1.7: Sexuality

Introduction

Individuals with intellectual disabilities experience difficulty in interpreting behavioural cues within their social environments. This may in turn create negative outcomes for their expression of sexuality (Meany-Tavaras & Gavidia-Payne, 2012). People with intellectual disabilities are overrepresented as both victims and perpetrators of sexual offences (Hogg et al., 2001; Lambrick & Glaser, 2004). According to Szollos and McCabe (1995), 50% of females with intellectual disabilities will be sexually assaulted in their lifetime, and males with intellectual disability are more likely to be sexually abused than other males.

One of the most significant factors in the sexual victimization of individuals with intellectual disabilities is their knowledge deficit regarding acceptable behaviour. More specifically, they may have limited sexual knowledge in the areas of consent and what constitutes appropriate sexual contact (Galea, Butler, & Iacono, 2004; Gust et al., 2003). They can find it difficult to assert their own opinions and they may give in to the suggestions or directions given by others, particularly when expressing their sexuality (Hayashi, Arakida & Ohashi, 2011).

People with intellectual disabilities depend on family members and service providers to teach them how to appropriately express their sexuality, which is a critical aspect of social competence. Many individuals with intellectual disability need ongoing education about sexuality, particularly self-protective strategies, so that others will not take advantage of them.

However, depending on past life experiences, the kind of education needed varies from one person to another. Individuals with a mild to moderate disability who live with their own or a foster family may have attended sexual health classes as part of the social skills training provided in schools, vocational programs, and sheltered workshops. Those with a severe or profound disability who live in group homes or institutions surrounded by professional caregivers and
others like themselves will have had fewer educational opportunities.

Those with more social skills training, more exposure to different life experiences, and more opportunities to function socially can be expected to demonstrate more social competencies (Abbott & McConkey, 2006; Simpson, 2010). Despite the diverse educational needs of individuals with intellectual disabilities, supporting them to show healthy expressions of their sexuality is important. In this chapter we discuss three critical areas that should be considered when providing sexual education support: discussion topics, understanding boundaries, and differentiating between challenging behaviours and sex offending behaviours.

Discussion Topics for Sexual Education Support

Although major gains have been made in the last two decades in normalizing, including, and integrating people with intellectual disability into community settings, their sexual health continues to be an overlooked area (Scotti et al., 1996; Thompson et al., 2014). Historically, in many countries intellectual disability or “feeble-mindedness” was considered hereditary, and individuals identified as mentally defective were sterilized without their knowledge to prevent procreation (Grekul, Krahn, & Odynak, 2004). Today, sexual education programs for people with intellectual disabilities are becoming more commonplace and researchers are beginning to understand the kinds of discussion topics that are most valuable.

Critical discussion topics that can help individuals begin to understand their own personal sexuality are puberty, menstruation, menopause, masturbation, relationships, protective behaviours, sexuality, safer sex practices, contraception, pregnancy and birth, sexual health screening tests, sexually transmitted infections, and legal issues regarding sexuality (Butler, Leighton, & Galea, 2003). Other topics are body grooming and cleanliness, first impressions in speaking to your partner, communication training, self-assertiveness training, a sense of space between participant and others, manners in public spaces, sexual harassment, stalker victimization, male–female relationships, and differences between male and female bodies (Hayashi, Arkida, & Ohashi, 2011). While support workers and family members themselves may not be the one delivering sexual education programs, it is helpful for all those involved to initiate discussions about these topic areas, invite further questions, and provide ongoing guidance.

A controversial sexual education topic that also needs to be discussed is parenting. Both family members and caregivers have expressed concern about parenthood and marriage for adults with intellectual disabilities (Oliver et al., 2002). Parents with intellectual disabilities represent one of the most vulnerable parenting groups (Booth & Booth, 2005). Most concerns relate to neglect or emotional abuse, with 40% to 60% of parents with intellectual disabilities having their children removed by child protective agencies because they failed to meet the standard of good enough parenting (Cleaver & Nicholson, 2005). Researchers believe that these numbers could be lowered if parents with intellectual disabilities had adequate supports and education (Cleaver & Nicholson, 2005; Murphy & Feldman, 2002). Specific areas these parents need help with are generalizing information from one setting to another; knowledge about normal childhood development and the care needs of infants, children, and adolescents; and knowledge about how to play with and show appropriate affection to their children (Wilson et al., 2013).

