



Making choices Keeping safe

Policy and Practice Guidelines on relationships and sexual wellbeing when working with people with learning disabilities.

If you ask we can also provide copies of the policy in the following formats from:

Health Promotion – Learning Disabilities
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Edinburgh EH8 9RS
Telephone: 0131 536 9275

- text only format on floppy disk or email
- larger print (up to font 16)
- audio CD
- Braille
- www.mcks.scot.nhs.uk



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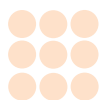
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1.1 Foreword

This policy and its associated guidelines have been produced as a response to the sexual health needs of people with learning disabilities. It has been written in wide consultation with, and with input from, people with learning disabilities, their parents and carers. It will be a supporting document to the forthcoming Edinburgh and the Lothians sexual health strategy.

A multi-agency pan-Lothian group has developed and adopted this policy and guidance to be used in all learning disability service areas. Workers and staff cannot offer support without support and guidance through organisational policy and procedures. 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 if workers or staff have difficulties with the sexual behaviours of their clients.



1.2

Group membership

The following people formed the writing group for the policy:

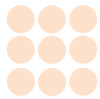
- Alistair Littlejohn, Clinical Service Development Manager, Lothian Primary Care Trust, (LPCT)
- Anthea Mason, Manager, Currie Hostel, City of Edinburgh Council
- Christine Schaffer, Planning and Purchasing Officer, Midlothian Council
- Gill Reid, Assistant Project Manager, FAIR
- Jane Kellock, Service Development Officer, West Lothian Council
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- Rachael Yates, Senior Health Promotion Specialist, Lothian NHS Board



1.3

Partners

City of Edinburgh Council
East Lothian Council
FAIR (Family Advice and Resource Centre)
Lothian NHS Board
Lothian Primary Care NHS Trust
Lothian University Hospital NHS Trust
Midlothian Council
Voluntary Health Scotland
West Lothian Council
West Lothian Healthcare NHS Trust



1.4

Introduction

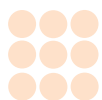
Many people with learning disabilities will not need intervention, or a response in their sexual lives, from workers. However, the pan-Lothian working group believe that all people with learning disabilities will benefit from guidelines that describe and explain workers' roles and responsibilities.

Some people with learning disabilities need help and guidance 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 sexuality
- 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 section 1.3.



1.5

Policy Values

This policy and its associated guidelines adheres to values that are firmly rooted within the United Nations Declaration on Human Rights¹ and the philosophy underpinning Harm Reduction². 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)³ 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 abused
- The right to humane and dignified environments.

This policy and guidelines would also add the following to the above principles:

- The right to explore and express sexuality and sexual orientation / gender.



2 - Easy Read Summary

Making Choices Keeping Safe

How your support workers must help you with relationships and sexual wellbeing

The following section has been written to summarise section 3 in a format that is easy to understand for people with learning disabilities. The group would recommend that this section is not simply photocopied and given out, but that a worker takes time to support a person to read it. This way the worker can explain words or ideas that are not understood. It may also be an opportunity to initiate discussions on the topic of sexual health and relationships.





Making Choices Keeping Safe

Talking about relationships and sex is difficult for everyone. If you have learning disabilities it can be even more difficult to get the information and help you need.

You may want to

- find out how your body works.
- find out how to say 'no' if you don't want a relationship
- find out about how the law can protect you
- ask your doctor about your health
- find out about clinics





●●● Who do you ask about ●●● sex and relationships?

You can ask your support worker about sex and relationships. If they can't answer all your questions, they will find someone else to help.

Lothian NHS Board and the Social Work Departments in Lothian have written a set of rules to help workers. They follow these rules, so you need to know about them too. This booklet will tell what is in the rules. It will also tell you what you can ask your workers about and how your workers should behave.

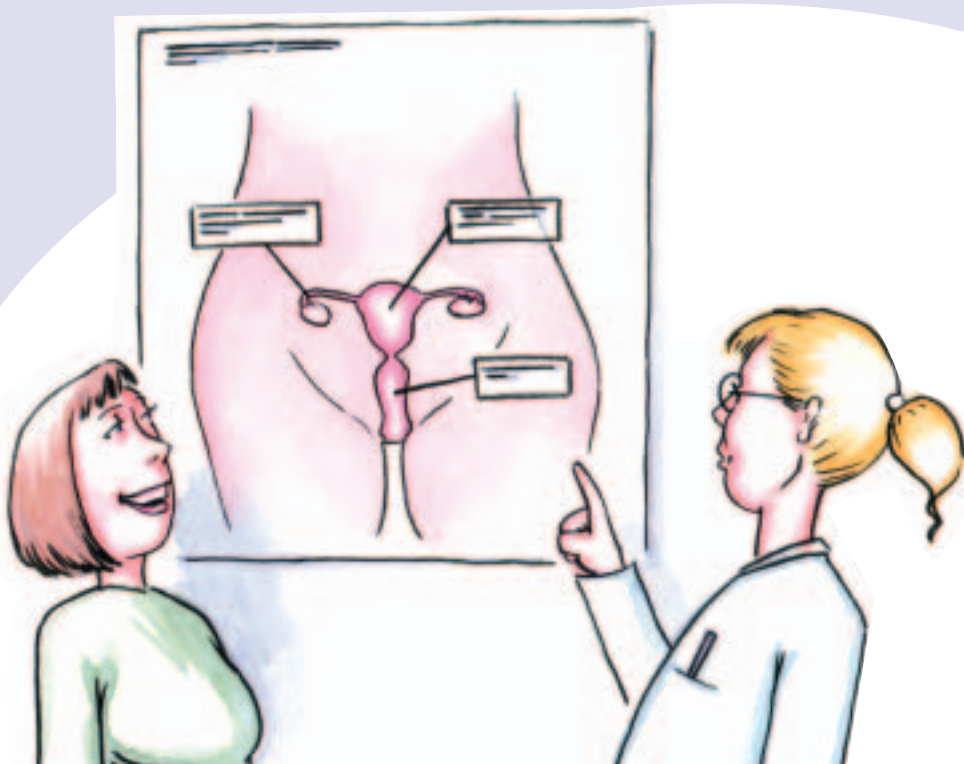
All the people working with you must use the rules in this booklet.



What are your rights?

You have

- The same rights as people without learning disabilities of the same age
- The right to be treated with respect
- The right to find out about your body
- The right to a private and family life
- The right to get information about your body, your feelings, and the way to behave
- The right to make and break relationships
- The right not to be sexually abused
- The right to marry and start a family
- The right to explore your sexuality to decide if you are attracted to people of the same sex or of the opposite sex





Getting the information you need

If you have any problems about sex and relationships, your worker should make sure you get the right help. Your worker may need help from other people to do this.

When you get information, it should be given to you in a way you can understand. This may mean getting it on tape or on video or getting someone to spend extra time explaining things to you.

You should also know how to complain about things and have help to complain.

There is a list of places you can go to for help and more information at the back of this booklet.



Keeping things private

Some things must be kept private. You need to know what things can be kept private and what things can't. The person working with you must talk to you about this. If the person working with you has to tell someone about your private business, it will be because they are worried that you could be hurt. Your support worker must make sure that you know they are going to tell someone.

If you are unhappy about what your worker says to other people, you can complain. Ask your worker, or someone you can trust about how to complain. If you don't live with your family you should be able to lock the door to your room and your worker should not come into your room without asking you if they can. Your worker should help you to have your friends round in private if you want to.

If you have sex it must be in a private place. It is against the law to have sex in the street or somewhere like your work place. You could speak with your worker to find a private space if you need to find one.

You may need help to decide whether you want to have sex with someone and your worker should find the best person to help you with this decision.





Keeping safe

Everyone has the right to feel safe. You may need to learn how to keep safe. Your worker will help you do this if you wish.

If you don't feel safe you must have someone you trust to talk to.

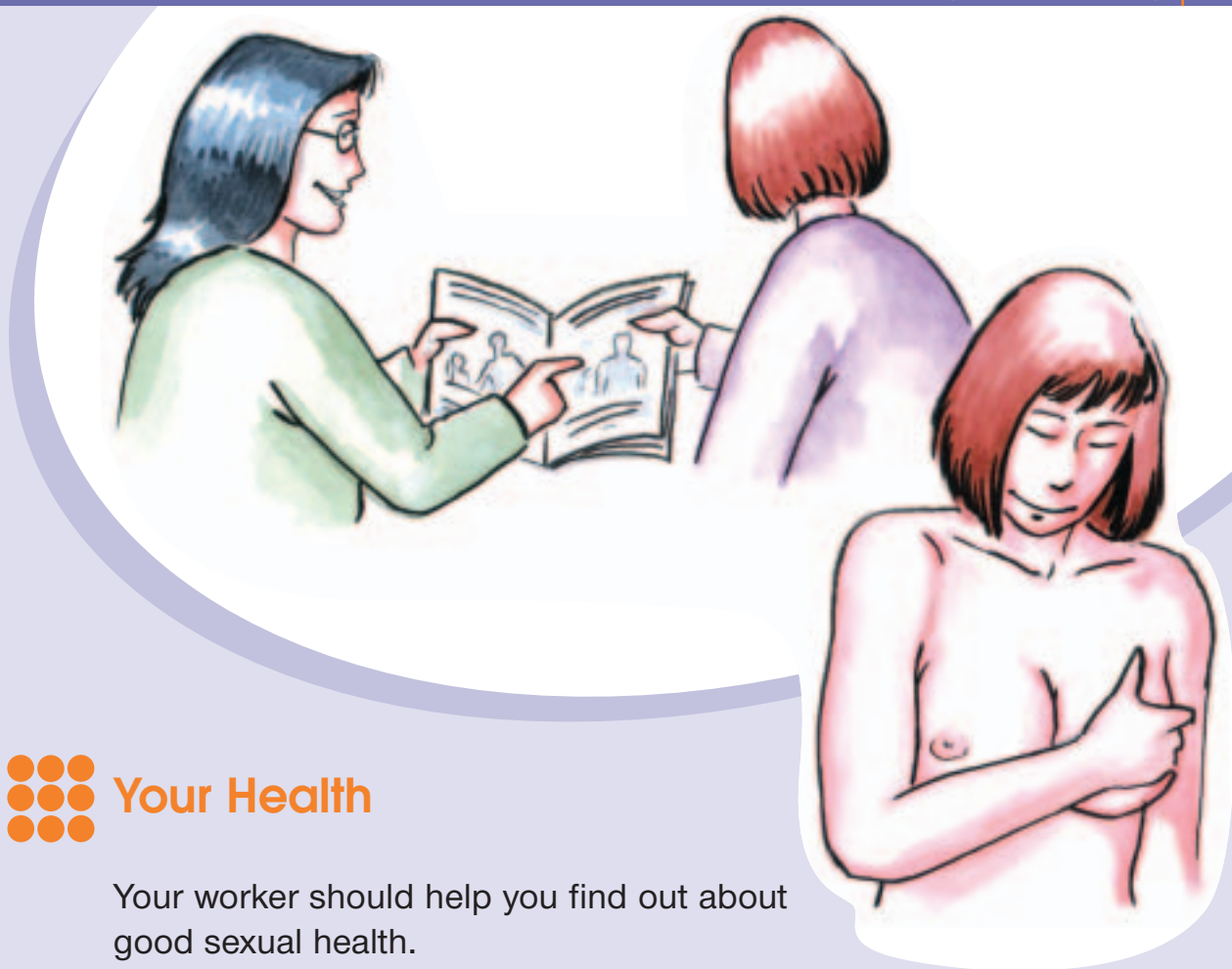
If someone is hurting you or you don't feel safe you must tell a worker. They must listen to you and respect what you say.



