



Gillian Eastgate

# Sex and intellectual disability

*Dealing with sexual health issues*

## Background

Sexual health is a vital but often neglected aspect of healthcare for people with intellectual disability. It may initially be difficult for the general practitioner to raise sexuality issues with patients with intellectual disability, but there is potential for simple interventions that offer great benefit.

## Objective

This article describes ways in which the GP may be able to assist people with an intellectual disability with their sexual health needs.

## Discussion

It is important to engage the person with intellectual disability directly, preferably alone. A person with intellectual disability is likely to have the same range of sexual and relationship needs as other adults. However, there may be multiple barriers to forming healthy, equal sexual relationships. Sexual abuse is widespread. Reporting abuse may be difficult for a person with limited verbal skills, and prevention and support services are limited. The GP is well placed to offer sexual health services such as information, contraception and cervical and sexually transmissible infection screening, and to discourage inappropriate treatments such as sterilisation for social rather than medical reasons, and androgen suppression.

**Keywords:** sexuality; disability, intellectual; general practice



A person with an intellectual disability, like any other person, is a sexual being. However, this is often not acknowledged or supported by those who support the person. While a person with intellectual disability may present to the general practitioner with multiple health needs, it is important to consider sexual health as one of these needs. It is also important for both carers and the GP to remain aware that a person with intellectual disability, like any other adult, has the right to make their own decisions.

It may be difficult to raise the issue of sexuality with a person with intellectual disability. They may have learned to be secretive about sex, and carers may be unaware of, or disapprove of, sexual activity. Discussion is especially difficult if the person needs assistance with communication.

However, with a little persistence, dealing with sexual health issues for this group is not as daunting as it may first appear. Some basic ground rules can set the scene for good communication (*Table 1*). Once the issue has been raised and some trust developed, many people with intellectual disability will communicate openly and directly about sexual health issues. Acceptance and the provision of simple information and basic sexual healthcare can make a big difference in the life of a person with intellectual disability.

Communication with a person with intellectual disability is likely to be slower than average. A long consultation, or more than one consultation, may be required to achieve what could usually be done in a standard consultation. Use of the Medicare Enhanced Primary Care items where appropriate may be helpful (*Table 2*).

## Understanding of sex and relationships

Many people with intellectual disability have a poor understanding of sexuality,<sup>1-3</sup> despite the development of sex education programs for people with low literacy levels.<sup>4-6</sup> Some people with intellectual disability receive sex education at school, but there are few programs for adults. A person with intellectual disability may have difficulty accessing 'informal' information via books or online, or may access inaccurate or inappropriate information such as pornographic or 'chat' sites. Television, especially 'soap operas', may contribute to



romanticised, unrealistic views of sex and relationships, especially for a person with limited real-life experience.<sup>5</sup>

Family planning organisations offer education programs and resources for people with intellectual disability (see *Resources*).

## Capacity to consent to sex

Broadly speaking, when a person has capacity to make a particular decision, they are able to do all of the following:

- understand the facts involved
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- communicate their decision.<sup>7</sup>

However, it can be difficult to ascertain how much a person with intellectual disability understands. A person may consent to initiating sexual activity, but additional nonconsensual activity may occur.

Legislation may also cause confusion.<sup>8,9</sup> Most Australian states and territories have laws designed to protect people with ‘impaired capacity’ from sexual exploitation.<sup>10,11</sup> However, these may sometimes be misunderstood 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 or tolerating sexual relationships.

Issues of consent, exploitation and abuse are complex, as they are for many in the community, but people with intellectual disabilities have the same right to consensual sexual relationships as others in the community.

## Appropriate sexual behaviour

Concerns are frequently raised regarding inappropriate sexual behaviours. These may include public masturbation or soliciting sex inappropriately, such as from minors or in public. It is not uncommon for a person with intellectual disability to be charged with a sexual offence.<sup>12</sup> Inappropriate behaviour is likely to occur when a person lacks more appropriate sexual outlets, or fails to understand the complicated social etiquette and legal issues around sexual behaviour and relationships.

The GP may be requested to prescribe an androgen suppressant medication such as cyproterone. This is rarely appropriate, and should never be considered in the absence of adequate education and intensive behavioural reinforcement.<sup>13–15</sup>

Some people with intellectual disability may have absorbed the message that any sexual expression is unacceptable. This may need to be addressed before more acceptable behaviours can be taught.

## Negotiating relationships

It can be difficult for a person with intellectual disability to negotiate the complex nuances of forming a sexual relationship. Their social circle may be limited. Carers may regard them as ‘childlike’ or ‘asexual,’ or conversely view their sexuality as something to be feared and controlled. The person with an intellectual disability is unlikely to have the same range of choices as their carers.