According to the International Association for the Scientific Study of Intellectual Disabilities (2008), parents with intellectual disabilities need both parenting skill education and a strong social network. When parents, especially mothers, are surrounded by helpful family members, friends, and professionals, they develop an increased capacity to
care for their children (Guinea, 2001; Koeske & Koeske, 1990; Wilson et al., 2013). Unfortunately, the reality is that these parents often find themselves with limited social and environmental support (Mayes, Llewellyn, & McConnell, 2006).

**Discussion Topics for Sexual Education Support**

**Key Points for Caregivers**

Sexual health is often overlooked in individuals with intellectual disabilities. They are very vulnerable to sexual abuse and may not understand what consenting to sexual activity means. They may not know how to express their sexuality. Sex education programs often include important discussions of normal expressions of sexuality such as masturbation, relationships, contraception, sexually transmitted diseases, and safe sex practices. These kinds of topics must also be part of the everyday conversations that take place between intellectually disabled individuals and the people in their lives. When individuals with intellectual disabilities are parents, they need a network of people around them and opportunities to learn about children’s development and showing appropriate affection to children.

**Understanding Boundaries**

Boundaries are the limits in relationships within which we feel psychologically safe (Kent, 2012). Individuals with intellectual disabilities may have difficulty understanding the boundaries that are expected in conventional social relationships. For example, they may interrupt, have difficulty taking turns or waiting for assistance, and steal other’s belongings. When interacting with caregivers, they may express sexual feelings through behaviours such as intruding into the caregiver’s personal space, requesting to be a boyfriend or girlfriend, and attempting to kiss or touch in a sexual manner. These behaviours leave caregivers feeling confused and uncomfortable. A fitting response is for staff groups to consistently and immediately provide straightforward feedback that these behaviours are not acceptable.

Similarly, individuals with intellectual disabilities may demonstrate inappropriate sexual behaviours in public. Examples are masturbation, genital exposure, inappropriate sexual touching, and embracing others too closely (Bielecki & Swender, 2004; Nagahama, 2003; Yamamoto, 1991). They may walk into public areas naked, touch others, or allow themselves to be touched. They may grab others roughly to get attention or indicate a personal need. In individuals with dual diagnosis, these overt sexual demonstrations may indicate an escalating psychiatric disorder. Rather than simply viewing these behaviours as distasteful, it is vital for caregivers to document, report, and discuss them with other staff members and health professionals.

It is important to hold these individuals accountable for their behaviour. When behaviours seriously violate the boundaries and feelings of psychological safety for caregivers and others, it is important to ask what would happen to those who are not intellectually disabled if they engaged in these same behaviours. If the answer is that they would be charged with sexual or physical assault, then involving the police must be considered. Treating people with disabilities differently suggests that they are not responsible for their actions and thus not real members of society.

Caregivers model the process of setting boundaries through their own actions. They can use anatomical rather than
slang or baby-talk words during discussions related to sexuality. They should avoid flirting, telling or listening to sexual jokes, and swearing or offensive language (Cooper, 2012). They can show respect for modesty by performing personal care in private rather than public spaces. Simple acts such as knocking before entering someone’s room and keeping doors open during private discussions communicate subtle cues about acceptable behaviour. Instead of allowing a non-verbal person to grab others in an aggressive way when he or she wants something, redirecting the action by demonstrating a more gentle way to reach out can be helpful. As previously mentioned and in accordance with any applicable agency policy, caregivers must confront and report inappropriate expression of sexual expression to their supervisors or even the police.

Providing Resources

For individuals with limited language or who use pictures as part of their communication strategies, signs and/or picture cards for yes, no, don’t touch, and stop are useful. As discussed in Chapter 5, prepared cards illustrating common needs and feelings are available at the Do2Learn (n.d.) website, http://www.do2learn.com.

