

Sex, consent and intellectual disability



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BACKGROUND

People with intellectual disability, as well as people with dementia or mental health disability, are vulnerable to sexual abuse and may lack the capacity to give valid consent to medical treatment. Their reproductive choices may be limited by their support needs, by social pressures or by sterilisation at a young age.

OBJECTIVE

This article uses case vignettes to illustrate key areas in dealing with sexual and reproductive health, and consent issues for people with intellectual disability. It also provides brief guidelines for assessing capacity to consent, and procedures to follow when there is no, or uncertain, capacity.

DISCUSSION

People with intellectual disability require education to help them resist abuse, and advocacy to ensure that their environment protects them. They require support and education when making reproductive choices and health care decisions. In cases where they do not have the capacity for informed consent, a substitute decision maker is required.

A woman with a disability may be confronted by particular challenges as she matures and develops her sexuality. Many women with intellectual disability are able to take an active and central role in health care decision making, but often feel excluded from decisions and feel that health professionals underestimate their abilities.¹ This is particularly so regarding sexual and

reproductive health.

A well informed general practitioner who is aware of the risks and challenges faced by women with disabilities can be a valuable resource. The GP can assist a woman with a disability to learn and adapt to changes in her life, and can advocate for her when needed. The following case vignettes are designed to assist the GP in providing high quality care.

The adolescent

Case 1

Lisa, aged 12 years, has Down syndrome. Her mother has brought her to see you because she is worried about Lisa going through puberty. She doesn't know how Lisa will handle having periods – Lisa is frightened by the sight of blood. She would like Lisa to have a hysterectomy because she is also worried that Lisa is vulnerable to sexual abuse and may become pregnant in the future. She is not aware of any incidents, but is worried about Lisa's safety at the special school where there are a number of older boys.

Menstrual management

Many women with intellectual disability can learn to manage menstruation successfully.² Family Planning and some disability organisations may offer education programs for people with disabilities. Such programs are likely to cover menstrual hygiene, sexuality and protective behaviours.

Suppression of menstruation should only be considered if education has been tried and failed, or if the woman herself requests treatment to control periods.³ Most women with intellectual disability can achieve acceptable period control by medical interventions such as the oral contraceptive pill or depot medroxyprogesterone acetate. Surgical intervention is rarely needed, although it has been resorted to in the past.^{4,5}

Consent to medical procedures for children

Parents of all children under 18 years of age automatically hold legal power to make decisions on behalf of their child. A child who is able to fully understand the nature and consequences of a procedure can give valid consent. In this situation, consent from a parent or guardian is unnecessary. However, parents cannot consent to certain medical interventions known as 'special medical procedures' including sterilisation, organ donation and experimental health care. These procedures require the authorisation of the family court or in some states the guardianship tribunal.⁶ Authority would generally be given only if it could be demonstrated that sterilisation was in the best interest of the child: in recent years there has been much criticism of the sterilisation of women with intellectual disabilities.⁷⁻⁹

Sexual abuse

Adolescents (and people of all ages) with intellectual and developmental disability are at risk of sexual abuse.^{10,11} Lack of understanding about sexuality may increase the risk of abuse;¹² poor understanding may be due to lack of information, or the inability to process information

offered. Children and adolescents with developmental disability experience similar distress and exhibit similar behavioural responses to abuse as children without disability.¹³ Abuse is often underreported because the abused person may not be able to adequately describe an incident or the offender.¹⁰ If the person does report abuse, she or he may not be believed. However, with intensive support even people with severe disability may be able to make an adequate report.^{14,15}

Preventing pregnancy, while important, is no substitute for effective prevention of sexual abuse. Anecdotal reports suggest that sterilisation may increase a child's risk of abuse because the perpetrator may believe there is less chance of being caught.

Lisa needs education to help her identify and report inappropriate behaviour from other people, and learn self protection skills.¹⁰ Any organisation with which she is involved (eg. special school, day services, residential care organisations) also need effective strategies to prevent and detect abuse.¹⁶

The young adult

Autonomy for adults with intellectual

Case 2

Sally, aged 24 years, has a mild intellectual disability. She lives in a flat with another young woman who also has an intellectual disability. A case worker drops by twice a week to help with shopping, budgeting and paying bills. Sally has come to see you for a repeat prescription for her asthma medications. While you are writing the prescription she mentions that she has a boyfriend, Sam, who she has met through supported employment. She and Sam would like to have a baby, but her mum doesn't seem too keen on the idea.

disability

It is easy to see why Sally's mother has concerns about her having a baby. However, Sally is an adult and has the same right as any other adult to have children. If Sally and Sam do have a child, they will need support, and exploration of the special issues they may face:

- they will need information about the realities of having and caring for a child (it is important to ensure that their plans are realistic)
- a planned pregnancy will maximise their access to support. It would be a good idea to see the couple together to discuss this. If they are currently sexually active, they need to be encouraged to use contraception until they are ready for a pregnancy
- depending on the cause of their disabilities, their child may be at increased risk of having an intellectual disability
- they are likely to need extra support with parenting¹⁷
- children of parents with intellectual disability may face discrimination, isolation and difficulty with school achievement, even if they themselves do not have an intellectual disability. Despite this, such children are usually positive about their parents
- they are likely to face financial difficulty while raising a child, as it is unlikely either of them will hold a well paid job.¹⁸

Contraception

Sally and Sam will need discussion on what contraceptive methods they will find easiest to remember and use.⁵ Many women with intellectual disability can take the contraceptive pill regularly with assistance. If there is doubt, Sally could consider a longer acting method such as the etonogestrel implant (Implanon), an intrauterine device or depot medroxyprogesterone acetate (Depo Provera, Depo Ralovera).

