

PEOPLE'S RIGHTS AND RESPONSIBILITIES

You should always start from the principle that people with learning disabilities have the same rights and responsibilities as anyone else. However, there are practical, legal and protection issues which may in some instances modify this in practice and you will see these exceptions under the relevant sections of these guidelines.

VALUING DIFFERENCE

Fife benefits from a wide range of diverse communities with their own distinctive cultural and religious beliefs and practices. Increasingly many staff, service users and parents will come from these minority communities some of which will have very clear views about the place of sexuality in people's lives. Matters such as sexual orientation, masturbation, pornography and sexual relationships outside of marriage will often present great difficulties for staff and parents from these communities. Contraception, for example, may be unacceptable or controversial for Roman Catholics and Muslims.

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

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

It is also important that where a person's ability to consent is very clear or where a particular course of action is seen as being in their best interests, just like anybody else the person has the right to step, or be aided to step, outside the values of their community, as long as they remain within the limits of the law. However, the consequences for the person of doing so will often have far reaching effects in terms of their place within their family and the larger community. At times like this, staff have a duty to act sensitively to the family's needs, therefore decisions which may have long-term consequences

must not be taken lightly, and should be part of the care planning process. Particularly sensitive issues should be discussed with your line manager.

You have your own attitudes and views about sexuality, and they may be different from those of the other people you work with. People's views vary on this subject because they come from different religions, cultures and backgrounds.

It is vital that staff have a basic knowledge of Human Rights legislation and that they ensure that the rights of service users are upheld in the context of this legislation. The Adults with Incapacity Act will also need to be taken into consideration when individuals are being supported to take a particular course of action.

(see Appendix re Legislative Framework)

In your work you need to be careful not to impose your views on other people. You may find certain behaviour unacceptable, but you shouldn't be openly disapproving if people have a right to do it. If you are concerned about certain behaviour, you should check with your line manager. If your feelings about the behaviour are still of concern, you have the right and the obligation to discuss this with your line manager. If you remain concerned, discuss this with another senior manager.

Our attitudes and views come across because of what we say, how we say it, and what we don't say. You and your colleagues should be consistent in how you respond to people's behaviour and needs, otherwise people will get confused or even frightened.

The care management process or individual care plan can define the best ways to help individuals express their sexuality. Any action that is agreed within a care plan should not be altered by individual members of staff. In any discussion (including the care plan) staff should ensure that individuals are enabled to contribute meaningfully in any meeting, even if this includes them making an input without attending should they feel unable to do so.

Issues of confidentiality need to be consistently addressed to recognise the rights of individuals. In general, information of a personal nature should be discussed sensitively and with respect for the person themselves and those who they want to be involved. In situations where workers feel the person themselves or someone else is vulnerable for whatever reason they should discuss the matter with their line manager.

STAFF RESPONSIBILITIES

It is not the job of staff to police the sexual relationships of other adults, but it is important that you are satisfied that abuse/exploitation is not taking place. However, there is a need to be aware of sexual issues that arise for individuals because there is a duty of care in order to ensure that:-

- Somebody is not breaking the law.
- The way one person expresses their sexuality does not impact negatively on themselves or the life of another person or persons.
- Individuals receive protection where necessary.

Difficulty can easily arise in making a sound judgement over all the points above. It is often impossible to make an objective decision in these matters and many situations may carry positive as well as negative outcomes. You must not make these decisions on your own.

If you feel that a sexual relationship or another matter around sexuality which worries you is developing, then discuss your concerns with your line manager, who is there to support you. It is important that you are satisfied that abuse/exploitation is not taking place. A risk assessment is one way in which this evaluation can be made.

It is important that we acknowledge the complexity of sexuality in relation to people with learning disabilities, and take this into account in our dealing with these matters. E.g. if two adults with learning disabilities say they want to have sex but are not informed about contraception, then there is a need to protect in this situation and it would be correct to advise the couple to “hold fire” until they were more aware of the consequences of their actions. However, no two situations are quite the same, and therefore it is advisable to speak with the individuals concerned as the relationship begins to develop. It is also important to check this out with your line manager so that it’s clear which staff member ensures that the matter is dealt with sensitively and that details of an individual’s sexuality does not become public property. (See section on Valuing Difference relating to issues of confidentiality).

N.B. Do not leave yourself or others vulnerable. If in doubt, discuss with your line manager or the most senior person available. Also see the guidelines on Sexual Abuse of Adults with a Learning Disability, Guidelines for Services in Fife.

