



**Guidelines for Implementing a Policy on
'Sexuality and Relationships for Disabled Adults'
for**

**Consultants working in
Secondary and Tertiary Care**

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Introduction

The Sexual Health and Disability Alliance (SHADA) was formed in 2005 by the Outsiders Trust to bring together and support professionals who work with disabled adults.

The following guidelines have been produced as a source of information for consultants working with disabled adults. We hope you find these guidelines useful in that they can provide a starting point for your unit to develop the best working practices for your disabled patients.

Why have a sexuality and relationships policy?

All types of service provision should allow for disabled adults to make informed choices and to be able to freely express their wishes and preferences. Therefore each person, whatever their impairment should, like any other person, be at liberty to pursue their sexual aspirations.

However, many disabled people complain that although their practical needs are met, their personal difficulties are rarely discussed, with the result that a newly disabled person, for example, may experience relationship break-ups, on-going depression and social isolation.

Patients with long term conditions such as renal failure sometimes describe their relationship with their consultant as like having a long-term partner they never chose. It is appropriate that this relationship is acknowledged and discussed, to help you both work well together.

Physicians should support the rights of disabled adults to develop and maintain social, personal and/or sexual relationships based on the recognition of their human rights.

That is to:

- If adult, be assumed to be sexual, whatever their impairment, size or age, even if sex appears to be low on their list of priorities at that time.
- Have their choice of relationships, including marriage, friendships, partnerships and same sex relationships respected and supported by all policies and procedures issued.
- Exercise choice and have their individual morality and beliefs respected.
- Have their privacy and confidentiality respected.
- Be informed about the impact their surgery or treatment will have on their sexual function, in the presence of their sexual partner if they so wish.
- Be informed when they can resume sexual activities after surgery or treatment, in enough detail to make it completely clear.

- Have opportunities to be alone with their sexual partner on a regular basis and both parties be supported through the process of adapting.
- If they have no sexual partner, be supported to enjoy sex like other single people as far as is possible, without causing embarrassment within the unit.
- Be offered counselling, information, advice and support to exercise or pursue any of their sexual rights so they can take risks and assume the responsibilities inherent in exercising these rights.

Policies need to:-

- Encourage peer support and support disabled adults in accessing a variety of opportunities enabling them to interact with other people.
- Provide appropriate support and guidance to facilitate the disabled adult's involvement in the wider community.
- Ensure your team and disabled adults are aware of professional boundaries.
- Provide sex education that is relevant to the disability
- Keep up-to-date on research on sex and disability, so that you learn about recent discoveries. For example, the medical measurements of the areas of paralysis on the body after spinal injury are not always the same as the areas where spinal injured people can experience sexual pleasure.

Staff may be apprehensive of the risks in disabled people developing relationships. Remember, risk is a normal part of developing personal relationships for anyone. However this apprehension should not stand in the way of your patient's rights. Take the challenge of ensuring policies are in place which can protect both your patients and staff. Ensure staff are provided with sufficient training to cope with these situations. Allow staff opportunities to air their concerns and check with other agencies and professionals to gauge good working practices. Remember SHADA members can assist with support and advice. Continue to develop your policy to ensure staff feel confident in supporting their disabled adults to achieve a crucial part of their social care.

Consent and choice

Patients should be encouraged to make their own decisions about their personal and sexual relationships. The law defines the age at which consent can be given for certain relationships and activities. It also requires that, for consent to be valid, it is freely decided and the individual(s) concerned is/are able to demonstrate a broad understanding of what is involved and have a basic understanding of the likely consequences of their actions. If anyone does not have this level of understanding then, in the eyes of the law, they may be unable to make the decision.

Training can help professionals to gain confidence and understand the basics:

- The social model of disability.
- That sex is more than intercourse, and pleasure is not dependent on erections and genital function.
- Sexual orientation - disabled people are the same as everybody else and may be gay, straight, transgender, etc. They may have fetishes, and enjoy a wide range of sexual tastes.
- Many disabled people find love, especially when they have learned to love themselves. Before this happens; it is painful for them to watch their peers enjoying intimacy, getting married and becoming parents when opportunities don't seem easy for themselves. Reassurance from professionals can help this process.
- Some adults with disabilities may have gaps in their knowledge about sex, simply because their lives are censored. Your team should not extend that censorship but know where to signpost them to gain knowledge.

