



**Joint Committee for Action in Community Care – 30 March 2007  
Report by Directors of Social Work and Community Care**

**PEOPLE WITH LEARNING DISABILITIES, RELATIONSHIPS AND  
SEXUALITY: POLICY AND PRACTICE GUIDANCE FOR STAFF**

Agenda Item	
Report No	

**1. Summary**

This report outlines recent legislation and national policy which requires public agencies to promote the rights of adults with learning disabilities to have a full private and family life, including sexual relationships, provided they have the capacity to consent to such relationships and there is no evidence of abuse.

To this end this report introduces draft policy and practice guidance for use by all staff providing learning disability services to people over the age of 16 in Highland.

**2. Background**

- 2.1 Every human being benefits from the sense of closeness and mutual support that comes from having a network of relationships developed through school, work, hobbies and community activities. Experience of a variety of relationships helps us to develop the social skills, confidence and self esteem that underpin our ability to make, sustain and break more personal relationships and to express our sexuality.
- 2.2 People with learning disabilities often have few opportunities to socialise, develop loving relationships and have their sexual needs met. They find it difficult to get the information they need about relationships and sex. People with learning disabilities are also around four times more likely to be abused than the general population. People with profound disabilities and complex communication needs are especially vulnerable. Highland Learning Disabilities and Relationship Group is a voluntary group of professionals and carers who have been raising awareness of this issue and providing relevant information and training in Highland for around 10 years.
- 2.3 Public agencies and care providers also have a role to play in changing this situation, by supporting people with learning disabilities to achieve their fundamental human rights, including the right to make an informed choice about whether or not to form relationships. The Human Rights Act 2000 underpins the right to a private and family life and the right to marry. People with learning disabilities have the same rights as others of the same age to have sexual



relationships, provided they have the capacity to consent and are not being abused. These legal rights are further supported by a range of national policies and standards which public agencies and social service workers are expected to work to, all of which promote the equal access of people with learning disabilities to services, including sexual health services and their right to be treated with dignity and respect. These rights and principles are reflected in the Highland Partnership in Practice Agreement for learning disability services.

2.4 Relationships and sexuality is a sensitive subject for most people. There are also some very real dilemmas to be faced in getting the balance right between keeping people safe and enabling people to lead as full a life as possible. It is important that staff have a clear framework within which to make decisions about what information and education to provide on relationships and sexuality, for everyone's protection. The existing Highland policy is now out of date and does not reflect current legislation nor learning disability policy. Some staff supporting people with learning disabilities have also said that they lack the confidence and skills to provide information and advice on relationships and sex.

2.5 Considerable support for raising awareness about this issue and production of guidance for staff was expressed at a very well attended conference organised by Highland Learning Disabilities and Relationship Group in 2005. The Group subsequently applied for and received funding to revise the existing guidance for staff, produced by the Highland Regional Council in 1996.

### **3. How the Policy and Practice Guidance were Drafted**

3.1 A Sub Group of Highland Learning Disabilities and Relationship Group has worked closely with lead officers in NHS Highland and Highland Council Social Work to review and revise the existing policy, ensuring close involvement of service users, staff and carers. A project consultant, Ann Clark, was employed by Highland Learning Disabilities and Relationship Group and she worked with People First Highland to take the project forward. Rather than reinventing the wheel, Highland Learning Disabilities and Relationship Group has drawn heavily on policies produced by Lothian and Glasgow Learning Disability Partnerships who have both given permission for their work to be adapted to suit the Highland context.

3.2 An extensive consultation process was carried out including:

- A workshop for staff and carers
- Meetings with staff and people with learning disabilities in four Local Implementation Groups in Skye, Lochaber, Inverness and Caithness
- Issuing of newsletters to over 150 individuals and groups involved in learning disability services
- Production of information for people with learning disabilities about the project
- Issuing of over 750 leaflets and 100 questionnaires to carers with the support of the Highland Carers Project.
- A meeting with families of residents in New Craigs

- Three focus groups with people with learning disabilities in Skye, Easter Ross and Lochaber as well as two pilot groups in Inverness and Caithness
- Issuing of written drafts of the policy and guidance to over 150 people involved in learning disability services.
- Meetings with relevant groups in the planning process including the Lead Officers Group for Learning Disability Services and the Chief Officers Group for the JCCC.

## **4. Responses to the Draft Policy and Practice Guidance**

### **4.1 People with Learning Disabilities**

4.1.1 In general the focus groups were lively and well received. However some people found it harder than others to talk about this subject and levels of knowledge about the topic of relationships and sexuality was very varied. It appeared that opportunities for participants to discuss these issues had been limited so far.

4.1.2 Views expressed by people with learning disabilities in the focus groups suggest that more information and support is needed, for example none of the women who took part seemed to know the relationship between their menstrual cycle and pregnancy. In general people with learning disabilities were keen to get ‘good’ information rather than what they were able to pick up from the TV or from friends.

4.1.3 “This has been a long time coming, we should have been talking about it 20 years ago.”, said one participant.

### **4.2 Views of Carers**

4.2.1 Over 20 responses were received from carers of people with learning disabilities and two carers have been members of the Highland Learning Disabilities and Relationship Group Sub Group. Carers views were more mixed than those of other groups consulted. Several gave their whole hearted support to the promotion of information and education on relationships and sex. A few felt any interest in this topic should be discouraged. There was a considerable emphasis on starting young, on promoting personal safety and on the need for staff to recognise that everyone is different. Carers generally thought that an individual’s stage of development, level of disability and personal interests should determine how and in what depth the topic of relationships and sexuality should be approached.

4.2.2 Responses confirmed that people with learning disabilities have difficulty making and keeping friends, especially in rural areas. Some carers felt they had had difficulties dealing with relationships and sexuality including dealing with masturbation, appropriate behaviour, being a single parent – lack of same sex role models, starting a family and pornography. Some carers said they didn’t know who to go to for advice and felt there was a lack of support for them.



#### 4.3 Staff and organisations in health, social work and the voluntary sector

4.3.1 Staff have been very positive about the policy and guidance. A number of detailed comments were received suggesting improvements, many of which have been taken on board. Some of the general issues raised were:

- The need for training and support from line managers if the policy is to be successful
- A worry that there isn't the funding to provide opportunities for people with learning disabilities to get out and about in the community
- The need to review how the policy and guidance are put into practice and to keep them up to date
- The particular needs of people with autism in terms of their learning styles and attitudes to social relationships

4.3.2 A number of detailed suggestions for minor changes were made and these have largely been taken on board. The revised drafts are circulated with this report.

### 5. Training and Awareness Raising

5.1 During the project many comments were made about the need for appropriate training and awareness raising on the policy for staff, people with learning disabilities and their carers. The following activities are planned to help implement the policy:

- A leaflet for people with learning disabilities giving information about the policy has been produced and this will be made available in a range of different formats
- Highland Learning Disabilities and Relationships Group has piloted an educational programme for people with learning disabilities in Inverness. Initial reactions have been positive and following a fuller evaluation it is hoped to produce a toolkit and train staff to deliver the workshops at other locations across Highland. Funding will need to be sought for production of the toolkit and training events.
- Information about the policy and practice guidance will be circulated via the Highland Carers Project and other appropriate routes. Discussions are to be held with the Highland Carers Project about an event for carers during National Carers Week.
- Introductory events for managers and staff in learning disability services in the public and independent sectors will be organised around Highland to raise awareness of the policy and inform staff how it will affect them. Given the numbers of staff involved this will be a rolling programme of local events over 9-12 months.
- An additional 15 places on a specialist training course of sex education and special educational needs will be made available to staff in learning disability services.
- Specialist resources will be available to staff through the NHS Highland Health Promotions Library.



## 6. Recommendations

Members of the Committee are requested to:

- a) approve the policy and practice guidance for use by all staff in learning disability services in Highland
- b) note the intention to introduce the policy with appropriate awareness raising and training

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Signature:

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POLICY FOR STAFF SUPPORTING PEOPLE WITH LEARNING DISABILITIES  
ON RELATIONSHIPS AND SEXUALITY.

## FOREWORD

We all benefit from the sense of closeness and mutual support that comes from having a network of relationships developed through school, work, hobbies and community activities. Experience of a variety of relationships helps us to develop the social skills, confidence and self esteem that underpin our ability to make, sustain and break more personal relationships and to express our sexuality.

Although things are changing, people with learning disabilities will often have too few opportunities to socialise, develop loving relationships and have their sexual needs met. Public agencies and care providers have a role to play in changing this situation, by fulfilling the principles of 'The Same As You?' – the national policy statement on services for people with learning disabilities. People with learning disabilities should be supported to 'be all they can be' and to achieve their fundamental human rights, including the right to make an informed choice about whether or not to form relationships.

Sadly, people with learning disabilities are around four times more likely to be abused than the general population.<sup>1</sup> People with profound disabilities and complex communication needs are especially vulnerable. There are very real dilemmas to be faced in getting the balance right between keeping people safe and enabling them to fulfill their potential as human beings. This is why we have developed this policy and practice guidelines for staff working with people with learning disabilities, on personal relationships and sexual wellbeing.

We want staff to have a clear framework within which they can provide information, advice and support to people with learning disabilities on personal relationships and sexual wellbeing, for everyone's protection. We believe this will lead to better decisions by staff, greater confidence in these decisions by carers and better outcomes for people with learning disabilities.

Christine Gow Chairperson, HLDRG (Highland Learning Disabilities and Relationships Group)

Harriet Dempster, Director of Social Work, Highland Council

Jan Baird, Director of Community Care, NHS Highland Board.

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<sup>1</sup> Mencap(2001)Behind Closed Doors:Preventing sexual abuse against adults with a learning disability. London. Mencap.

## 1. POLICY AIMS AND OBJECTIVES

This policy sets out guidelines for all staff in Highland supporting adults with learning disabilities in non school settings who wish to develop personal relationships and/or to explore their sexuality. For the purposes of this policy adults includes any person over the age of 16 and the definition of learning disability in 'The Same As You?' has been adopted, which includes people with autistic spectrum disorders. It has been developed by the Highland Learning Disabilities and Relationships Group following consultation with people with learning disabilities, carers<sup>2</sup> and staff. It has been supported by the Highland Council and NHS Highland Board and will apply to everyone involved in service provision to people with learning disabilities in Highland.

The policy aims to:

- Provide you with relevant information about rights and responsibilities when adults with learning disabilities develop personal relationships and explore their sexuality, including the legal framework
- Give clear guidance on how you should respond in specific situations and what support you should receive from your employer
- Increase your confidence and competence in dealing with situations at work relating to relationships and sexuality

If the policy is used consistently by staff we expect that

- People with learning disabilities will be:
  - Supported to achieve their rights to have personal relationships and explore their sexuality, in a safe environment
  - Able to access appropriate information and services about relationships and sexual health
  - Treated with respect and dignity
- Carers will be:
  - Confident that good decisions are helping to keep their loved ones safe
  - Clear that staff are expected to support the rights of the person they care for
  - Able to access information advice and support about this policy

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<sup>2</sup> We use the term 'carers' in this document to include parents and other people who play a significant role in the lives of people with learning disabilities without being paid to do so.



## 2. POLICY CONTEXT

Agencies in Highland have adopted the principles of 'The Same As You?' and are working to ensure that people with learning disabilities are able to lead full and active lives and have equal access to local services in their communities. The ability to develop close personal relationships, to explore and express our sexuality<sup>3</sup> is an important part of normal human life which is underpinned by the Human Rights Act 2000, for example the right to a private and family life and the right to marry. People with learning disabilities have the same rights as others of the same age to have sexual relationships, provided they have the capacity to consent and are not being abused.

There are few instances where the law permits the limiting of the rights of people with learning disabilities and these are set out in the Adults with Incapacity (Scotland) Act 2000..The legislation promotes the maximum possible involvement of people with learning disabilities in decisions which affect them and permits intervention only when this is really necessary. The principles of the Adults with Incapacity Act are that permission to make decisions on behalf of another adult should only be granted when someone has been deemed incapable and:

- this will benefit the person concerned and this benefit cannot be achieved in any other way
- it is the least restrictive way to achieve the benefit
- the person has been asked what s/he wants to happen
- the views of the person's nearest relative and primary carer, any guardian or attorney or other relevant people have been sought

These principles and legal rights are further supported by a range of national policies and standards which public agencies and social service workers are expected to work to, all of which promote the equal access of people with learning disabilities to services, including sexual health services and their right to be treated with dignity and respect.

Unfortunately people with learning disabilities, especially those with profound and complex disabilities, are often denied their fundamental human rights. People with learning disabilities may have more limited opportunities to develop relationships through school, work, hobbies or leisure activities. The social skills, sense of identity and self esteem that are at the root of our ability to develop healthy and respectful personal and sexual relationships are therefore more difficult to acquire. People with learning disabilities are sometimes regarded as

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<sup>3</sup> This policy takes a broad view of 'sexuality' to include understanding changes to our bodies, emotional development, self-image and personal identity, sexual feelings and behaviours, sexual health and the wider beliefs, attitudes and values associated with sexual relationships in our society.

incapable of sexual feelings or as sexually deviant because of inappropriate behaviour in public. As in many families, carers can find it difficult to deal with their loved ones developing their sexual identity or may be worried about the risk of abuse.