PARENTS AND CARERS INVOLVEMENT

The involvement and co-operation of parents is very important. Parents will be involved in different ways depending on the situation of the service user.

We should not assume that a parent will view their son or daughter’s sexuality in a negative light. More and more parents are seeing the need for matters around sexuality to be dealt with in a positive way. It is important to remember that if parents have a ‘protective’ attitude this can often be because of their awareness of their son’s or daughter’s particular vulnerability. There must be a balance between parents’ wishes being acknowledged and the right of an adult person with a learning disability to make their own choices.

Problems may arise where the wishes of parents are different from those of their son or daughter. Parents and carers have the right to receive support. Where conflicts of interest arise, service users have the right to an independent advocate. Ideally you will be working with parents and the person with learning disabilities towards the same end.

You may need to discuss matters relating to sexuality with an individual's parents. You should be clear on what is okay in this regard. In particular you need to be clear that you have the person's permission to talk about personal matters with his or her parents. If in doubt you should assume you don't have permission. Having said this there will be some situations where, in order to protect the individual, you have a responsibility to inform and involve parents. Check out any uncertainties you may have with your line manager and keep him/her in touch with what is going on. Individual wishes should be noted in the care planning process. (See also under Contraception and Pregnancy and Parenthood).

When sexuality work is proposed for someone living with their parents, it is important that they are informed in order to support the learning. If someone lives in a group home etc the same code of practice applies with the person's primary carers and parents, if they are still involved in their life. Parents and other primary carers will benefit from having some idea of what material will be used before a programme starts, and having the chance to discuss it with those planning to do the work. Again, talk through the reasons for letting parents/carers know with the individual so that he/she has the opportunity for discussion.

SEXUAL ACTIVITY

It is difficult to make hard and fast rules about appropriate and inappropriate touch. It is always important that a number of key questions are asked of staff or service users if they have not invited another person to touch them:

- Do I feel comfortable being touched in this way?
- Is this touch intended to convey friendship?

If the answer to these questions is 'yes' then it may be that this touch is okay but it would also depend on whether it is appropriate. People within the community of learning disability often hug and greet one another with great enthusiasm. French people seem to often do the same! In a way it has become a tradition of both cultures. By being too rigorous in setting rules about touch, we may deprive people of a very meaningful part of the way they relate to those they care about. Having said this, it is absolutely essential that any forms of touch, be that anything from a handshake to a kiss, should be mutually consenting and appreciated by both parties.

It would never be appropriate for one service user to touch another service user or staff member if the touch was not welcomed or if it had an intention, that was other than conveying friendship. Often the kind of touch which is of

concern to staff is that which is made as a means of sexual gratification. Where staff feel this is the case (be it towards a staff member or service user) they have the duty to:

- Point out to the service user how unwelcome or inappropriate the touch is.
- Report the concern to the line manager.
- Monitor the situation and in consultation with the line manager to give consistent messages of disapproval if the behaviour continues.

Very often this type of behaviour continues to exist because service users are given unclear and conflicting messages by staff. Remember, that even the most negative behaviour will have a reason behind it. It may be that the service user has needs that have gone unrecognised and unmet and this behaviour is a symptom of the inability of those around him/her to deal appropriately with it.

PORNOGRAPHY

The word 'pornography' means different things to different people. These Guidelines accept the following definition:

"Writing, pictures or films etc that are intended to stimulate erotic feelings by description or portrayal of sexual activity".

If a service user brings pornography into an establishment, it is important to remember that people with a learning disability have a right to acquire and use pornographic material at the same legal age as anybody else (currently 18). This includes magazines, videos and books. It is illegal to sell or distribute some extreme pornography but not to possess it.

You should not criticise a service user for having or using pornography. However, this is a delicate matter as the sharing of material could in itself be abusive.

You may wish to discuss with someone who uses pornography the way in which such material can:

- Give a distorted picture of sexuality.
- Degrade people.
- Cause offence.

You may need to explain that pornography can only be displayed or used in a private place such as a bedroom. If you are aware that one service user is inviting another into his/her room to look at pornographic material you need to ask yourself if the second person is able to give consent to this as otherwise this may in itself be a form of exploitation or sexual abuse. It could also be a

stage in 'grooming' somebody for sexual abuse. If you have concerns you should always check with your line manager.

Staff and visitors must not bring pornographic material to any day care, residential, housing or other support service even if the visitor is a service user. If you are not sure if a picture or video is pornographic, check with your manager who can if necessary take legal advice. Pictures or films from educational teaching packs are okay if they are being used as part of a teaching programme. These too should be agreed by your line manager.

