Intellectual disability and sexuality

Summary

- People with intellectual disability can express their sexuality in satisfying ways.
- The attitudes and support of other people are essential in helping people of all abilities to have healthy personal and sexual relationships.
- Sexual abuse or exploitation is always wrong and should be treated as a very serious matter.

Sexuality is a key part of human nature. People with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else. To understand and enjoy sexuality, everyone needs adequate information and support from a young age.

Sexuality has psychological, biological and social aspects, and is influenced by individual values and attitudes. A person's sexuality develops throughout childhood and adolescence, and is a key part of their identity. The way each person understands and interprets their sexuality varies significantly, and often changes over time. Healthy self-esteem and respect for self and others are important factors in developing positive sexuality.

Most people with intellectual disability can have rewarding personal relationships. However, some may need additional support to develop relationships, explore and express their sexuality, and access sexual health information and services.

In Victoria, all people aged 16 years and over, including those with disability, are entitled to privacy and choice, within the law, regarding their sexuality and sexual activity.

Sexuality education for people with intellectual disability

A child’s sexuality education comes from a range of sources, including their parents, teachers and friends. People with intellectual disability also require sexuality education that:

- teaches them that people with disability can have fulfilling sex lives
- covers age-appropriate sexual issues that may be associated with their particular disability
- explains social rules, such as telling the difference between private and public behaviours
- is delivered in a way that a person with intellectual disability can understand.

It is important for parents to have access to the information they need to support their child in dealing with particular challenges they may face.

Some adults with intellectual disability may have received adequate sexuality education at school, while others may have missed out. Those who have received adequate education may need follow-up information that is suitable for an adult of their level of ability and literacy. For those who have missed out, it is important to start at the beginning, no matter how old they are.

Social opportunities, sexual relationships and intellectual disability

The opportunity to mix with other people of both sexes, whether socially, at school or at work, is important in developing confidence and social skills. However, some people with intellectual disability may have fewer opportunities to form social and sexual relationships for a number of reasons, including:

- a lack of privacy
- being dependent on others for daily living
- a lack of confidence about their physical appearance and ability
- less knowledge of how to negotiate relationships and express their sexuality
- a limited social circle and a lack of social experience
- physical or cognitive limitations
- carers who wrongly think of them as childlike or asexual
- carers who view their sexuality as something to be feared and controlled.

A person with intellectual disability may need additional support to explore sexuality and relationships. This can be particularly relevant to people with high support needs, for example, those who live with their parents or in supported housing, or those who need help with communication or personal care, such as toileting.

People in these situations may want sexual relationships, but wrongly, this may not be permitted by their parents or carers. They may lack the privacy needed for sexual activity. Restrictions at home may lead some people into unsafe or illegal activity, such as sex in parks or other public places.

Sexual sensation and function and intellectual disability

There are many different types of disability. Intellectual or cognitive disability may be caused by a genetic (inherited) condition, difficulties that occurred during childbirth, an illness or an accident.

Sometimes, a person with intellectual disability may be less able to enjoy sex, which may be due to:
- the disability itself or its physical or emotional consequences
- a physical injury
- prescribed medication
- ageing
- psychological illnesses, including depression.

A person with intellectual disability who is experiencing problems with sexual sensation or function can talk to a doctor, sex therapist or support group for suggestions on how to overcome these challenges.

Body image, intellectual disability and sexuality

In some ways, society presents a narrow view of how men and women should look, particularly through the media. A person with intellectual disability may feel less worthy of a healthy sexual relationship because they do not match this idealised image. Talking with other people who have overcome body image concerns or a counsellor may help.

Appropriate sexual behaviour and intellectual disability

Sometimes, a person with intellectual disability may exhibit inappropriate sexual behaviour, such as public masturbation, or soliciting sex from minors or in public. This is more likely to occur when the person lacks more appropriate sexual outlets, or has not been provided with appropriate education about the complicated social etiquette and legal issues around sexual behaviour and relationships.

Sometimes, police may charge the person with a sexual offence. The person may also be restricted in unreasonable ways, such as a man being prescribed medication by a doctor to suppress androgens (male hormones). However, appropriate education and behavioural training are, in most cases, better ways of addressing issues such as these.