There may be very real dilemmas to be faced when people with learning disabilities explore relationships and sexuality and staff will find getting the balance right between opportunities and protection challenging. Some people with learning disabilities may not find it possible to express their sexuality physically and some may choose not to. However we are convinced that the provision of information and advice about relationships and sexuality, appropriate to someone's developmental age, interest, motivation and experience, can help improve the choices and outcomes for people and help keep them safe. This policy is part of our commitment to providing a supportive framework within which staff can achieve a more positive, informed and inclusive practice around relationships and sexuality for adults with learning disabilities

### 3. RELATIONSHIPS

All people with learning disabilities have the right to experience a full range of relationships, including friendships and community links, as well as personal relationships.

To achieve these rights means also having the freedom to take informed risks. Support should be provided with social activities which are planned according to individual needs, interests and personal circumstances rather than the needs of the service. Activities should be appropriate to an adult lifestyle and support personal growth and development. People should have access to accurate information and responsible guidance to enable informed choices about any activities that may involve risk. Assessments of people's needs and any support required should be part of the individual care planning process and recorded and monitored as in other areas of support.

Staff should ensure a range of opportunities and support are available including:

- to help people present themselves as adults and individuals, in a way which encourages self-expression and choice, including discreet help with clothes, personal hygiene and appearance and in accordance with any relevant cultural or religious beliefs
- to acquire social skills by positively modelling appropriate behaviour and discouraging inappropriate behaviour
- to identify and pursue interests outside the home through attendance at college, work, day centres, voluntary activities, community events etc.
- to meet others without regulation of the relationship by workers
- to take informed risks
- to encourage personal safety by developing communication skills, assertiveness, awareness of social boundaries, circles of support, access to advocacy services and personal safety information including useful contacts and numbers

#### 4. PERSONAL RELATIONSHIPS AND SEXUALITY

All people with learning disabilities have the same rights to develop personal relationships and express their sexuality as everyone else. This includes the right to consent to sexual relationships including same sex relationships. These rights can only be denied on the basis of evidence of impaired capacity as defined by the Adults with Incapacity (Scotland) Act 2000, or abuse.

Staff should offer information, advice and support, appropriate to their role and level of competence in the area of relationships and sexuality, which facilitates the fulfillment of these rights. Information, advice and support should be provided following appropriate individual needs assessment and in consultation with line managers and multi-disciplinary colleagues where necessary. What support and assistance will be required will vary widely depending upon people's developmental age, communication levels, cognitive and conceptual abilities, interests, motivation and personal needs. For example people with autistic spectrum disorders may have very different learning styles and views about relationships from other people with learning disabilities. Information, advice and support on relationships and sexuality should not be provided only when an individual requests it, as the duty of care requires that these issues be addressed proactively as well as reactively, as part of the personal care planning process. However staff must be satisfied that the information, advice and support to be provided is desired by an individual and is appropriate to their stage of development, learning abilities and experiences. Help should be available with:

- Understanding and expressing feelings such as pleasure, anger, happiness, loss, love, desire, intimacy, arousal
- Appreciating different sensory experiences including massage, food, music, dance, exercise, warm baths, colours, smells etc.
- Appreciating a sense of spirituality for example, closeness to nature, religious and other belief systems
- Understanding 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
- Understanding and recognising the many different means of sexual expression for example touch, masturbation, sexual intercourse, same sex relationships, celibacy, pornography
- Developing an ability to communicate effectively about relationships and sexuality using language and other communication methods, including pictorial methods, depending upon individual needs
- Developing and feeling comfortable with personal and sexual identity including information and support for lesbians, gay, bisexual and

transgender people, older people, people with physical disabilities and people from black and minority ethnic groups.

- Opportunities to develop and enjoy personal and consensual sexual relationships by providing independence and privacy
- Understanding rights and responsibilities around consensual, non-abusive and healthy relationships including issues of consent, mutuality, and respect
- Accessing information and services to enable safe sexual practices including contraception and sexual health services
- Understanding the responsibilities and commitments involved in different kinds of relationship including marriage and parenting
- Understanding the variety of beliefs and attitudes held about personal relationships and sexuality in our society and the laws on inappropriate sexual behaviour

Staff should ensure that people's rights are supported as fully as possible according to the ability and wishes of the person they are working with, as well as in accordance with care plans and risk assessments and in accordance with the policy on the protection of vulnerable adults. Guidance on appropriate assessment and decision making processes are provided elsewhere in this policy and in the accompanying Practice Guidance.

## 5. SEXUAL HEALTH

People with learning disabilities have the right to access sexual health services and to consent to treatment and care, within the parameters of the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003.

Staff should:

- Be confident and competent to discuss sexual health topics with people with learning disabilities
- Promote safer sex practices
- Make people with learning disabilities aware of what sexual health services are available, the help they can provide and provide support to access these services if required

## 6. CONFIDENTIALITY

People with learning disabilities have the right to confidentiality about all aspects of their relationships and sexuality, unless there is evidence of abuse or significant concern about the possibility of abuse.

Staff should:

- Tell people with learning disabilities about their right to confidentiality and in what circumstances information can be shared without their consent.
- Regularly reinforce people's rights to confidentiality and provide appropriate opportunities and encouragement for people to talk about aspects of their private life, if they choose to do so
- Tell people with learning disabilities how they can complain if they feel confidentiality has been wrongly broken and ensure they get any necessary support to do so, including advocacy
- Seek permission before providing information to or consulting with someone's carer and respect their wishes if s/he does not want a carer to be informed or involved
- Written information, for example in case files, should be kept in a way that supports confidentiality and should not be shared with someone else without the explicit consent of a person with a learning disability
- Be familiar with the Highland Policy on Protection of Vulnerable Adults and refer any concerns or disclosures of abuse to the appropriate agency, in accordance with that policy
- Ensure that where there are concerns or disclosures about abuse that mean confidentiality cannot be guaranteed, the person with a learning disability is kept informed and reassured about what is happening and the reasons for breaching confidentiality are clearly recorded using appropriate procedures

## 7. PROTECTION AND SAFETY

People with learning disabilities have the right to be protected from any situation where they are vulnerable to exploitation and at unacceptable risk of physical, sexual or emotional abuse. The Highland Policy on Protection of Vulnerable Adults and associated Good Practice Guidance and Procedures ensures the protection of individuals and others who may be at risk.

Staff should:

- Never form a sexual relationship with an individual in their care
- In the event of evidence of or disclosures of abuse, implement the Highland Policy on Protection of Vulnerable Adults and follow the Good Practice Guidance and Procedures to ensure the protection of the individual concerned and any other people who may be at risk
- Ensure that people with learning disabilities know and understand that they have the absolute right to feel safe and what to do if someone is abusing them or they are unhappy with a relationship
- Ensure that people with learning disabilities develop the skills to keep themselves safe and to assess risks including decision making, communication skills, assertiveness, learning about safe sexual practices
- Ensure that people with learning disabilities are equipped with the appropriate knowledge and skills to decide how to express their sexuality in a way that is protective of themselves and others
- Be able to communicate effectively with people with profound or complex disabilities and be alert to behaviour which may signal abuse (see Section 9 of the Practice Guidance)
- Undergo training on effective protective behaviours and how to deal with disclosure of abuse, including confidentiality issues



## 8. MAKING GOOD DECISIONS

People with learning disabilities have a right to services which take account of their individual needs, abilities and wishes and are based upon planned, co-ordinated and documented, care management processes.

### Staff should

- Keep the individual as the focus of decision making at all times
- Assess people's needs in terms of relationships and sexuality at times of significant decision making, e.g, transition from school to adult services, leaving home, starting college or work placements as well as part of ongoing personal care planning
- Actively work with other professionals, families and people who know individuals well, in a way which respects privacy and confidentiality, to ensure the best possible information is available for decision making
- Have knowledge of different agencies' roles, practices and of appropriate specialist services and use this to enable individuals to access the services they need
- Involve and work positively with colleagues in other agencies and professions when a multi-agency approach to assessing and meeting an individual's needs is required
- Discuss and record within their support planning and supervisory structures, in a way which respects privacy and confidentiality, the provision of support to individuals about relationships and sexuality
- Involve and consult with people with learning disabilities and their carers in the planning of services and policies and use feedback from service users and carers, including information from complaints, to improve the quality of service provided.

## 9. WORKING WITH CARERS

Carers of adults with a learning disability have the right to be consulted about important decisions, life changes or support plans, provided the individual with a learning disability agrees

Carers are an important and influential part of the lives of people with learning disabilities. It is important to work in partnership with carers wherever possible, consulting them and listening to their views whilst respecting the rights and wishes of people with learning disabilities.

Staff should:

- Ensure good communication with carers exists and that their views are listened to and treated with respect in relation to important decisions, life changes or support plans
- Make carers aware of this policy and support them to understand its implications
- Offer carers access to information and learning opportunities that may support them in discussing issues about relationships and sexuality, including the opportunity to meet other carers
- Take seriously any issues raised by carers relating to the personal safety of a person with a learning disability by undertaking appropriate risk assessment
- Consult carers when decisions are being made by their organisation or another person on behalf of someone with learning disabilities under rights granted by the courts
- Ensure that carers know how to make a complaint and where to get support to do so, including availability of local advocacy services

## 10 SUPPORTING STAFF

People with learning disabilities have the right to be supported by staff with relevant knowledge, skills and resources to enable individuals to explore and develop relationships and their sexuality. Staff have the right to feel supported and equipped to do so. Staff have the right to hold their own values and beliefs but they are not entitled to impose these on people with learning disabilities.

Staff should:

- Be made aware of all relevant policies and guidance and have their training needs assessed as part of their induction process
- Follow the appropriate provisions of the Scottish Social Services Council Codes of Practice for Social Service Workers and Employers
- Regularly update their awareness of all relevant policies and guidance and have training needs assessed as part of support and supervision processes
- Have access to and undertake approved and relevant training on relationships and sexuality to meet their assessed training needs
- Have access to appropriate information and resources for their own use and for people with learning disabilities and their carers
- Provide information, advice and support to people with learning disabilities appropriate to their role and to their own level of competence.
- Inform their line manager if their personal values and beliefs are in serious and substantial conflict with an individual's choices about relationships and sexuality, discuss the issues with their line manager and agree how support will be provided.
- Have clear guidance on how to access specialist services and support when they are not the appropriate person to provide support
- Have access to regular support and supervision from their line manager
- Have access to grievance and whistleblowing policies and procedures

It is the responsibility of both the employer and individual staff to ensure this section of the policy is implemented.

## 11. LIFELONG LEARNING

All people with learning disabilities have the right to lifelong information and learning to facilitate their rights to form personal relationships and express their sexuality.

Staff should:

- Ensure that regular assessments of people's needs for information and learning about relationships and sexuality are made as part of on going personal planning processes
- Agree with individuals how assessed needs will be fulfilled. If access to specialist knowledge or services is required appropriate referrals should be made.
- Respond positively to all spontaneous requests for information about relationships and sexuality or to specific incidents which indicate a need for information or learning exists
- Access resources from a range of reliable sources, for example the NHS Highland Health Information and Resources Service, the Highland Learning Disabilities and Relationships Group, Highland Sexual Health, Reach Out Highland and Highland Brook. Information on relevant resources is given in the Practice Guidance
- Ensure information is easily accessible and in appropriate formats for individual needs, including for people with complex communication needs
- Follow the practice guidance when individuals with profound or complex disabilities require one to one teaching methods involving personal touch.

## 12. ADVOCACY SUPPORT

People with learning disabilities have the right to support, from someone independent of their formal and informal care providers, to understand this policy and to facilitate their rights to personal relationships and to express their sexuality.

Staff should

- Ensure that people with learning disabilities are aware of national and local advocacy services and support them to access these services



**WORKING WITH PEOPLE WITH LEARNING DISABILITIES ABOUT  
RELATIONSHIPS AND SEXUALITY**

**GOOD PRACTICE GUIDANCE FOR STAFF**

The Highland Learning Disabilities and Relationships Group would like to acknowledge the help and assistance provided by the organisations involved in the production of 'Making Choices: Keeping Safe', the Lothian, policy and guidance. Their work can be accessed at [www.mcks.scot.nhs.uk](http://www.mcks.scot.nhs.uk).



We also benefited greatly from the work of the Glasgow Learning Disability Partnership who have produced a policy and guidance called 'Relationships and Sexual Wellbeing' This policy and guidance has drawn heavily on both the Lothian and Glasgow policies and we are grateful for permission to do so. We are also grateful to Common Knowledge for permission to reproduce extracts from 'Batteries Not Included', an excellent resource for people working with people with complex communication and support needs.

As part of the process of developing the policy and practice guidance, HLDRG consulted widely with people with mild and moderate learning disabilities, their carers and staff working with people with learning disabilities. We held an all day workshop for staff and carers, attended four local meetings of staff, carers and service users in Caithness, Skye, Lochaber and Inverness, held focus groups with people with learning disabilities and issued questionnaires to over 100 carers. A separate report of the focus groups with people with learning disabilities is available and some of the views expressed during the focus groups are included to illustrate points in the guidance. A summary of responses from carers to the questionnaire is included at Appendix Two. We thank everyone who took part for their time and commitment.