Staff (or others) must never photograph or video people with learning disabilities in a way that is indecent or might damage their reputation.

If a service user living in supported accommodation requests assistance to obtain sexually explicit materials, this must be discussed with the Manager and the outcome recorded. When/if the agreement is made to assist the service user to buy pornographic materials it is imperative that only legal material are purchased.

Service users may have access to the Internet. Staff must not support service users to download material, which falls within the definition of pornography as stated previously.

MASTURBATION

Masturbation is normal and almost everyone does it some time. You must never make people feel that it is bad or dirty thing to do. But they do need to know it has to be done in private. Do not allow masturbation in public in a setting where you think no-one minds, because then the person concerned could offend others or get into trouble when they go to different places. A man could be prosecuted for indecent exposure even if he did not know anyone was watching or he did not mean to offend anyone.

Remember, a toilet is not a private place.

If you cannot explain to someone about public and private places you may have to take them to private place every time they masturbate, and leave them alone to finish. Individual establishments may decide to draw up more detailed guidelines for individuals, and a consistent approach should exist between home and other services.

If someone is masturbating all the time then it could be that they are bored or they got into the habit of it at a time that they were bored. Make sure they have other enjoyable things to do. It could also mean that they are not getting any satisfaction from it as they don't know how to do it properly. This can cause frustration, aggression and behaviour problems.

Some people may need advice and help about masturbation. This may be true for both men and women although it is likely to be more of a problem area for some men. Any work around masturbation must be made part of a

person's care plan. It is important that such undertakings and their outcomes are properly recorded with due respect for confidentiality.

SEXUAL ACTIVITY WITH A PARTNER OF THE OPPOSITE SEX

The law says that any person (including those over 16 with learning disabilities) has the right to have sex with a partner of the opposite sex. This includes sexual intercourse and other ways of giving and receiving sexual pleasure. This however will not be the case for all service users, because of the severity of their learning disability. (See Consent section).

The law is quite complex on this matter and the right to have sex is dependent on:

- The level of ability of both partners.
- Whether there is mutuality in the relationship.
- Whether or not exploitation is taking place.

If you are unclear always speak to your line manager.

SEXUAL ORIENTATION

People are heterosexual, lesbian, homosexual or bisexual (attracted to both men and women) for all or part of their lives.

Be careful not to jump to conclusions about people's sexual orientation or give them labels.

Sometimes people have had homosexual experiences because they were in a single sex situation rather than because they are homosexual by choice. This is also the case for some people with learning disabilities.

Some people, particularly those with profound learning disabilities, will not understand the usual ideas and words that describe sexuality.

The way some people express their sexuality may result more from past experience of closeness which may have been with someone of the same gender.

You should respect a person's sexual orientation and behaviour as long as it is within the law. Most people with learning disabilities will need help to understand what is and is not appropriate behaviour in a range of situations. Explanation and discussion is more helpful to them than rules which may actively obstruct their development.

You may need to help someone who is lesbian, homosexual or bisexual to feel okay about who they are, as other people may have tried to make them feel bad about it. However, you may not be the best person to do this work. Therefore, it is important that you check with your line manager as to which agency can best fulfil this need.

WHEN DO STAFF NEED TO INTERVENE?

Staff need to intervene:-

- 1) when they think that one person is abusing or exploiting another,
- 2) if the activity is taking place in an inappropriate setting,
- 3) where there is a need to protect.

You have a duty to protect the person who is being abused or exploited. If possible you must try to prevent abuse and exploitation and should seek line manager or specialist advice. If you suspect that someone is being abused and exploited you must immediately notify your line manager verbally and follow this up in writing within 24 hours. For the actual procedure in these situations you must refer to guidelines for Services in Fife, Sexual Abuse of Adults with Learning Disabilities

It may not be possible to tell whether a person with a severe learning disability is consenting to a sexual act. In order to protect people in this situation the law says it is illegal to have sex with someone who is not clearly able to consent. However, it is unlikely that prosecution would follow if their partner also had a learning disability and it was not felt that exploitation had taken place.

When a person can make an informed choice and express their own wishes, staff must be careful not to impose their own views on how that person should lead their life (whilst making sure the person has enough information about the consequences of their choice). Remember, you have a duty of care not only to the client you are dealing with but to any person who may be involved in the consequences of their actions.

It is important that everyone involved in caring for the person with learning disabilities should try to agree on what should be done. It must be made clear that no individual staff member can make a decision in isolation. Sometimes an independent advocate may be needed.