Another useful resource to promote awareness about boundaries is the Circle of Relationships activity (Walker-Hirsch & Champagne, 1991). Here, different levels of intimacy and appropriate social behaviours are indicated by colour groups (see Table 7.1). A hand-out of Table 7.1 could be provided to participants, who can then be invited to link names of people they know to a colour group.

Table 7.1 Circle of Relationships activity

<table>
<thead>
<tr>
<th>Colour Code and Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purple Private Circle</td>
<td>You are important and you will decide who can touch you. No one should touch you unless you want to be touched. Sometimes people in your Blue, Green, Yellow, Orange, or Red Circles will try to get too close to you. You need to say STOP. No one touches you unless you want to be touched and you do not touch other people unless they want to be touched.</td>
</tr>
<tr>
<td>Blue Hug Circle</td>
<td>It is a mutual decision to kiss and hug and be close. If you do not want to, you must say STOP. Sometimes you may not feel like being touched. This does not mean that you are no longer close with your partner, but only that you are not feeling loving at that moment. Your partner can say STOP to you too.</td>
</tr>
<tr>
<td>Green Faraway Circle</td>
<td>Sometimes a friend may want to be closer to you than you want. You just explain to your friend and say STOP. You may give a faraway hug only on special occasions. You can say “You are not in my Blue Hug Circle.”</td>
</tr>
<tr>
<td>Yellow Handshake Circle</td>
<td>Sometimes someone whose name you know may ask for a Faraway Hug. You can say NO. No one can touch you unless you want to be touched. You can use a handshake to greet this person if it feels right for you.</td>
</tr>
<tr>
<td>Orange Wave</td>
<td>Wave to an acquaintance who is too far away for a handshake. Sometimes children will want to hug and kiss you, but you can say NO. It is best to wave to children. Children do not know as much as you,</td>
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</table>
Some people stay strangers forever. You may talk about business to a stranger who is a community helper. Other strangers do not talk to you or touch you. If a stranger touches you after you have said STOP, go get help and tell someone.

Understanding Boundaries and Providing Resources

Key Points for Caregivers

Establishing boundaries in relationships can create safe psychological spaces. When individuals with an intellectual disability express their sexuality in inappropriate ways, their behaviour needs to be addressed just as it would with non-disabled individuals. Open demonstrations of sexuality may be linked to mental illnesses and must be reported and discussed with other staff and health professionals. In some instances, the behaviour must be reported to police. Caregivers can model respectful behaviour that shows the difference between private and public actions. This is an important way for individuals with intellectual disability to learn about setting boundaries. Resources are available, such as picture cards and the Circle of Relationships activity.

Differentiating between Challenging Behaviours and Sex Offending Behaviours

People with intellectual disabilities and offending behaviour, including sexual offending, usually access services from both the justice system and disability care services. Staff from different professional groups may not agree on whether the behaviour should be viewed as challenging or sex offending. Problematic sexual behaviour can be aligned with clinical processes and viewed either way (Doyle, 2004). Although philosophies about challenging behaviour and sex offending behaviour have some characteristics in common, knowing that significant differences exist can be helpful in understanding how to provide consistent and informed support.

Challenging behaviours are viewed as violent and have been defined as “behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities” (Emerson, 1995, p. 4). Sexually violent behaviour includes actual, attempted, or threatened sexual contact with a person who is non-consenting or unable to give consent (Boer et al., 1997). This includes all sexual contact with children. The behaviour may interfere with the gaining of new skills and learning opportunities, so that the quality of life of others may be impacted as well as the quality of life of the individual with the challenging behaviour. Examples of challenging behaviours include self-injury, self-stimulation, physical and verbal aggression, sexually inappropriate behaviour, and property destruction (Doyle, 2004).

The term challenging behaviour has been used as an attempt to avoid further stigmatizing a population of individuals.
who are already marginalized. It is meant to demonstrate that the behaviour is an adaptive response to other factors or a means of communicating distress to others (as discussed in Chapter 6). Assessment is likely to incorporate indicators of psychiatric disorders. Interventions focus on exploring the environmental, biological, educational, and social factors responsible for the behaviour rather than placing the blame on the individual participating in the behaviour. It is within this way of thinking that clinicians are trying to come to terms with and develop interventions for sexually violent behaviour.

