Chapter 18

Promoting Healthy Sexual Lives For Young People With Learning Difficulties

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Sexuality: It's Not Just About Sex

A useful definition of sexuality takes us beyond the narrow confines of biology, i.e., that it is just about sexual intercourse between a man and a woman, and reproduction. Sexuality is a normal part of human development that is expressed through every life stage. Gender, sexual identity, reproduction, and orientation are all aspects of sexuality. Beliefs about sexuality are influenced by biology and also the social, cultural, religious, legal, and political worlds in which people live. Sexuality is expressed in many ways, not just through sexual activity, and may be demonstrated through the varied roles and relationships that people have.

In this chapter, the term 'person with a learning difficulty' is used to encompass any young person whose disability or mental health diagnosis impacts on their learning capacity. There is an emphasis on young people with an intellectual disability. 'Sexuality education' is used as a broad term that includes a range of actions from providing information to delivering formal structured education.

Regardless of their ability, all young people have the right to education, information, and support to enable them to experience their sexuality in a positive way and to have safe, healthy relationships. This support can influence their sexual health, ability to make informed decisions, develop relationships, and stay safe. Lack of support in this vital area of a young person's development may lead to less positive outcomes including exploitation, vulnerability to abuse (Blanchett & Wolfe, 2002; Servais, 2006), and contact with the criminal justice system. It may also lead to poor health including risk of sexually transmitted infections and HIV.

What Do Young People With Learning Difficulties Need And Want?

In the authors' experiences of providing sexuality education, young people with learning difficulties want the same experiences and opportunities as their peers. To enable this it has been identified that young people with a learning difficulty need:

- Information about their changing bodies and the integrity of their body;
- Rules about social sexual behaviour;
- To be in safe environments free from abuse;
- People who will support them towards developing positive sexuality and not see it as a problem;
- Skills in developing and maintaining friendships;
- Opportunities to develop intimate relationships;
- Opportunities to take risks that will enable the to become more independent;
- Access to health services; and
- People to advocate with them for their rights.

Why Don't People Talk About Sexuality More?

Professionals, parents, and carers will often say that sexuality education is the domain of experts and therefore it is someone else's responsibility (Chivers & Mathieson, 2000). However if sexuality is seen as a normal part of human development, young people need to be supported in the same ways as for their intellectual, physical, social, and emotional development. Anyone supporting a young person needs to consider their role in sexuality education. There are a number of issues that impede carers and professionals from taking on this task. These issues include: lacking the confidence to teach young people with learning difficulties; fear that talking about sexuality may create more problems; a belief that this education is not necessary; confusion about duty

of care and other legal issues; anxiety about conflict with parents and other staff; and personal cultural, and religious beliefs (McConkey & Ryan 2001; Chivers & Mathieson, 2000; Löfgren-Mårtenson, 2004).

Often young people with learning difficulties are stereotyped as asexual, or there are concerns they will be sexually inappropriate and unable to control themselves. One of the consequences of this is that education may be either purposely withheld or not seen as important. Parents and carers may not want to provide education for fear of awakening sexual interest and creating problems. Even if people can get past these barriers, and they do provide some sexuality education, it may be more focused on the dangers and avoidance of risk rather than aspects of positive sexuality such as love, intimacy, pleasure, and fun.

Good Practice In Providing Sexuality Information And Education

Planning And Preparation

A supportive environment where the young person feels he or she has permission to ask questions, seek information, and receives accurate positive responses from approachable people is important. While the provision of sexuality education and information should be a planned process, it should not take away from the day to day opportunities that arise as teachable moments. An assessment of the person's existing level of knowledge and skills will ensure that education and information is accurately focused. It cannot be assumed that the person will have even basic knowledge such as names for private body parts.

It is important to address misinformation and myths that may be believed by young people for example, that masturbation leads to blindness or that they will not get

pregnant having sex for the first time (Blanchett & Wolfe 2002). Garwood and McCabe (2000) in a comparative study of pre-knowledge of men who participated in a sex education program report that misinformation held by the men included that HIV is transmitted by coughing, sneezing, and kissing. Also some believed that sexual intercourse is 'bad'.

Two tools that can assist in assessing a young person's knowledge about sexuality issues have been developed in Victoria, Australia. The first of these tools is the *Human Relations and Sexuality: Knowledge Awareness Assessment for People with an Intellectual Disability* (Family Planning Victoria, 1997). This tool is designed to identify knowledge about the body, concepts of private and public places and behaviours, sexual activity and other topics. The second assessment tool is the *Assessment of Sexual Knowledge (ASK)* (Butler, Leighton, & Galea, 2003) that is reliable and includes a problematic socio- sexual behaviour checklist that can be administered by trained clinicians. Other assessments to consider are sexual health history including; impact of medications; medical conditions and syndromes; contraceptive use; lifestyle and environment; sexual activity and orientation.