Unfortunately, some people with intellectual disability may have received the message that any sexual expression is unacceptable. This may need to be addressed before the person can learn more acceptable behaviours.

Contraception for people with intellectual disability

All women and men, including those with disability, have the right to make their own informed choices about which method of contraception they use. To make these choices, people need adequate, accurate and accessible information about reproduction, the purpose of contraception and their contraceptive options.

Some people with intellectual disability may find it difficult to access contraception and other sexual health products and services, especially if they cannot be open with their family or carers about their sexual activity.

The contraceptive choices available to a person with intellectual disability may be limited for a number of reasons, including:
- Certain medication can interfere with oral contraception, the contraceptive vaginal ring, the contraceptive
implant or emergency contraception (EC, also known as ‘the morning after pill’).

- The contraceptive injection (depot medroxyprogesterone acetate, known as Depo-Provera) and contraceptive implant (Implanon NXT) may cause unpredictable bleeding that can be difficult for some women with an intellectual disability to manage.
- There can be difficulties with insertion of the contraceptive implant or an intrauterine device, which can be overcome by having the procedure while sedated or under anaesthetic.
- Some women have difficulty remembering to take tablets such as the contraceptive pill regularly. This can be overcome by supervised use.
- Some people with intellectual disability may have difficulty negotiating the use of condoms.

It is important to remember that EC can prevent pregnancy after having unprotected sex, for example, if a pill is missed, a condom breaks, or a woman is sexually assaulted. EC is available from pharmacists without a doctor’s prescription. It should be taken as soon as possible, ideally within 24 hours of having sex, but it still works well within 96 hours (four days). It can be taken within 96 to 120 hours (five days), but it will not be very effective.

It is legal in Victoria for any woman to seek to terminate a pregnancy. All people are entitled to access support and counselling about issues relating to abortion.

Reproductive rights for people with intellectual disability

Most Australian states and territories, including Victoria, have laws designed to protect people with ‘impaired capacity’ from sexual exploitation. However, people sometimes misunderstand these laws to mean that it is illegal for a person with intellectual disability to have sex. This may make families and support organisations wary of supporting sexual relationships.

While the question of understanding and giving informed consent to sexual activity may sometimes be more complex for people with intellectual disability, they still have the same right to consensual sexual relationships as others in the community.

The law states that a court or tribunal authority is needed before a child can be lawfully sterilised, unless the sterilisation is associated with surgery to treat a medical condition or disease, and that sterilisation is the last resort. An adult with intellectual disability can choose to be sterilised if they have the capacity to make the decision. If they lack the capacity to make this decision, it must be referred to a tribunal authority.

For more information about forced sterilisation and consent to medical procedures, contact the Office of the Public Advocate or Victorian Civil Administrative Tribunal.

Genetic services for people with intellectual disability

Some people with intellectual disability who are pregnant or are considering having a child may want to use genetic services such as diagnosis, screening and testing, counselling, education, clinical research and information on the management of individuals and families with a history of particular health conditions. Access to services such as these will help people to make the best decisions for themselves and their children.

Pregnancy, parenthood and intellectual disability

Some people with intellectual disability, such as men and women with Down syndrome, have lower fertility, but many others are as fertile as the general community. Many people with intellectual disability want to have children. However, their own family or carers may oppose this, making it difficult for the couple to plan for pregnancy and parenting, and to access the necessary services for themselves and their baby.

Many people with intellectual disability can be loving partners and parents, maintain strong relationships and care for a child. Parents with intellectual disability usually need additional support, as do many other groups in our community, such as parents who are very young or who are experiencing mental health issues.

Sexual health and people with intellectual disability

People with intellectual disability should have the same choice regarding preventive health measures for sexually transmissible infections (STIs) and other conditions as people without disability, including:

- Condoms should be used to prevent the transmission of STIs. The person with disability may need to be provided with appropriate and accurate education about STIs and condoms, including the opportunity to

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practice how to put condoms on correctly.