What about your family?

It is important that your worker listens to what your family says and makes sure they can get information and help if they feel they need it. However, remember you have the right to keep some things private from your family.





Your Health

Your worker should help you find out about good sexual health.

If you are a woman you may need to find out about:

- Getting a smear test
- Finding out about having a baby
- Finding out how **not** to have a baby
- Checking your breasts for unusual lumps or bumps

If you are a man you may need to find out about:

- Checking your testicles for unusual lumps or bumps
- How to have a baby with someone
- How **not** to have a baby with someone

Both men and women may need:

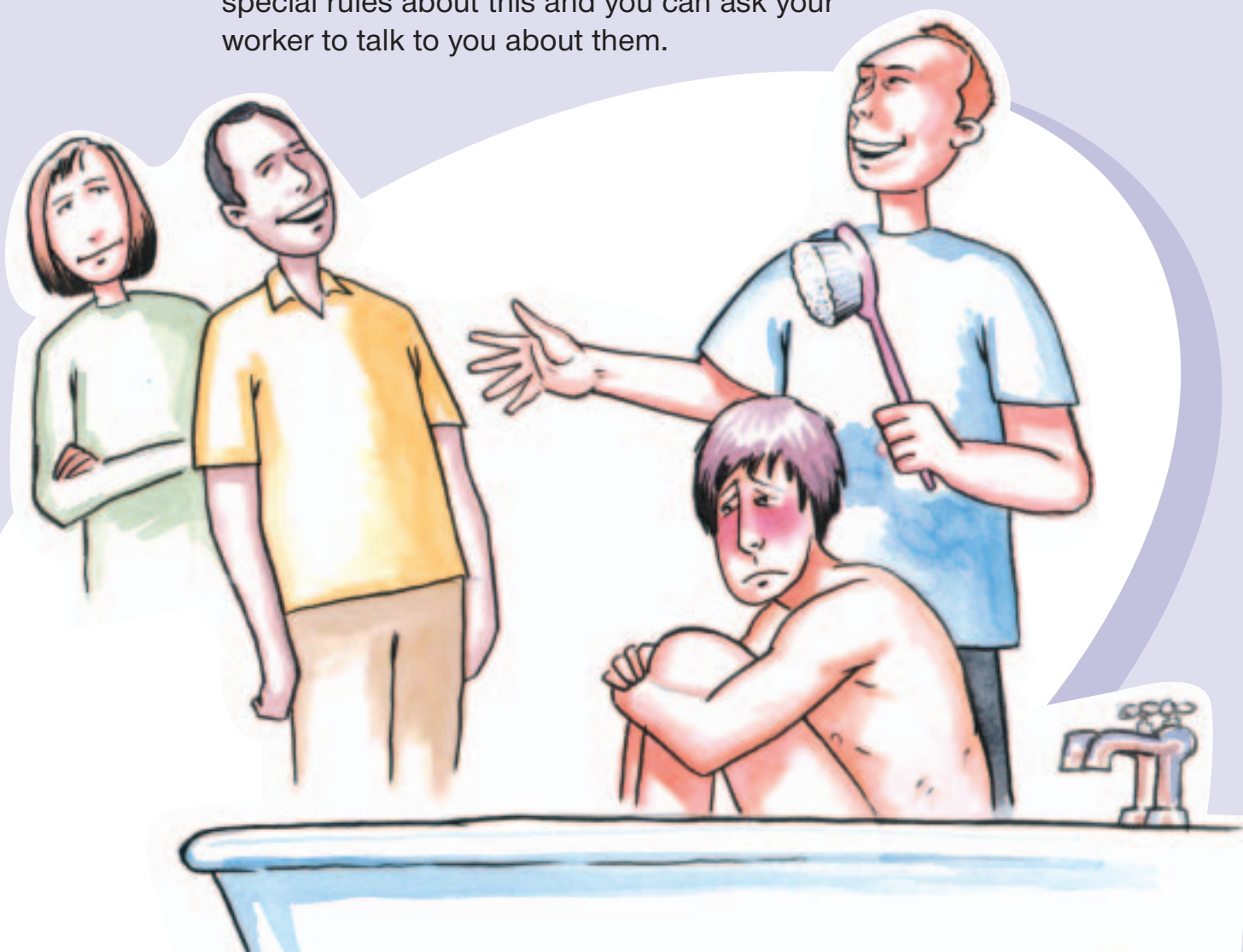
- information about infections such as HIV, AIDS or Chlamydia, that can be caught by having sex with someone
- Help if they have sexual problems.

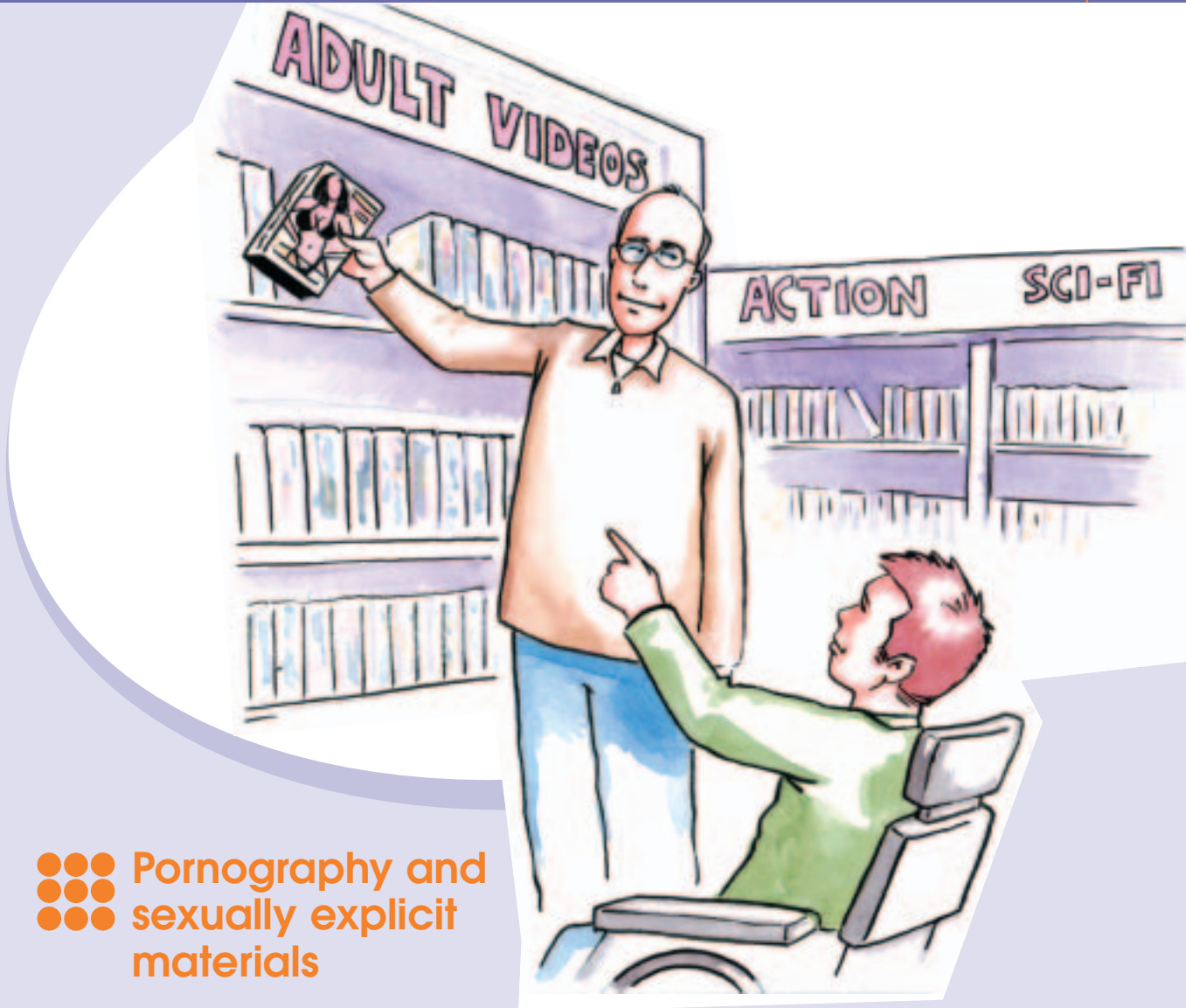
●●●● Finding out about sex and relationships.

If you need to find out more about sex and relationships, your worker should help you do this.

●●●● Intimate Care

If someone has to help you bath or help you when you go to the toilet, this should be done in private. There are special rules about this and you can ask your worker to talk to you about them.





●●●● Pornography and sexually explicit materials

If a book or videos about sex can be bought or borrowed from a shop, you can ask for help to get them. Some people do not like pictures or videos about sex, so you will need to look at some things only in private.

Some books and videos about sex are not allowed by law. Your worker will explain this to you and will not help you get these.

