessment and interventions in relation to sexual health needs. They offer sexual health and relationship education on a one-to-one or group basis, and signpost to other sexual health services. There are eight community teams based locally across Lothian.

#### PAMIS

Springfield House 15 /16 Springfield University of Dundee Dundee DD1 4JE

Telephone: 01382 385 154 Email: pamis@dundee.ac.uk Website: www.pamis.org.uk

PAMIS offers a comprehensive free information service on all matters concerning people with profound and multiple learning disabilities and their carers.

#### **People First Scotland**

77-79 Easter Road Edinburgh EH7 5PW

Telephone: 0131 478 7707 Email: peoplefirst1@btconnect.com Website: www.peoplefirstscotland.org

Independent self-advocacy for people with learning difficulties.

#### Respond

3rd Floor 24-32 Stephenson Way London NW1 2HD

Telephone: 020 7383 0700 Helpline Telephone: 0808 808 0700 Email: admin@respond.org.uk Helpline Email: helpline@respond.org.uk Website: www.respond.org.uk

Provides counselling and therapy for people with learning disabilities who have been sexually abused and may be abusers themselves.

## **Sexual Health**

#### **Chalmers Sexual Health Clinic**

2A Chalmers Street Edinburgh EH3 9ES

Telephone: 0131 536 1070 www.nhslothian.scot.nhs.uk/GoingToHospital/Locations/Pages/Chalmers

NHS Lothian's Sexual and Reproductive Health Service (formerly Family Planning and Well Woman services and the Genitourinary Medicine (GUM) department) now operates from the Chalmers Sexual Health Centre. A range of services are available at the Chalmers Centre including:

- Contraception advice and supplies
- Emergency contraception
- Free condoms
- STI testing and treatment
- HIV including Post Exposure Prophylaxis (PEP)
- Pregnancy testing
- Referral for termination of pregnancy
- Community gynaecology
- Menopause and Premenstrual syndrome
- Gay men's clinics
- Colposcopy
- Advice on sexual problems
- Support following sexual assault

#### fpa (Family Planning Association) Scotland

www.fpa.org.uk

A sexual health charity offering information, advice and support on sexual health, sex and relationships.

#### **Healthy Respect**

Chalmers Sexual Health Centre 2A Chalmers Street Edinburgh EH3 9ES

Telephone: 0131 536 1520 or 0131 536 1522 Email: healthy.respect@lhb.scot.nhs.uk Website: www.healthyrespect.co.uk

Through coordinating a network of organisations and services dedicated to young people living in Lothian, Healthy Respect works to improve young people's sexual health and wellbeing, and supports them to enjoy healthy and respectful relationships. It also facilitates a specialist network for individuals and organisations working with young people with learning disabilities, with a focus on sexual health-related topics.

#### MYPAS (Midlothian Young Persons Advisory Service)

176 High Street Dalkeith Midlothian EH22 1AY

Telephone: 0131 454 0757 Email: Enquiries@mypas.co.uk Website: www.mypas.co.uk

Community-based organisation aims to improve the health and wellbeing of young people in Midlothian: sexual health, mental health, substance misuse.

#### **NHS Health Scotland**

Website: www.healthscotland.com

Extensive information, resources and education on all aspects of health.

#### **ROAM Outreach Clinic**

Chalmers Sexual Health Centre 2a Chalmers Street Edinburgh EH3 9ES

Telephone: 0131 536 1773 Mobile: 07774628227 Email: enquiries@roam-outreach.com Website: www.roam-outreach.com

Offers a wide range of services for men who have sex with men (MSM) and for men engaged in the sex industry.

#### **Waverley Care**

3 Mansfield Place Edinburgh EH3 6NB

Telephone: 0131 558 9710 Website: www.waverleycare.org

Waverley Care is Scotland's leading charity providing care and support to people living with HIV or Hepatitis C. As part of its work, it also strives to raise awareness of these conditions and their prevention.

## LGBT

#### Waverley Care

3 Mansfield Place Edinburgh EH3 6NB

Telephone: 0131 558 1425 Website: www.waverleycare.org

Formerly a HIV and Hepatitis C charity, Waverley Care now provides gay men's health services in Edinburgh and Lothian.