- Nearly all women with intellectual disability can learn menstrual hygiene, just like any other woman. A woman’s menstrual cycle should not be suppressed just because of her intellectual disability.
- Women who are or have been sexually active should have a regular pap test to help prevent cervical cancer. If a woman with intellectual disability has difficulty with pap tests, she can contact PapScreen Victoria.
- People with disability should participate in immunisation programs, including the HPV (human papillomavirus) vaccine and immunisation program, which helps prevent cervical cancer.
- Women need to understand the importance of being aware of how their breasts normally look and feel and should be encouraged to see a doctor if they notice anything unusual.
- Women aged over 50 years need to consider having a mammogram for the early detection of breast cancer. A doctor can provide more information about this.
- Men need to understand the importance of seeing a doctor if they notice a lump or anything unusual with their testicles.

When providing health services to people with intellectual disability, doctors and other healthcare professionals need to take into account the particular disability and circumstances of their client. For example, some women with intellectual disability can find a gynaecological examination or procedure such as a pap test overwhelming. It is important for people with intellectual disability to provide informed consent before these procedures are carried out, unless in the case of medical emergency.

**Sexual abuse or exploitation of people with intellectual disability**

All people, including those with intellectual disability, have the right to enjoy relationships and sexuality without being abused or exploited. Unfortunately, statistics show that people with disability experience all forms of abuse at much higher rates than people without disability.

Reasons for this include:

- inadequate sexuality education on where and when it is acceptable to be touched by other people
- inability to resist, protest against or stop abusive behaviour from happening
- not knowing that a person has the right to decide what happens to their body, especially if they are used to other people constantly attending to their physical needs
- being raised in situations where they are used to being told what to do and therefore going along with requests or demands made by an abuser
- agreeing to engage in sexual activity to fulfil unsatisfied cravings for attention, affection or rewards
- consenting to initial sexual activity, but not to sexual activity that follows, which amounts to abuse.

Just as in the wider population, assaults against people with disability are more likely to be perpetrated by somebody they know, such as a family member, carer, work colleague or someone they live with. Research also shows that sexual assaults on people with disability are less likely to be reported.

Reasons for this include:

- Some people with disability find it difficult to communicate with others.
- A person may tell someone of the assault, but that person may not understand them.
- A person may have limited knowledge or ability to report what happened to them.
- Some people wrongly think the effect of sexual assault on a person with disability is not as serious as an assault on someone without disability.
- A person may not be believed.

Any sexual assault is a very serious matter and should be referred to police and sexual assault support agencies.

The carers of a person with intellectual disability can help by modelling assertive behaviour, making referrals if the person needs further training or support, and explaining the basics of protective behaviours, including:

- Every person has the right to say what happens to their body.
- Everyone has the right to feel safe.
- There are laws that protect a person’s right to live safely without being harmed or exploited.
• There are many people who can be trusted, but also some who cannot be trusted.
• Some types of behaviour are appropriate for yourself and others, but some types are not.
• You can communicate assertively and say 'no' to unwanted behaviour.
• It is okay to change your mind about sexual behaviour or activity, even if you have already agreed to something.
• There are people who can help if you are being abused or exploited in any way.

Where to get help

• Your doctor
• Family Planning Victoria Tel. (03) 9257 0100 or 1800 013 952
• Yooralla Tel. (03) 9666 4500, TTY (03) 9916 5899
• Centre Against Sexual Assault (CASA) crisis line Tel. 1800 806 292
• National Sexual Assault, Domestic and Family Violence Counselling Service (Australia) Tel. 1800 RESPECT (1800 737 732, telephone counselling service operating 24 hours, 7 days)
• Office of the Public Advocate Advice Service Tel. 1300 309 337, TTY 1300 305 612
• Victorian Civil Administrative Tribunal Tel. (03) 9628 9900
• PapScreen Victoria Tel. (03) 9514 6100

Things to remember

• People with intellectual disability can express their sexuality in satisfying ways.
• The attitudes and support of other people are essential in helping people of all abilities to have healthy personal and sexual relationships.
• Sexual abuse or exploitation is always wrong and should be treated as a very serious matter.

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