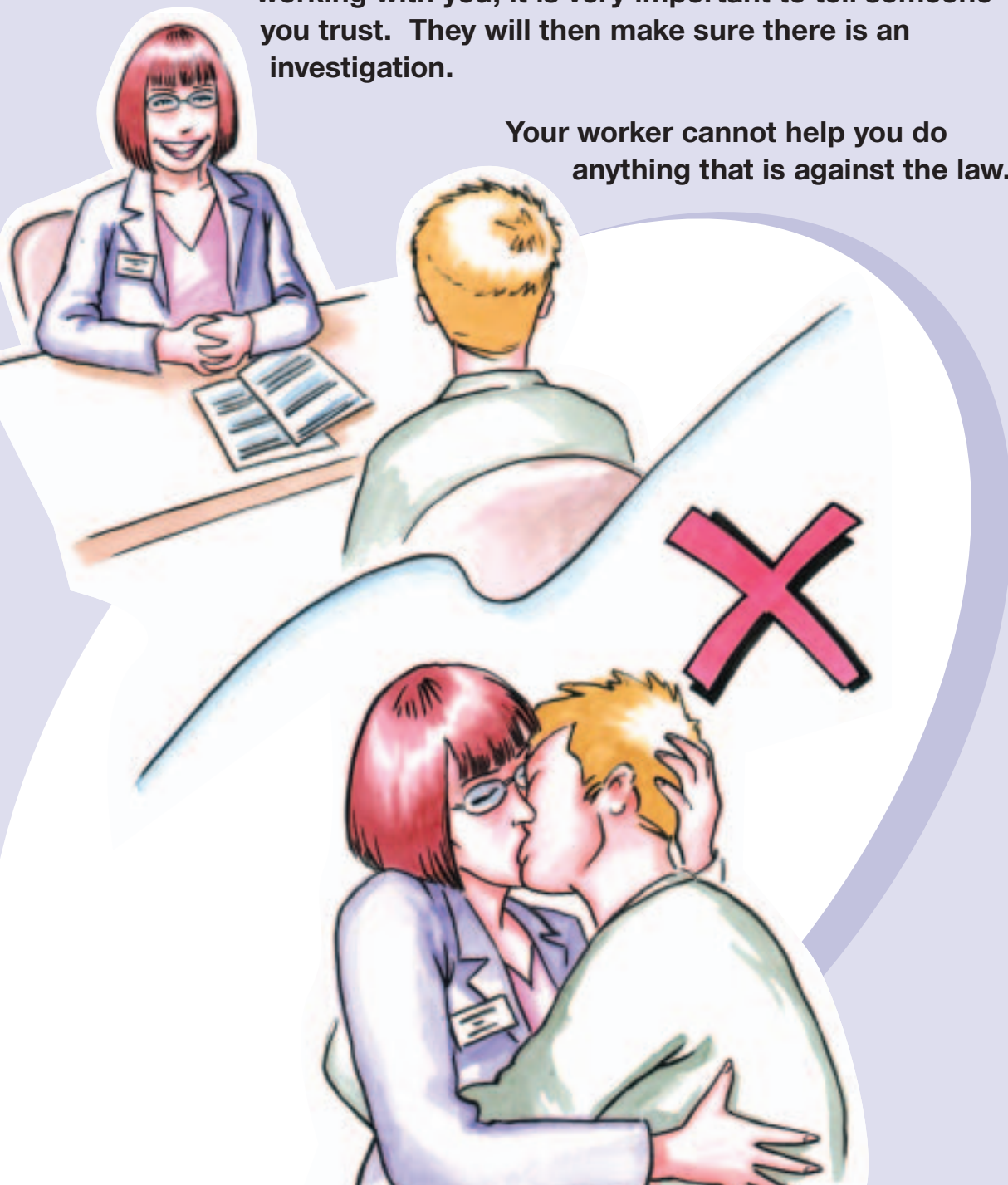
You may need to ask your worker about looking for things on the Internet. Both of you will need to ask your worker's manager for advice about this as it is important to make sure you are safe on the Internet.



Very important rules

The person working with you must not be your girlfriend or boyfriend and they must not have sex with you. If you are having problems with the person working with you, it is very important to tell someone you trust. They will then make sure there is an investigation.

Your worker cannot help you do anything that is against the law.



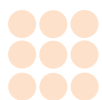


3

The Policy

Sexuality is a subject that people often find difficult to discuss but it is a part of everyone's life. Women and men 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.



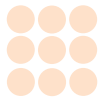
3.1

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.

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 men and women, 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 4.19 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 black and ethnic minority groups, older adults, people with HIV, gay men, lesbians



3.2

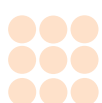
Confidentiality

People with learning disabilities have the right to absolute confidentiality, unless there is concern about abuse or risk of abuse. 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 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 this policy when working with people with learning disabilities
- ensure each person with a learning disability using the service/resource is aware of the policy and 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 well being 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 abuse to the relevant agency, whilst making sure each person is aware of the process

- be familiar with guidelines on legal constraints to maintaining confidentiality - **see Appendix 1 or "Protecting Vulnerable Adults"** ^a
- inform people with learning disabilities about complaints policies and procedures and support them to use these as appropriate.



3.3

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 well being.

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
- have access to specialist and peer support where required
- have access to 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.

^a The Lothian and Borders Protecting Vulnerable Adults Policy and Guidelines is available on the web at www.westlothian.gov.uk/partnerships/protecting_vulnerable_adults/default.asp or copies may be obtained from local community care teams.



3.4

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 abuse.

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 given 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 training⁵.

The person with a learning disability should be taught to

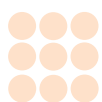
- **recognise the signs when personal safety is compromised**
- **learn strategies on how to feel safe and protect oneself**
- **negotiate saying 'yes' and saying 'no'.**

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^b so that workers know how to facilitate an effective protective behaviours programme and how to deal with disclosure of abuse

^b Organisations that can offer training in this area are listed in Appendix 3.

- in the event of a person disclosing a situation of concern 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. **Refer to Appendix 1 and the Protecting Vulnerable Adults policy⁶, Section three, for relevant legislation.**



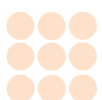
3.5

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 3.2)
- 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.

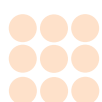


3.6

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
- consult about any decisions in relation to the person with learning disabilities if a welfare proxy decision maker has been appointed (this could be a welfare guardian, intervener or someone who has welfare power of attorney)
- 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 well being.
- ensure that families and carers have access to the appropriate complaint procedure.



3.7

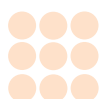
Information giving

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

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, video, 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), Caledonian Youth, LGBT Youth, Respond, Community Learning Disability Teams, Primary Care.
- people with learning disabilities, workers and families and informal carers all have information about how to disclose abuse or suspected abuse
- people with learning disabilities have information on how to complain about services or individuals. They should be given support by a worker^c in making a complaint if they wish or require it.



3.8

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.

^c See Appendix 3 for People First or other organisations which could help.

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

- confident and competent to discuss sexual health 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.

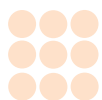
The following issues could come into a sexual health discussion. (See Section 4 for further information)

- Smear Tests
- Testicular Awareness
- Breast Awareness
- Periods
- Premenstrual Tension/Syndrome
- The Menopause
- Hormone Replacement Therapy
- Sexual dysfunction (e.g. impotence)
- Condoms
- Sexually Transmitted Infections (STIs)
- Oral, anal and vaginal sex
- Masturbation
- HIV and AIDS
- Contraception
- Emergency Contraception
- Sterilisation
- Abortion
- Pregnancy Testing
- Antenatal Care
- Antenatal screening and genetic counselling
- Family planning
- Sexuality
- Sexual abuse
- Relationships / friendships



4

Good Practice Guidelines



4.1

Practice Guidance for Workers

Note: This document should be read in conjunction with the Protecting Vulnerable Adults Guidelines⁶, and individual agencies policies and Confidentiality Guidelines. Workers should be aware of the National Care Standards⁷ and the Scottish Social Services Council Employer and Employee Codes of Practice⁸.

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 situation. These guidelines will not under any circumstances permit, encourage, or condone any activity which is illegal. Throughout the guidelines it is indicated where the law is particularly important. Appendix 1 gives further information on sexuality and the law as it applies to people with learning disabilities.

The sexuality 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 abuse. Any attempts to strike a balance must inevitably be imperfect.

Supporting people with learning disabilities in the area of sexuality and relationships 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.

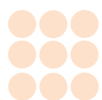
People with learning disabilities are entitled to confidentiality – see guidance on confidentiality, individual agency policies and National Care Standards⁷.

However, workers do have an overriding responsibility to report disclosures of abuse or illegal acts to their line manager immediately (See Protecting Vulnerable Adults Policy⁶).

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.



4.2

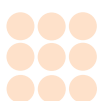
Relationships

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 standards⁷ on rights to privacy.

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 activity between workers and a vulnerable adult is exploitative, abusive and is forbidden by law.

Any allegation of abuse made against a worker will be investigated. The Policy on Protecting Vulnerable Adults from Abuse explains this procedure in detail (available from local authorities and the NHS board)⁶.



4.3

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

- closing toilet / bathroom / bedroom doors
- consulting 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

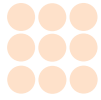
Negative comments and disapproval expressed through word or body language should be avoided by workers.

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.

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.

The emotional and physical safety of workers should be considered at all times e.g. using safe manual handling techniques.



4.4

Elements of a sexual health and relationship education programme

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 sexuality.

The following list is not exhaustive and should be referred to as a basis for planning sexual health and relationship 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.

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 parental concerns. Parents may wish to have the opportunity to discuss the programme and view materials with the consent of the person with learning disabilities.

Social Skills

Research suggests that sex and personal relationship education offered to small groups of people with learning disabilities is beneficial. For this reason, initial work on the following areas will be needed

- Establishing rules and boundaries
- Forming a group

- Awareness of self in relation to others
- Family, friends and relationships
- Societal and cultural attitudes
- Marriage and responsibilities to partners
- Validity of other types of relationship

Body awareness and basic information about sex

- Human Biology
- Reproductive function
- Puberty
- Masturbation, ejaculation
- Menstruation
- Pregnancy; conception; needs of a baby; reality of parenthood
- Same sex relationships

Personal health and contraceptive advice

- How to access a range of services within Family Planning Services and within Primary Care, for example, family doctor and practice nurse
- Sexually transmitted infections
- HIV and AIDS

Appropriate behaviour

- Time and place
- Body language
- Private and public behaviour
- Difference between child and adult behaviour
- Appropriate expression of feelings and emotions
- Use of sexually explicit materials

Assertion: Protection against abuse

- 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 abuse if it happens and reporting it

The Law

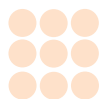
Responsibilities of the individual, workers and parents.

Awareness of Media Influence

Issues around possible devaluation and exploitation of people through pornography and stereotyping.

Lifestyle choices

- monogamy
- marriage
- celibacy
- multiple partners
- choice of partner



4.5

Sexually Explicit Materials

For legal, professional, moral and ethical reasons this policy 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 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.

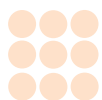
An interest in such material can be seen as sexual development, especially where the opportunity of sexual discussion is limited or suppressed.

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.



4.6

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.

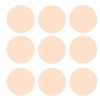
People with learning disabilities should have the opportunity to develop a range and variety of relationships. Relationships that develop may or may not have a sexual element. Residential establishments need to cater for privacy and the following principles should apply.

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. Day Centres are public buildings and consequently are not acceptable venues for any sexual behaviour which may cause offence to others.

In providing privacy for residents, workers will need to remain aware that some people with learning disabilities are vulnerable to abuse 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.



4.7

Masturbation

Masturbation may be an outlet for sexual feeling and it is considered an acceptable sexual behaviour for females and males. People should not be discouraged from masturbating, providing that it is done in private.

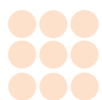
If masturbation seems to be taking place excessively, for example if it is interfering with day to day living, or taking place in inappropriate situations, it may indicate other issues which need to be addressed. Workers should consult with their line manager. Points for consideration may include

- Sexual frustration
- Are they experiencing difficulties with a relationship?
- Is the person bored or needing other stimulation?
- Is he or she able to masturbate effectively? (If not, see below)
- Is the environment appropriate? i.e. privacy.

Some people with learning disabilities may need specific support in being able to masturbate. For example, intervention from a sexual therapist (Couple Counselling Scotland offer this service - see useful contacts in Appendix 3). It is essential that this be discussed with your line manager. Line managers should be consulted about any proposed training programme or intervention and permission and guidelines should be written down.