Collaboration among the key people in the person's network including parents and support workers will enhance the effectiveness of sexuality education (Blanchett & Wolfe, 2002). People who have close personal or professional relationships with the person will be in a position to create opportunities to reinforce skills, answer questions, and use teachable moments. Young people are strongly influenced by the values and agenda of family and staff. There may be some resistance to young people's rights to sexual expression. Carers and staff can benefit from information about sexuality to assist them to develop a more positive perspective.

Many people with a disability are victims of sexual assault. Goodfellow and Camilleri (2003) reviewed research over the previous decade and reported that the incidence could be as high as ten times that of people without a disability. Any person providing sexuality education should be prepared to respond to a disclosure of past or current abuse. Knowledge of mandatory reporting, support services and organisational procedures are essential.

What To Include In Sexuality Information And Education

Sexuality is a private area of people's lives and education brings it out into a more public arena. Education can be as readily used to control people's behaviour as it can be used to open up opportunities for them. While sensitivity to culture and personal values is appropriate, this needs to be balanced with the provision of accurate and contextually useful information. The trainer needs to reflect on his or her own personal values, concerns and beliefs, and how these may influence what information is provided and how it is delivered.

When information or education about sexuality is provided trainers tend to focus on danger, risk management, and protection (Blanchett & Wolfe, 2002). There is a need to balance this by focusing on the emotional aspects of sexuality such as skills in forming, developing, and ending relationships (Garwood & McCabe, 2000). Comparative studies of sexuality education curricula reported that two areas that are silent in much sexuality education are pleasure and sexual diversity, including homosexuality. Löfgren-Mårtenson (2004) in her study of young people attending dances reported that homosexuality in young people with an intellectual disability was often misinterpreted by carers and parents as friendships or as misdirected sexual expression. Sexual orientation is often ignored or

attempts are made to adjust it. Also, when sexuality education discusses positive sexuality (such as pleasure, intimacy, caring, and sexual diversity), the young person may be better equipped to make informed choices about their sexual life.

Research, available literature, and clinical practice have found that education is most effective when received from a young age and that it should reflect a comprehensive developmental framework. Such frameworks have been developed by McDonagh, Barrett, and Ryan (2000) who identified four main domains of sexuality education and suggested possible sequences for teaching topics. These frameworks are outlined in Table 18.1.

[Insert Table 18.1 here]

How To Teach Sexuality Information And Education

Most professionals working in the disability area have experience in supporting the development of skills and knowledge in many areas of a young person's life. It is often personal discomfort or lack of role clarity that can inhibit them in the area of sexuality. Yet the principles and methods are similar. Programs and resources can be tailored to suit the person's current level of knowledge, learning style and capacity. They are delivered in ways that use the person's individual communication methods. Using visual resources and drama or role play assists learning for many people.

Providing key messages and giving examples that emphasise social norms, acceptable behaviour, and the law reinforce rules about sex and relationships is important. Using terms for body parts and sexual activity that are accurate and generally socially acceptable is good practice. The use of slang should be avoided because it can be

offensive or have negative connotations. Peer interaction can be an effective learning process so consider presenting information in a group setting. Progress of learning should be monitored frequently to check that key messages are being understood.

There are many educational resources that use accurate explicit images. If using explicit material explain to the person what will be shown and seek their consent. It may be necessary to also seek agreement of parents or guardians. Always let the person know that they can stop the learning or say no at any point. The use of pornography as an educational tool is not appropriate and is likely to be illegal.

Using opportunities in every day situations will reinforce learning. For example, contemporary TV drama can be used to illustrate relationships, both healthy and unhealthy. Although at times it may be necessary to provide support and education to deal with specific issues, for example masturbation in public, this could also be considered an opportunity to open the discussion about what other education might be needed and how best to provide it. The following case study demonstrates a simple process for developing and supporting a collaborative approach to learning by assessing knowledge and learning styles, identifying learning needs, working in partnership, using appropriate resources, and creating opportunities for practice.