## INTRODUCTION

Working with people with learning disabilities<sup>1</sup> about relationships and sexuality will raise questions and sometimes dilemmas, as you seek to maintain an appropriate balance between securing people's rights and protecting them from abuse and exploitation. This practice guidance will not answer all your questions or make you an expert on relationships and sexuality. However when read alongside the Highland Policy on Learning Disabilities, Relationships and Sexuality and other relevant policies it should make you aware of:

- The law as it applies to people with learning disabilities
- Sources of further information and guidance on particular topics
- The sensitive approach and positive attitudes to relationships and sexuality required of all staff working with people with learning disabilities in Highland
- Good practice examples which you can draw upon to decide how to address a range of issues which are likely to arise when working in this area
- When to draw upon the support of colleagues or your line manager to decide whether and how to offer support about relationships and sexuality

Please familiarise yourself with the contents and use it to assess whether you need access to specialist support services or further training to be able to make full use of the guidance.

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<sup>1</sup> 'A learning disability is a significant, lifelong condition which has three facets: reduced ability to understand new or complex information or to learn new skills; reduced ability to cope independently; and a condition which started before adulthood (before the age of 18) with a lasting effect on the individual's development.' It includes people with autistic spectrum disorders.

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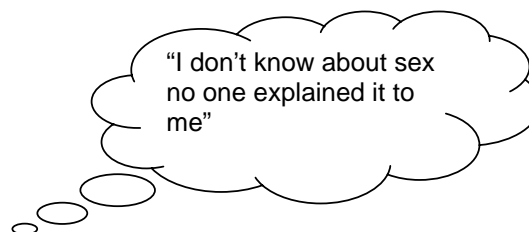
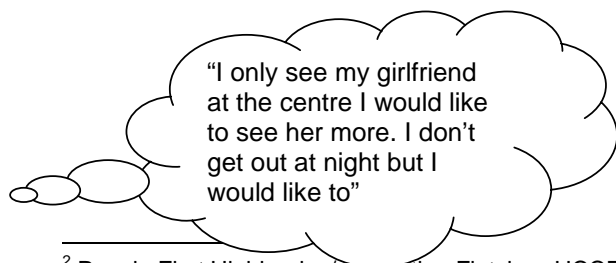
## 1. SUPPORTING PERSONAL RELATIONSHIPS

People with learning disabilities are individuals, with their own unique abilities, interests, experiences and aspirations. Part of fulfilling our duty of care towards people with learning disabilities involves ensuring that they have the same opportunities to express their needs and interests and to learn from experience, as others without a disability do. This applies equally to forming relationships and fulfilling sexual needs as any other area of daily life. Throughout this document we have provided quotes from people with learning disabilities living in Highland, which illustrates their experiences of relationships and sexuality. A full report of three focus groups held with people with mild and moderate learning disabilities is available from People First Highland<sup>2</sup>

Some people with learning disabilities will be able to develop a range and variety of relationships without help. Others will need support and assistance throughout their life. What support and assistance will be required will vary widely depending upon people's developmental age, communication levels, cognitive and conceptual abilities, interests, motivation and personal needs. For example people with autistic spectrum disorders may have very different learning styles and views about relationships from other people with learning disabilities. Staff should proactively assess people's current experience of personal relationships, their capacity to develop different types of relationship and whether they need support in this area.

All staff providing services to people with learning disabilities have a potential role to play in helping them to develop personal relationships. This could be practical assistance such as transport, shopping for clothes or supporting privacy and dignity when cleaning accommodation. Or it could be facilitative such as:

- Supporting people to attend activities and meet new people
- Providing opportunities to discuss relationships and sexual health issues
- Helping people to celebrate important anniversaries
- Actively seeking out places where couples can have private space alone together and/or facilities for an overnight stay
- Providing information about sexual health services – what they can and can't do and helping people to access services
- Providing a structured programme of sex education (see section 6)



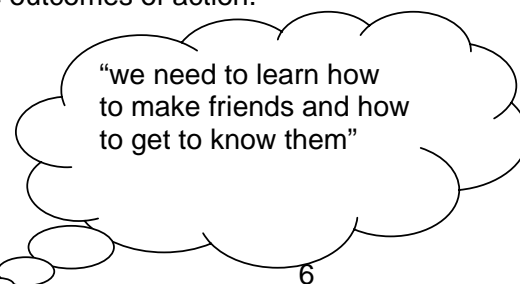
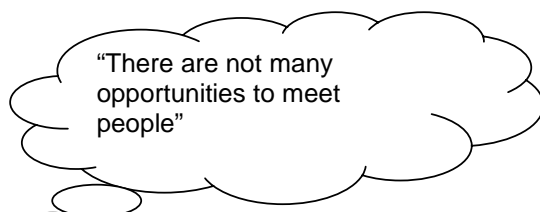
<sup>2</sup> People First Highland. c/o Christine Fletcher. HCCF. Highland House, 20 Longman Rd. Inverness.

It is important that staff access information, training and line management support so that they feel confident and comfortable about discussing relationship and sexuality issues with people with learning disabilities. Guidance is given on specific issues such as masturbation, sexually explicit material, intimate care and contraception elsewhere in this document. Information is provided on the law and a list of useful resources and specialist services is provided in the Appendices. Staff should use this guidance to improve their practice and to review and assess their competencies in this area with line managers and agree how any identified training needs will be met.

There are a number of key principles that staff should follow in supporting people with personal relationships, which may or may not include sexual relationships:

- What support people need and want in this area should be clarified as part of care and support planning, recorded and outcomes monitored
- People should be supported to socialise as individuals or in small groups and without regulation by staff unless there are concerns about vulnerability
- Help should always be offered in a discreet and adult manner
- Staff should model socially appropriate behaviour both for individuals with learning disabilities and for others in social situations.
- A degree of risk taking is a normal part of personal relationships. Staff should make sure people have information, advice and guidance on which to assess risk and make informed choices
- Staff should not impose their own beliefs on individuals or other members of staff but should ensure that people are aware of the range of views held within society about relationships and sexuality
- Sexual activity between workers and a vulnerable adult is exploitative, abusive and is illegal. Any allegation of abuse made against a member of staff will be investigated. Any member of staff found to be engaging in a relationship or sexual activity with a person in their care will face disciplinary action and will be reported to the police. The Highland Protecting Vulnerable Adults Good Practice Policy and Procedure 2005 explains this in detail.

There may be occasions when staff become aware that an individual is attracted to them or vice versa. Staff should approach their line manager to discuss and agree how to proceed. The situation should be regularly monitored and assessed and detailed records kept of any decisions taken and the outcomes of action.



## 2. CONSENT

The issue of consent is at the heart of decisions about whether sexual relationships are illegal or abusive. Some people with profound or complex disabilities may be considered unable to give consent to sex. Others may have the capacity to consent to sex but not in a meaningful way because the relationship is abusive.

### Capacity

The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 are the most significant pieces of legislation in the protection of vulnerable adults. The purpose of these laws is to protect people who do not have the capacity to consent, from abuse and exploitation and to prevent unnecessary interventions in their lives. Information on the special offences created by the 2003 Act is provided in Appendix One.

Two key principles of the Adults with Incapacity Act are that the Courts will only intervene when the individual concerned will benefit and when this benefit cannot be achieved in any other way. Adults will be deemed incapable if they are 'incapable of:

- Acting
- Making decisions
- Communicating decisions
- Understanding decisions, or
- Retaining memory of the decision

in relation to any particular matter, by reason of mental disorder or inability to communicate because of physical disability'. If difficulties in communication can be overcome with human or technological assistance the Act may not apply. A person will also not fall within the definition only because of dependence on drugs or alcohol or by reason of conduct considered immoral or promiscuous.

Who decides whether someone has capacity depends on the circumstances and the nature of the decisions that need to be made. Decisions about capacity to marry for example are taken by the Registrar. A medical practitioner can certify incapacity in relation to some decisions, e.g. medical conditions. This may be a GP or, when the care and treatment required is within their professional remit, another professional who has undergone the required accredited training. On more complex welfare matters a range of techniques are available to make decisions or manage the affairs or welfare of an individual. In these circumstances guidance from senior managers and a mental health officer of the local authority would be required. As far as reasonably possible, the individual concerned and any significant people in their life should be involved.

Whilst a person may be incapable of making certain decisions in their life, they may be capable of making other decisions. An assessment of capacity for the purposes of sexual relationships should be specifically about the adult's abilities to understand personal and sexual relationships. A person's potential to make decisions should be maximised at all times, for example by appropriate communication techniques, provision of advocacy support, allowing sufficient time for assessments etc.

## **Consent**

A person may have the capacity to make decisions in relation to sexual relationships but the issue of consent should still be considered if there are any concerns about whether a particular sexual relationship or act may have been coercive or abusive. Consideration should be given to:

- Whether an individual is able to give consent
- Whether the individual gave consent.

There are clear situations in which any consent given would be considered invalid. These include if a person does not:

- really understand what is being asked
- know they have the right to refuse sex
- know how to refuse sex or is too afraid to do so
- know that sex is not meant to be painful or uncomfortable
- know that he or she is being exploited when a reward/incentive or payment for sex is used
- know that some relationships are illegal

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.

It is very important to think about the degree to which a learning disability is significant in terms of meaningful consent and those people who know an individual well should do this. Evidence of mutuality should be looked for by those assessing consent, to show that the relationship is not abusive. This could be reflected in factors such as:

- both parties seeking each other out and spending time together
- both parties enjoying the experience and appearing happy
- an absence of indicators normally associated with abuse (see pp34)

Staff should not make value judgements about the appropriateness of different types of sexual activity. Many people engage in activities which others view as morally wrong or not in their best interests. However staff are expected to be sensitive to the possibility of abuse and to act on any concerns in accordance with the Highland Good Practice Guidance and Procedures for the Protection of Vulnerable Adults.

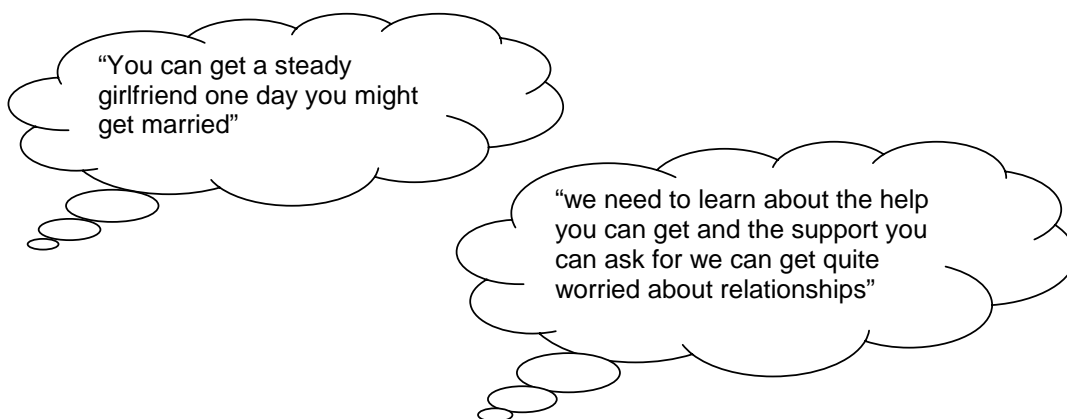
### 3. LIVING TOGETHER, MARRIAGE AND CIVIL PARTNERSHIPS

People with learning disabilities have the same rights in law as anyone else, to live together, marry or enter into a civil partnership, subject to people's capacity to consent. The District Registrar can refuse to authorise a marriage or civil partnership if he or she believes one of the partners 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 move in together, to get married or enter a civil partnership they should be supported to do so for example by:

- arranging suitable accommodation
- explaining the implications for someone's legal and financial obligations
- providing information and assistance in understanding the responsibilities of different types of relationship
- exploring the likely reaction of relatives, friends, workmates and other members of the community and how a couple will deal with any differences of view or objections
- enabling access to relationship services and other specialist services such as Citizens Advice Bureaux and sources of legal advice.

All relationships go through difficult patches and people with learning disabilities in long term relationships may experience difficulties which in some cases will lead to separation and/or divorce. If requested to do so, staff should offer guidance on the implications of any action and be aware of support services on offer to couples experiencing difficulties. Couples who separate may need additional support from solicitors and housing agencies as well as emotional support.