#### LGBT Health and Wellbeing

9 Howe Street Edinburgh EH3 6TE

Telephone: 0131 523 1100 Email: admin@lgbthealth.org.uk Website: www.lgbthealth.org.uk

Improving the health and wellbeing of lesbian, gay, bisexual and transgender communities. Providing a varied programme of services, groups, courses and events. This includes individual appointments for information and support. LGBT awareness training may be available for staff teams and organisations on request. The website has a range of resources to download, including a 'what is transgender?' easy-read booklet

#### LGBT Helpline Scotland

Telephone: 0300 123 2523 Email: helpline@lgbthealth.org.uk Website: www.lgbt-helpline-scotland.org.uk

Open on Tuesdays and Wednesdays 12:00-21:00

Information and support for lesbian, gay, bisexual and transgender people, those questioning their sexual orientation or gender identity and their families, friends and supporters, including professionals.

#### LGBT Youth Scotland

40 Commercial Street Edinburgh EH6 6JD

Telephone: 0131 555 3940 Email: info@lgbtyouth.org.uk Website: www.lgbtyouth.org.uk

LGBT Youth Scotland is the largest youth and community based organisation for lesbian, gay, bisexual and transgender (LGBT) people in Scotland. The charity's mission is to "empower lesbian, gay, bisexual and transgender young people and the wider LGBT community so that they are embraced as full members of the family at home, school and in every community."

#### **NHS Lothian Gender Clinic**

Telephone: 0131 536 1505 (Chalmers Clinic)

Ask for the 'gender clinic secretary'

The NHS Lothian gender clinic for people who have, or think they may have, gender dysphoria. The clinic is for will see any person aged 18 and over who has concerns about their gender or cross-dressing. Clinic staff will see people with any other coexisting physical, psychological or psychiatric condition including depression and personality disorders.

#### **Scottish Transgender Alliance**

30 Bernard Street Edinburgh EH6 6PR

Telephone: 0131 467 6039 Email: info@scottishtrans.org Website: www.scottishtrans.org

Works to improve gender identity and gender reassignment equality, rights and inclusion in Scotland. There is also a range of guidance and resources on their website.

## **Physical Disability**

#### Action on Hearing Loss (previously RNID)

Empire House 131 West Nile Street Glasgow G1 2RX

Telephone: 0141 341 5330 Textphone: 0141 341 5347 Fax: 0141 354 0176 Email: scotland@hearingloss.org.uk Website: www.actiononhearingloss.org.uk

Provides day-to-day care for people who are deaf and have additional needs; supplies communication services and training; offers practical advice to help people protect their hearing; campaigns to change public policy around hearing loss issues and supports research into an eventual cure for hearing loss and tinnitus.

#### **Capability Scotland (Head Office)**

Westerlea 11 Ellersley Road Edinburgh EH12 6HY

Telephone: 0131 337 9876 Textphone: 0131 346 2529 Website: www.capability-scotland.org.uk

Provides advice and information on any aspect of disability

#### **Deaf Action**

49 Albany Street Edinburgh EH1 3QY

Telephone: 0131 556 3128 Textphone: 0131 557 0419 Website: www.deafaction.org.uk Fax: 0131 557 8283 SMS: 07775 620757 Videophone: 82.71.100.1212.71.100.121

Deaf Action delivers a range of services to people in Scotland with sensory support needs, including those who are blind, partially sighted, deaf, deafblind and hard of hearing.

#### **Down's Syndrome Scotland**

158 /160 Balgreen Road Edinburgh EH11 3AU

Telephone: 0131 313 4225 Email: info@dsscotland.org.uk Website: www.dsscotland.org.uk

Promotes the interests of people with Down's syndrome and their families in Scotland by influencing public policy and attitudes and by providing a range of services and activities to help those with the condition reach their full potential.

#### **Royal National Institute of Blind People**

12-14 Hillside Crescent Edinburgh EH7 5EA

Telephone: 0131 652 3140 Helpline Telephone: 0303 123 9999 General Enquiries Email: rnibscotland@rnib.org.uk RNIB Edinburgh and Lothians Email: rniblothian@rnib.org.uk Website: www.rnib.org.uk/scotland

RNIB offers a wide range of services and support for people of all ages living in Scotland with sight loss.

#### Sense Scotland

43 Middlesex Street Kinning Park Glasgow G41 1EE

Telephone: 0300 330 9292 Email: info@sensescotland.org.uk Website: www.sensescotland.org.uk

Provides a range of projects and services to support disabled people and their families throughout Scotland.