Case Study

Ricky was 11 years old, had autism, and a moderate intellectual disability. He lived at home with his parents and siblings, and attended a special class in a mainstream school. His parents contacted the local disability caseworker anxious to get help regarding how to provide sex education to Ricky. They were keen to take on this role but did not know

where to begin. Ricky's school was to commence sex education classes but his parents were concerned that the information would be too complex.

Through parent interview, a simple assessment was done of Ricky's current level of knowledge and effective ways to help Ricky to learn were identified. Ricky enjoyed computer based and visual learning. The caseworker liaised with the school to review the mainstream sexuality education program and was able to modify the information to suit Ricky's learning style. The content was simplified and condensed into key messages. The focus was on *puberty, friendships, and protective behaviours* as these were relevant to his learning needs. Ricky's parents were further supported with the provision of information and resources.

Through the program, Ricky continued to gain knowledge relevant to his developmental needs and his parents felt more confident in their role as educators. They were equipped with knowledge, resources and had access to professional support as required. A collaborative approach was developed between the family, the school, and the disability service to support on-going learning and a plan was developed to extend Ricky's sexuality education as he developed. Ricky was provided with opportunities to practice and develop appropriate social interactions through participation in a local dance class and a sporting group.

Being Proactive Rather Than Reactive

Often clinicians only receive referrals around sexuality when there is a problem or issue for a young person, rather than such requests being included in a planned process before an issue arises. This approach can reinforce people's anxieties and beliefs about sexuality being a problem. A more proactive approach is underpinned by education and

supporting a positive approach to sexuality. Clinicians can work in partnership with schools, parents, and carers to proactively support young people to develop healthy sexual lives.

This can commence from early childhood when parents can set the basis for future sexuality education. Clinicians can play a role in this early work by having discussions with families about the importance of planning for this part of their children's education in the same way that they do for other aspects of their development. Concepts of private and public places, learning names for body parts, setting boundaries around behaviours, and preparation for puberty are all important at this time. Learning in these areas can be incorporated in a range of other skill development areas, for example, opportunities arise when teaching toileting skills to name private body parts and reinforce concepts of private places and behaviours.

It is sometimes assumed that there are few resources to assist in talking about these issues with young people, staff, and families. However, there has been considerable work done both internationally and in Australia to develop a wide range of resources including easy English health booklets, plain English teaching materials, interactive computer games, DVDs, websites, anatomically correct dolls as well as some culturally specific resources. One resource that is readily available is *Sex Safe and Fun* (FPA Health, 2006). This is a free, easy English teaching resource which has been widely distributed throughout NSW, Australia, and internationally. It supports people to talk about sexuality by delivering positive messages about safety, consent, privacy, fun, and caring. It was originally developed for adults with a learning disability but it has been used extensively with young people over the age of 16 years.

Sex Safe and Fun (FPA Health, 2006) was created in close discussion with young people with learning difficulties who provided input on the written and visual content. Young people with a learning disability wanted a book that was explicit so they could really understand the messages but had pictures that were not so realistic that it caused them embarrassment. This resource is easy to use and has the acceptance of a wide range of people including professional staff, teachers, parents, disability workers, sexual health workers, youth workers, and people with learning difficulties themselves.

The resource has two parts, i) a colourful booklet using comic-style pictures with key messages about good and bad touching, safe sex practices, sexual diversity, and consent; and ii) a *Readers Guide* that gives clear brief directions about how to talk with the person about the pictures in the booklet. The guide provides practical general information about providing sexuality education. It explains the importance of gaining consent from the person prior to delivering information, how to prepare, implement and provide feedback, and reinforcement.

The guide can also be used as a whole program, as groups of topics, or individual units could be used to address particular issues. A major strength of the resource is that it can be used to promote positive and healthy sexual behaviour both in individual and group learning situations. It also assists in creating environments that are supportive of people's learning by giving permission to talk about sexuality and providing clinicians, carers, and staff with the tools they need to make them confident in carrying out this task. Other resources designed for young people with learning difficulties are outlined in Table 18.2.

[Insert Table 18.2 here]

Opportunities

For education to be integrated, it needs practice, and practice requires opportunity. Young people are more likely to be restricted and organised by others in regards to their social interactions. They accept that parents and staff will make such decisions for them (Löfgren-Mårtenson 2004). Opportunities for practicing romantic relationships skills, dating, and expressing their sexuality in less public and scrutinised ways need to be constructed by staff and carers as they are less likely to happen without this support. This requires creativity and advocacy. Lumley and Scotti (2001) noted that efforts to address sexuality education must move beyond knowledge to behaviour. They recommended that person centred planning and a team approach is necessary to enable application of knowledge and skills acquired in an education program.

