Responding to Sexual Behaviours of Children and Young People with an Intellectual Disability

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Introduction

Children and young people with an intellectual disability have the same rights and similar goals, desires and feelings as their typically developing peers (United Nations, 1989; United Nations, 2006). This includes their aspirations relating to sexuality and relationships. Understanding healthy sexual development plays a key role in guiding how we shape and respond to sexual behaviours in children and young people with an intellectual disability. This is an area of practice that often raises a degree of apprehension and may leave clinicians wondering if there is something additional or different they should be providing. While some specialist knowledge is required, clinicians will have pre-existing knowledge and skills that can be applied to the presenting situation. They will also be influenced by their own values, beliefs and experiences. This article aims to provide scaffolds and resources to further help them in this work.

What is Sexuality?

"Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed.

Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors."

(World Health Organisation, 2006)

Healthy Sexual Development

As with all forms of development, sexuality follows a fairly typical sequence. This is true for both people with and without an intellectual disability. An understanding of these developmental stages and milestones provides guidance in responding both proactively and reactively (Brennan & Graham, 2012; Family Planning Queensland, 2012; Johnson, 2015).

For example, toddlers are naturally immodest and openly curious about their own and other people's bodies and bodily functions. By pre-school, children are more aware of gender differences and may engage in exploratory play, taking the role of "doctor" or "nurse". Through their primary school years, children become increasingly aware of social rules and tend to be more modest, seeking privacy. It is also the time when the age old question of *"where do I come from"* is explored. In adolescence, young people experience puberty, sexual feelings and an interest in romantic relationships. The role of peers and body image also become more important as teens explore their self-identity. It is during this developmental stage, that young people reach the legal age of consent for sexual interactions, which is 16 years in New South Wales (Scott, 2014).

Throughout all life stages, healthy sexual exploration is a voluntary, spontaneous and playful information gathering process amongst equals. This means the children or young people involved are of similar age, size and ability level. Healthy sexual exploration is limited in the type and frequency of the behaviour(s) displayed. It is also easily redirected and balanced with interest in other aspects of life.

(Family Planning Queensland, 2012; Johnson, 2015)

A Proactive Approach to Sexuality

It is important to acknowledge that children and young people learn about sexuality in many ways. It is not *all* learnt at home or in the classroom, in the playground or online. Sexual knowledge, development and behaviour is shaped and influenced by a range of factors including the media (including social media), culture, living arrangements, the child's neighbourhood, the age of siblings, family norms, values and religion (Johnson, 2015).

A proactive, educative approach is needed to promote healthy sexual development and provide safeguards against harm. This education can begin in early childhood with parents teaching the names of body parts, introducing the concepts of public and private places, setting bounda-

Framework	*1*	*2*	*3*	*4*
Domain	*Sexuality*	*STIs/AIDS*	*Relationships*	*Health & hygiene*

Possible sequence of topics
 	
(Figure one)
	• Self-awareness and self-esteem
	• Body parts and functions
	• Puberty
	• Feelings
	• Sexual feelings
	• Being sexual
	  ○ What does it mean?
	  ○ Legal rights
	  ○ Decision-making and assertiveness
	  ○ Protective behaviour
	• STIs and HIV/AIDS
	• Pregnancy and contraception
		• Self-awareness and self-esteem
		• Sexuality
		• Sexual relationships, rights and responsibilities
		• Decision-making
		• Sexual health and diseases
		• HIV/AIDS
		• Signs of STIs
		• Transmission
		• Preventing diseases
		• Condoms: how to use and where to buy
		• Safe sex: practices and communication skills
		• Testing (STIs): rights and procedures
		• Treatment
			• Self-awareness and self-esteem
			• Feelings about others and choosing friends
			• Circle concept: different types of relationships
			  ○ Communicating
			  ○ Making friends
			  ○ Maintaining relationships
			  ○ Different things we 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
				• Body parts and functions
				• Feelings: body awareness
				• Self-awareness and self-esteem
				• Nutrition and exercise
				• Feeling healthy and feeling ill
				• Health care
				• Contagious and communicable diseases
				• STIs and HIV/AIDS
				• Using medical practitioners and health services

ries for protective behaviours as well as preparing their children for puberty. Teachers and clinicians also play an important role in sexuality education, providing not only knowledge, but building skills and behaviour as well. Jones and Chivers (2011) proposed the following framework for sexuality education including a possible sequence of topics (See table).