## **Sexual Abuse**

#### Barnardos Skylight / Lighthouse Service

111 Oxgangs Road North Edinburgh EH14 1ED

Telephone: 0131 446 7000 Email: skylight/lighthouse@barnardos.org.uk Website: www.barnardos.org.uk/skylight

The Lighthouse/Skylight Service is a specialist service designed to support the Edinburgh and West Lothian communities to address issues associated with young people and sexual abuse.

#### **Edinburgh Rape Crisis Centre**

1 Leopold Place Edinburgh EH7 5JW

Helpline Telephone: 0131 556 9437 Business and Administration Telephone: 0131 557 6737 Business and Administration Email: info@ercc.scot Support and Email Support Email: support@ercc.scot Website: www.ercc.scot

Free and confidential service for women who have been raped or sexually assaulted.

#### **SHAKTI Womens aid**

Norton Park 57 Albion Road Edinburgh EH7 5QY

Telephone: 0131 475 2399 Email: info@shaktiedinburgh.co.uk Website: www.shaktiedinburgh.co.uk

Helps BME women, children and young people experiencing, or who have experienced, domestic abuse from a partner, ex-partner and/or other members of the household and provides training and consultancy for agencies working with BME women, children and young people.

#### **Drug and Alcohol**

#### MELD

Mid & East Lothian Drugs 6a Newmills Road Dalkeith EH22 1DU

Telephone: 0131 660 3566 Email: office@meld-drugs.org.uk Website: www.meld-drugs.org.uk

Provides locally accessible, confidential and non-judgemental services to promote recovery and reduce substance misuse-related harm to individuals, families and the wider community across Midlothian and East Lothian.

#### West Lothian Drug and Alcohol Service

1st floor Almondbank Centre Craigshill Livingston West Lothian EH54 5EH

Telephone: 01506 430225 Email: enquiries@wldas.org Website: www.wldas.com

Provides easily accessible, confidential and non-discriminatory services to reduce substance misuse-related harm to individuals, families and the community of West Lothian.

## Other

#### **GPs (Family Doctors)**

A GP can provide many of the contraceptive and genitourinary medicine services. However, it is important that there is a choice of service available.

#### **Health Promotion Resource Centre**

NHS Lothian Blackford Pavilion Astley Ainslie Hospital 133 Grange Loan Edinburgh EH9 2HL

Telephone: 0131 537 9337 /8 E mail: resource.centre@nhslothian.scot.nhs.uk Website: www.nhslothian.scot.nhs.uk/services/a-z/ healthpromotionresourcecentre

Anyone can register here to access information and resources on all aspects of health. Includes a section on sexual health and learning disabilities.

## Appendix 3 RESOURCE LIST AND USEFUL WEBSITES

## **Resource List**

Non exhaustive list of learning disability-specific sexual health resources:

Database of Sexuality and Disability Resources (2012) Author: Kelly, Grace et al Author: Connect People Network www.academia.edu/2241679/Database\_of\_Sexuality\_and\_Disability\_Resources Full database with a very wide range of resources over the decades

Growing and learning about sexual health: a resource to support parents and carers and young people with a learning disability (2005) Author: Keeling, Jane Publisher: Jane Keeling Teaching pack

How to put a condom on (2011) Author: NHS Lothian CLDT and Health Promotion Service Publisher: NHS Lothian Accessible easy read leaflet

How it is: An image vocabulary for children about feelings, rights and safety, personal care and sexuality (2002) Author: NSPCC Publisher: NSPCC ISBN: 184228018X Accessible booklet and CD-ROM resource on the topic of abuse

Making sense of sex: A forthright guide to puberty, sex and relationships with Asperger's syndrome Author: Attwood, S. & Powell, J. (2008) Publisher: Jessica Kingsley ISBN-10: 1843103745

Management of erectile dysfunction in adult men with learning disabilities and diabetes (2012) Author: Brown, M. Duff, H, Boyd, M. & Shaw, J. Journal: Diabetes & Primary Care Volume14 No 2 120-126 Journal article exploring good practice

More than a friend? Asking someone out and going on a date (2012) Author: Sandbox Learning Publisher: Kindle edition Stories designed for teens with additional support needs Puberty & Sexuality for children and young people with a learning disability Contributors: Children's Learning Disability Nursing Team (2009) Publisher: NHS Leeds

