Sexuality and Sexual Health Education in Children with Disabilities

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Sexuality is a core aspect of being human involving various physical, cognitive, emotional and social aspects. Children with disabilities are sexual beings too. They experience sexual development and changes as they grow and have sexual feelings, desires and needs just like their non-disabled peers. Unfortunately, their sexuality is often not accepted or addressed, because of which many do not receive sexual health education either at home or in school. They lack the knowledge required to develop a healthy sexual identity, thereby increasing their vulnerability to experience negative sexual outcomes. Research consistently shows that individuals with disabilities are at greater risk of sexual abuse, exploitation, unwanted pregnancies and sexually transmitted diseases.

As a researcher, I have worked in the area of sexual health education with several parents and teachers of children with special needs, particularly those with autism. Though it has been challenging at times, it has also been very fulfilling to address a topic that is still considered taboo in many respects.

Sexuality

Sexuality encompasses nearly every aspect of one's being, be it attitudes, values, feelings or experiences. It is not just about the physiological aspects of sexual development or the physical aspects of sex, it is more about how individuals experience and express themselves sexually. It reflects in the choices that individuals make, such as what they choose to wear, how they interact with others, what activities they choose to engage in, who they are attracted to and how they show their affection and intimacy. Sexuality is a core part of the human experience from birth through adulthood. It is influenced by one's upbringing, experiences, values, spirituality and culture.

Sexuality in typical children

In order to understand sexuality in children with disabilities, it is essential to understand sexuality in children without disabilities. During the early years of life, children develop an emotional and physical foundation for sexuality in subtle ways through daily life activities, such as being fed, held, cuddled, bathed and changed. They may learn about their bodies as they touch themselves or see themselves in the mirror. By age three, most children develop an awareness of gender. They can identify themselves and others as being male or female and associate certain behaviours as being more male or female, thereby gaining an understanding of gender roles.

During the preschool years, children are very curious about everything around them. They ask endless questions and may find simple answers to questions such as, 'Where do babies come from?' or 'Why are girls different from boys?' or 'Why don't girls have penises?'. Additionally, their own social interactions with peers, playing *doctor* or *mummy-daddy* helps them gain a better understanding of sexuality. In late childhood, children are less interested in matters related to sex and prefer to play with peers of the same sex. However, even though this period is often referred to as the latent period in the sexual development of children, they are exposed to bad language, dirty jokes and some information about sex from their peers or siblings.

By the end of late childhood, most children begin to develop the tell-tale signs of approaching puberty, such as growth of pubic hair, changes in height, weight and body structure, appearance of acne and facial hair, etc. These are soon followed by menstruation in girls and nocturnal emission in boys. This is a very confusing and turbulent time for most young teens as they experience changes in their mood along with changes in their bodies. They actively pursue knowing more about sex from various sources that they are comfortable with, such as friends, books and electronic media. As a part of adolescent development, they want to establish their own identity and distance themselves from their parents. They spend more time with peers and are often attracted to those of the opposite sex. They seek privacy and may spend long hours grooming themselves. Due to hormonal changes and development of secondary sexual characteristics they experience sexual urges and arousal. While exploring their growing bodies

they are likely to find self-stimulation of their genitals very pleasurable and satisfying. Some may seek a girlfriend or boyfriend to experience sexual relations with a partner.

Sexuality in children with disabilities

Sexual maturation

Children with disabilities undergo the physical aspects of sexual development in the same way as their non-disabled peers. Their bodies grow and change as they attain sexual maturation. However, some children with disabilities begin puberty earlier and complete puberty later than their typically developing peers. As with other developmental aspects, they may just take a little longer to catch up with their peers. Puberty is as confusing, if not more, than it is for the rest.

Parents tend to worry about menstruation in girls and often see it as a burden to both themselves and their child. But research shows that girls with disabilities accept menstruation in a very matter-of-fact manner. They may need extra help managing their personal hygiene and self-care. The key to making them feel at ease with the changes in their bodies is to provide education, deliberate practical training, various skill-building opportunities and reinforcements to promote independence in self-care activities.