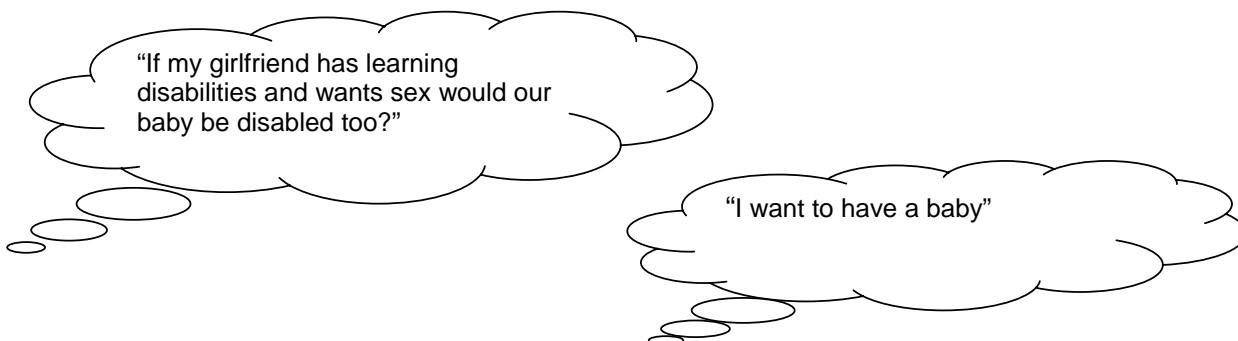


#### 4. PARENTHOOD

People with learning disabilities have a right to be parents and many of them have a desire to choose to become parents. However these rights have to be balanced with the responsibilities of parenthood and the need for education on these responsibilities. Some people may need help to explore their expectations and to assess their capacities to meet parenting responsibilities. Some people may require practical assistance in looking after any children and this may be provided as part of a care package based on assessed need.

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

- What is the expectation of the individual or couple about becoming parents? ( sometimes having children can be seen as a “passport to normality”)
- How much help would realistically be needed to help this couple cope with a child and is it likely to be available?
- Is help expected from existing carers<sup>3</sup> and if so what additional support needs will they have?
- Is genetic counselling necessary?
- Are there risks to a baby?
- What are the financial implications of parenthood?



People with learning disabilities can be good parents. It should not be assumed that they will necessarily have children who have learning disabilities. It is important that individuals 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.

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

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<sup>3</sup> We use the term ‘carers’ in this document to include parents and other people who play a significant role in the lives of people with learning disabilities without being paid.

parents have learning disabilities or not. However 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.

For some people with learning disabilities who want to become parents, conception may not be possible or may be unlikely. In such circumstances people may need specialist counselling and support and they should be referred to relevant agencies. It is important to be realistic and not raise people's expectations.

Addressing the issue of parenthood may be difficult for staff and support should be sought from line managers and specialist services.



## 5. CARERS VIEWS

This guidance is written from the perspective of supporting the rights of people with learning disabilities, whilst balancing these against the need for protection. It has also been written with reference to Scottish law, which generally puts the rights of individuals before the greater good of the community and assumes people have the capacity to make decisions for themselves until proved otherwise.

People with learning disabilities come from the full range of backgrounds, communities, cultural and religious beliefs found in our society. In enabling people to make informed decisions and judgements about relationships and sexual behaviour it is important to appreciate the wider context of an individual's life, including the values and attitudes of their family and community. When supporting someone to make decisions about relationships and sexuality it is important that cultural and religious perspectives are part of the information people with learning disabilities take into account in making decisions.

People with learning disabilities have the right to step, and be aided to step outside the values of their family and community, so long as they remain within the law. However the consequences for an individual of doing so may have far reaching effects in terms of their relationships with family, friends and the wider community.

Some families will be entirely supportive of their relative developing a healthy network of social relationships and expressing their sexuality in healthy, positive ways. Others will have strong views on matters such as same sex relationships, masturbation, pornography and sexual relationships outside marriage. Others Many people with learning disabilities continue to live with parents or other close family carers and even where they do not, the influence and importance of these relationships should be respected. It is important that staff are aware of the range of views carers are likely to hold and Appendix Two gives an illustration of the diversity of opinions held by carers who replied to a questionnaire issued as part of the process of developing the Highland policy on relationships and sexuality.

Carers should be offered opportunities to comment and be involved in the planning of approaches to education and support about personal relationships and sexuality for people with learning disabilities. Carers of adults with learning disabilities can participate in discussion about their relative's personal and sexual relationships where the individual concerned has given their permission. However, they do not have a right to a say in what their relative does, unless they have been granted that right by the court. The views of carers must also be taken into account when considering an intervention under the Adults with Incapacity Act or the Mental Health Act.

## 6. EDUCATION ABOUT RELATIONSHIPS AND SEX

Most people with learning disabilities now receive relationships and sex education while at school. Many will also have received advice, guidance and training from parents who are best placed to build understanding about privacy, self-esteem and decision making, which form the basis of any sex education. However some people with learning disabilities will have missed out, others will require early learning to be constantly reinforced as an adult and some may be having specific difficulties with relationships and sex. Staff may therefore wish to arrange a variety of types of relationships and sex education including one to one support, group work, access to formal educational programmes or access to specialist services.



Although this guidance is concerned with adults, the Scottish Executive’s advice on sex education in schools is a source of information on the principles and aims of sex education which staff should consider when planning relationships and sex education programmes. The key principles are:

- sex education should be viewed as one element of health education, set within the wider context of health promotion and health promoting ethos of the school
- sex education should contribute to the physical, emotional, moral and spiritual development of all young people within the context of today’s society
- education about sexuality and relationships should reflect the cultural, ethnic and religious influences within the home, the school and the community
- sex education should be non-discriminatory and sensitive to the diverse backgrounds and needs of all young people
- sex education starts informally at an early stage with parents and carers and continues through to adulthood both within the home and at all stages of school life

Central features of any programme of relationships and sex education should include:

- respect and caring for oneself and others
- respect for individual differences and choices about sexuality
- ways to express and deal with feelings and emotions
- ways to keep safe.

It is good practice to consult with parents and carers when planning a programme of relationships and sex education and again the Scottish Executive guidance related to schools may be useful. Some carers may wish to have the opportunity to discuss the programme and view materials. Carers do not have the right to prevent someone with a learning disability over the age of 16 from taking part in relationships and sex education, nor to insist on changes to the content of such a programme, unless they have welfare guardianship rights to consent on behalf of that individual.

Staff should keep up to date records of what they are planning to do within sessions, what has been delivered and outcomes arising from these sessions. Good record keeping will enable staff to evaluate the sessions, learn and to develop future practice. Staff should involve managers in planning and agreeing relationships and sex education sessions.

Although what is appropriate will vary from individual to individual, staff should ensure the learning process is tackled logically and in stages that build upon each other. Staff should carefully consider for each stage whether they have the appropriate knowledge and skills or whether specialist help is needed. Different levels of understanding may be present within a group. Materials and facilitation styles need to be appropriate to the learning needs of individuals and adapted accordingly. Steps must be taken to ensure education activities are accessible for people with visual or hearing impairments.

There will be particular issues to address when working with people with profound or multiple learning disabilities who have complex communication and learning needs. In such situations both the individual with learning disabilities and staff working with them are especially vulnerable. Before any programme of sex education is undertaken individual, multi-disciplinary assessments must be carried out and specialist techniques may need to be used to establish what and how people need and want to learn. Staff will need clear evidence that the individual has a need or desire to learn more about relationships and sexuality. If assessments conclude that more abstract methods of learning involving pictures, line drawings, videos etc. will not work for the individual, more direct and concrete methods may be necessary. The least intrusive methods should always be used first of all and the need for the involvement of staff with specialist skills such as a sexual therapist should be considered. Careful recording at all stages of the process and regular reporting to and discussions with managers will be

vital to safeguard both the individual and members of staff. 'Batteries Not Included' is a useful resource for staff working with people with complex communication needs. (Details in Sexual Health and Relationships. A Review of Resources For People With Learning Disabilities)

The following are key components of an education programme. Staff should assess people's current knowledge, identify gaps and agree achievable goals in relation to all of these topics:

### **Social and Relationships Skills**

- Awareness of self in relation to others
- Different types of relationships – family, friends, colleagues, personal
- Emotions and how to deal with them
- Skills for relationships – decision making, negotiation etc.
- Responsibility and commitment within relationships

### **Body Awareness and Basic Information About Sex**

- How bodies grow and change
- Language about the body and sex
- Own body image and self worth
- Puberty
- Masturbation
- Menstruation
- Contraception, abortion
- Pregnancy, needs of a baby, reality of parenthood

### **Sexual Health and Wellbeing**

- Sexual feelings and how to cope with them
- Same sex relationships
- Awareness of gender identity
- Sexually Transmitted Infections
- Safe sex practices
- HIV and Aids
- Sexual Health Services and how to access them

### **Appropriate Behaviour**

- Public and private behaviour
- Time and place
- Difference between child and adult behaviour
- Appropriate expression of feelings and emotions
- Use of sexually explicit materials

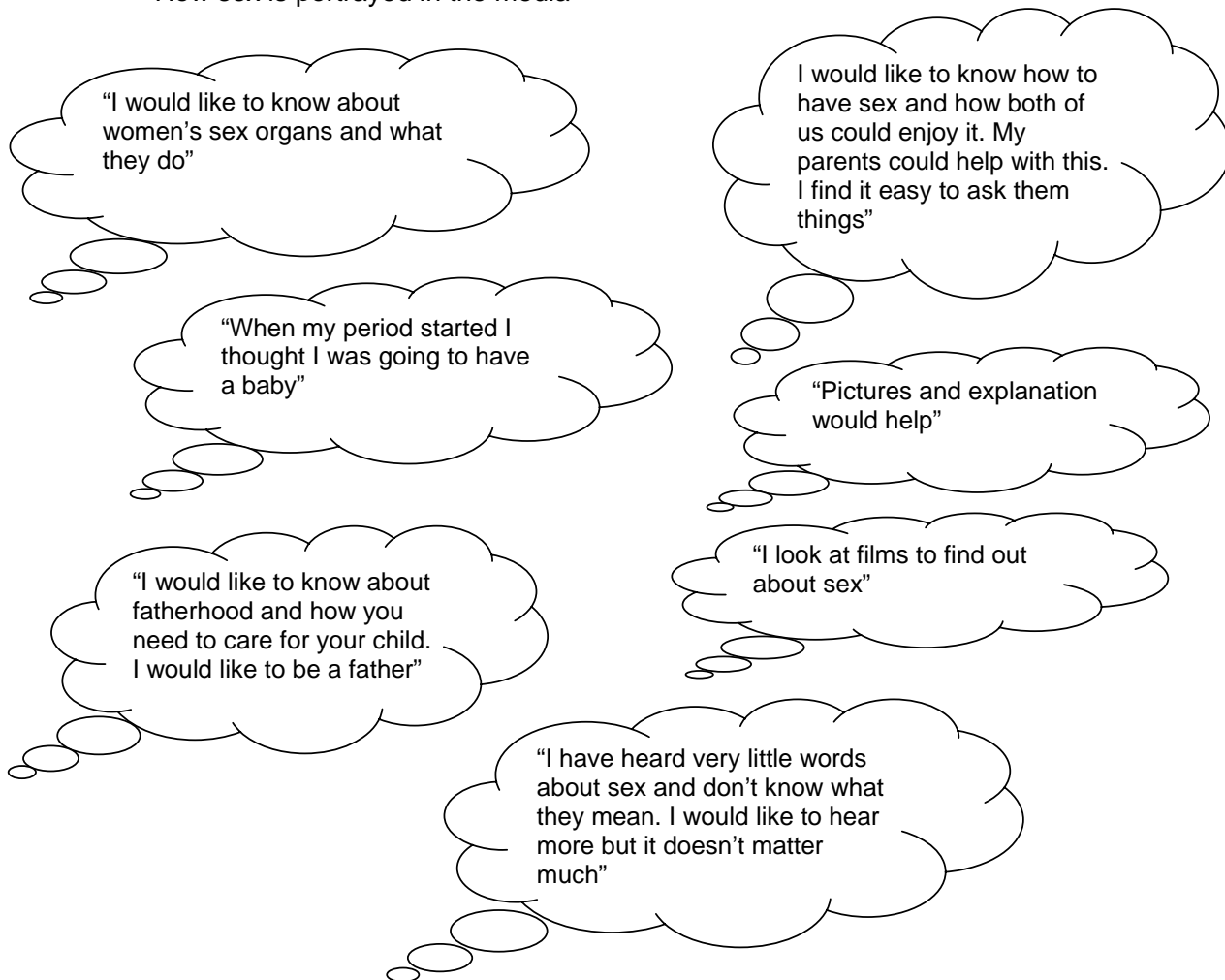
### **Personal Safety**

- Negotiating and decision making skills

- How to say yes and no assertively
- Personal rights and responsibilities to others
- Good touch and bad touch
- Protective behaviours
- Identifying and reporting abuse
- The law
- Prostitution and exploitation

### Values and Attitudes About Relationships and Sex

- Different social, religious and cultural attitudes to relationships and sex
- Lifestyle Choices – marriage, celibacy, multiple partners, same sex relationships
- How sex is portrayed in the media



## **7 SEXUALITY**

### **7.1 Privacy and Dignity**

People with learning disabilities have the right to privacy both in terms of personal space and personal information. Staff should respect the privacy and dignity of people with learning disabilities and adhere to the National Care Standards for care homes relating to private life. In practice this means:

- ensuring people with learning disabilities know the meaning of privacy and when and where it is appropriate to discuss issues of a personal nature.
- not going into an individual's room without first seeking permission or having a very good reason, such as a medical emergency. If a mistake is made and a staff member enters an individual's room without permission an apology should be offered.
- having an awareness of people's individual religious and cultural beliefs
- making clear that sexual activities such as masturbation should take place in private and the potential consequences of sexual behaviour in public. Public buildings such as Day Centres are not acceptable venues for any sexual behaviour.
- if someone behaves in an inappropriate manner, explanations are given about what was inappropriate and why, whilst acknowledging those aspects of the behaviour that were appropriate. Behaviour is often a means of communication and care should be taken to explore what lies behind people's behaviour. For example if someone starts masturbating on a shopping trip, are they bored, aroused by someone attractive or could they have an STI?
- People with a learning disability should be able to lock their bedroom doors. Alternative strategies for ensuring the privacy of individuals with physical disabilities or profound and complex disabilities should be discussed with the individual and managers and recorded in the care/support plan.