Relationships, Sexual Health and Parenthood for young people with ASD Author: Hannah, A et al (2008) Publisher: Learning & Teaching Scotland Training pack

Secret Loves, Hidden Loves? Exploring issues for people with learning difficulties who are Gay, Lesbian or Bisexual Author: Abbott, D & Howarth, J. (2005) Publisher: Policy Press ISBN: 1861346905

Sexuality & Developmental Disabilities: A guide for parents (2009) Author/Publisher: Alberta Health Services www.arc-spokane.org/PDFs/Sexuality%20and%20Developmental%20 Disability%20parent%20guide.pdf

Sexuality & Women with Learning Disabilities Author: McCarthy, M. (1999) Publisher: Jessica Kingsley ISBN: 1853027308 Stop – No More Abuse! Publisher: VOICE UK Accessible and easy-read leaflet promoting safety

Teaching Children with Down Syndrome about their bodies, boundaries & sexuality: A guide for parents and professionals (2007) Author: Couwenhaven, T Publisher: Woodbine House ISBN-10: 189062733X

The Big Question? Assessment of sexual knowledge for people with learning disabilities Author: Mathieson, J. & Waye, D. Publisher: NHS Lothian

#### Assessment tool for professionals

The facts of life – and more: Sexuality and Intellectual Disability Author: Walker-Hirsch, L (Ed) (2007) Publisher: Brooks Publishing Co ISBN-10: 155 766 7144 The Healthy Woman's Project: Cervical screening for women with learning disabilities Resource Pack (2007) Publisher: NHS Lothian A resource pack on cervical screening

You don't know what it's like: Finding ways of building relationships with people with severe learning disabilities, autistic spectrum disorder and other impairments (2004) Author: Caldwell, P. Hoghton, M. Publisher: Pavilion Publishing ISBN: 1841960233 Aimed at parents, carers and staff working with people with severe and profound learning disabilities

## **Useful Websites**

#### **British Institute of Learning Disabilities**

#### www.bild.org.uk

- Exploring sexual and social understanding: Dodd, K et al (2007) ISBN: 1-905218-01-x
   Illustrated resource pack to assess sexual knowledge
- We all need friends
   4 min you tube from Mencap
- Information on Dating Download accessible easy read booklet

#### **Brook Advisory Centre**

#### www.brook.org.uk

• Living your life: Craft, A. (2010 revised) Training pack

#### **Central Sexual Health: NHS Forth Valley**

#### www.centralsexualhealth.org/professionals

Selection of lesson plans and activity ideas for young people with learning disability, including photostories which address issues around relationships and sexual health for young adults with additional support needs. Guidance notes are available to be downloaded for educators/carers to use on an individual basis or within small groups.

## Centre for HIV and Sexual Health in Sheffield: www.sexualhealthsheffield. nhs.uk/publications

• Periods

Training pack

- Sexual Health Skills
   Manual & CD for trainers on sex and relationships
- Sexual Knowledge and Behaviour Assessment Tool Sexual Knowledge Assessment tool
- Values Pyramid

#### Change

#### www.changepeople.org

Runs projects, delivers training and develops resources in key areas that affect the lives of people with learning disabilities. The specialist areas of work include: parenting, health, employment, independent living, disability hate crime, advocacy, sexual health and relationships, and the rights of children and young people with learning disabilities.

Accessible visual picture cards:

- Sex and relationships
- Physical abuse
- Sexual abuse
- Pregnancy part 1
- Pregnancy part 2
- Supporting parents with LD part 1
- Supporting parents with LD part 2

Accessible easy-read booklets:

- Sexual abuse ISBN: 9781905506897
- Safe sex and contraception ISBN: 9781905506903
- Lesbian, gay, bisexual & trans ISBN: 9781905506910
- Sex and masturbation ISBN: 9781905506927
- Friendships and relationships ISBN: 9781905506934

#### Other

- My Pregnancy My Choice: A guide to pregnancy in pictures ISBN: 97819055506958
- Depo provera easy-read booklet

#### **Common Knowledge**

#### www.ckuk.org.uk/index.php/ck-learn/learn-about/sex-relationships

- Interactive CK sex talk provides young people with information about sex and relationship education (SRE)
- Batteries not included: A sexuality resource pack for working with people with complex communication support needs (2005) Author: Hart, P. Douglas-Scott, S. ISBN: 1899751424