Sexuality and social development

Social development is largely experiential and children with disabilities lose out on it greatly. Due to their limitations, they may have far fewer opportunities for social interaction than their typically developing peers, which can hinder crucial learning experiences that all children ought to experience. They may not have picked up cues from their environment about the subtle social rules that govern the expression of sexuality. They do not get to learn about sex and sexuality from peers and friends, therefore, they know less. This often results in them being somewhat awkward.

Again, their expression of sexuality is considered inappropriate and problematic to others around them because their errors in social judgment can interfere with their ability to assess whether they should perform certain behaviours in public or private places. Therefore, instead of the feelings of pleasure and fulfilment that come with expressing one's sexuality in a healthy manner, children and youth with disabilities are often chided and made to feel ashamed of their inappropriate socio-sexual behaviours.

Sexual behaviours

When adolescents with disabilities begin to feel or respond to hormonal changes and sexual feelings, parents and professionals are often disturbed, confused and even offended by the emerging behaviour. Masturbation is a normal behaviour through which most adolescents learn about their own sexual functioning and in which most non-disabled children typically engage in varying degrees through childhood and adolescence. It goes unnoticed because they learn to effectively hide it from others. They are quick to learn which behaviours are acceptable based on the reactions of the adults around them and over time, expressions of sexual behaviours change to being more covert. But children with disabilities need to be taught to do, or not do, certain things in public. This is one of the reasons we see more sexual behaviour among those with disabilities.

Privacy

Caregivers can sometimes be over-protective and may tend to infantilise children with disabilities; children who have long-term needs for assistance with self-care activities, such as going to the toilet, bathing, and dressing. Out of concern, they may always be around the child, supervising his/her activities resulting in the child never getting personal time or privacy. A boy with cerebral palsy with accompanying speech problems once texted me that he was frustrated with his mother being around him all the time. The only time he got for himself is when his mother went to the bathroom because she was there to assist him even when he went to the toilet.

Parents must be encouraged to give their growing children some privacy each day, because it is a developmental need especially during adolescence. Giving them privacy on a regular basis will enable them to explore their sexuality in safety and reduce the incidence of inappropriate behaviours in public. If parents cannot provide the child with a separate room, the bed can be curtained off. It is important for parents to take measures to establish comfortable responses to the needs of their children with disabilities so that they achieve greater maturity and independence in the future.

Sexual expression in daily life

Even young children assert themselves and make small decisions in their daily lives, such as what they want to wear or how they want to style their hair. Children with disabilities are often denied freedom to make the very same choices, as caregivers do most of it. Most adolescent girls with disabilities are made to wear their hair short for reasons convenient to caregivers, such as easy maintenance or because it will make them less attractive. They hope that such measures will save their children from any unwanted attention and potential abuse. Children with disabilities are often plainly dressed because caregivers assume it does not matter to them.

But we must remember that the presence of a disability itself affects the development of a healthy sexual identity, confidence, desire, function, and even their ability to find a partner in the future if they so desire. Children and adolescents with disabilities must be taught as much as possible to make decisions for themselves about the things that concern them. Parents, caregivers, and professionals must work towards empowering and not curtailing the rights of children with disabilities.

Sexual abuse

Several studies have reported that children with disabilities are more than twice as likely to be sexually abused than children without disabilities. This could be explained by some of the following reasons.

- Their daily dependence on others for intimate care makes them lose a sense of ownership over their own bodies. Caregivers routinely feel free to touch them in very intimate ways without asking their permission or giving them any control and often do not think about their feelings of modesty and dignity. Unfortunately, this makes it difficult for children to recognise abuse when someone is taking advantage of them.
- They are exposed to many caregivers in many settings, which means many people touch them in different ways for many reasons.
- Their inappropriate social skills and poor judgment may sometimes lead them to situations where they are exploited. Parents and caregivers may react to the fears of sexual abuse by protecting them from unsupervised social contacts, thereby inadvertently denying them critical opportunities to develop social skills and appropriate personal boundaries.
- They may be unable to seek help or report abuse because of their disability. Often children do not report abuse because they simply do not know what to say.
- They lack strategies to defend themselves against abuse.
- Children with disabilities are taught to comply from a very young age. They get accustomed to doing what they are asked to do and they are never taught to say *no*.