### **PRACTICE EXAMPLE**

Mary is 25 years old and congenitally deafblind. She likes her own space and spends a lot of time in her room. She is very aware of who her parents and sister are when they visit but doesn't show any real preference for different people otherwise. Mary uses a lot of signs and gestures to communicate. Although she doesn't write she uses lots of pictures to explain what is in her mind. She can be aggressive if people appear not to understand her communication. Only the staff team who support her and her family are fully able to understand what she is trying to communicate.

She has good residual vision which she uses to get about and watch TV. She reads magazines and catalogues and appears to recognise details. She like watching TV and could probably relate videos to her situation. She has learned lots of recipes at college and cooks in her house. She follows recipes using combinations of line drawings and photographs of ingredients and processes. She has pictures that she uses to plan out her day/week.

Observing her behaviour over many weeks, staff believe that she does not understand issues around public and private behaviour. When she goes swimming she runs her hands down the front of her body to clear water from her costume and perhaps to some people in the pool her behaviour could be interpreted as a sexual invitation. At home she leaves the toilet door open, wanders around the house with her housecoat open and sometimes opens her bedroom curtains before getting dressed.

Staff think that Mary is not that aware of her sexuality, although she is aware that she is a woman and most key people in her life think that she considers herself to be a young girl. She does not appear interested in sex as such and has never been known to masturbate. No one knows much about any sex and relationships education that Mary has had in the past.

Staff decided to support Mary to appreciate that she was a grown woman and what behaviours might be appropriate/inappropriate at the swimming pool and in the house. Elsewhere there were no particular issues arising. Once a week at a set time a number of role play situations and discussions with Mary were followed through using picture sequences of how to get about the house, what to do when you get up, what to do after a bath, what to do at the pool once you have your shower etc. A number of videos and line drawings were available to support this learning. Staff also reinforced the messages at the pool, after she had had a bath, when she was getting up. Two staff developed the sessions and the whole staff team and her family reinforced them. After a few months staff saw a reduction in inappropriate behaviours.

(Reproduced with permission of Common Knowledge, from 'Batteries Not Included')

## 7.2 Intimate Care

Some people with learning disabilities will require staff to assist them with their personal hygiene and to carry out intimate care tasks. Intimate care needs and how they are to be met should be outlined in people's personal care plans. If they are able to, people should choose who they would like to perform their intimate care. Their choice should be adhered to as often as possible and explanations given when this is not possible, e.g. because of sick leave or holidays.

Intimate care should be carried out in private and the dignity of people with learning disabilities maintained at all times. This involves:

- Closing toilet/bathroom/bedroom doors
- Obtaining permission before starting any intimate care
- Explaining any new procedures clearly and why they are necessary
- Avoiding negative comments or language which could imply disapproval or disgust or that may embarrass the individual with a learning disability
- Being aware of religious and cultural beliefs and practices and providing intimate care accordingly
- Prioritising intimate care tasks to ensure the physical comfort of people with learning disabilities

Staff should familiarise themselves with health and safety guidelines in relation to intimate care and manual handling techniques to ensure both the emotions and physical safety of people with learning disabilities and themselves.



### 7.3 Masturbation

Masturbation is a normal sexual behaviour which many people find to be a useful outlet for sexual feelings. For some people with learning disabilities it may be the only way they can achieve orgasm. People should not be discouraged from masturbating but should be supported to understand the difference between public and private space and that masturbation should be done in private. If it takes place in a public space, care must be taken to ensure individuals know it is the space, not the behaviour, which is inappropriate.

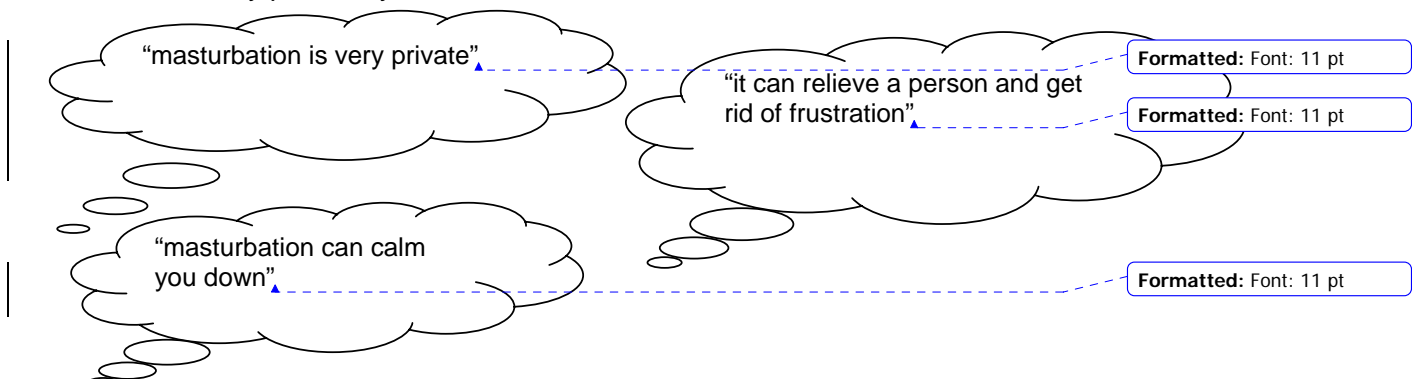
Where someone is unable to masturbate effectively but is expressing a desire to do so there are a variety of ways in which staff could offer education and support, ranging from pictorial information or videos to a structured and recorded programme of support to use a sex aid. What action is appropriate will depend upon the ability of the individual to communicate their wishes and their learning needs.

Support should be agreed as a part of the personal planning process, with the involvement of line managers and should be carefully recorded. Records kept should include details of risk assessments, including how the potential for abuse of individuals or allegations of abuse against staff will be dealt with. Outcomes need to be monitored and decisions on support regularly reviewed.

Staff are strictly forbidden to perform physical sexual relief or other sexual acts with or for an individual in their care. If staff are found to have done so this will result in disciplinary action and may result in a charge of indecent assault.

If masturbation is taking place in inappropriate situations on a regular basis, it may indicate other issues which need to be addressed and staff should seek advice from line managers. Points for consideration may include:

- Is the person able to masturbate effectively?
- Are there difficulties with a relationship?
- Is the person bored and in need of greater stimulation?
- Is there any possibility of abuse?



## PRACTICE EXAMPLE

Colin is 23 years old. He comes from a large family and enjoys the regular visits of his brothers and sisters. He likes going with them to the local café and going for a pint with the male staff.

He has good vision but has a significant hearing impairment. He has a hearing aid but prefers not to use it. Colin has a reasonable grasp of BSL and supports his signs with gestures. He sometimes draws pictures if he gets stuck but these can be difficult to interpret. He enjoys the TV and videos and can follow simple instruction leaflets with assistance.

Staff have noticed over the last few months that Colin is attempting to masturbate more often than before and sometimes for up to two hours. On a few occasions he has come out of his room with his underwear down and approached other people, whilst still attempting to masturbate. It is known that advice was sought 5 years ago from a specialist but no physical causes were discovered for his difficulties with masturbation. So this is an issue going back over a number of years but has only recently been observed again. Some people think it is beginning to interfere with other activities Colin enjoys. Staff have interpreted his recent behaviour in coming out of his room as a plea for assistance. Staff have interpreted his behaviour in two ways: he needs to be given some sort of stimulation to encourage satisfactory masturbation and he needs to develop a better technique for achieving orgasm.

Colin has participated in some SRE classes at the day centre and shows some awareness of relationships and sexual activity, although it is difficult to be sure what he really understands. He appears to be able to relate pictures and drawings to his own situation, for example he can match pictures of himself at different ages to appropriate line drawings. He does not attempt to masturbate in any other inappropriate places nor does he show any sexual interest in other people.

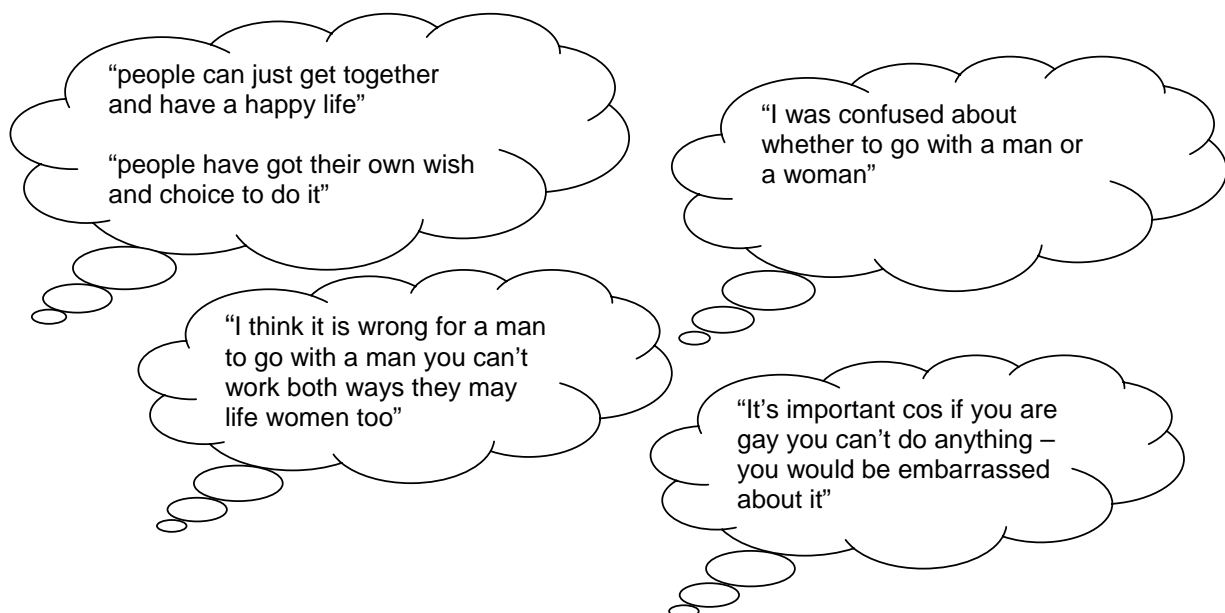
It is agreed that staff will use a combination of line drawings, photographs, models and videos illustrating where and how to masturbate effectively. Staff will support Colin's learning in one hour slots, twice a week over a number of weeks. Colin will also have access to pictures of men and women, heterosexual and homosexual sex in the sessions and at any time when he attempts to masturbate in the house. If none of these suggestions work, staff will support Colin to purchase a latex vibrating vagina that he can use over his penis to support masturbation. As Colin can see well, he can be helped to understand the instructions and to relate these to himself.

(Reproduced with permission of Common Knowledge, from 'Batteries Not Included')

## 7.4 Same Sex Relationships

A substantial minority of the population are gay, lesbian, bisexual or enjoy occasional same sex relationships. People with learning disabilities are as likely to be lesbian, gay or bisexual as the rest of the population and they have the same rights to conduct a consenting same sex relationship as any one else.

Some people with learning disabilities may have formed same sex relationships due to being segregated in same sex environments or because they have not been allowed to form heterosexual relationships. Some people with learning disabilities will not have been aware that same sex relationships are a possibility. Others may be attracted to same sex partners but be fearful of the consequences of expressing this attraction.



Some people may be happy to disclose their sexual orientation, others may not. It is important that people decide for themselves and are not pressured into making disclosures. On the other hand it is important not to limit people's choices in sexual and relationship partners. Any information and support provided to people with learning disabilities about relationships and sexuality should encourage people to discuss their feelings in relation to same sex attraction and make it clear that they would receive full support to discover and express their sexuality. There are agencies and support groups which can be accessed and these are listed in Appendix Three.

Just as it would be appropriate to consider the potential risks for an individual with a learning disability developing any new relationship, staff should consider the most appropriate ways in which individuals might meet same sex partners whilst keeping safe.

It is unacceptable for staff to impose negative beliefs or attitudes about same sex relationships on individuals with learning disabilities or their carers or to discriminate unfairly against them on the basis of these views and beliefs. It is the responsibility of staff to ensure that they and other staff do not treat people differently based on their relationship choices. Staff should avoid making assumptions about people's likely sexual orientation and sexual practice. It can be helpful to avoid using language that assumes someone is heterosexual, for example refer to someone's 'partner' rather than 'boyfriend/girlfriend'.

It is also unlawful to discriminate against staff on the basis of sexual orientation. Encountering homophobic behaviour in their workplace may be grounds for staff to raise a complaint of discrimination. Jokes, language assumptions and behaviour that discriminate against people who are gay, lesbian or bisexual should be challenged.

## PRACTICE EXAMPLE

John is deafblind as a result of congenital rubella syndrome and lived in a hospital for 20 years from the age of 16. He has been discharged from hospital to live in supported accommodation. Staff are supporting John to learn everything about his new home and about living in a town with neighbours who are not other hospital patients or staff. John communicates using sign language and symbols.