#### **Disability, Pregnancy & Parenthood International**

#### www.disabledparent.org.uk

• Advice and information about pregnancy and parenting

#### **Diverse City Press**

#### www.diverse-city.com

- Fingertips: Hingsburger, D. & Haar, S. (2000) Book and video to teach about female masturbation
- Handmade Love: Hingsburger, D. (1995)
   Book and video to teach about male masturbation
- Under Cover: Dick Hingsburger, D. (1996) Book and video teaching men about condom use
- Just say know! Understanding and reducing the risk of sexual victimisation Hingsburger, D. (1995)
   Book and video to stop victimisation

#### **Down's Syndrome Scotland**

#### www.dsscotland.org.uk

Accessible easy-read leaflets:

- Let's talk about periods
- Let's talk about puberty

# Easy Health

### www.easyhealth.org.uk

Download accessible easy-read leaflets:

- Breasts
- Cervical Screening
- Contraception
- Menopause
- Periods
- Pregnancy
- Puberty
- Relationships
- Sexual Health
- Smear Tests
- Testicles

# **Elfrida Society**

#### www.elfrida.com

- Accessible easy-read booklets:
- Cathy has thrush
- Getting rid of fibroids
- Hysterectomy is it right for you
- Hysterectomy having the operation
- Period problems
- Relationships in the lives of people with LD
- Your private parts pack

# **Enable Scotland**

### www.enable.org.uk

 Dating for people with disability Family Advice Information Resource (FAIR) www.fairadvice.org.uk Accessible easy-read leaflets and e-leaflets

# Keep yourself healthy series:

- A guide to having your period
- A guide to the menopause
- A guide to examining your testicles
- Breast self examination
- Do I need a smear test
- Everything you need to know about HIV/Aids
- How to put a condom on
- Thinking about sex?

# **Family Planning Association**

### www.fpa.org.uk

- Contrapack: Visual representation teaching pack on contraception
- All about Us DVD-ROM, CD-ROM and Lessons Plan Manual Information about sexuality, safe sex and contraception
- Talking Together: about contraception Scott, L. & Kerr Edwards, L. (2010) ISBN: 97819005506460
- Talking Together: about growing up Scott, L. & Kerr Edwards, L. (2010) ISBN: 1 899194 96 7
- Talking Together: about sex & relationships: Scott, L. & Kerr Edwards, L. (2010) ISBN: 9781908249081
- Target: Focusing on the sexual and emotional needs of people with learning disabilities
   Burton, L. Valenti, I. & Warren, S. (2000)
   ISBN: 1 899194 17 7
- Learning Disabilities Sex & the Law: A practical guide Fanstone, C. & Andrews, S. (2009) ISBN: 978 1905506750
- Sexuality and Learning Disability: A resource for staff Fanstone, C. & Katrak, Z. (2003) ISBN: 1 899194 58 4 Describes issues and concerns and constructive ways of working
- Kylie's Private World: DVD ISBN: 9780955173547
   For females, with a strong emphasis on consent and saying NO
- Jason's Private World: DVD ISBN: 9780955173530
   For males with a strong emphasis on consent and saying NO
- You, your body and sex: DVD ISBN: 9780955173523
   Based on Kylie & Jason with additional material

# Get2gether (Dates 'n' Mates)

### http://get2gether.org.uk/about

A charity providing safe opportunities for love and friendship for anyone with a disability, to tackle isolation and to promote and support personal relationships

# **Health Edco**

#### www.healthedco.com

A range of training materials including:

- Breast Self Examination: Model
- Condom Training: Model
- Testicular self examination: Model

### Images in Action Sex and Relationship Education for people with disability

www.imagesinaction.com

- Lets Do It: Johns, R. et al (2007) Accessible creative activities
- Lets Plan It: Scott, L. & Duignan, S. (2005) Accessible creative activities
- The confidence factor Image in Action (2010) Sarah Duignan
- Going Further: Getting started Free download
- Going Further: SRE Course Free download

# Life Support Productions

www.lifesupportproductions.co.uk

DVD and Information Pack sets:

- You, your body and sex ISBN: 978-0-9551735-2-3
- Kylie's Private World ISBN: 978-0-9551735-4-7
- Jason's Private World ISBN: 978-0-9551735-3-0
- The Primary Guide to Growing up, Relationships & Sex ISBN: 97800-9551735-7-8
- The New Guide to Relationships & Sex ISBN: 978-0-9551735-5-4