These reasons bring to light certain things that caregivers need to learn, as well as unlearn, for the benefit of their children. Depending on the degree of their disability, children can learn to protect the privacy of their own bodies assertively and to recognize and report violations to trusted adults. They can learn only when they are intentionally taught. The United Nations Convention on the *Rights of the Child* has stated that *all* children are entitled to accessible and appropriate education, guidance, support, and play opportunities. They have the right to be heard, respected and protected from exploitation and abuse.

Sexual health education

The important stakeholders in the lives of children with disabilities are parents and educators. Parents stand at an advantageous position to teach their child about sexuality, but they often feel so overwhelmed by other aspects of the child's disability that they may lack knowledge and skills to teach their child appropriately and feel awkward discussing sexuality with their child. They, in turn, often look to teachers to help. Hence, teachers and schools, in general, need to be well-equipped to take up the task of teaching sexual health education. It is specified in UNESCO's *Strategy on Education for Health and Wellbeing* that good quality school-based comprehensive sexuality education is essential as it increases correct knowledge, promotes positive attitudes and values and develops skills to make informed choices. Comprehensive sexuality education is defined as 'an age-appropriate, culturally relevant approach to teaching about sex and relationships by providing scientifically accurate, realistic, non-judgmental information'.

Teaching sexual health education requires educators to step out of their comfort zones and prepare to overcome any hindrances or discomfort in having open and detailed discussions on sexuality. It may be easier to provide a textbook education of the biology of sexual organs, pregnancy or childbirth,

but unfortunately many times it is not understood by those with disabilities. They need the same education about sexuality as their peers, but often the education must be modified to allow the information to be presented in such a way that they can benefit from it despite their limitations. An appropriate sexual health education programme for children with disabilities should include these topics: body parts, pubertal changes, personal care and hygiene, medical examinations, social skills, sexual expression, abuse prevention skills, and the rights and responsibilities of sexual behaviour.

Just as regular classroom teaching is modified to suit the individual needs of children with disabilities, the regular sexual health education curriculum could be modified for children with disabilities by simplifying information, using special teaching materials, such as illustrations, puppets, stories, anatomically correct dolls and frequent reviewing of what has been taught. When teachers plan Individualised Education Plans (IEPs), they could include age and need appropriate sexuality education for children with disabilities. A basic tip to make sexual health education more meaningful to the learners is to begin early. Children should be taught names of all the parts of the body, even the parts that we tend to omit, such as penis, breast, etc. Knowing the names of body parts is foundational to further learning about sexuality.

Additionally, in our society, the approach to providing sexual health education must change from being *reactive* to being *proactive*. Most parents and educators address sexual health only when the child's behaviour becomes problematic or when the child does something inappropriate. Parents and educators tend to talk about sexual health more to girls because menstruation is a more apparent event in a child's life. On the other hand, boys are often not taught about sexual health: they are expected to find out for themselves from various sources. However, in the disabled population, deliberate instruction on sexual health must be provided proactively to improve health and empower youngsters. It should not merely be a measure of rectification when something goes wrong.

Conclusion

Children with disabilities are no different from children without disabilities when it comes to sexuality. They just need extra help, support and education to deal with this rather complex aspect of their lives. The presence of a disability does not override the rights of children and adolescents to express their sexuality, to be treated with dignity or to have access to appropriate sexual health education. Parents, caregivers and educators need to increase their awareness on matters related to the sexual health of the disabled. We need to work together to promote their overall wellbeing. I believe that educators can make a difference in the lives of these children. I strongly encourage professionals and family members to gain more knowledge about this topic and also find time to share their knowledge with others.

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