It is clear that John has had anal intercourse but what is not clear is if he consented to this and there is nothing in his records about relationships that he has had in the past. In his new home John shows a preference for male staff and regularly tries to touch staff and his male flat mates. John also masturbates in public areas of the house.

Some staff are concerned that John has previously been abused and needs help to reconcile this. Others think he is gay as he is clearly sexually aroused by other men and shows no interest in women at all. He has some vision and his interest in men extends to pictures and men on television.

Staff work hard to develop John's understanding of inappropriate touching of others, particularly other service users to whom they have a duty of care. This is proving a challenge as one of the other men lies on the settee a lot in the evenings and John seems really attracted to him. The other man seems neither to encourage his attention nor reject it. However it is always initiated by John and as consent is not clear, staff intervene and are now vigilant to try and avoid the situation arising. They are also trying to help him realise that the only appropriate places to masturbate are in his room or in the toilet. To help him with the former his room has recently been decorated with his favourite pictures of male stars that he helped choose out of magazines.

At John's review meeting everyone agrees that he should be supported to visit the local sexual health clinic for men who have sex with men for a sexual health screening and advice. They also discuss the possibility of supporting John to visit gay venues but these are mainly pubs and clubs. John has never shown an interest when he has visited pubs before. The concern is if John did meet another gay man who was interested in having sex with him would he be able to give consent and understand his right to insist on safer sex? This idea is not supported and instead the group ask staff to look at with John is what he enjoys doing socially by trying out more conventional social arenas rather than gay venues. They are also going to explore other ways for John to meet other gay men, such as a hill walking group as this is an activity he really enjoys.

(Reproduced with permission of Common Knowledge, from 'Batteries Not Included')

## 7.5 Pornography

In UK law, pornography is not illegal unless it qualifies as being obscene according to the provisions of the Obscene Publications Act 1959. Therefore it is the right of people with learning disabilities who are over the age of 18 to access and purchase legal pornographic materials. Staff have a duty of care to support individuals in making decisions and accessing appropriate support even if it is not in accord with their own personal beliefs. Staff may therefore be required to support individuals wishing to purchase or access legal pornography for their private use.

In these circumstances appropriate support to an individual with a learning disability would include pointing out that some people find pornography offensive. The range of perspectives and feelings held by various groups, particularly women's and faith groups on the use of pornography should be explained and how the use of such materials could infringe the rights of other people explored. People should be encouraged to make appropriate decisions about the private use of such materials. For example, it would not be acceptable for staff or other service users to be exposed to the use or display of pornography in public areas of residential accommodation or in day centres. Nor would it be acceptable for staff to have to provide intimate care in an individual's bedroom whilst pornographic materials were playing on a video.

Staff should also make clear the range of potential offences that could be committed if an individual uses pornography, including the dangers of using the internet for this purpose. Pornographic material is considered to be 'obscene' if it is judged to have a 'tendency to deprave and corrupt' the intended audience. As a rough guide, material that is offered for sale in newsagents and in licensed sex shops can be assumed to be legal. Possession of child pornography (indecent photographs of children under the age of 16) is a serious criminal offence. Staff must not assist with the purchase of material that is illegal.

Internet pornography has become popular due to the level of anonymity that it provides and the fact that pornography is available in large quantities at a fraction of the cost of published material. Staff should be aware that individuals might access pornography by this means and that some sites contain illegal pornography. Staff should highlight to individuals the types of images/sites that should be avoided. As a general rule, access to websites that contain references such as extreme/obscene, sex, nudity, dating and several other categories are blocked when using computers covered by public agency websites. Many other employers also operate such systems and have IT policies on accessing sexually explicit material at work. However staff should still be able to access e-learning tools and recommended internet sites around relationships and sexual wellbeing for use as part of an educational programme, if they make a request in the required format using approved procedures.

## 7.6 Contraception

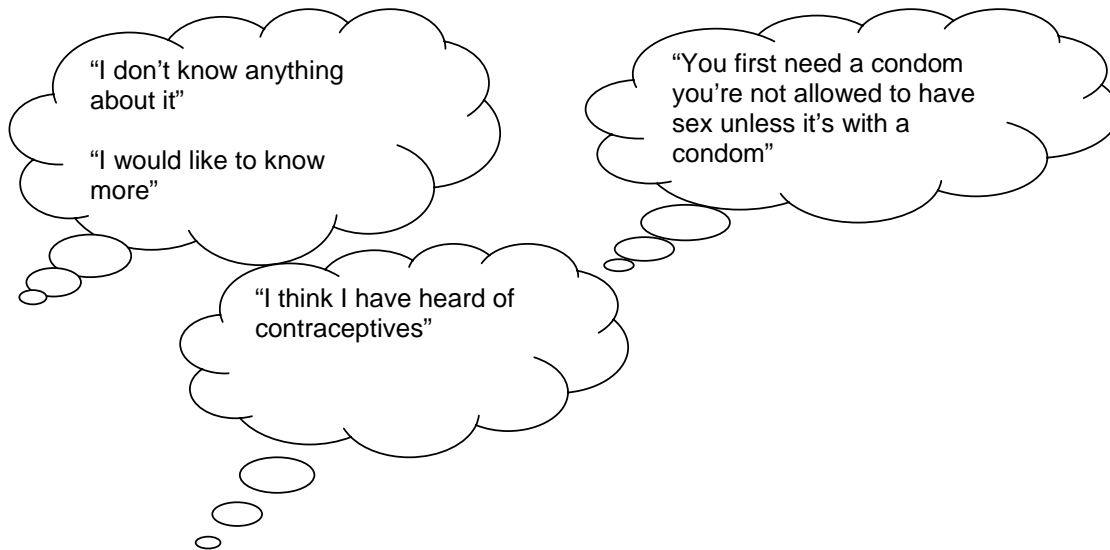
People with learning disabilities have the same rights as others to access information and support with contraception. Ideally individuals with learning disabilities should choose the method of contraception that suits them best and should be supported through referral to primary care resources and specialist agencies as appropriate. Staff, carers and service providers can highlight the benefits of contraception and ensure individuals understand the information given about choices and use.

Contraception should be seen in terms of the needs of the individual rather than in terms of relieving the anxieties of workers and relatives. Staff should not inform an individual's relative or partner about contraceptive choices unless they are given permission to do so. Staff and carers do not have the right to make decisions about contraception for someone with a learning disability without the individual's consent, unless they have been given authority by the court to do so. Staff should check that any decision by the court covers this area.

Staff should familiarise themselves with the different methods of contraception available so that they can answer any queries individuals have or discuss the issue as part of personal care planning about relationships and sexuality. Consideration should be given to an individual's cultural and religious views, which may forbid the use of some forms of contraception. It would be good practice for all care venues to have a choice of condoms and lubricants available to people with learning disabilities either to buy through condom machines or to source free provision through Highland Sexual Health. Contraception such as 'the pill' or depo provera needs to be prescribed by a GP or sexual health service. Emergency contraception can be prescribed by GPs and sexual health services and can also be bought at local pharmacies. It is available free of charge from A&E departments out of hours and NHS 24 can arrange for it to be supplied.

Staff should promote 'safe sex' practices which offer protection against HIV and other sexually transmitted infections as well as unwanted pregnancy and encourage the use of condoms as an appropriate 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 the use of condoms with a partner
- Which condoms are appropriate for anal sex, oral sex and vaginal sex
- Information about the use of lubrication
- What to do if a condom bursts, falls off or is removed during intercourse



### PRACTICE EXAMPLE

Susan is 21 and has been having a relationship with Bill, who is 32, for a number of months. Recently Bill has been visiting Susan regularly at home and they have been spending a lot of time in her bedroom. Susan confides in a member of staff that she and Bill both want to have sex but that she is worried she might get pregnant.

Having agreed with Susan that she would like to discuss this further and that she wants Bill to be involved, a series of meetings are arranged with Susan and Bill individually and together. Initially staff explore with Susan and Bill individually what their understanding of sex is and that it is a joint decision for them to have sex. Staff also check whether there might be any need for emergency contraception to be offered but this doesn't seem to be the case. Susan and Bill are reassured about confidentiality issues and encouraged to contact staff at any time if they have any questions before the next meeting.

At a meeting with Susan and Bill, information is provided on the different methods of contraception and how these can be obtained. Staff explain that it is up to the couple to decide what method of contraception will suit them best and that if they are unsure they can get further advice from their Doctor, Highland Sexual Health or the Brook Advisory Service, given Susan is under 26. Staff also explain that using condoms can help protect them from infections.

Bill decides he would like to speak to his GP first and Susan wants more advice from the Brook. Staff offer to help arrange their appointments and ask whether Susan and Bill would like someone to go with them. Susan decides to ask her sister to go with her. Bill decides to go on his own. Staff ask if they want to arrange a follow up meeting after their visits and this is agreed.



## **7.7 Sterilisation and Vasectomy**

Sterilisation covers both the sterilisation of women and vasectomy for men. Both terms are used in this section however the word sterilisation is used in relation to women only.

Sterilisation and vasectomy are generally chosen when people have decided they never want to have children or don't want to have more children. They should be regarded as permanent methods of contraception, although some procedures are reversible. Sterilisation is an invasive procedure and can be traumatic. Whilst women may be given a hysterectomy for medical reasons this is radical surgery and should be a last resort. Care needs to be taken that medical reasons are not being used inappropriately to justify sterilisation. Whilst sterilisation and vasectomy will prevent pregnancy, neither will protect against HIV and other sexually transmitted infections.

A decision to undergo sterilisation or vasectomy is clearly a decision of magnitude that requires careful consideration. Individuals with learning disabilities who are considering these methods of contraception must be offered the appropriate support and guidance from specialist services to ensure they understand the procedures and the implications of the procedure.

A multi-disciplinary approach to providing accessible information, advice and support should be adopted to assist the individual to make a decision with no one person having undue influence. Demands for sterilisation or vasectomy from family members or partners should not take precedence over the needs and wants of people with a learning disability. This should be clearly explained to anyone requesting such procedures.

If an adult with a learning disability lacks the capacity to make informed decisions about any form of medical treatment, their doctor should ensure that their treatment needs are detailed in a relevant certificate and treatment plan (Part 5, Section 47 of the Adults with Incapacity (Scotland) Act 2000) This section covers all health matters not just sexual health. When consent cannot be given, sterilisation for non-medical reasons can only occur with the sanction of the court.

## 7.8 Abortion

A woman with learning disabilities has the right to information, counselling and support to make an informed decision about whether to continue a 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. Parental or carer demands for a termination must not override the rights and well being of the woman concerned. Information, pregnancy testing and referral for termination is available from GPs, Highland Sexual Health and Highland Brook Advisory Centre.

Abortion is regulated by statute and can only be authorised by appropriate medical practitioners. Judgements on the ability of a person with learning disabilities to be a parent are not grounds for termination of pregnancy, just as this would not be considered sufficient grounds for anyone else. 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.

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. The decisions 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.

When a decision has been made regarding the outcome of a pregnancy, a multi-disciplinary approach should be planned in order to offer and/or arrange support for the individual as appropriate, for example counselling in the case of abortion or antenatal care for women continuing with a pregnancy.

## **8 SEXUAL HEALTH**

### **8.1 Sexual Health Services**

People with learning disabilities have the same rights to services and information as everyone else. Staff should make individuals aware of sexual health services, what they can provide and where and how they can be accessed. Details of some services are provided in Appendix Four. Full details are provided in a Directory of Sexual Health Services available from Highland NHS Board Health Information and Resources Service.

Accessing sexual health services can be embarrassing and difficult for some people. It may be appropriate for staff to accompany people with learning disabilities to such services if someone wants or requests this.

Individuals have the right to access medical notes about themselves. Staff should make people aware of these rights and support an informed decision about whether or not people make a request to view their notes. Time should be taken to explain the notes to an individual in a way that enables them to understand what is written.

Where sexual health services fail to meet the needs of people with learning disabilities staff should make people aware of complaints procedures and advocacy services. Staff should encourage people to participate in opportunities to be involved and consulted about the development of sexual health services.

## 8.2 Sexually Transmitted Infections

People with learning disabilities have the right to be sexually active and are therefore as likely as the rest of the population to come into contact with sexually transmitted infections. STIs have significant health implications for individuals and their partners. They can cause pain, infertility and even death if left undiagnosed and/or untreated.

People with learning disabilities need to know:

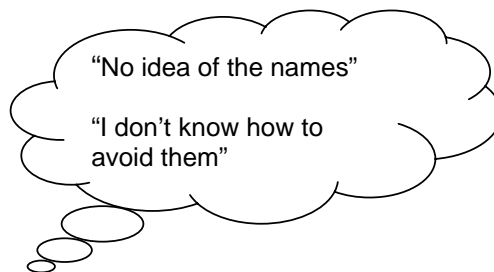
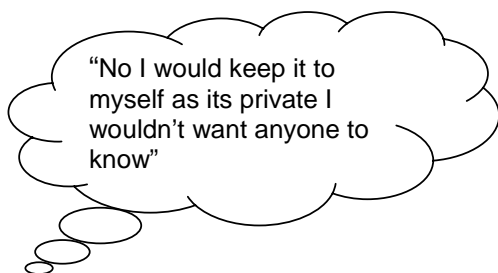
- The range of different STIs and possible symptoms
- How an STI is passed on
- How to prevent infection
- Where to go for testing and treatment
- Who to talk to for confidential information and advice

Staff should be aware of the symptoms associated with STIs and of the services available locally. Awareness and use of sexual health services should be encouraged and promoted. If someone complains of symptoms associated with STIs staff should discuss and agree a plan of action with the individual, including seeking medical advice and treatment as appropriate. Some STIs have no symptoms therefore it is important that people are encouraged to use screening services irrespective of any indications something is wrong.