SEXUAL HEALTH

It is considered essential that schools provide young people with learning disabilities with teaching and guidance about sexuality and relationships. It is important therefore that we continue this process for the adults who use our services.

Staff need to have an awareness of the principles for sexual health which are stated at the beginning of this guideline. Through the care planning process it is important that it is acknowledged who will provide the individual with the support to ensure that all aspects of their sexuality and sexual health are addressed. The process of person centred planning should ensure that individuals are given information about sexuality and sexual health in a way, which is appropriate to their needs and wishes.

Service users must be encouraged /supported to access mainstream health services through the normal NHS facilities ie well woman/well men clinics, cervical smear testing, breast screening clinics as well as the usual health checks. Explanations as to why these checks are necessary should always be given to individuals before checks are carried out

SEXUALLY TRANSMITTED INFECTIONS

For many service users a sexual relationship with another person may not be likely or possible. But for others it would lead to their lives being made happy and fulfilled. Where this is the case it is important that they know how to be assertive and what words to use when deciding whether and how to have sex. People with learning disabilities have the right to appropriate information, education, confidentiality and services about sexually transmitted infections (STIs) including HIV and AIDS.

Anybody having sexual intercourse (or who may have sexual intercourse) needs to know about safer sex and how to use condoms. Be clear whose role it is to do this work. Check this out with your line manager. It should be identified in the service users Person Centred Plan how condoms will be obtained.

If someone wants a test to see if they have an S.T.I. this can be done by their doctor as a special G.U.M. (genito-urinary medicine) clinic. G.U.M. clinics have much stricter confidentiality and usually give quicker results. Remember, whilst it is essential that we look towards the rights of people with learning disabilities, it is equally important that we do not overload them and give information in a way that they can not assimilate. To do so may render them more vulnerable than they were before work began.

NOBODY CAN BE TESTED FOR S.T.I. WITHOUT THEIR KNOWLEDGE AND CONSENT. In exceptional cases a court may decide, if someone is unable to give consent.

If someone decides to have a test then they have the same rights to counselling as anybody else, before and after the test. This is especially important for an HIV test.

Information about STI's must be kept highly confidential (see point about issues of confidentiality under Valuing Difference).

Primary health care checks for people with learning disabilities are available through their GP's.

CONTRACEPTION

Contraception is a crucial issue not to be taken lightly. If people are starting to have sexual intercourse they may need help to get information and advice about contraception. Help may be needed to find doctors or clinics. A person may also need to be accompanied to appointments, with their permission.

Make sure that people are getting the help they need in order to make decisions about contraception and that it is not just happening to help staff or parents feel less worried.

You would not normally discuss someone's contraception with their parents unless the individual consents. If the person doesn't consent and you believe there is a good reason for parents being involved check this out with your line manager. Remember the guiding principle is what is in the person's best interests. (See Pregnancy and Parenthood).

Usually decisions about contraception involve consideration of sexually transmitted infections as well.

If a sterilisation operation is being suggested, then a case conference must take place involving the service user. Their views can only be overridden by a court ruling.

A man or woman can only be sterilised if they agree to the operation, after it is explained to them.

If they are under 18 or not able to understand enough to give informed consent, then a court must decide if the operation can go ahead. It will also decide if there has been any doubt or disagreement about consent. The court will only agree if it is in the person's best interests and not for someone else's convenience.

NOBODY CAN BE GIVEN CONTRACEPTION WITHOUT THEIR KNOWLEDGE AND CONSENT UNLESS A COURT DECIDES OTHERWISE.

ABORTION

If a woman becomes pregnant she may need counselling to help her decide what to do. If she decides she wants an abortion then two doctors must also agree that it is the best thing for her.

NOBODY CAN BE GIVEN AN ABORTION WITHOUT HER KNOWLEDGE AND CONSENT UNLESS A COURT DECIDES OTHERWISE.

If she cannot understand enough to consent or if there is doubt or disagreement, then the courts will have to make the decision.

She will need counselling to prepare for any operation and to help deal with the deep feelings of loss afterwards.

PREGNANCY AND PARENTHOOD

A woman may decide to get pregnant or she could get pregnant without meaning to. People with a learning disability have the right in law to become parents either as part of a couple or as lone parents. Support should be offered to people for whom this is an issue.

It is very important to give appropriate and timely support to the prospective parents, or the woman as an individual if she is to go through the pregnancy and birth without a partner's support.