Workers are strictly forbidden to perform physical sexual relief or other sexual acts, with/for a service user. Any contravention of this instruction 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).



4.8

Same Sex Relationships

People with learning disabilities have the right to conduct a consenting sexual relationship with someone of the same gender.

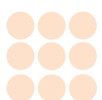
Workers need to be aware of their own values around same sex relationships on ethical, moral or religious grounds. Workers should not impose their own beliefs on people with learning disabilities and any discrimination must be challenged.

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 their sexuality. This could perhaps involve contacting agencies to meet other LGB people, or to access specific support or counselling (see Appendix 3).

The same might apply to people who are questioning their gender. People with learning difficulties are just as likely to be lesbian, gay, bisexual or transgendered as the general population.

Sexual health and relationship education programmes may provide an appropriate forum for fuller discussion of the issues.

These important issues are regularly addressed through the worker's training programme and workers' supervision.



4.9

Marriage, Living Together 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.

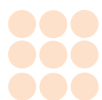
If people with learning disabilities express a desire to marry or live together, workers should be willing to discuss this option with them sensitively and seriously. Only if the couple agree, can workers involve parents and carers. However, the benefit of parental/carer support should be emphasised. 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 and relationships involving people with varying degrees of learning disability. However, as with other couples, there are examples of unsuccessful marriages, some of which may end in divorce. It is important that workers and/or parents 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 Couple Counselling 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.



4.10

Diverse Community Views

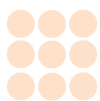
The Lothians benefit from a wide range of diverse communities with their own distinctive cultural and religious beliefs and practices. Increasingly, many people with learning disabilities, workers, and parents will come from these minority communities, some of which will have very clear views about the place of sexuality in people's lives. Workers and parents 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.



4.11

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 birth control methods, individuals should be supported through referral to the normal 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.

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.

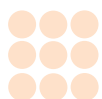
Where a person with a learning disability is unable to understand and take responsibility for contraception, involved parties, including carers, should meet to address issues around the apparent need for contraception and to establish programmes for future work in support of that person. It may be necessary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

Remember if a woman has not used contraception or her contraception has failed e.g. she has had a burst condom, she can access emergency contraception from a Family Planning Clinic, Caledonia Youth or her family doctor (see Appendix 3 for contact details). Emergency Contraception (2 tablets) should be taken within 72 hours of intercourse – the sooner the better.

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.

Leaflets on the 13 methods of contraception are available free from fpa (Scotland), and from family planning clinics (see useful contact details in Appendix 3).



4.12

Sterilisation

Sterilisation as a means of contraception is a medical intervention and is a radical procedure intended as an irreversible course of action. This can have major consequences for people with

learning disabilities. Therefore all other acceptable alternative methods of birth control must be considered first. Demands for sterilisation from parents or relatives must not override the well being of the individual and their right to choose.

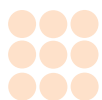
A person with learning disabilities who chooses sterilisation must have the opportunity to receive intensive counselling from a specialist medical advisor, to understand the emotional and permanent implications of sterilisation.

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 (see Appendix 1 to get further information).

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. 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 Family Planning and Well Women Services, or referral to gynaecology or urology. Vasectomy is a less complicated procedure and is also more effective than female sterilisation. There is a good fpa leaflet on sterilisation available.

(See Appendix 3)



4.13

Abortion

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

A woman 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 her choice. The well being of the woman must always come first and she has the right to choose. It is unlikely that a woman will be given a termination in Scotland in the later stages of pregnancy unless there is severe foetal abnormality or her life is at risk.

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

Parental or carer demands for a termination must not override the rights and well being of the woman 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.

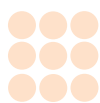
If an abortion is chosen, this must be carried out in a supportive atmosphere, with sufficient information available and on-going counselling if required.

When a woman 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. 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. (See Appendix 1).

It is safer for the woman if the abortion is performed at below twelve 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 Family Planning and Well Woman Services and via the general practitioner (family doctor). Leaflets about abortion are available free from the Lothian NHS Resource Library, from Family Planning Clinics and GPs (family doctors). See Appendix 3 for contact details.

Women 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 poor sex education or sexual health opportunities.



4.14

Parenthood

People with learning disabilities have a right to be parents and many of them have a desire to choose to become parents. Those who do should be given access to unbiased pre-parenting advice, if requested. (It is recognised that giving non-prejudicial advice around parenting can be difficult, and workers are encouraged to seek support from their supervisor). However, these rights do have to be balanced with the responsibilities of parenthood and the need for education on these responsibilities.

Counselling people with learning disabilities who wish to be parents involves the exploration of their expectations, for example, sometimes having children can be seen as "a passport to normality", or there may be unrealistic ideas concerning the responsibilities and restrictions children place on parents. It should be noted that people with learning disabilities can be good parents.

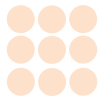
Many believe that people who have learning disabilities will, because of this, have children who will have learning disabilities. This is not always the case, and should not be assumed.

Addressing the issue of parenthood may be new for workers and anxiety may be understandably high. It is important however, that people with learning disabilities who wish to be parents, should not be expected to give guarantees on good parenthood in a way that is not expected of those who do not have learning disabilities.

Some of the areas that could be explored with the individual or couple who wish to be parents are:

- What is the expectation of the individual or couple about becoming parents?
- How much help would realistically be needed to help this couple cope with a child?
- Is this level of help likely to be available?
- What other support is available -
 - From the individual or couples friends or families?
 - From statutory services: Housing, Social Work, and National Health Service
 - From private and voluntary services?
- Is genetic counselling necessary? Are there risks to the baby?

The Children (Scotland) Act 1995 stresses that the welfare of any child will be paramount and generally will prevail over the interest of the parents, whether the parents have learning disabilities or not. However, it should be remembered that parents also have rights. The local authority has a duty to provide a range and level of services appropriate to children in need who are in its area and to promote their upbringing by their family.



4.15

Sexually Transmitted Infections

STI is the name used to cover Sexually Transmitted Infections including

- chlamydia
- genital herpes
- genital warts
- gonorrhoea
- pubic lice (crabs)*
- Hepatitis B*
- HIV and AIDS*
- NSU (non specific urethritis)
- syphilis

* *These infections can also be transmitted in other ways.*

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 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 need to be aware of existing agencies offering advice/support and treatment of STIs, such as GUM, Family Planning Services, Caledonia Youth or Primary Care. (See Appendix 3).

Workers should take an active role to encourage and promote the use of appropriate services. Part of a sex education programme could involve visits to GUM Clinics and well woman clinics, as well as others.

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:

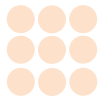
- itchiness around the genitals
- lower abdominal pain
- pain during sex
- blisters, sores or lumps, spots in or around the genitals
- unusual or smelly discharge from the penis or vagina
- pain when urinating (peeing)
- unusual or abnormal bleeding
- It is also important to know that some STIs may have 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^d.

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 Lothian NHS Board Resource Library, Family Planning Clinics, GPs (family doctors). (See Appendix 3 for details)

^d To get accurate information on safer sex and condom use contact Harm Reduction Team, or one of the organisations listed in Appendix 3.



4.16

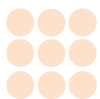
Other infections

Thrush, Cystitis and BV (Bacterial Vaginosis) are other infections that have some of the symptoms of STIs, but are not necessarily sexually transmitted. They are very common and easily treated. In women, because the anus (back passage) is so close to the vagina, it is easy for bacteria and yeasts, that usually live harmlessly elsewhere in the body, to get from the bowel into the vagina that can then cause these infections. Strange discharge and smell, itchiness, soreness when urinating (peeing) can be signs of these infections.

BV is easily diagnosed by a swab test and treated with antibiotics.

Thrush is easily treated with tablets (pessaries) inserted into the vagina and cream for the surrounding skin. Thrush is not sexually transmitted, although yeasts can pass to the skin of the penis during sex, causing an itch that only lasts for a day or two.

Cystitis is easily diagnosed either by the story alone, or by a simple urine test. Drinking more can soothe it. Bicarbonate of soda or cranberry juice alkalise the urine which helps to ease the symptoms and also soothe the bladder. Seek medical advice if in any doubt.



4.17

HIV and AIDS

As with other STIs, HIV and AIDS pose 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 AIDS 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

Basic information on HIV and AIDS can be found in leaflets held at Lothian NHS Board Health Promotion Library or from the Solas information centre. Other good sources of information can be provided by 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 3).

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.

These might include

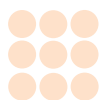
- support to access monitoring and treatment, and information on adherence to drug regimes
- provision of accessible information about HIV transmission and prevention

- 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.

Workers should familiarise themselves with local Information and Guidelines on HIV and AIDS particularly Training and Support and Guidelines on Hygiene and Infection Control (see Appendix 3 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.



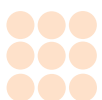
4.18

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 reduce risk of STIs as they act as a barrier to virus and bacteria. Safer sex practice 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
- which condoms are appropriate for anal sex, oral sex as well as vaginal sex - with information about the use of lubrication
- what to do if a condom bursts.



4.19

Consent

Consent is crucial in deciding whether a particular sexual relationship or act is abusive. What needs to be decided is:

- whether consent was **able** to be given, and
- whether it **was** given by the individual.

There are some individuals with a learning disability who would be considered as being unable to give consent and lack capacity (the ability to make informed choice). This is a complex decision and workers should seek guidance.

The Adults with Incapacity (Scotland) Act 2000 is now the most significant piece of legislation in the protection of vulnerable adults. It is concerned with incapable adults who are defined as being:

'incapable of acting, making decisions, communicating decisions, understanding decisions, by reason of mental disorder or physical disability'

These laws are written to protect people from 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 abusive. This is reflected in factors 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
- 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.

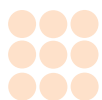
There are situations where people may be engaging in activities which other people view as morally wrong or not in the best interests of the individual. Some examples are same sex relationships, not using condoms, having multiple partners, or being in a violent relationship. The individual could be very 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 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 is, in their opinion, abusive they should take immediate action to intervene. (See Protecting Vulnerable Adults Policy⁶). The welfare and well-being of those in their care are of prime importance and not to act quickly would be to have neglected their duty of care.



5
Appendices



Appendix 1

Legal Framework^e

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 mentally disabled and perceived as being more vulnerable¹⁰.

General offences include rape, indecent assault, shameless indecency, breach of the peace, incest and sexual relationships with young people.

Special provisions are covered under sections 106 and 107 of the Mental Health Scotland Act 1984. This legislation is soon going to be replaced by the Mental Health (Care and Treatment) (Scotland) Act 2003 which comes into force in October 2004.