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

The medical background and matters relating to the sexual health of someone with learning disabilities is strictly confidential and information on STIs must be restricted to those who need to know.

Staff should be aware that an STI is a possible indicator of sexual abuse. However if someone with a learning disability presents with an STI, this in itself, should not be seen as sufficient reason to activate the Vulnerable Adults Policy.



### 8.3 HIV And AIDS

As for the general population, HIV and AIDS pose a severe health risk to people with 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 that is accessible to them.

People with learning disabilities need to know:

- What are HIV and AIDS?
- How HIV and AIDS are passed on
- How to prevent infection
- Where to get tested and treated
- Medical and social implications of infection
- Rights to confidentiality

Basic information on HIV and AIDS can be found in leaflets held at NHS Highland Board Health Promotion Library, from Terence Higgins Trust Highland, Highland Sexual Health clinics and Brook.

People with learning disabilities who are HIV positive, their parents and carers will need specific resources and support, which take account of their differing needs. This might include:

- Support to access monitoring and treatment and information on drug regimes
- Provision of accessible information about HIV transmission and prevention, including access to condoms and the skills to use them effectively
- Information about other STIs and the particular relevance these have for people with HIV
- Support around disclosure of HIV status
- Support in dealing with the psychological and social impact of HIV and discrimination
- Access to peer support and voluntary services

Services and professionals should address the needs of people with learning disabilities and HIV in a way which is accessible and appropriate to their communication needs.

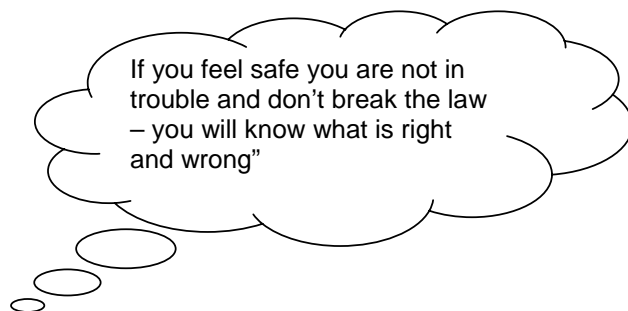
Staff should familiarise themselves with local information and guidelines on HIV and AIDS particularly training and support guidelines and hygiene and infection control.

## 9. SAFETY AND PROTECTION

People with learning disabilities have the right to be protected from situations which leave them vulnerable to physical, emotional, or sexual abuse or exploitation by others. Carers have the right to know that there is appropriate protection to ensure the 'safety' of the person they care for.

The Highland Policy, Good Practice Guidance and Procedures on the Protection of Vulnerable Adults provides guidance on what staff must do if they have been informed that abuse is occurring or there is suspicion that it might be. Staff should be familiar with the content of the policy and guidance and what procedures need to be followed when abuse is suspected. All staff must also have an enhanced Disclosure Scotland check performed.

One of the best ways to protect people from abuse is to give them information about personal safety and opportunities to develop skills to keep themselves safe. The more people are able to try things out for themselves and set their own boundaries the better they will be at stating and managing those boundaries and asserting their rights. Staff should make it clear to people with learning disabilities that if they tell staff that they do not feel safe they will be listened to, informed and involved in decisions about what course of action to take.



To mature and learn risk assessment skills people with learning disabilities need to be given the space and freedom to make choices for themselves and to make mistakes and learn from these. However people with learning disabilities, especially those with profound and complex disabilities, may be unable to communicate feeling unsafe or things that may have happened to them. Staff should be alert for signs of emotional or physical changes and changes in behaviour that might indicate abuse.

***The following indicators are not in themselves proof of an abusive situation nor are they an exhaustive list. They are a guide which may indicate some forms of abuse. The absence of the physical indicators of sexual abuse does not necessarily invalidate a complaint or disclosure.***

### **1. Behavioural Indicators of General Abuse**

- Overly compliant behaviour
- Acting out aggressive behaviour
- Reluctance to be at home
- Poor peer relations, inability to make friends
- Lack of trust, particularly with significant others
- Regressive behaviour
- Withdrawal behaviour
- Drop in performance
- Attempts to leave home
- Self harming behaviour
- Suicidal feelings
- Depression
- Sudden onset of eating problems

### **2. Sexual Abuse Indicators**

- Hints about sexual activity that is unrelated to an appropriate relationship
- A sudden change in uncharacteristic sexual 'play' with objects, peers or themselves
- Sexually aggressive behaviour towards others
- Excessive fear/apprehension of or withdrawal from relationships or conversely very aggressive behaviour
- Excessive attachment to people
- Inappropriate seductive behaviour
- Excessive fears of settling in bed or being left alone
- Unusual reluctance to join in activities involving the removal of clothes such as swimming

### **3. Physical Indicators of Sexual Abuse**

- Torn, stained or blooded underclothes
- Foreign bodies in the genital or rectal openings
- Bruising, laceration, bleeding of external genitalia
- Overt trauma to same areas leading to difficulty in walking or sitting, constipation or pain/bleeding urinating or defecating, internal vaginal bleeding etc.
- Infections, discharges or STIs
- Pregnancy

## **APPENDIX ONE LEGAL FRAMEWORK**

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

There are two groups of legal rules which are relevant to sexual relationships and people with learning disabilities. The first group are those which apply to everybody and the second are the special provisions which are intended to give extra protection to people who are mentally impaired and perceived as being vulnerable.

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

Special provisions are now covered under **the Mental Health (Care and Treatment) (Scotland) Act 2003**.

It is an offence for any person, male or female, to engage in a sexual act with someone with a learning disability if the individual did not consent or was incapable of consenting, or their consent cannot be regarded as valid, e.g. due to threats or intimidation. Someone is regarded as incapable of consenting if they are unable to:

- Understand what the act is
- Form a decision about whether to engage in the act; or
- Communicate any such decision

Sexual act means any activity which a reasonable person would regard as sexual, previously only sexual intercourse was illegal.

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

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 the Act to have unlawful sexual intercourse.

### **Adults With Incapacity (Scotland) Act 2000**

The purpose of this Act is 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.



## **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 practical 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.

## **Disclosure of Abuse**

Staff need to be aware of the Highland Policy, Good Practice Guidance and Procedures on the Protection of Vulnerable Adults which sets out 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 but not women. Under the Act homosexual acts are legal if:

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

## **APPENDIX 2 CARERS VIEWS**

As part of the Love Is...project there have been a number of attempts to obtain the views of families and unpaid carers. Originally the plan was to carry out a focus group discussion and a leaflet was produced describing the project and opportunity to join a focus group. Over 750 leaflets were distributed through a variety of means:

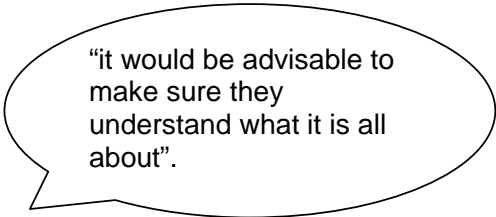
- Mailed direct to families via the Princess Royal Trust Highland Carers Project
- Available to pick up at the PRT open day for carers during Carers Week
- Distributed through key contacts such as the National Autistic Society development officer and the Highland Council Autism Services development officer
- Distributed at LIG meetings and via other forums such as the New Craigs families group and local community care forums.
- Sent directly to Enable branches in Highland and followed up with phone calls.

Unfortunately only two people responded to the focus group invitation therefore a short questionnaire was issued again via the Highland Carers Project. The New Craigs families group also agreed to discuss the issue at one of their meetings.

19 questionnaires have so far been returned (from around 100 issued). Thanks are due to all those people who took the time to reply and to the Highland Carers Project for their assistance.

### **Should People With Learning Disabilities Be Encouraged To Form Friendships And Personal Relationships?**

Nine carers simply answered yes to this question. A number of responses were qualified by concerns for personal safety, the needs of the individual and the availability of support from staff. One carer felt that there should be no encouragement but if it happened:



“it would be advisable to make sure they understand what it is all about”.

**Other comments included:**

“friendships yes,  
personal relationships –  
depends on many  
things but probably yes”

“yes but this  
encouragement should be  
natural and allowed to  
develop at an individual’s  
pace and not forced in any  
way. By forced I mean  
‘over-actively encouraged’.

“As long as they  
are supervised”

“..they are exactly the  
same as any other human  
being its just that they  
need that little bit of extra  
care”

“if it is fine with that  
person and within a  
safe environment”

“yes, but needs managed.  
Don’t open doors that can’t  
close – stress destroys the  
family”

**Do You Think People With Learning Disabilities Have Sexual Feelings And Needs?**

Nearly everyone answered yes to this question. A few answers referred again to differences between individuals and this needed to be taken into account.

“I know my son has,  
although he very rarely says  
anything. He does want to  
live with a girl and have a  
child”

"yes...to varying degrees"

"...everyone has needs these people are the same regarding feelings as anyone else. Some people don't think they have."

"some do, some do not"

"..some people do not seem to develop beyond 'child-like' emotional/physical status and this should also be respected"

### **Do You Think The Sexual Awareness of People With Learning Disabilities Should be discouraged, tolerated, encouraged or none of these?**

There were a range of views expressed in response to this question and a number of people either did not answer or gave a qualified response. Six carers chose tolerated, six chose encouraged with two carers qualifying their answers with comments. Five chose 'none of these'.

"encouraged – naturally not actively"

"I wouldn't encourage it. But would try to advise as best as possible, after all they are normal people with feelings as well"

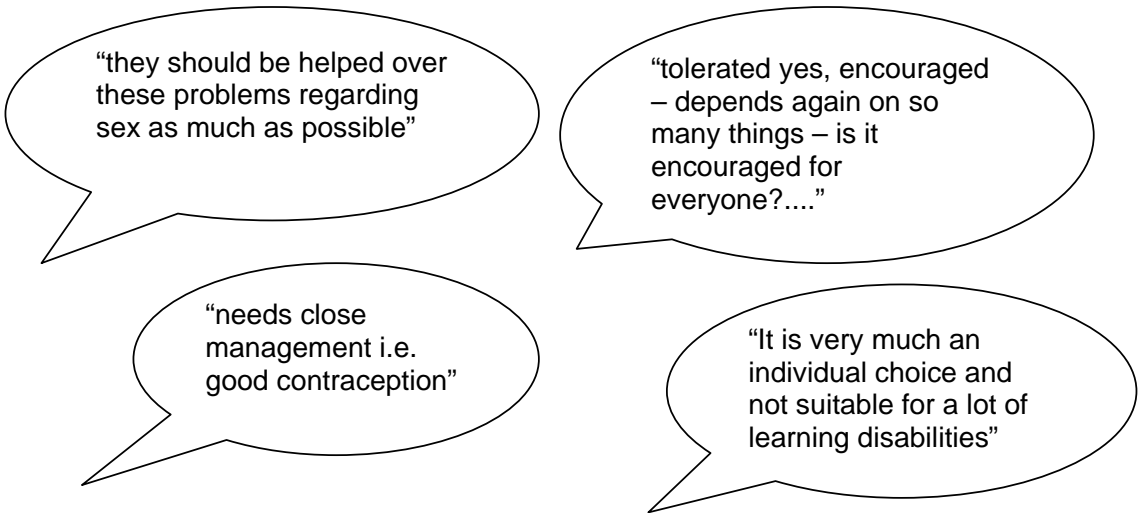
"encouraged – though supervised"

"discouraged/tolerated, but understood sympathetically"

"Maybe not encouraged but supported"