### Table 1. Discussing sexual issues with a person with intellectual disability

See the person alone for at least part of the consultation if at all possible. If the person is unable to communicate without support, address questions directly to the person and observe their response to the question and to their support person’s reply. Assume that the person understands more than they can express

Ask the person’s permission to discuss sexual issues. The person may need reassurance that it is acceptable to be sexually active and to talk about it

Use plain language but accurate terms for body parts. If the person uses their own terms, clarifying meaning and matching the person’s language may be useful

Ask open ended questions as far as possible. However, be aware that the person’s language skills may not allow detailed answers

Visual material such as pictures or models can be very helpful, especially for a person with limited verbal skills

### Table 2. Using Enhanced Primary Care Medicare item numbers for patients with intellectual disability

Health assessments (items 701–707): people with intellectual disability are a target group. Sexual health should be one of the issues addressed in a comprehensive health assessment

Mental Health Care Plan (items 2702–2713): intellectual disability itself is not a sufficient criterion for the use of these item numbers. However, many people with intellectual disability experience mental health disorders such as anxiety and depression (sometimes related to sexual abuse), warranting use of these items

Chronic disease management (items 721–732): many people with intellectual disability also have chronic medical conditions and complex care needs, including sexual health needs

Exploring sexuality and relationships can be especially difficult for people with high support needs, for example those who live with parents or in supported housing, or those who need help with physical self-care such as toileting. People in these situations may want sexual relationships, but may not be permitted by parents or caregivers, or lack privacy for sexual activity. Restriction at home may lead to unsafe or illegal activity such as sex in parks or other public places.

## Safer sex and contraception

A person with intellectual disability may experience difficulty obtaining condoms, contraception and medical testing such as cervical screening and testing for sexually transmissible infections (STIs), especially if sexual activity is hidden or not acknowledged.

A couple with intellectual disability should be involved as far as possible in any decision regarding contraception. They should be offered the same range of choices as any other couple, with



consideration of their ability to use each method. Long term depot medroxyprogesterone acetate is commonly given to women with intellectual disability,<sup>16</sup> but this is associated with weight gain and osteoporosis,<sup>17,18</sup> especially if the woman has other risk factors.<sup>19,20</sup> Other and often better choices include supervised use of oral contraceptives, the subcutaneous progestogen implant or the progestogen containing intrauterine device, although a woman with intellectual disability may need sedation or anaesthesia for insertion.

Doctors are often approached regarding 'menstrual suppression', sterilisation or hysterectomy for a girl or woman with intellectual disability. The usual reasons given are concern about menstrual management (most women with intellectual disability can learn basic menstrual hygiene), sexual abuse and risk of pregnancy.<sup>21,22</sup> It is important to point out that contraception or sterilisation will not prevent sexual abuse.

All states and territories in Australia have legal restrictions relating to sterilisation for women with intellectual disability: in general this must be approved by the relevant guardianship authority (see *Resources*), and approval is likely only when all other appropriate alternatives have been tried and failed.<sup>23</sup>

## Pregnancy and parenting

Most people with intellectual disability have normal fertility, and many desire children. They may encounter opposition to their intention to have children, making it difficult to plan for pregnancy and parenting, and to access the social support they and their children are likely to need. While parents with intellectual disability usually need support, so do many other groups such as very young parents and those with substance use or mental health issues.

Parents with intellectual disability may have difficulty understanding and responding to their children's needs. Most have low incomes, limiting their children's access to important developmental activities. Depending on the cause of the parents' disability, their children may be at increased risk of having an intellectual disability. Children who do not have intellectual disability may surpass their parents' cognitive ability at a young age. However, such children are generally positive about their parents and good outcomes are possible with appropriate support.

## Sexual abuse

Sexual abuse is extremely common in people with intellectual disability<sup>24-27</sup> (see also the article 'Women with intellectual disabilities: a study of sexuality, sexual abuse and protection skills', in this issue of *AFP*). Perpetrators of abuse include family members, caregivers and cotenants or coworkers with intellectual disability.<sup>25</sup>

Reasons for this vulnerability to abuse include poor understanding of what is appropriate, difficulty in negotiating equal relationships, and difficulty reporting abuse (although a person with limited verbal skills can still disclose abuse with assistance).<sup>28,29</sup> A person with an intellectual disability may not feel they have the right to make their

own decisions about sex, or may be manipulated into an abusive relationship with rewards or flattery.

Long term sequelae of sexual abuse include maladjustment, poor sexual and relationship function, high risk sexual activity and repeated victimisation.<sup>30</sup> In a person with intellectual disability and communication impairment, a change in behaviour may be the only way of communicating distress: relevant behaviour changes may be sexualised or may be less specific, reflecting associated anxiety or depression.

General practitioners may be reluctant to ask about sexual abuse due to time pressure or reluctance on the part of family members or support workers to discuss the issue. However, it is important to be aware that the GP may be one of the few people in a position to identify abuse. Once identified, action can be taken to ensure the person's safety and prevent further abuse.

## Conclusion

A person with intellectual disability may experience many needs and difficulties with respect to their sexual health. The GP is well placed to identify and address these needs. This takes time and creativity to fit into a busy practice, but offers considerable rewards for simple interventions.

## Resources

- Sexual Health and Family Planning Association (links to state and territory organisations): [www.shfpa.org.au/](http://www.shfpa.org.au/)
- Australian Guardianship and Administration Council (links to state and territory organisations): [www.agac.org.au/links](http://www.agac.org.au/links)
- Centre for Developmental Disability Health, Victoria (booklet on menstrual management): [www.cddh.monash.org/assets/supporting-women-gp.pdf](http://www.cddh.monash.org/assets/supporting-women-gp.pdf).

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