The main changes under the new Act are

- The sexual offences, which used to only protect women with learning disabilities from male abusers, are now gender neutral. Now, men and women can be abusers and victims under the law.
- The emphasis now is on capacity to consent, whereas before the rules were based on someone having a learning disability. So if someone is able to make decisions, they should be allowed to engage in sexual activity.
- The sentence for sexual offences under these sections, which used to be up to 2 years, has been increased to be the same for rape.
- It is now an offence to engage in any sexual activity with someone who cannot consent; previously only intercourse was illegal,

^e Information in this section was taken from ENABLE legal department, Legal Services Agency, and Scottish Association for Mental Health (contact details in Appendix 3)

- It is no longer an offence to 'encourage' a woman (for example through sex education, provision of contraception or allowing couples to share rooms) protected by Section 106 to have unlawful sexual intercourse.

It remains an offence for a worker to engage in sexual activity with someone in their care.

Adults with Incapacity (Scotland) Act 2000

The purpose of this act is not only to protect the individual but also to allow them as much autonomy in their life as possible. It is now the most significant piece of legislation in the protection of vulnerable adults. Listed below are the principles of practice found at www.scotland.gov.uk/about/JD/CL/00016360/home

Principles

The Act provides various methods of intervening (that is, taking decisions or action) on behalf of an adult. Interventions can cover property and financial affairs, or personal welfare matters, including healthcare. When deciding whether to intervene, you must always apply the following principles.

- Your intervention must be necessary and must benefit the adult.
- Your intervention must be the minimum necessary to achieve the purpose.
- You must take account of the adult's present and past wishes and feelings and you must try every possible means of communicating with the adult to find out what these are.
- You must take into account the views of the adult's nearest relative and primary carer, and of any other person with powers to intervene in the adult's affairs or personal welfare, or with an interest in the adult, so far as it is reasonable and practicable to do so.
- You must encourage the adult to use any skills he or she has.

You should also consider whether it would be possible to intervene without using the Act.

See Protecting Vulnerable Adults guidelines⁶ for further information.

Disclosure of abuse

Workers need to be aware of the Protecting Vulnerable Adults guidelines⁶ which give the legal framework regarding abuse, including sexual abuse.

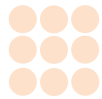
Homosexual activity

Section 13 of the Criminal Law (Consolidation) (Scotland) Act 1995 (as amended by the Sexual Offences (Amendment) Act 2000 and the Convention Rights (Compliance) (Scotland) Act 2001) regulates homosexual acts between men, not women, in Scotland.

Under the provisions of Section 13, homosexual acts are legal if

- the parties consent
- the parties are over 16, and
- the act does not take place in a public toilet

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



Appendix 2

Definitions

In keeping with the language used in 'The same as you?'¹⁰, the term 'learning disability' is used throughout this document. The group of people who wrote 'The same as you?' consulted widely on the relevance and purpose of giving a definition of learning disability. In the end, the following definition was given¹¹,

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

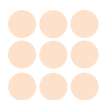
- understand information:
- learn skills; and
- cope independently.

The term learning disabilities is now used throughout the UK, particularly in health and social care settings¹². We are aware there are some mixed views about this, and consistent with 'The same as you?', can review the use of this term at some point in the future.

The definition of 'incapacity' outlined in the Adults with Incapacity (Scotland) Act 2000 is that someone is 'incapable' 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.

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 'situation specific' so a person with learning disabilities may not have any degree of incapacity.



Appendix 3

Useful contact details



The Ann Craft Trust

Centre for Social Work, University Park, Nottingham NG7 2RD

Tel: 0115 951 5400

Email: communityaction@nottingham.ac.uk

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



AVERT

4 Brighton Road, Horsham, West Sussex RH13 5BA England

Tel: 01403 210202

Website: www.avert.org

AVERT is an international HIV and AIDS charity based in the UK, with the aim of AVERTing HIV and AIDS worldwide.



Benefits - The Department of Social Security Benefits

Helpline telephone: 0800-882200

Can advise about other benefits to which people may be entitled.



BILD (British Institute of Learning Disabilities)

Campion House, Kidderminster DY10 1JL

Tel: 01562 723010

Website: www.bild.org.uk

BILD is the British Institute of Learning Disabilities, a not for profit organisation with charitable status, which 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.



Caledonia Youth

5 Castle Terrace, Edinburgh, EH1 2DP

Tel: 0131 229 3596

Free and confidential sex advice and contraception for young people up to the age of 25.

**Care Commision****Stuart House, Eskmills, Musselburgh EH21 7PB****Tel: 0131 653 4100 or lo-call 0845 60 30 890****Fax: 0131 653 4149****Email: (through their website) www.carecommission.com****c:card****Tel: 0800 224488 (Free)****Website: www.ccard.org.uk**

The c:card network provides free condoms at over 60 c:card points across Lothian.

**Citizens Advice Scotland****Spectrum House, 2 Powderhall Road, Edinburgh EH7 4GB****Tel: 0131 550 1000****Fax: 0131 550 1001****Email: info@cas.org.uk**

An umbrella body for all Citizens Advice Bureaux (CAB) in Scotland, and can give information on the nearest CAB.

**Community Nursing Service for People with Learning Disability****Tel: Janette Mathieson on 0131 537 4219****or Alistair Littlejohn on 0131 446 6808**


Community Learning Disability nurses can offer support to access mainstream sexual health services. They can also offer sexual health and relationship education on a one to one or group basis.

**Consent****Woodside Road, Abbots Langley, Hertfordshire WD5 0HT****Tel: 01923 670796**


Consultancy, training, education and supervision on a broad range of sexuality issues for people with learning disabilities.

 **Couple Counselling Scotland**
18 York Place, Edinburgh EH1 3EP,
Tel: 0131 558 9669

Couple Counselling Scotland exists to promote, develop and co-ordinate a confidential counselling service for people in marriage and other intimate personal relationships.

 **Edinburgh Women's Rape and Sexual Abuse Centre**
Outreach Project, PO Box 120, Brunswick Road,
Edinburgh EH7 5XX
Tel: 0131 556 9437

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

 **Enable**
6th Floor, 7 Buchanan Street, Glasgow G1 3HL
Tel: 0141 226 4541

'Educate and protect from sexual abuse' is a one year project to train people with learning disabilities to support the delivery of training on sexuality and relationships for adults with learning disabilities.

 **FAIR (Family Advice Information Resource)**
25-27 West Nicolson Street, Edinburgh EH8 9DB
Tel: 0131 662 1962
Email: fair@fairadvice.org.uk

This is a local service for people with learning disabilities in Edinburgh. They give advice and information for people with learning difficulties, their carers and professionals. They give information on money & benefits, health, travel, leisure, housing, education, work, and holidays.

 **fpa (Family Planning Association) Scotland**
Unit 10, Firhill Business Centre, 76 Firhill Road,
Glasgow G20 7BA
Tel: 0141 576 5088 (helpline)
Website: www.fpa.org.uk

National helpline for all sexual health information including advice on conception, contraception, abortion and STIs.

 **Family Planning and Well Woman Services**
(Central Clinic) 18 Dean Terrace, Edinburgh EH14 1NL
Tel: 0131 332 7941

There are also family planning clinics in the following locations: Sighthill, Craigroyston, Musselburgh, Craigmillar, Linlithgow, Bathgate, Whitburn, Craigshill, Howden, Dalkeith. The clinics provide a full range of contraceptive and sexual health services including screening for sexually transmitted infections, cervical screening, pregnancy testing, emergency contraception, pregnancy counselling and referral for termination of pregnancy. For an appointment at any of these clinics call the central phone number of 0131 332 7941.

 **Gay Men's Health**
10a Union Street, Edinburgh EH1 3LU
Tel: 0131 558 9444
Email: mail@gmh.org.uk
Website: <http://www.gmh.org.uk>

Gay Men's Health is a charity working towards improving the health of gay men. This includes mental health, HIV prevention and care, as well as more general health matters such as alcohol use and diet.

 **GPs (Family Doctors)**

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

 **GUM (Genito Urinary Medicine) Clinic**
Royal Infirmary, Level 1, Lauriston Building, Lauriston Place
Edinburgh EH3 9YW
Tel: 0131 536 2103(men)
0131 536 2104 (women)

Counselling, information and testing for all sexually transmitted infections. Also provides emergency contraception, and is a c:card point.

 **Healthy Respect**

**Lothian NHS Board, Deaconess House, 148 Pleasance,
Edinburgh EH8 9RS**

Tel: 0131 536 9454

Email: healthy.respect@lhb.scot.nhs.uk

Website: www.healthy-respect.com

A Lothian wide sexual health project aimed at improving the sexual health of young people. Some specific work is targeting those with special needs and learning disabilities.

 **Legal Services Agency**

Tel: 0131 228 9993

Website: www.lsa.org.uk

 **Lesbian Line**

Tel: 0131 557 0751 (7.30 – 10pm Mondays and Thursdays)

Information, education and support for lesbians.

 **LGBT Centre for Health and Wellbeing**

9 Howe Street, Edinburgh EH3 6TE

Tel: 0131 523 1100

Email: admin@lgbthealth.org.uk

Website: www.lgbthealth.org.uk

Promoting Lesbian, gay, bisexual and transgender health in South-East Scotland. The 'Hub' is a first point of contact for LGBT community members with the Centre for Health and Wellbeing. Access to health information, internet access, community activities.

 **LGBT Youth Scotland**

John Cotton Centre, 10 Sunnyside, Edinburgh EH7 5RA





Tel: 0131 622 2266

Youthline: 0845 113 0005 LGBT, Tuesday 7.30pm - 9pm

Email: info@lgbtyouth.org.uk

Website: www.lgbtyouth.org.uk

LGBT Youth Scotland (formerly Stonewall Youth) provides services and opportunities for LGBT young people (under 26) which empower them to make positive choices about their lives. They offer advice, safer sex supplies, volunteering opportunities and housing support and run a range of groups for young LGBT people.

-  **Lothian Lesbian and Gay Switchboard**
Tel: 0131 556 4049 (7.30 – 10 every evening)
Advice on sexual health and HIV/Aids and all matters relating to the gay and lesbian community.
-  **Lothian NHS Board**
Deaconess House, 148 Pleasance, Edinburgh EH8 9RS
Tel: 0131 536 9000
Has a Health Promotion library where people can access information and resources on all aspects of health. Includes section on sexual health, and on learning disabilities. Lothian NHS Health Promotion department produces its own training programme including sexual health training. Contact 0131 536 9436 to request a copy.
-  **NHS Health Scotland**
Health Education Board for Scotland, Woodburn House, Canaan Lane, EDINBURGH EH10 4SG
Tel: 0131 536 5500
Textphone: 0131 536 5503
Fax: 0131 536 5501
Website: hebsweb@hebs.scot.nhs.uk
NHS Scotland offers training on sexual health. To see the current programme of courses and conferences click on:
**[http://www.hebs.scot.nhs.uk/services/pubs/pdf/ProgConfere
nce.pdf](http://www.hebs.scot.nhs.uk/services/pubs/pdf/ProgConfere
nce.pdf)**
-  **Pathway**
89-95 Fountainbridge, Edinburgh EH3 9PU
Tel: 0131 622 7083
Supports young women who have been sexually abused.