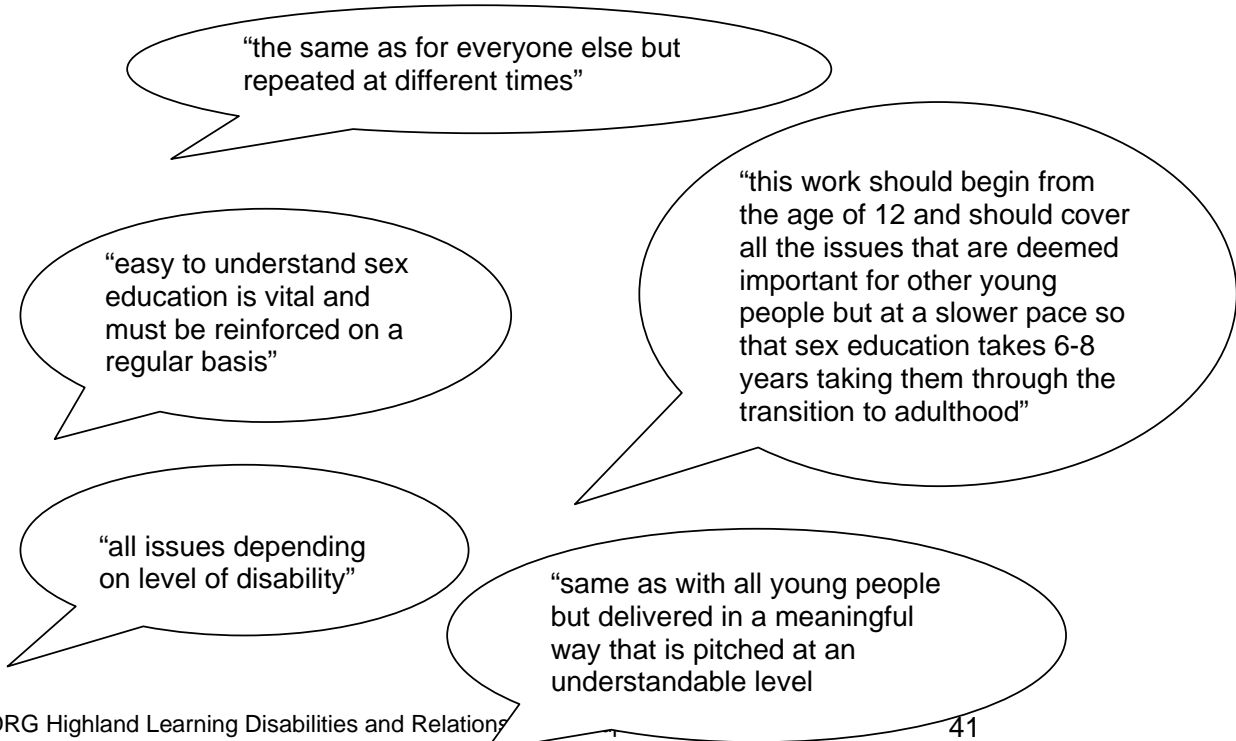
"Should begin in secondary school. Should have simple pictures /videos and cues to support the teaching"

"as far as possible their sexual awareness should be treated in the same way as those without learning disabilities – obviously everyone is different and should be treated so."



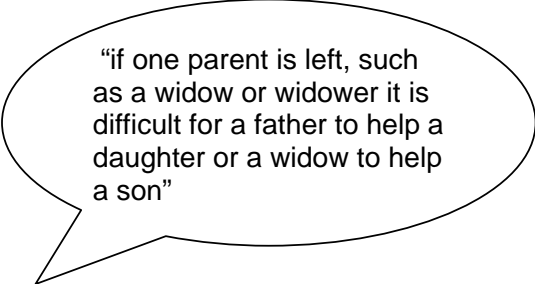
### **What Issues Should Be Covered in Sex Education Work With People With Learning Disabilities?**

A number of practical topics were mentioned in response to this question including contraception, sexually transmitted infections, cleanliness, body awareness, babies, pornography and dangers of the internet. Others mentioned emotional aspects of relationships, developing respect for self and others and decision making skills. Again carers emphasised the need to relate sex education to people’s individual abilities and to reinforce messages on an ongoing basis.

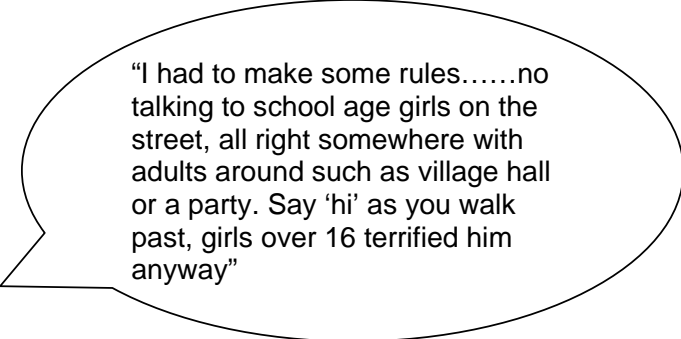


## What Aspects of Relationships and Sexuality Create Difficulties For You As A Carer Of Someone With A Learning Disability?

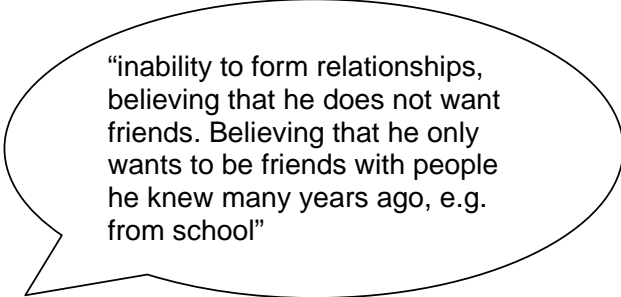
A number of carers said they had had no difficulties so far. Issues mentioned by others most often included: appropriate behaviours - with regard to other people and masturbation – preventing pregnancy, having children and keeping people safe. A couple of carers mentioned emotional issues such as developing an awareness of other people's needs and feelings. Three carers mentioned difficulties in relation to a lack of male or female role models in the family when raising children on their own.



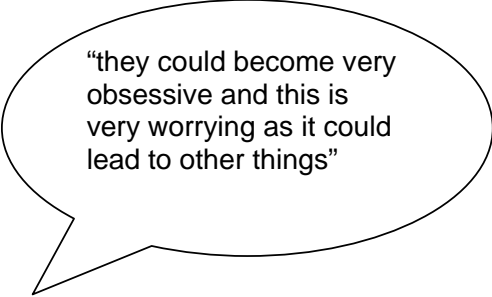
"if one parent is left, such as a widow or widower it is difficult for a father to help a daughter or a widow to help a son"



"I had to make some rules.....no talking to school age girls on the street, all right somewhere with adults around such as village hall or a party. Say 'hi' as you walk past, girls over 16 terrified him anyway"



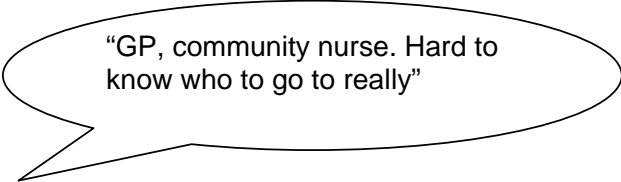
"inability to form relationships, believing that he does not want friends. Believing that he only wants to be friends with people he knew many years ago, e.g. from school"



"they could become very obsessive and this is very worrying as it could lead to other things"

## Who Would You Approach For Information And Advice?

Three carers said they didn't know who they would approach. Nearly all of the other respondents indicated either a GP or someone from Social Work. Other suggestions included learning disability nurse, a psychologist, the school, the Carers Service and friends and family.



"GP, community nurse. Hard to know who to go to really"

## Other Comments

Carers made some general final comments on this topic, a number of them referred again to the need to deal with this topic on a one to one basis depending on the abilities and needs of individuals.

"It is a very complicated issue and each case should be treated individually as far as possible"

"My son is 9. I am preparing for the teenage years now by curbing inappropriate behaviours now. I also take every opportunity to talk openly about issues, e.g. my niece is having a baby and we are looking closely at this process as she develops her 'bump'. I believe early intervention is the key to making relationships and sexuality understandable and meaningful for people with learning disabilities"

"Friendships are probably the most difficult aspect of life to deal with, it has to be so individualistic. My son was not quick to develop sexual awareness – probably ten years behind his brother and now that he is 37 I feel that he is 'over' the 'problem' as a problem. He is very shy and would I think like very much to have a girl-friend/male chum but so far no luck. It is difficult to asses how much this upsets him."

"This is an especially difficult issue for me with a seventeen year old son with special needs, as I am a single parent. I can only demonstrate a female perspective and feel there must be a gap for my son, which only a male influence can fill"

"I think it is very important for the person's social background and beliefs to be considered when teaching this topic. As a committed Christian we taught our daughter that sex outside marriage is wrong. Therefore we would seek to uphold that belief with our learning disabled son who is also a Christian (by choice)."

"I think people with learning difficulties should be allowed the same choice as everybody else. Also I have seen how frustrated they can get and it can lead to hostility as they don't know how to deal with what's wrong with them as it has never been explained to them properly"

## **APPENDIX THREE USEFUL RESOURCES**

### **Sexual Health and Relationships. A Review of Resources For People With Learning Disabilities**

**Publisher Name: Sexual Health and Wellbeing Learning Network**

**Editors: K Hasler, R Yates and J Anderson.**

**[www.healthscotland.com/sexualhealth](http://www.healthscotland.com/sexualhealth)**

**Very useful review of resources on relationships and sexuality aimed at people with learning disabilities. It contains comments from professionals about how useful each resource is. Other resources are detailed below.**

### **Autism – Asperger’s and Sexuality: Puberty and Beyond.**

**Authors – J and M Newport, T Bolick. Available through Amazon.**

### **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.**

### **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**

### **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**



**Hysterectomy – having the operation**  
**Publisher Name: Women’s Health and The Elfrida Society**  
**All about having a hysterectomy**

**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**  
**Publisher: Walsall Women’s Group**  
**Video on safety for women with learning disabilities and information pack**

**No More Abuse**  
**Publisher Name: VOICE UK**  
**A book for people with learning disabilities to help them look after themselves and make sure they are safe.**

**Out and About! Supporting people with learning disabilities around same sex relationships**  
**Publisher Name: Partners in Advocacy**

**Period Problems – What can you do?**  
**Publisher Name: Women’s Health**  
**Information about what to do about period problems**

**Planning a Baby**  
**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**

**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**  
**Publisher Name: Frances Lea**  
**Drama about how a women with learning disabilities decides whether to have sex with her boyfriend.**

**Sexual abuse of adults with learning difficulties**  
Authors: H Brown, V Turk and J Stein  
Publisher Name: Joseph Rowntree Foundation

**Social Care Research Findings No 46 1994**  
**Sexual Knowledge and Education**  
Publisher Name: BILD  
Collection of papers

**Sexual Relationships**  
Publisher Name: BBC Recorded  
Heart of the Matter programme about problems of sexual relationships for people with learning disabilities

**Sexuality and Sexual Rights of People with Learning Disabilities**  
Author: P Cambridge  
Publisher Name: BILD Publications  
ISBN: 1873791739

**Sexuality and Learning Disability**  
Author: Jennie Holmes  
Publisher Name: Contact A Family  
Report on a conference

**Stop – No More Abuse**  
Publisher Name: VOICE UK  
A book for people with learning disabilities, to help them look after themselves and keep safe.

**Your Rights About Sex**  
Author: Michelle McCarthy  
Publisher Name: BILD Publications  
ISBN: 1873791526  
Booklet for people with learning disabilities

**The Big Sex Show: A Lawnmowers booklet about sex, meeting people and condoms.**  
Publisher Name: The Lawnmowers  
A guide to safe sex. A pack with a video and booklet made by people with learning disabilities for people with learning disabilities.

**Understanding Sex**  
Author: M Doyle and D 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: A Craft and D Stewart

Publisher Name: The Home and School Council

ISBN: 0901181706

#### **USEFUL WEBSITES**

[www.bild.org.uk](http://www.bild.org.uk)

British Institute of Learning Disabilities

[www.brook.org.uk](http://www.brook.org.uk)

Brook Advisory Centres

[www.healthscotland.com](http://www.healthscotland.com)

NHS Health Scotland

[www.highland.gov.uk](http://www.highland.gov.uk)

Highland Council

[www.scotland-autism.org.uk](http://www.scotland-autism.org.uk)

National Autistic Society in Scotland

[www.autism-in-scotland.org.uk](http://www.autism-in-scotland.org.uk)

Scottish Society for Autism

[www.healthyhighlander.org.uk](http://www.healthyhighlander.org.uk)

health information and resources approved by NHS Highland

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

British Foundation for Learning Disabilities

[www.lgbthealth.org.uk](http://www.lgbthealth.org.uk)

Lesbian, Gay, Bisexual and Transgender Centre for Health and Wellbeing

[www.me-and-us.com](http://www.me-and-us.com)

list of useful resources for relationships and sex education

[www.nhshighland.scot.nhs.uk](http://www.nhshighland.scot.nhs.uk)

NHS Highland Board

[www.tash.org](http://www.tash.org)

website of American association of people with learning disabilities

[www.mcks.scot.nhs.uk](http://www.mcks.scot.nhs.uk) - Lothian policy website

## **APPENDIX FOUR USEFUL SERVICE CONTACTS**

### **Highland Sexual Health**

Highland Sexual Health is for anyone needing a full specialist clinical service for contraception and family planning, diagnosis and treatment of sexually transmitted infections and general sexual health advice, information and treatment.

Clinics are held throughout Highland  
For details contact 01463 704202

### **Terence Higgins Trust Highland**

A FREE confidential and anonymous service providing information, testing, support and counselling for anyone living with HIV and AIDS or for those close to them. Support services for anyone whose sexual choices have raised uncomfortable issues for them, their partner or family. Support and social groups for the lesbian, gay, bisexual and transgendered community in Highland.

34 Waterloo Place Inverness IV1 1NB 01463 711585

### **Highland Brook Advisory Centre**

Brook provides a free and confidential sexual health service for under 25s. This includes information, advice, counseling and treatment.

77 Church St. Inverness IV1 1ES 01463 24243