Understanding challenging behaviour requires believing that human behaviour occurs for some reason and within a certain context. Functional analysis is the way clinicians and workers in the intellectual disability field attempt to understand the meaning or communicative intent of the behaviour. The relationship between the behaviour, the preceding events, and the consequences of the behaviour are explored. Treatment processes then look at ways to alter preceding events or consequences in order to change the behaviour and to address the needs the individual is attempting to communicate.

Treatment approaches that view the behaviour as sexual offending regard the same actions as violent but emphasize protecting the community and preventing the behaviour from reoccurring. Rather than considering the meaning behind the behaviour, this view suggests that individuals must take responsibility for their behaviour and for the consequences of their actions. This way of thinking highlights that there is a risk for both the community and the offending individual if the seriousness of sex offending is underplayed. For example, we cannot hold children or vulnerable disabled adults responsible for triggering an offender’s behaviour, and we cannot just dismiss the damaging consequences of the sex offending behaviour.

There are two important arguments against viewing sex offending behaviour as being simply challenging. First, treatment framed from a sex offending view does not reflect the values inherent in the process of conducting a functional analysis. Second, there is a risk for both the community and the offending individual if the seriousness of sex offending is underplayed. Table 7.2 presents differences between behaviours that are challenging and those that are sex offending (Doyle, 2004).

Table 7.2 Values-based assumptions: Challenging behaviour versus sex offending behaviour

<table>
<thead>
<tr>
<th>Challenging Behaviour</th>
<th>Sex Offending Behaviour</th>
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<tbody>
<tr>
<td>The primary intention of a functional analysis approach to challenging behaviour is</td>
<td>Evaluation of intent and motivation is key to understanding offending behaviour. Darke</td>
</tr>
<tr>
<td>to identify the purpose, meaning, and communicative intent of a behaviour in order to</td>
<td>(1990) indicates that committing sexual offences achieves power and control over more</td>
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<td>provide behavioural support.</td>
<td>vulnerable people through the use of sexual aggression. Sorting out the how and</td>
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<td></td>
<td>identifying the form the behaviour takes and the circumstances under which the behaviour</td>
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<td></td>
<td>occurs is paramount in order to develop relapse-prevention strategies.</td>
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<td></td>
<td>The risky nature of sexual offending behaviour means that the focus needs to be on the</td>
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<td></td>
<td>behaviour itself rather than the meaning behind the behaviour. The damage to vulnerable</td>
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<td></td>
<td>victims can have great impact on them for the rest of their lives. While the dignity of</td>
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<td></td>
<td>the offender is of concern, protecting the community and managing the risk of</td>
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<td></td>
<td>reoffending behaviour both compete for priority.</td>
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</tbody>
</table>

The primary intention of a functional analysis approach to challenging behaviour is to identify the purpose, meaning, and communicative intent of a behaviour in order to provide behavioural support.

Once the purpose of the individual’s behaviour has been determined, behavioural support is given with the primary aim to hold that individual’s dignity as a primary concern.
In functional analysis, the goal is to understand the purpose of the behaviour in order to teach and develop effective alternatives. The approach is educational and involves the systematic instruction of new adaptive skills.

Assessment of sexual offending behaviour is carried out to prevent and protect the public and not necessarily to understand the purpose of the behaviour for the offender. The educational focus is relapse prevention and addressing contributing factors such as problem solving and decision making, anger management, alcohol and drug abuse prevention, sexuality, and legal issues such as consent. The Association for the Treatment of Sexual Abusers website is a helpful resource (http://www.atsa.com/index.html).

Functional analysis is designed to determine the relationships between environmental conditions and the person’s behaviours. The environment has an ongoing reciprocal role in shaping the behaviour and is the focus of developing alternative strategies. Precipitating environmental factors and factors that reinforce or maintain the behaviour are adapted to facilitate the development of more adaptive behaviours. The individual is not blamed.