PHACE Scotland

49 Bath Street, Glasgow G2 2DL

Tel: 0141 332 3838

Fax: 0141 332 3755

Email: contact@phacescotland.org

Website: <http://www.phacescotland.org>

PHACE Scotland aims to promote health and wellbeing with regard to HIV and AIDS, other blood borne viruses and sexual health.



People First Scotland

34b Haddington Place, Edinburgh EH7 4AG

Tel: 0131 478 7707

Email: p1stscot@aol.com

Independent self-advocacy for people with learning difficulties.



Respond

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

Tel: 020 7383 0700

Helpline: 0808 8080700

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



Scottish Association for Mental Health

**Information Centre, Cumbrae House, 15 Carlton Court,
Glasgow G5 9JP**

Tel. 0141 568 7000

Fax. 0141 568 7001

Email. info@samh.org.uk



Scottish Consortium for Learning Disability

**The Adelphi Centre, Room 16, 12 Commercial Road, Glasgow
G5 0PQ**

Tel: 0141 418 5420

Fax: 0141 429 1142

Email: administrator@sclld.co.uk

SCLD is a charity and an independent company made up of 13 Partner Organisations who have joined together with funding from the Scottish Executive to become the Scottish Consortium for Learning Disability. They offer training course entitled Relationships and Sexuality, which is a module accredited at SVQ level 3.

 **Sexual Health National Learning Network**

The Scotland-wide Sexual Health Learning Network will help by drawing on skills base, knowledge and experience; sharing various approaches and our experiences of them; and developing ways of effectively sharing information.

To join the network, contact

**Shirley Fraser, Sexual Health Learning Network Co-ordinator
Public Health Institute of Scotland, Clifton House, Clifton Place,
Glasgow G3 7LS**

Tel: 0141 300 1047

Fax No: 0141 300 1020

Email: shirley.fraser@phis.csa.scot.nhs.uk

 **Terrence Higgins Trust**

52-54 Grays Inn Road, London WC1X 8JU

Tel: 020 7831 0330

Fax : 020 7242 0121

Email : info@ttht.org.uk

UK's leading HIV/AIDS Charity.

 **Waverley Care SOLAS**

2/4 Abbeymount, Edinburgh EH8 8EJ.

Phone: 0131 661 0982.

Email:solas@waverleycare.org.

Website: <http://www.waverleycare.org>

Waverley Care SOLAS Information Centre offers support services, information and an informal meeting place for people living with HIV. They encourage people to make positive choices about healthy living by offering a range of practical and emotional support services.

 **West Lothian Drug and Alcohol Service**

43 Adelaide Street, Craigshill, Livingston,

West Lothian EH54 5HQ

Tel: 01506 430225

WLDAS has an extensive library on sexual health, HIV and other Blood Borne Viruses. Includes several resources on working with people with learning disabilities. Provides training and information.



Appendix 4

Resource List



Books and videos available on sexual health

Batteries Not Included.

Publisher Name: fpa

Author: Paul Hart and Susan Douglas-Scott

A sexuality resource pack for those working with people with complex communication and support needs. This resource is forthcoming and will be published early 2004.

Be Breast Aware

Publisher Name: Surrey Oaklands NHS Mental Health and Learning Disability Trust

A teaching pack for women with learning disabilities and those who work with them.

Breaking In.... Breaking Out

Publisher: Working with Men and the B Team

Social and sex education for men with learning difficulties.

Cathy has Thrush

Publisher Name: Women's Health and The Elfrida Society.

Picture book about preventing thrush and getting it treated.

Consenting Adults? – Sexual Abuse and Adults with Learning Disabilities – A Framework for Practice Guidelines.

Publisher Name: Enable

ISBN: 1874030403X

Guidelines for dealing with the sexual abuse of adults with learning disabilities.

Dealing with Relationships

Publisher Name: Wayland Publishers Ltd

ISBN: 0705209933

Information and advice for young people.

Depo Provera

Publisher Name: Change North

Information about Depo Provera, the contraceptive injection.

Falling in love

Author: Sheila Hollins

Publisher Name: Book Sales, Royal College of Psychiatrists

ISBN: 1901242323

A booklet in the stories without words series. Tells a love story tracing the ups and downs of the relationship until Janet and Mike decide to make a commitment. It only uses pictures to describe the story.

Helping People with a Learning Disability Explore Relationships

Publisher Name: Jessica Kingsley

ISBN: 1853026883

Designed for adults with a learning disability to read alone or with a carer.

Holding on; Letting Go

Author: Drury, Hutchinson and Wright

Publisher Name: Souvenir Press

A book for parents and carers on how to do sex education.

Hug Me Touch Me

Author: Sheila Hollins

Publisher Name: Book Sales, Royal College of Psychiatrists

ISBN: 1874439052

A booklet in the stories without words series. Book about hugging and touching – when to do it and when not to do it.

Hysterectomy – having the operation

Publisher Name: Women’s Health and The Elfrida Society.

All about having a hysterectomy.

It’s only natural

Publisher Name: Bradford Health Authority

Video looking at issues of sexuality and sexual health. Has a booklet to go with it.

Jenny Speaks Out

Author: Sheila Hollins

Publisher Name: Book Sales, Royal College of Psychiatrists

ISBN: 1874439001

A booklet in the stories without words series. A book designed to help a person with learning disabilities to open up about their experience of sexual abuse. This is done through a story about Jenny moving into a new home.

Keeping Healthy "Down Below"

Author: Sheila Hollins, Jackie Downer

Publisher Name: Book Sales, Royal College of Psychiatrists

ISBN: 1901242544

A booklet in the stories without words series. This is designed to support women who are asked to have a smear test.

Looking after my breasts

Author: Sheila Hollins, Wendy Perez

Publisher Name: Book Sales, Royal College of Psychiatrists

ISBN: 1901242536

A booklet in the ‘stories without words’ series.

Meeting The Personal And Sexual Relationship Needs Of Children And Young Adults With A Learning Disability

Publisher Name: Barnardos

Guidelines for staff on the subject of personal and sexual relationships.

No Means No

Author: Walsall Women's Group

Publisher Name: Walsall Women's Group

Video on safety for women with learning disabilities, and information pack to accompany video on safety for women with learning disabilities.

No more abuse

Author: VOICE UK

Publisher Name: VOICE UK

A book for people with learning disabilities. It is to help them look after themselves and make sure they are safe. It is free to people with learning disabilities.

Period Problems - What can you do?

Author: Women's Health

Publisher Name: Women's Health

Information about what to do about period problems.

Planning a Baby

Author: Change North

Publisher Name: Change North

Information for women hoping to become pregnant..

Practice Issues In Sexuality And Learning Disabilities

Author: Ann Craft (Ed.)

Publisher Name: Routledge **ISBN: 0415057353**

Down to earth and practical guide for people who work with people with learning disabilities.

Pregnancy and Childbirth

Publisher Name: BILD

ISBN: 1902519884

What will happen, what to do, and what not to do during pregnancy and childbirth.

Release Me

Author: Frances Lea

Publisher Name: Frances Lea

Drama. Describes how a woman with learning disabilities decides upon whether to have sex with her boyfriend. The woman lives with 3 other people and they help her decide and also tell her mother about her decision.

Sex

Publisher Name: BILD Publications

Health information for people with learning disabilities.

Sex and Staff Training – A training manual for staff working with people with learning difficulties

Author: Michelle McCarthy and David Thompson

Publisher Name: Pavillion

ISBN: 1871080347

The manual is designed to raise staff's awareness of the sexuality of people with learning difficulties, deal with the implications that this may involve and encourage people with or without training experience to attempt to run sex education work themselves.

Sex Education For Visually Impaired Children With Additional Disabilities

Author: Issy Cole-Hamilton

Publisher Name: Royal National Institute For The Blind

ISBN: 1858780918

Developing school policies and programmes.

Sexual abuse of adults with learning difficulties

Author: Hilary Brown, Vicky Turk & June Stein

Publisher Name: Joseph Rowntree Foundation

Social Care Research Findings No. 46 January 1994.

Sexual Health Education & Children & Young People With Learning Disabilities

Author: Karen Adcock & Gill Stanley

Publisher Name: BILD Publications ISBN: 1873791380

Pack for professionals, parents & carers.

Sexual Knowledge and Education

Author: BILD

Publisher Name: BILD

BILD collection of papers.

Sexual Relationships

Author: BBC

Publisher Name: BBC recorded

Heart of the Matter Programme about problems of sexual relationships for people with learning disabilities.

Sexuality

Author:

Publisher Name: BIMH

Special issue of British Institute of Learning Disabilities. Covers a wide range of topics on the subject of sexuality and relationships.

Sexuality & Sexual Rights Of People With Learning Disabilities (The)

Author: Paul Cambridge

Publisher Name: BILD Publications ISBN: 1873791739

Booklet for staff & carers.

Sexuality And Learning Disability

Author: Jennie Holmes

Publisher Name: Contact A Family

Report on a conference.

Sexuality and Learning Disability: A resource for staff

Author: Claire Fanstone and Zarine Katrak

Publisher Name: fpa ISBN: 1 899194 58 4

Describes issues and concerns of staff, and illustrates constructive ways of working.

Sexuality And Young People With Learning Difficulties

Author: Karen Aram

A booklet for carers and parents.

Stop – No More Abuse

Publisher Name: VOICE UK

A book for people with learning disabilities. It is to help them look after themselves and make sure they are safe. It is free to people with learning disabilities.

Susan's Growing Up

Author: Hollins, S. Sinason, V. Illustrated: Brighton, C

Publisher Name: Gaskell / St George's Hospital Medical School

Picture book about a girl going through puberty.

Talking together about growing up.

Author: Lorna Scott, Lesley Kerr-Edwards

Publisher Name: Family Planning Association (fpa)

ISBN: 1 899194 96 7

A workbook for parents of children with learning disabilities.

Talking Together Talking Together.....About Growing Up: A Workbook for Parents of Children with Learning Disabilities

Authors: Lorna Scott, Lesley Kerr-Edwards

Publishers: Family Planning Association

Your Rights About Sex**Author: Michelle McCarthy****Publisher Name: BILD Publications****ISBN: 1873791526**

Booklet for people with learning disabilities.

Target focusing on the sexual and emotional needs of people with learning disabilities.**Author: Lorraine Burton, Izzy Valenti, Sally Warren****Publisher Name: The Family Planning Association****ISBN: 1 899194 17 7****The Big Sex Show: A Lawnmowers booklet about sex, meeting people, and condoms****Publisher Name: The Lawnmowers**

A guide to safe sex. It is a pack with a video and booklet. Made by people with learning disabilities for people with learning disabilities.

Understanding Sex**Author: Margaret Doyle & David Lambert****Publisher Name: HarperCollins Publishers****ISBN: 0004708504**

Top tips for tempestuous times! (Or, everything you ever wanted to know about sex but were too shy to ask).

What About Us? Sex Education For Children With Disabilities**Author: Ann Craft And David Stewart****Publisher Name: The Home and School Council****ISBN: 0901181706**

A book written for parents. Ann Craft has written extensively on the subject of sexuality and individuals with learning disabilities.