There is a wide range of resources available to aid sexuality education. Some of these may be borrowed or purchased from *Family Planning NSW* (see http://www.fpnsw.org.au/disability_catalogue_2013_4.pdf). For organisations specialising in relationships and reproductive health in other states and territories please refer to the *Family Planning Alliance Australia* website (see http://familyplanningallianceaustralia.org.au/services/)

Special Considerations

When educating children and young people with an intellectual disability about sexuality it is important to consider their specific learning requirements and provide information in a way they can understand.

Special considerations may include:

- Building on their existing knowledge, skills and behaviours
- Providing additional time for them to process information and adjust to developmental changes: this may mean the same information is presented several times and in different ways
- Ensuring the clarity of language used (e.g., avoiding figurative language)
- Using visual supports to augment information
- Taking into account any sensory issues
- Ensuring significant time and focus is given to safety, protective behaviours and consent
- Helping to build the accompanying social skills, problem solving skills and decision making skills
- Providing information about social rules, boundaries and relationships (potentially through a Social Story™ format)
- Providing information and support to increase their ability to anticipate changes as well as potential consequences

(Hagiliassis, DiMarco, Gulbenkoglu, Iacono & Watson, 2006; Raising Children Network, 2013)

The *Raising Children* website (see http://raisingchildren.net.au) has further information and practical tips to assist parents, teachers and clinicians alike in their role of raising sexually healthy children. Family Planning NSW (2015) has also developed a tool to guide clinicians in supporting people with an intellectual disability (over the age of legal consent) to make their own decisions about their reproductive and sexual health. This is a useful companion to the Capacity Toolkit (NSW Attorney General's Department, 2009) when exploring an individual's capacity to consent.

When are Sexual Behaviours of Concern?

It is estimated that between 40 - 85 % of children will engage in some form of sexual behaviour before the age of 13 (Johnson, 2015). Despite this, many children and young people with an intellectual disability find their behaviour labelled as "deviant" or "problematic" even though it could indicate typical development.

"Children who are wrongly assessed as having problem sexual behaviour when they do not (a false positive) are at greater risk of being deprived other human rights."

(Webster & Butcher, 2012)

As such it is imperative that clinicians seek to understand rather than label sexual behaviours. This requires a good understanding of child development and careful consideration of the social, cultural and family context within which the behaviour occurs.

Sometimes however, a child or young person's sexual behaviours can be a source of concern – particularly if they are excessive, coercive, secretive, degrading or not among equals (Brennan & Graham, 2012; Evertsz & Miller, 2012; Family Planning Queensland, 2012; Johnson, 2014; Lamont, 2010; NSW Department of Health, 2005; Ryan, 1997; Pratt, Miller & Boyd, 2012).

- ***Excessive*** means it is occurring at a high frequency (or duration) to the detriment of the child's interest and participation in other areas of life. E.g., a child spending most of their waking hours masturbating in their bedroom to the exclusion of other activities and time with family or friends.
- ***Coercive*** means a degree of pressure has been placed on the child to achieve compliance. E.g., the use of physical force, threats, manipulation, trickery or bribery.
- ***Secretive*** means the child has been encouraged to hide the behaviour and is prevented from talking about it. E.g., *"you can never tell …. this will be our little secret."*
- ***Degrading*** means it causes humiliation to the child or loss of self-respect. E.g., naked selfies being emailed to classmates.
- ***Inequality*** means there is an imbalance of power, control and / or authority. E.g., sexual interactions involving a teacher and a student.