# Me and Us Resources

### www.me-and-us.co.uk/publications

- Chance to Choose: Teaching pack birth, parenting, being sexual, body awareness, communication and relationships
- Songs for my body (2010): A CD of 12 songs about SRE
- Condom cards: illustrated cards how to use condoms safely (2008)
- Periods a practical guide: Rees, M. Et al (2008)
- I change my pad
- Picture Yourself 1 & 2: Social and sex education for pwld Dixon, Hilary
   4 sets of line drawings in PDF format on CD
- Body Board & other products Marshall, T.
- Desmond & Daisy: anatomically correct male and female cloth models
- Talking Together: about contraception Scott, L. & Kerr Edwards, L. Revised (2010) ISBN: 9781905506460
- Talking Together: about growing up Scott, L. & Kerr Edwards, L. Revised (2010) ISBN: 1 899194 96 7
- Talking Together: about sex & relationships Scott, L. & Kerr Edwards, L. Revised (2010) ISBN: 9781908249081Mental Welfare Commission

### www.mwcscot.org.uk

- Consenting adults?(2011): Guidance for professionals and carers when considering rights and risks in sexual relationships involving people with mental disorder
- Justice Denied (2008): Report about the care and treatment of a woman who experienced serious sexual assaults

# Midlothian Council New Media Education Project

www.moodle.borderscollege.ac.uk/course/view.php?id=1234

Training materials encouraging the safe and productive use of Social Media for young people with learning disabilities, parents and carers. Materials cover:

- Friendships
- Money and Shopping
- Chat and Communication
- Security
- Meeting in Real Life
- Taking Photos and Video
- Personal Information
- Smartphone Safety
- Online Gaming
- Cyberbullying

# NHS Fife

### www.nhsfife.scot.nhs.uk

Download leaflets on:

- Menopause
- Relationships
- Chlamydia for men
- Chlamydia for women
- A guide to personal safety
- Keep safe at home
- DVD: Going for a mammogram
- Pregnancy Support pack

### **NHS Health Scotland**

www.healthscotland.com/topics/health/wish/resources.aspx

Wellbeing in Sexual Health and HIV resources on:

- Gonorrhoea
- Chlamydia
- Genital warts
- Genital herpes
- Vaginal health
- Pre-menstrual syndrome and period pains
- Cystitis
- Your guide to longer-lasting contraception leaflet
- Your guide to longer-lasting contraception poster
- Talking with your child about relationships and sexual health
- Talking with your teenager about relationships and sexual health

### NHS Lanarkshire Adult Learning Disability Service

www.healthelanarkshire.co.uk

• A website hosting information in different formats, including easy-read booklets and DVDs on cervical smears, mammogram, breast self examination, prostate and testicular self examination

# **NHS** Lothian

### www.lothiansexualhealth.scot.nhs.uk

Here you can access support, services and information on contraception, pregnancy, sexually transmitted infections (STI) and sexual problems. You can also find out more about the specialist clinics provided in Chalmers Sexual Health Centre.

### **NHS Inform**

#### www.nhsinform.co.uk/Easy-Info

NHS Inform's Learning Disability Zone has pages on health and wellbeing, including contraception, in easy-read forms

# **Pavilion Publishing**

### www.pavpub.com

- Becoming a woman: Cooper, Emma (1999) ISBN: 1 900600 986 Teaching pack on menstruation
- Living Safer Sexual Lives: Frawley, P et al (2003 and revised 2010) ISBN: 1841961159 Training resource
- Making the change: Cooper, Emma & Welsh, Rebecca (2001) ISBN: 1900600986 Teaching pack on menopause
- Male Sexual Abuse & Trauma: Jones, Peter (2011) ISBN: 184196283X Training pack
- Men with Learning Disabilities who sexually abuse: Working Together to Develop Response-Ability: Thompson, D & Brown, H. (2005) ISBN: 1841961353 Training pack
- Sex and 3R's Rights, Responsibilities and Risks: McCarthy, M. & Thompson, D. (1998) ISBN: 1871080347 Training pack
- Sexuality & Sexual Health: Thompson, D ISBN: 908993073
   Training pack, CD-ROM & learner workbook
- Sexuality and Learning Disabilities: A handbook: McCarthy, M. & Thompson, D. (2010)
   ISBN: 10 1841962864
- Supporting women with learning disabilities through the menopause McCarthy, M. & Milliard, L. ISBN: 978 1 84196 106 4 CD-ROM & DVD