Useful Websites

www.bild.org.uk

Website for British Institute of Learning Disabilities.

www.ccard.org.uk

Website for the Harm Reduction Team's c:card scheme, to access free condoms.

www.eastlothian.gov.uk/

Website for East Lothian Council.

www.edinburgh.gov.uk/

Website for City of Edinburgh Council.

www.healthy-respect.com

Website for young people, parents and professionals on sexual health covering Lothian.

www.hebs.scot.nhs.uk

Website for NHS Health Scotland, where training for sexual health is offered.

www.lgbthealth.org.uk

Website for the Lesbian, Gay, Bisexual and Transgender Centre for Health and Wellbeing.

www.lothianhealth.scot.nhs.uk/

Website for NHS Lothian, where training on sexual health is offered.

www.me-and-us.com

A website which lists useful resources which can be bought or downloaded.

www.midlothian.gov.uk/

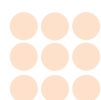
Website for Midlothian Council.

www.ruthinking.co.uk

Website for young people on sexual health.

www.westlothian.gov.uk/

Website for West Lothian Council.



Appendix 5

References

Ref no.	References
1	UN Convention on the Rights of the Child. Information is available from Scottish Executive's 'Guide for Young People' and from the CRC Summary – http://www.cwd.co.uk/scf/summary.htm)
2	Harm Reduction definition can be found from the Harm Reduction Coalition – http://www.harmreduction.org/ .
3	Craft, A (1987) Mental Handicap and Sexuality: issues and perspectives , Tunbridge Wells, Costello.
4	Protecting Vulnerable Adults: ensuring rights and preventing abuse , Interagency guidelines for people working in health and social care settings (Jan 2003) written jointly by East, Mid, West Lothian Councils, City of Edinburgh Council, NHS Lothian, NHS Borders, Lothian and Borders Police, Scottish Borders Council, Page 8.
5	Harper G, Hopkinson P and McAfee J (2002), Protective behaviours: a useful approach in working with people with learning disabilities , British Journal of Learning Disabilities Vol 30 No 4 December 2002.
6	Protecting Vulnerable Adults: ensuring rights and preventing abuse , Interagency guidelines for people working in health and social care settings (Jan 2003) written jointly by East, Mid, West Lothian Councils, City of Edinburgh Council, NHS Lothian, NHS Borders, Lothian and Borders Police, Scottish Borders Council.
7	National Care Standards , Care Commission, (2002).
8	Code of Practice for Social Service Workers and Code of Practice for employers of Social Service Workers , Scottish Social Services Council (September 2002).
9	McKay, Colin, (1996), Sex, Laws and Red Tape: Scots law, personal relationships and people with learning difficulties , ENABLE
10	The Same As You?: A review of services for people with learning disabilities , (May 2000), Scottish Executive Publications.
11	The Same As You?: A review of services for people with learning disabilities , (May 2000), Scottish Executive Publications, page 3.
12	The Same As You?: A review of services for people with learning disabilities , (May 2000), Scottish Executive Publications, page 101.

Appendix 6

Acknowledgements

We would like to thank the following organisations for their contribution, comments and advice during the course of developing this policy and guidelines.

- City of Edinburgh Council
- East Lothian Council
- FAIR (Family Advice and Resource Centre)
- Lothian NHS Board
- Lothian Primary Care Trust
- Lothian University Hospital NHS Trust
- Midlothian Council
- West Lothian Council
- West Lothian Healthcare NHS Trust

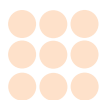
Thanks are also extended to Gerrie Douglas-Scott of 'Difference Solutions' for proofreading and for guidance on the accessibility of the document.

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



6
Training Guide



6.1

Introduction

This training programme is intended to support the implementation of Making Choices Keeping Safe. It aims to give workers and their managers an opportunity to become familiar with the policy and to explore the issues raised as a result of it. Participants in the training will be asked to consider their own attitudes and beliefs and how these compare with the value base underpinning the policy. Participants will also be asked to refer to case studies to explore the issues raised within a safe and supportive setting.

There are various ways this training programme could be delivered. We would recommend that the best way to deliver the training would be in a multi-disciplinary way, or even in teams. The training on the policy could be done as a self study. Workers would be given time to go through it, and then given time to discuss with their manager. We recommend that some training for trainers is given to managers – the local training development departments could offer further help.

The training programme will not provide the participant with knowledge of how to deliver all aspects of sexual health support. Some workers and managers may wish to develop their skills and knowledge in the area of sexual health further, and again, local training development organisations or some of the agencies in the contacts section could be of use. A useful resource for further training in this subject area is ‘Sex and Staff Training’ by McCarthy and Thompson which is listed in Appendix 4.

Since all the partners have signed up to the policy, workers and managers can be reassured that their employer, be that a local authority or the NHS, supports them in implementing the policy. It is also worth remembering that the National Standards⁷, which are mandatory and policy, include the area of sexual health.



6.2

Self study instructions

1. The manager should detach the 'Answers to Handout 1' before giving Handout 1 and the policy to the worker.
2. Before reading the policy, the worker should give their answers to the questions in Handout 1. The worker may add in any additional and relevant questions that occur to them.
3. The worker should then read through the policy and guidelines and amend their answers, if need be.
4. The manager should then give the worker 'Handout 2 – case studies' and ask the worker to work through the relevant case studies, answering the questions relating to each case study.

Topics covered in the case studies are as follows:

- Case Study 1 includes accessing services and sex education
- 2 includes non-consensual sex
- 3 includes same sex relationships
- 4 includes masturbation and
- 5 includes parental involvement.

Managers may choose case studies which are appropriate to the contexts the workers are in.

5. The manager and the worker should then spend time going through the answers to Handout 1 (plus any additional questions that the worker may have added). The manager should share the suggested answers with the worker.
6. The worker should then share their response to Handout 2, and discuss with the manager.
7. The training session should end with the worker and manager feeding back what they have gained from the session, identifying any training or resource need they may have.



6.3

Team or group study instructions

1. The facilitator (who could be the manager or one of the workers) should read through 'Useful tips on groupwork' found at the end of this section.
2. A programme for team training could be as follows, with suggested timings:

Programme

Introductions

What people can expect from the training; warm-up exercise or icebreaker^f. (10 minutes)

Handout 1

Each worker is given Handout 1. On their own they work through the questions, before referring to the policy and adding in their own questions. Then, using the policy and guidelines, they may wish to amend their answers. This could take up to 30 minutes. The facilitator then brings the whole group together to compare answers and the facilitator clarifies the answers. (1 hour)

Handout 2

Split the team into groups of 3 – 4 people. Each group get a case study to read and discuss by answering questions. Give each group 10 – 15 minutes to discuss amongst themselves and answer the questions. Then come back together as a team and discuss. (40 minutes)

Topics covered in the case studies are as follows:

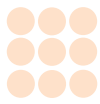
- Case Study 1 includes accessing services and sex education
- 2 includes non-consensual sex
- 3 includes same sex relationships
- 4 includes masturbation and
- 5 includes parental involvement.

Managers may choose case studies which are appropriate to the contexts the workers are in.

Feedback, questions and future needs

Group could each feedback what they have gained from the session and identify any needs they now recognise (training or other needs). (10 minutes)

^f Pathways to Sexual Health, Lothian Health, 1996 has a selection of icebreakers that could be used. This is available from Deaconess Resource Library.



6.4

Answers to questions

(for use by managers or facilitators)

- 1 Should workers give information and education on same sex relationships to adults with learning disabilities?

Answer

YES. Section 3.1 states that 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. In practice this means that workers should ensure a range of opportunities, including providing information on different means of sexual expression, for example same sex relationships.

2. Name an organisation and find the contact details that can give support and advice to people on lesbian, gay, bisexual or transgender issues.

Answer

LGBT Youth; Lothian Lesbian and Gay switchboard; LGBT Centre for Health and Wellbeing. (Appendix 3)

3. If two people in my care (of the same sex) seem to be starting a relationship what should I do?

Answer

As long as there are not concerns over consent (which you would check by looking for evidence of mutuality, section 4.19), then you would offer all the support the people would need to establish a relationship. This could include reminders of sexual health and relationships education; arrangements for privacy etc (see 4.2 Relationships).

4. What should I do if my personal views are at odds with the policy?

Answer

You are entitled to uphold your own beliefs. However, all workers have to uphold equal opportunities in their work, and need to be careful not to impose their own beliefs on to people with learning disabilities.

5. Name two places you can get specially written sexual health care information for people with learning disabilities.

Answer

Any two from: FAIR, Caledonia Youth, Family Planning and Well Woman Services, Lothian NHS Board resource library.

6. Where is the best place for someone with learning disabilities to get legal advice?

Answer

Your local solicitor; ENABLE'S solicitor; BILD

7. Where would a person with learning disabilities get free condoms?

Answer

From the c:card scheme – Harm Reduction Team would tell you the nearest place to get one; Family Planning and Well Women's Centre; or ask at your health centre.

8. Why would someone go to a GUM (Genito Urinary Medicine) clinic?

Answer

Anyone who needs counselling, information and testing for all sexually transmitted infections. Someone who needs free condoms through c:card. Someone who needs emergency contraception.

9. Where would you contact the community nursing services in Lothian for people with learning disabilities?

Answer

Contact details are in Section 5, Appendix 3.
Community Nursing Service for People with Learning Disability
Tel: Janette Mathieson on 0131 537 4219 or
Alistair Littlejohn on 446 6808

10. What is the most significant piece of legislation in the protection of vulnerable adults?

Answer

The Adults with Incapacity (Scotland) Act 2000

11. List three factors that provide good evidence of mutual consent and which suggest that a relationship is not abusive?

Answer

Three of the following a) Both parties seeking each other out b) spending spare time together c) shared resources d) shared leisure activity e) restriction of activities with other potential partners.

12. List three factors that might make an individual's consent to sex invalid

Answer

Three of the following a) If a person does not really understand what is being asked b) If a person does not know they have the right to refuse sex c) If a person does not know how to refuse sex d) If a person is afraid to refuse sex e) If a person does not know that sex is not meant to be painful or uncomfortable f) If a person does not know that he or she is being exploited when a reward or incentive or payment for sex is used g) If a person does not know that some relationships are illegal, such as those within families, or between workers and clients.

13. Is someone with a learning disability legally able to engage in sexual activity?

Answer

In the Mental Health (Care and Treatment) (Scotland) Act 2003, the emphasis is on capacity to consent, whereas in the past the rules were based on someone having a learning disability. So if someone is able to make decisions they are allowed to engage in sexual activity.

14. When are homosexual acts legal?

- a) Both parties consent
- b) Both parties are over 16
- c) The act does not take place in a public toilet
- d) All of the above

Answer

d) all of the above. If a person is lesbian, gay or bisexual, they are equally entitled to get support to meet friends and prospective partners as heterosexual or 'straight' people (section 3.1 and appendix 1).