The ideal is that all professionals who come into contact with disabled people are trained in sex and disability so that disabled people always feel able to include sex and relationship concerns in their conversations. It is useful to attend a workshop that demonstrate how it feels to have your basic ideals and needs denied to you, and increase awareness that sexual rights are human rights.

Policies may need to include situations like the following:

- A disabled adult cannot masturbate because of impairment.
- Disabled adult needs a gadget a sex worker to enable him or her to achieve sexual fulfilment
- Disabled person displays inappropriate behaviour.
- Disabled person suffers from low self esteem.
- Disabled person suffers with depression resulting from the above.

When discussing situations like the scenarios described above, staff should consider:

Disabled adults need reassurance, respect and privacy. When talking to a disabled person about their sexual feelings and desires, they need to be alone or with their sexual partner, not with care workers, parents, or anyone else in the room.

- You may need to allocate extra time for people with speech impairments both to learn how to communicate and to engage in conversation, as the person who normally translates for you should not be in the room, unless the disabled person is sure that is OK.
- Ensure that disabled patients are informed how and when they can proceed with sexual activity, e.g. after accidents, renal failure, hip replacement or continence-related operations.
- Relevant publications and leaflets are given in formats they can access.

- Information and advice about contraception and sexually transmitted infections are provided in formats they can access
- Sufficient signposting information is available.
- Whether the disabled adult has sufficient equipment to support their sexual activities e.g. hoists.
- If the disabled adult presents with depression or gives any clues that they may be deeply unhappy, check if they are experiencing any personal / sexual difficulties.

What else should your policy contain?

A leaving pack created specially, containing their personal needs and providing a resource of the support networks available.

Have a universal approach with all services provided by your unit and ensure sufficient information on sexuality and relationships is available to your entire team.

Examples:

Use your database to provide leaflets on other agencies that can help e.g.

The Sex and Disability Helpline 0707 499 3527 11am to 7pm weekdays

www.sexycord.com

www.spinalinjury.net

http://nsrc.sfsu.edu/article/users_guide_paralyzed_penis_sex_after_spinal_cord_injury

<http://dailyuw.com/2009/2/6/sex-and-disability-sex-after-spinal-cord-injury-to/>

http://www.stroke.org.uk/information/our_publications/factsheets/sex_after_stroke.html

www.outsiders.org.uk

www.tlc-trust.org.uk/about/index.php

www.fpa.org.uk/Homepage

http://www.loversguide.com/sex_and_disability.html

www.spokz.co.uk/

www.beecourse.com/

Ensure your **database** includes contact details of all agencies providing support and relevant information on sexuality and relationships.

Put **procedures** in place to demonstrate how referrals and signposting should be carried out.

It may help to develop **partnerships** with other units to ensure high standards of service are being delivered to your client group.

Include sexuality and relationship **information** in your leaflets and publications.

Confidentiality

Any discussions with patients surrounding the personal issues of sexuality and relationships remains confidential and that it should only be broken in certain circumstances. Patient's sexual information should only be discussed amongst staff on a 'need to know' basis and targeted to the appropriate people. There are occasions when information needs to be shared to protect the interests of the staff or client, for example it may be necessary to pass on information to professionals or others in the public interest, for instance, where personal health or safety is at risk, or if required by law.

Parental Involvement

Parents, whilst having no legal rights over their adult children, will invariably feel concern and a responsibility to protect, guide, care for, advise and be a friend to their son or daughter. To harness the contribution a parent has to make can be of great benefit to their son or daughter. For a variety of reasons many parents may need help in coming to terms with their son's or daughter's sexuality. Unit staff should be aware of this and offer support to parents as appropriate. If necessary, parents should be given information on your organisation's approach to sexuality and personal relationships.

Staff Protection

For a variety of reasons some staff may not be willing to participate in the sexuality and relationships agenda. Draw up a list off those in your team who are willing to participate and ensure non-participative staff refer their clients to staff members willing to provide support in line with the policy. Willing staff should feel confident their unit will fully support them in their handling of this sensitive subject and offer supervision and specialist counsellors.

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