Overall, sexual behaviours tend to be considered a concern when they are developmentally inappropriate (i.e., reflecting sexual knowledge beyond their years), when they place the child or young person at risk of harm, when they cause offence to others, possibly because they break a social convention (i.e., occurring in the wrong place at the wrong time) or because they breaks the law (Evertsz & Miller, 2012; Family Planning Queensland, 2012; Johnson, 2014; Lamont, 2010; NSW Department of Health, 2005; Ryan, 1997; Pratt, Miller & Boyd, 2012).

A Rights Centred Response Framework

Safety and the protection of children must be addressed as the priority. This may involve developing a safety plan (or incident prevention and response plan) whilst a more comprehensive assessment is undertaken. Consideration must also be given to child protection and mandatory reporting requirements. Clinicians are encouraged to consult the online Mandatory Reporter Guide (MRG) for more guidance (see www.keepthemsafe.nsw.gov.au). Promoting safety however, is only one part of a holistic response.

Webster and Butcher (2012) assert that a rights centred approach to sexual behaviours in children and young people involves three essential stages. Firstly, clinicians need to *recognise* the variation in normative sexual development in order to identify when sexual behaviours are of concern. Secondly, clinicians need to *reflect* on the information available through a sound clinical assessment process. Thirdly clinicians need to *respond* by putting interventions in place which meet the child, young person and family's bio-psycho-social needs while ensuring safety, dignity and rights are maintained.

The *Traffic Lights* framework is one tool which aims to guide practitioners through the process of identifying, assessing and responding to sexual behaviours (Family Planning Queensland, 2012. This resource uses the metaphor of traffic lights to describe the continuum of sexual behaviours as either:

Green = "normal" or healthy sexual behaviour and indicative of an opportunity to provide positive feedback and information.

Orange = "outside the norm" and signalling the need to take notice and gather information to assess and take action.

Red = "outside the norm" and requiring immediate action.

The Traffic Lights tool then provides a useful scaffold for identifying actions in response to the hypothesised function of the behaviour(s). For more information please see the *TRUE* (previously known as Family Planning Queensland) website (see http://www.fpq.com.au/publications/fsBrochures/Br_Sexual_Behaviours.php). A *Traffic Lights* App is also available via i-tunes (Family Planning Queensland, 2015).

Some Case Examples

Scenario One. Two kindergarten students were found giggling and showing each other their genitals in the school toilets. While the children were easily redirected by the teacher, she wanted to know what other action should be

> "All work should be undertaken with the aim of promoting rights, maintaining dignity and building a sense of worth."

taken. Using the Traffics Lights framework, the teacher, principal, and school counsellor hypothesised that the behaviour reflected "normal" curiosity in sexual development. With this in mind, the team determined that further education around protective behaviours, and public and private spaces would be beneficial. The children's parents were also informed.

Scenario Two. The school received a phone call from a distressed mother. She informed the school that her daughter with Down syndrome had received texts from a classmate (who also had Down syndrome) pressuring her to send him naked selfies or else they would no longer be friends. Using the Traffic Lights framework to facilitate further discussion, the teacher, principal, parent, school counsellor and case worker determined that the behaviour was of significant concern given the coercive and threatening nature of the texts. It was hypothesised that the girl's strong desire for friends and limited opportunities for social connections were increasing her vulnerability to such requests. In response the mother decided to continue closely monitoring the use of technology / social media, talk with her daughter about peer pressure and look into social activities such as joining a dance group. The teacher decided to develop lessons for the whole class around cyber bullying and peer pressure. This was an initiative that the principal hoped would then be rolled out school wide. The Traffic Lights framework was also used to develop a behaviour support strategy in relation to the other student involved.

Conclusion

Clinicians play a critical role in the promotion of healthy relationships for children and young people with an intellectual disability. While an understanding of typical sexual development should be used to guide responses to sexual behaviours, it is important to remember that each child, family and service system is unique and will require an individualised approach. All work should be undertaken with the aim of promoting rights, maintaining dignity and building a sense of worth. This includes initial safety responses to sexual behaviours and the design and delivery of interventions which meet underlying needs and promote well being. Clinicians are encouraged to apply their existing knowledge, skills and experience, the scaffold described here and the many resources available in both the mainstream and disability literature to inform their response to sexual behaviour in children and young people with an intellectual disability.

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