15. Is it safer for a woman to have an abortion before she is over 12 weeks pregnant?

Answer

Yes. That is why it is important that if the woman suspects that she is pregnant, she should have access to pregnancy testing, counselling and possible referral for termination of pregnancy if she decides not to continue with the pregnancy. (section 4.13)

16. Which services should a woman seek help from if she suspects she is pregnant?

Answer

Either from her GP (family doctor), Family Planning and Well Women Services or Caledonia Youth (if she is under the age of 25 years).

17. If a woman or man had caught a sexually transmitted infection from their partner, would they have symptoms?

Answer

Not necessarily. Often the most common sexually transmitted infections have no symptoms.

18. If a man or woman were to get symptoms of an STI, describe some of the symptoms they might have.

Answer

Itchiness around the genitals; lower abdominal pain; blisters, sores, lumps spots in or around the genitals; unusual or smelly discharge from the penis or vagina; unusual or abnormal bleeding. (section 4.15)

19. Can you describe emergency contraception and where a woman would get it from?

Answer

Sometimes confusingly known as the 'morning after pill', these two pills are taken together up to 72 hours after intercourse where either contraception has not been used or the contraception has failed e.g. burst condom. However, the sooner it is taken the better. It is available from GP (family doctor), Family Planning Clinics, Caledonia Youth or the Genito-Urinary Medicine clinic. (Section 4.11)

20. Who are the best people to give intimate care?

Answer

People with learning disabilities should be allowed to choose the workers that they want to provide intimate care. Where it is difficult for people to make choices, then it should be offered by workers that the person knows and trusts. (See Section 4.3)

21. Is it appropriate for workers to offer intimate care in someone's living room?

Answer

NO. Intimate care should only be undertaken in private.

22. What should workers think about and do before going into a person's bedroom?

Answer

Workers should ask the person's permission before going into their bedroom. If it is difficult for the person with learning disabilities to make choices, the worker should only go into the person's bedroom for a very good cause. (see 4.6)

23. In a residential care home, should people with learning disabilities have the right to entertain their boyfriend/girlfriend in their own room?

Answer

YES. Workers should enable people to have private time and space with their chosen partner, including the means to lock their bedroom door.

24. If you suspect that a person with a learning disability is being abused, what should you do?

Answer

Everyone has the right to engage in relationships that are not abusive. If there is a suspicion that abuse is present, then the worker should report this to their line manager. The policy document outlining what should happen, when abuse is suspected, is the "Policy on Protecting Vulnerable Adults: ensuring rights and preventing abuse". (See 4.2 and Appendix 6)

25.Is masturbation acceptable behaviour for people with learning disabilities?

Answer

YES for both men and women. (see 4.7)

26.When would/should you be concerned about people with learning disabilities masturbating?

Answer

If masturbation is taking place very frequently or in inappropriate places then the worker should check out other issues (see 4.7)

27.Is it acceptable for workers to give physical assistance to someone who has physical difficulties masturbating?

Answer

NO. This would be a disciplinary matter. (see 4.7)

28.Where can adults with learning disability get support in being able to masturbate?

Answer

Couple Counselling Scotland offer a sexual therapy service. (see Useful Contacts, Section 5, Appendix 3)



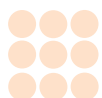
6.5

Notes for managers / facilitators on Handout 2⁹

Here are some suggested general key points and questions, for all case studies, to raise during discussion.

- Responsibility is shared between the person with learning disabilities, the worker, the service (including managers and administrators up to government level, who may ultimately dictate policy/law and fund the service), and any sexual partners
- How much responsibility does the person with learning disabilities have? This could range from none to total responsibility for the consequences of any sexual behaviour.
- Who decided on the level of responsibility of the person with learning disabilities?
- Should people with learning disabilities only gain responsibility for their sexual behaviour once they have demonstrated they could cope with this responsibility?

⁹ These points are taken from Sex and Staff Training, McCarthy and Thompson, page 44.



6.6

Handout 1

1. Should workers give information and education on same sex relationships to adults with learning disabilities?
2. Name an organisation and find the contact details that can give support and advice to people on lesbian, gay, bisexual or transgender issues.
3. If two people in my care (of the same sex) seem to be starting a relationship, what should I do?
4. What should I do if my personal views are at odds with the policy?
5. Name two places you can get specially written sexual health care information from for people with learning disabilities.
6. Where is the best place for someone with learning disabilities to get legal advice?
7. Where would a person with learning disabilities get free condoms?
8. Why would someone go to a GUM (Genito Urinary Medicine) clinic?
9. Where would you contact the community nursing services in Lothian for people with learning disabilities?
10. What is the most significant piece of legislation in the protection of vulnerable adults?
11. List three factors that provide good evidence of mutual consent and which suggest that a relationship is not abusive
12. List three factors that might make an individual's consent to sex invalid
13. Is someone with a learning disability legally able to engage in sexual activity?
14. When are homosexual acts legal?
 - a) Both parties consent
 - b) Both parties are over 16
 - c) The act does not take place in a public toilet
 - d) All of the above

15. Is it safer for a woman to have an abortion before she is over 12 weeks pregnant?
16. Which services should a woman seek help from if she suspects she is pregnant?
17. If a woman or man had caught a sexually transmitted infection from their partner, would they have symptoms?
18. If a man or woman were to get symptoms of an STI, describe some of the symptoms they might have.
19. Can you describe emergency contraception and where a woman would get it from?
20. Who are the best people to give intimate care?
21. Is it appropriate for workers to offer intimate care in someone's living room?
22. What should workers think about and do before going into a person's bedroom?
23. In a residential care home, should people with learning disabilities have the right to entertain their boyfriend/girlfriend in their own room?
24. If you suspect that a person with a learning disability is being abused, what should you do?
25. Is masturbation acceptable behaviour for people with learning disabilities?
26. When would/should you be concerned about people with learning disabilities masturbating?
27. Is it acceptable for workers to give physical assistance to someone who has physical difficulties masturbating?
28. Where can adults with learning disability get support in being able to masturbate?



6.7

Handout 2 - Case Studies



Case Study 1

Sarah (young woman with learning disabilities) confides in her support worker about the difficulties she is having with her boyfriend. Sarah and her boyfriend (young man with learning disabilities) want to have sex but they are unsure about "safer sex". The worker advises them of the different organisations that have up to date information in user friendly format that would provide them with some knowledge of "safe sex". The worker also advises them that these organisations can provide support and help in talking over the issues.

Questions:

What responsibility does the worker have at this stage?

What responsibility does the person with learning disabilities have?

Who else has responsibilities and what are they?



Case Study 2

A worker reports to her manager that Dave, who has profound learning disabilities, has indecently assaulted Tracy, who also has very profound learning disabilities. She would not understand about consent and was not in a position to protect/defend herself.

Questions:

What responsibility does the worker have at this stage?

What responsibility does the person with learning disabilities have?

Who else has responsibilities and what are they?

Case study 3

John is a 30 year old man with moderate learning disabilities who attends a supported work placement. He lives at home with his parents, who are elderly and quite conservative in their views. John has come to the attention of his key worker at work because of reports that he and another male employee, who also has a learning disability, have been found masturbating each other in the toilets at work and hugging and kissing at a bus stop near work. The other man also lives at home with his parents.

Both men are considered able to give consent regarding sexual relationships. John's work supervisor is concerned that John and the other man are leaving themselves vulnerable by engaging in sexual activity in public places.

Questions:

What responsibility does the worker have at this stage?

What responsibility does the person with learning disabilities have?

Who else has responsibilities and what are they?

Case Study 4

A young male, Mark, who has profound learning and physical disabilities and is a wheelchair user, appeared to want to masturbate on a very regular frequent basis. He was indiscriminate where he chose to do this and would often start to do it in the presence of other service users and workers.

When he began to masturbate, workers would take him along to his room; hoist him onto his bed so he had freedom, privacy and the opportunity to masturbate in his room with no on-lookers. However, his behaviour became increasingly concerning to workers as he didn't seem to be having much relief, became more frustrated and upset when allowed to masturbate for a long time.

As Mark had no speech, it was very difficult to assess why he was becoming distressed.

Questions:

What responsibility does the worker have at this stage?

What responsibility does the person with learning disabilities have?

Who else has responsibilities and what are they?

 **Case Study 5**

A young woman, Anne, with mild learning disabilities who enjoys going for regular breaks at a respite unit, likes the fact that her boyfriend can come and visit her.

However, her mother is against this. She does not approve of the boyfriend as she feels he is too controlling of their relationship. Anne and her boyfriend see each other through the day at their day placement and are keen to socialise more but Anne's mother has prohibited her from contacting him from home.

Anne regularly phones her boyfriend when in respite and is clearly very happy with him. Her mother has phoned the Respite Unit to tell workers that Anne's boyfriend must not come and visit her.

Anne's support worker discussed the situation with Anne and advised her that the Unit would support her decision if she wanted him to come for a visit but it was her decision whether she discussed it with her mother.

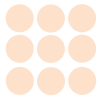
The workers at the Respite Unit felt that Anne was more than able to make her own decisions, but also felt they needed to be working with the parent.

Questions:

What responsibility does the worker have at this stage?

What responsibility does the person with learning disabilities have?

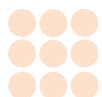
Who else has responsibilities and what are they?



6.1

Checklist for managers / facilitators

- Workers have a copy of 'Making Choices Keeping Safe' OR know where they can easily access a copy.
- Workers have answered the questions in Handout 1 and know the correct answers. They now have a clearer understanding of the content of the policy.
- Workers know where to access guidance and support on legal and consent issues regarding sex and relationships.
- Workers have discussed the case studies and have had an opportunity to think about putting it into practice.
- Worker who has completed the above has a certificate of completion.



Useful tips for sexual health groupwork

- It is natural to feel embarrassed and if you're feeling this way, the chances are everyone else is too. Simply acknowledging these feelings can help to make them more manageable, and may even help to avoid potential disruptive behaviour which can often be a way of masking embarrassment.
- Take some time to think in advance about your own personal boundaries and be clear about how you would respond to questions about your personal life. What, if any, personal questions are you prepared to respond to, and how will you handle questions you judge to be intrusive and inappropriate?
- If you don't know the answer to a question, be honest about this. You can always find out from elsewhere or suggest the group finds out.
- Approach the work with an open mind and a sensitivity to sexual lifestyles and identities which may differ from your own.
- If guidelines for sexual health work exist in your particular organisation make sure you are familiar with them. If they don't exist, raise this with the people you work alongside and with your management.
- Make sure you have adequate sources of support for yourself e.g. think about co-working with a colleague. Working with a colleague can be very supportive, and it also requires time to plan and establish a comfortable co-working relationship.

(Taken from Pathways to Sexual Health, Lothian Health, 1996, Book 1 page 11).



Certificate of Completion

This is to certify that

has successfully completed the self study or training on
the Making Choices Keeping Safe Policy.

The learning outcomes for the programme are:

- To become familiar with the content of the policy
- To increase confidence in implementing the policy
- To explore issues relating to the delivery of the policy in the work setting
- To develop an awareness of the responsibilities workers have in supporting people with learning disabilities in their sexual health and wellbeing.

Facilitator / Manager

Date



West Lothian
Council



Midlothian



East Lothian
Council