# A Picture of Health

### http://www.apictureofhealth.southwest.nhs.uk/

Easy-read accessible leaflet on sexual health, including:

- Contraception
- Feeling
- Growing up
- Menopause
- Menstruation
- Resources
- STDs
- Thrush

# **Royal College of Psychiatrists**

#### www.rcpsych.ac.uk

Beyond Words Series: Accessible easy read books

- Falling in Love: Hollins, S et al (1999) ISBN-10: 978-1-901242-32-4
- Hug Me Touch Me: Hollins, S. (1994) ISBN-10: 1874439052
- I can get through it: Hollins, S. et al (1998) ISBN-10: 978-1-901242-20-1
- Jenny Speaks Out Hollins, S. & Sinason, V. (2005) ISBN-10: 978-1-904671-14-4
- Keeping Healthy "Down Below": Hollins, S. et al (2000) ISBN-10: 978-1-901242-54-6
- Looking After My Balls: Hollins, S. & Wilson, J. (2004) ISBN-10: 978-1-904671-05-3
- Looking After My Breasts: Hollins, S & Perez, W. (2000) ISBN-10: 978-1-901242-53-9
- Loving each other safely: Hollins, S. et al (2011) ISBN-10: 978-1-908020-29-1
- Supporting Victims: Hollins, S. et al (2007)
- ISBN-10: 1904671527
- Susan's Growing Up: Hollins, S. & Sinason, V. (2001) ISBN-10: 978-1-901242-51-5

# Scottish Government Sexual Health and Blood Borne Viruses

www.gov.scot/Topics/Health/Services/Sexual-Health

Hosts the Scottish Government's Sexual Health and Blood Borne Virus Framework 2015-2020 Update

#### **Scottish Government Sexual Health Scotland**

www.sexualhealthscotland.co.uk

A source of information on Sex and Relationships, STIs, Contraception and Pregnancy as well as a sexual health service finder.

### University of Bristol School for Policy Studies

www.bristol.ac.uk/sps/research/centres/norahfryresearch/resources

- Download accessible easy-read leaflets: Phil's Story Jan's Story Both same sex relationship photo story
- A booklet about challenging homophobia and heterosexism for people with learning difficulties and the staff who support them (2005): Abbot, D.

# **HIV EDUCATION**

There should be a provision of specific resources for people with learning disabilities, who are also HIV positive. These might include:

- Support to access monitoring and treatment, and information on adherence to drug regimes
- Provision of accessible information about HIV transmission and prevention
- Access to information and support to help maintain control over exposure of the virus to sexual partners. This would include access to condoms and the skills necessary to use them effectively
- Support and information to access clinical sexual health services (as opposed to HIV-specific clinical services)
- Information about other STIs and the particular relevance these have for people with HIV
- Support around disclosure of HIV status as appropriate
- Support in dealing with the psychological and social impact of HIV diagnosis
- Support in dealing with the double stigma of HIV infection and learning disability
- Access to appropriate peer support and voluntary sector services
- Integration of service provision by agencies concerned primarily with HIV and those concerned with learning disabilities.

This list is by no means exhaustive, but clearly illustrates that all of the fundamental issues faced by any person with HIV in Lothian are relevant to those who also experience learning disabilities. It is essential that service provision takes account of the different and differing needs of people with HIV who also experience learning disabilities. Services and professionals should address those needs in a way which is accessible and appropriate, non-judgmental, and free from assumptions about individuals, communities or the opportunities available to them.

# **ERECTILE DYSFUNCTION**

### What is erectile dysfunction?

Erectile dysfunction is defined as the consistent inability to reach and maintain an erection satisfactory for sexual activity.

Some causes of erectile dysfunction

- Smoking
- Diabetes (at least 50% of men with diabetes will suffer from erectile dysfunction at some stage)
- Psychological issues
- Increasing age
- Surgery and trauma
- Renal failure
- Alcohol
- High cholesterol
- Vascular and cardio vascular disease
- Medications.

### **Medications**

- Some known side-effects for anti-convulsant and psychotropic drugs can cause problems with erections and ejaculation
- Recreational drugs are another common cause with people who have learning disability and the mainstream population.