Removing personal responsibility for offending behaviour is potentially dangerous. In the case of the sexual offender, the environment may be seen as only eliciting the expression of an existing deviant sexual orientation and hence is not a true interaction. Children and vulnerable individuals cannot be held responsible for the offender’s behaviour. Many people with intellectual disability who commit sexual offences have limited internal inhibitors and a poor understanding of the legal consequences of their behaviour. It is important to emphasize that the behaviour is wrong, it hurts others, and it has legal and emotional consequences that may affect the quality of life of the offender as well as the victims.

Differentiating between Challenging Behaviours and Sex Offending Behaviours

Key Points for Caregivers

Inappropriate expressions of sexuality are very serious. Whether they are open or violent, they can traumatize victims and leave offenders facing lifelong consequences. Different professional groups do not all agree on the best treatment approaches. Some view sexually violent behaviours that hurt others and interfere with quality of life for others as challenging. Others view these behaviours as sexual offending.

Treatment approaches that view the behaviour as challenging will try to find out why individuals act this way, what the behaviour means, and how it meets an otherwise unmet need. When caregivers are involved, they will admit that the behaviour is unacceptable and hurts others as well as themselves. They will also recognize that the behaviours are occurring for a reason and they will guide individuals toward meeting their needs with more acceptable behaviours.

Treatment approaches that view the behaviour as sexual offending will not focus on what the behaviour means. Here, when caregivers are involved, they will still admit that the behaviour is unacceptable and hurts others as well as themselves. However, they will pay more attention to strategies that prevent the behaviour from reoccurring and to protecting all the people in the community that the individual interacts with.

Although views about treatment approaches are different and each individual is unique, inappropriate expressions of sexuality must all be reported, discussed, and addressed as a team.
Conclusion

In this chapter we have discussed how caregivers can provide sexual education support to their clients through discussion topics, understanding boundaries, and differentiating between challenging behaviours and sex offending behaviours. Individuals with intellectual disabilities are very vulnerable to sexual abuse and victimization. They may not fully understand how to express their sexuality in socially acceptable ways and their consent for sexual activity may not be well informed. Those who are dually diagnosed with a psychiatric disorder are even more vulnerable. Their behaviour may be directly related to a psychiatric disorder and may indicate an escalating mental health crisis.

Caregivers can supplement existing sexual education programs in which clients are or have been involved, through conversations about normal expressions of sexuality such as masturbation, relationships, contraception, sexually transmitted diseases, and safe sex practices. Individuals with intellectual disabilities may be parents. For these parents to be supported toward retaining custody of their children and enjoying their family life, they need most to be surrounded by a network of caring, helpful people.

Understanding boundaries, or the limits we create within relationships to feel psychologically safe, is critically important. Inappropriate expressions of sexuality such as masturbation in public, genital exposure, inappropriate sexual touching, and embracing others too closely should not be tolerated. When non-disabled individuals demonstrate this behaviour, it is viewed as inappropriate and often reported to police. Individuals with disabilities are just as accountable for their behaviour. Caregivers and others in their environment should not be made to feel uncomfortable or psychologically unsafe because of an individual’s behaviour. The behaviour should not be ignored. It should be discussed among agency staff, recorded, and reported according to agency policy. Caregivers can model how to set boundaries by requiring acceptable personal space during their interactions with clients.

Any inappropriate expression of sexuality must be taken seriously. People who witness, who are victimized, or who are assaulted as a consequence of these behaviours can be left devastated. Perpetrators are usually penalized. Although professionals do not always agree about whether the behaviour should be viewed as challenging or as sex offending, there is a clear consensus that the behaviour is hurtful, unacceptable, and must stop. Children and other adults must be protected and individuals must find strategies to prevent the behaviour from reoccurring.

Finally, adults with intellectual disabilities can embrace their sexuality every bit as fully as everyone else in society. Knowing this, seeking ways to ensure these adults have the knowledge they need can become a priority. Increasing clients’ expressions of their sexuality in healthy ways will allow others to see their capabilities and personalities as people we value and want to come to know.

Chapter Audio for Print

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References