People who have learning disabilities should not necessarily be prevented from becoming parents. It is crucial that an individual understand the implications and consequences of choosing parenthood in order to make a responsible decision. Becoming a parent is a life changing event and it is essential that couples or individuals know:

- about the body changes that happen in pregnancy
- about what happens during birth
- what it is like to look after a child
- what happens during abortion if that's what she/they decide
- about what support they might need and the likelihood of this being available
- about the circumstances in which a child might be taken away from her/them

A person living at home with their parents may be considering pregnancy but not want the parents to know. Depending on the person's level of ability, what you know of them and their family circumstances a decision will have to be made about whether the person's wishes in relation to their parents are overridden. You and the parents have a duty of care to the person and that should be the guiding principle. Discussions and decisions in this area should involve a senior manager.

In reality the above situation will be rare. More likely is the scenario where a woman puts herself at risk of pregnancy via unprotected sex. If you work with somebody where this is likely to happen you have a duty to ensure that work is done with the individual, or couple, to address the matter. Be clear that she/they understand the issues, the consequences and the realities of a sexual relationship. If you feel she/they do not understand sufficiently well then you have a duty of care to protect her/them. Each situation is different but in many cases it would be right to involve parents in any discussion about

this matter if they have consistently shown themselves to be central in the person's life and committed to their well being.

It is important not to assume that if a person lives separately from their parents, the parents should not be involved. However, it is equally important that the rights of the individual are upheld. How you respond will need to be based on the person's level of ability, what you know of them and their family circumstances.

It is vital that there is an enabler or advocate who pushes for the rights of the person with learning disabilities without losing sight of the importance of the person who is ready to protect where necessary. This is a role that most parents have assumed from the beginning. It is an essential role and one that must be valued.

MARRIAGE AND LIVING TOGETHER

Different living arrangements may have to be organised for people who are living together or being supported in being parents.

Many people who have learning disabilities have a right to marry/live together. If people do want to live together you may need to help them to understand what that means in practical, emotional and legal terms.

Staff have no right to impose their views about whether the relationship will succeed or not.

In discussing their plans, the couple who intend to live together should be supported by people of their choice.

If couples choose to live in setting with other people, communally or with other families, then they should be helped to live as normal a life as possible there.

CONSENT IN SEXUAL RELATIONSHIPS

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

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

There are some individuals with a learning disability who would be considered as being unable to give consent. For women this is defined under Mental Health (Scotland) Act 1984 Section 106 as those who have "a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning". Men unable to consent are defined as having a "severe mental handicap" (Sexual Offences Act, 1967) which has the same meaning. It must be remembered however that these

laws are written to protect from abuse. As it is only the courts, which can make a definite judgement about this, it is unlikely that any relationship, which is not considered to be abusive, would get to court.

In practical terms undoubtedly many individuals with a learning disability could be considered to have a severe impairment of intelligence. Assessing the degree to which this is significant in terms of meaningful consent in a person's life should be done by those who know them well. One criteria could be the social functioning shown by individuals within a relationship; for example, whether there is evidence of mutuality such as both parties seeking each other out, spending spare time together, sharing leisure activities, sharing resources and restricting activities with other potential partners.

There are clear situations in which any consent given would be considered to be invalid. This is the case where there is:

- The presence of a parental or family relationship between the persons involved.
- The use of a weapon, threat of injury or use of force by the first person.
- The presence of a power imbalance between the persons involved which precludes consent by the weaker person.

As a member of staff you are not expected to make a value judgement about the rightness of any sexual activity which is taking place. However, you are expected to be sensitive to the possibility of abuse. If you are unsure, you **must** bring any observations or concerns to the attention of your line manager.

If however you become aware of a particular situation or act taking place at that time which is, in your opinion, abusive you should take immediate action to intervene. (See Guidelines for Services in Fife). The welfare and well-being of those who you work with are of prime importance and if you do not act quickly you could be said to have neglected your duty of care.

INVOLVING THE POLICE

If an illegal act has or is taking place then the police must be informed. This is likely to be done by a senior manager. Where possible, the victim (who has the learning disability) should be involved in the decision to contact the police. It is important to remember that if an illegal act has, or allegedly has, taken place the organisation has a duty to ensure that criminal justice is initiated. Individual members of staff also have the right to go to the Police directly; no organisation can take this right away.

LAST WORD

These guidelines will not answer every question you may have. Each situation will be different and everyone you work with is an individual. We hope the guidelines will help everyone involved to think about these important matters within a framework which will help to protect and enrich the lives of people who have a learning disability and help staff and carers to feel able to give consistent support to those they care for.

Do not leave yourself or others vulnerable. If in doubt share your concerns with a senior person. Don't make important decisions on your own.