Consent to medical treatment

Capacity to consent

There is no universally accepted standard for

Case 3

June, aged 54 years, has moderate intellectual disability and lives in supported residential care. She is brought in for a 'check up' by a support worker. June's periods stopped about 3 years ago, but over the past few weeks she has had some blood on her underpants. June has very limited verbal expression and is unable to indicate whether she has any pain or discomfort. She is not very cooperative with examination, and you manage only a limited abdominal palpation. It is clear that June needs further examination and investigation.

assessing capacity to make health care decisions. The law speaks of the ability to understand the nature and effect of a decision. Health practitioners need to assess each situation and consider whether the person is able to make a meaningful decision. Patient competency has been expressed in terms of the capacity to:

- receive, comprehend, retain and recall relevant information
- integrate the information received and relate it to one's situation
- evaluate benefits and risks in terms of personal values
- select an option and give cogent reasons for the choice
- communicate one's choice to others
- persevere with that choice, at least until the decision is acted upon.¹⁹

A person with an intellectual disability may be able to make a decision if complex information is presented verbally in a simplified way.^{19,20} It is possible that a person with a disability may be able to give informed consent in some situations but not in others where the level of understanding required may be more complex.

In June's case it would appear that she is unable to understand the reason for being examined, and will need a substitute decision maker.

Substitute decision making

Substitute consent is required for all medical treatment for an adult with impaired capacity, except:

- in a life threatening situation, or one where there is significant pain or distress and it is not reasonably practicable to get substituted consent, and
- where the health care is minor and uncontroversial, there is no disagreement between the persons involved, and the adult with a disability is not objecting to the treatment by word or deed.^{21,22}

Minor and uncontroversial care may include physical examination, noninvasive investigations such as X-ray or ultrasound, and blood tests. Formal consent should be sought for more invasive examinations such as vaginal or rectal examination.

Who can give consent?

In all states (but not territories) where an adult is unable to make his/her own decisions about health care issues, a close relative or unpaid carer is able to make decisions on the adult's behalf without the necessity of a formal appointment.²³ This person is usually called the 'person responsible' or 'statutory health attorney'. The parents of an adult with intellectual disability no longer have automatic power to make decisions, but may well be the most appropriate 'person responsible'. A paid carer such as a disability support worker cannot consent to medical treatment for an adult with impaired decision making capacity.²³ The main reason for this is to avoid potential conflict of interest. If there is no appropriate relative, or where there is conflict between relatives, all states and territories provide for a guardianship tribunal or board to appoint a guardian for health care and lifestyle decisions, an administrator for financial decisions, or both. The guardian and administrator may be the same person.

If there is doubt about a person's capacity to consent to treatment, or doubt as to who is the most appropriate person to give substituted consent, it is advisable to contact the relevant guardianship authority (see *Resources*).

Conclusion

This article has outlined some of the social and legal issues faced by women (and many men) with intellectual disabilities. Such women need education to assist them to resist sexual abuse. They may also need advocacy to ensure that their environment (eg. living situation, level of support) protects them from abuse as far as possible. They may need support when making reproductive choices. While women with intellectual disability can and should be involved in making their own health care decisions, they may need assistance. This may involve simplifying the information given, or involving a substitute decision maker. A well informed GP can be an excellent support in dealing with these complex issues.

Resources

Sexual Health and Family Planning Australia (links to state organisations): www.fpa.net.au
 Australian Guardianship and Administration Committee (links to state guardianship authorities and public advocates): www.ijcga.gov.au
 Centre for Developmental Disability Health (links to two excellent printable documents on menstrual management for GPs and carers): www.cddh.med.monash.edu.au
 Queensland Centre for Intellectual and Developmental Disability: www.sph.uq.edu.au/QCIDD
 Centre for Developmental Disability Studies: www.cdds.med.usyd.edu.au

Further reading

Brady SM, Cooper DM. A question of right treatment – special medical procedures for children: an introductory guide. Melbourne: Family Court of Australia Publication, 1996. This publication contains a comprehensive

explanation of competency of a child to consent to medical treatment.

Lennox N, Diggins J. Management guidelines: people with intellectual and developmental disabilities. 1st ed. Melbourne: Therapeutic Guidelines Limited, 1999. This book covers a wide range of health and legal issues facing people with intellectual and developmental disabilities.

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