### Impact of erectile dysfunction problems

- Issues with psychological and social wellbeing, including depression, anxiety and low self-esteem
- · Can negatively impact on personal relationships

# What to do if you suspect someone an adult with learning disability has erectile dysfunction issues?

- Support them to access their GP
- GP can arrange for referral on to specialist services for further assessment and intervention.

### **Further reading**

References- Brown, M. Duff, H. Boyd. M. Shaw. J. (2012) Management of erectile dysfunction in adult men with learning disabilities and diabetes Diabetes & Primary Care Vol 14 No 2 2012

# **ALCOHOL SUPPORT SERVICES**

### Al-Anon/Alateen

Unit 6, 22 Mansfield Park Mansfield Street Partick Glasgow G11 5QP

Telephone: 0141 339 8884

# **Alcoholics Anonymous**

www.alcoholics-anonymous.org.uk 24-hour Helpline Telephone: 0845 7697555 (for individuals seeking help, e.g. with finding an AA meeting).

Edinburgh Group Telephone: 0131 225 2727

# Breathing Space (If you feel depressed or in low mood).

Please phone an advisor between 6pm and 2am every day of the week.

Telephone: 0800 838587 (free)

# **Down Your Drink**

#### www.downyourdrink.org.uk

This website lets you assess your drinking and work through a planned programme of change to reduce your drinking to a healthier level if necessary.

### **Drink Aware**

www.drinkaware.co.uk

Impartial, evidence-based information, advice and practical resources, raising awareness of alcohol and its harms

# Drinkline

For general advice on alcohol issues.

Telephone: 0800 7 314 314 (24 hours a day, 7 days a week).

# ELCA (Edinburgh and Lothian Council on Alcohol)

Telephone: 0131 337 8188.

### **MEHIP (Minority Ethnic Health Inclusion Project)**

MEHIP aims to link people from minority ethnic communities with primary healthcare services across Lothian. Languages: Arabic, Bengali, Chinese, Gujarati, Hindi, Kurdish, Nepali, Punjabi, Urdu and access to interpreters. Springwell House, Ardmillan Terrace, Edinburgh, EH11 2JL.

Telephone: 0131 537 7565.

### North Edinburgh Drug Advice Centre (NEDAC)

Telephone: 0131 332 2314

### **Turning Point Scotland Leith**

Telephone: 0131 554 7516.

### West Lothian Drug and Alcohol service

43 Adelaide Street, Livingston, West Lothian, EH54 5HQ.

Telephone: 01506 430225.

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# **APPENDIX 8**

# ACKNOWLEDGEMENTS

# **Group Membership**

The following formed the writing group for the original guidelines (2004):

- Alistair Littlejohn, Clinical Service Development Manager, Lothian Primary Care Trust
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- Gill Reid, Assistant Project Manager, FAIR
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- Polly Wright, Commissioning and Development Officer for Learning Disability, East Lothian Council
- Rachael Yates, Senior Health Promotion Specialist, Lothian NHS Board

# Partners

Thanks to the following partner organisations for their contribution, comments and advice during the course of developing the original guidelines (2004):

- City of Edinburgh Council
- East Lothian Council
- FAIR (Family Advice and Resource Centre)
- NHS Lothian
- Midlothian Council
- Voluntary Health Scotland
- West Lothian Council

Thanks are also extended to Gerrie Douglas-Scott of 'Difference Solutions' for proofreading and for guidance on the accessibility of the original document.

We gratefully acknowledge the support and helpful comments from the following organisations and individuals who freely shared their experience of developing guidelines and their publications.

All those who shared comments during the original consultation process

- Barnardos Connect Project
- Carol Painter
- Consent
- Healthy Respect
- Mark Ward
- TARGET

# 2013-15 Review Group and Other Contributors

The following people formed the group in 2013-15 for the review of the original guidelines following the Justice Denied Mental Welfare Commission report with others contributing out with the meetings:

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- Walter Anderson (Local Area Coordinator, City of Edinburgh Council)
- Wendy Ramsay (Adult Protection Lead, West Lothian Council)
- George Burrows (Community Development Worker, LGBT Health & Wellbeing) We also gratefully acknowledge the following Health Boards who have kindly agreed to allow NHS Lothian to update relevant content in line with their versions.
- NHS Fife
- NHS Tayside