Education Alone Is Not Enough

In an ideal world an educative approach would equip all young people with the knowledge and skills they need to have healthy sexual lives. However, some young people will require more support because their behaviour continues to cause problems for themselves and others and perhaps brings them into contact with the criminal justice system. In these situations it is important to ensure that people are assessed comprehensively so that their needs are identified and appropriate therapeutic services provided.

It is a commonly held belief that inappropriate sexual behaviour occurs because of lack of sexual knowledge. A review of the research conducted by Lindsay (2005), on sexual offending and intellectual disability, reported on several motivations for

offending, with poor sexual knowledge being only one aspect. However, it is still acknowledged that intervention should include the provision of education. Furthermore, there should also be a focus on the provision of opportunities that promote appropriate relationship building, sexual behaviour, and encouragement to engage with society.

Conclusion

Sexuality is a normal part of the development of all young people. They need to learn how to experience their sexuality in positive, safe, and healthy ways. Education is the responsibility of parents, carers, and professionals working together. There are many resources that will assist in assessing knowledge and providing ways to talk about sexuality.

While it is acknowledged that some young people need support to manage particular difficulties with their sexual behaviour, the provision of sexuality education provides an appropriate framework for any intervention. There is a need to focus on the provision of clear basic knowledge but it is of equal importance that young people are provided with opportunities to develop and maintain relationships. Enlightened future approaches to promoting positive sexual lives for young people with learning difficulties will see an emphasis on education, positive risk taking and the encouragement of opportunities for healthy sexual expression.

Table 18.1

Frameworks For Sexuality Education And Possible Sequences For Teaching Topics

Framework	**1**	**2**	**3**	**4**
Domain	**Sexuality**	**STIs/AIDS**	**Relationships**	**Health and Hygiene**
Possible sequence of topics	▪ Self-awareness/self esteem ▪ Body parts and functions ▪ Puberty ▪ Feelings ▪ Sexual feelings ▪ Being sexual - What does it mean? - Legal rights - Decision-making/ assertiveness	▪ Self-awareness/self esteem ▪ Sexuality ▪ Sexual relationships/ rights and responsibilities ▪ Decision-making ▪ Sexual health/ sex diseases ▪ HIV/AIDS ▪ Signs of STIs	▪ Self-awareness/self esteem ▪ Feelings about others/ choosing friends ▪ Circle concept/ different types of relationships - Communicating - Making friends - Maintaining relationships - Different things we	▪ Body parts and functions ▪ Feelings – body awareness ▪ Self-awareness/self esteem ▪ Nutrition and exercise ▪ Feeling healthy/ feeling ill ▪ Health care ▪ Contagious and communicable diseases

	- Protective behaviour ▪ STIs and HIV/AIDS ▪ Pregnancy and contraception and	▪ Transmission ▪ Preventing diseases ▪ Condoms – how to use/ where to buy ▪ Safe sex – practices/ communication skills ▪ Protective behaviours ▪ Testing (STIs)/ rights and procedures ▪ Testing (HIV)/ rights and procedures ▪ Treatment	do with friends - Appropriate behaviour ▪ Sexual relationships ▪ Consequences of being sexual ▪ Caring for ourselves and our partner ▪ Rights and responsibilities ▪ Preventing STIs including HIV ▪ Problem solving	▪ STIs and HIV/AIDS ▪ Using medical practitioners and health services

(Adapted from McDonagh, Barrett, & Ryan, 2000).

Table 18.2

Other Educational Resources

Resource	Description
Feel safe - CD Rom (Family Planning Queensland, 2002)	This interactive CD Rom supports the development of protective behaviours and assertiveness skills.
Friendships and Dating: Information about relationships for parents, carers and young people (Shine SA, 2009)	This booklet uses cartoon style pictures and straight forward information to guide appropriate choice making about relationships.
Jason's Private World (Life Support Productions, 2002a) *Kylie's Private World* (Life Support Productions, 2002b)	These animated DVDs cover a range of topics from puberty to relationships to sexual interactions in an engaging and accessible manner.
Love and Kisses (Family Planning NSW, 2007)	A DVD that presents people with intellectual disabilities describing their thoughts and experiences of relationships and sexuality and asserting their right to be treated as adults.
Special Boys Business (Anderson, Angelo, Stewart, & Taylor, 2007). *Special Girls Business* (Angelo, Pritchard, Stewart, & Davey, 2005).	These two books teach about puberty through the use of colourful cartoons with simple factual information that young people readily respond to.