– SEXUAL HEALTH ISSUE BRIEF –
Autism Spectrum Disorder: Information for Sexual Health Educators

Autism spectrum disorders (ASDs) include a range of conditions that are characterized by difficulty with communication and social interaction, repetitive behaviours, and a tendency toward narrow, focussed interests. The terms autism and Asperger syndrome refer to conditions on the spectrum of autistic disorders. A diagnosis of Asperger syndrome traditionally has been applied to those who are considered to be higher functioning. Individuals with autism exhibit symptoms that range from mild to severe. Currently, the designation autism spectrum disorder (ASD) is used to encompass all individuals with autistic symptoms of varying severity and prevalence. In May 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) combined *Autistic Disorder*, *Asperger's Disorder*, and *Pervasive Development Disorder Not Otherwise Specified* (PDD-NOS) under the umbrella term *Autism Spectrum Disorder*. It is important to note that youth with ASD have a range of cognitive and mental abilities: some are below average while others are average or above average.

Social norms and standards for negotiating and navigating romantic and/or sexual relationships can be difficult for adolescents and young adults with ASD. For example, people with ASD may have trouble interpreting and detecting various relationship cues because of difficulties with communication and social skills. In this Sexual Health Issue Brief, we provide general information on the implications of ASD for sexuality and development, key points to consider in providing sexual health education to youth with ASD, and a list of relevant resources for sexual health educators.

Prevalence of ASD

The most recent data from the United States Centers for Disease Control and Prevention (CDC, 2014) indicates that approximately one in every 68 children has ASD. The CDC report suggests that ASD is about four times more common in boys (one in 42) than in girls (one in 189). There are no comparable national statistics for Canada but it is likely that the prevalence of ASD in Canada is similar to the United States (MacDonald, 2014).

The data from the CDC (2014) suggests that the prevalence of ASD may be increasing: 2012 data indicated that 1 in 88 children had ASD compared to one in 68 in the 2014 report. However, these statistics should be viewed in the context of how ASD prevalence data is acquired. There is no known specific biological marker for ASD that can be identified through a common or universally administered blood or neurological test. Thus, ASD is typically diagnosed based on observable criteria such as trouble with communication and social interaction, repetitive behaviours, and unusual or severely limited interests. Because data on the prevalence of ASD relies on health care providers making a formal diagnosis based on these criteria it is difficult to ascertain if the prevalence of ASD is increasing. For example, if growing societal awareness of ASD results in more children being assessed and diagnosed, this will result in higher prevalence statistics. Nevertheless, it is clear that ASD is a common condition among North American children, especially boys.

ASD and the Development of Sexuality

Developing romantic and/or sexual interests is a developmental milestone; many pre-adolescents become romantically interested in others or develop crushes around the age of 9-13 years which coincides with the onset of puberty (Arnett, 2013). Although individuals with ASD may experience delays in the development of social communication skills, the onset of puberty and an increasing interest in sexuality is typically not delayed.

Young people with ASD have difficulty reading social cues, such as facial expressions and body language, which can make the formation of peer relationships difficult. Some children and adolescents with ASD may be hypersensitive, where physical touch and stimuli is unpleasant and even painful, and others may be hyposensitive, which leads to an increased need for sensory information in order to feel comfortable and secure. Both of these conditions may lead to sexual and relationship problems. A hypersensitive person may avoid physical intimacy. A person who needs constant or excessive stimulation may experience difficulties with arousal and orgasm.

Although young people with ASD have the same desire for romantic relationships, including sexual involvement as their typically developing peers (Chan & John, 2012), research indicates that youth with ASD often have less sexual health knowledge than their peers (Mehzabin & Stokes, 2011). Youth often rely on peers as a main source of information about sexual and romantic relationships, and those with ASD have fewer chances to interact socially and to learn the "rules" of appropriate sexual and relationship behaviour.

Since youth with ASD often lack social interaction skills and sexual knowledge, they may have difficulty in grasping the concept of public and private space, and may display inappropriate sexual behaviour such as unwanted touching and masturbation and undressing in public. A key concern for parents is that others will mistakenly interpret innocent missteps in behaviour as purposeful deviant sexual activity. As a result, youth with ASD often only receive sexuality information related to the appropriateness of touching, privacy, and hygiene (Ballan, 2012). Even parents of individuals with ASD at high functioning levels sometimes tend to cover only these general topics while avoiding the provision of other, equally important, information such as how to use a condom or sexual activities besides intercourse (Holmes & Himle, 2014).

As they progress through adolescence and young adulthood, many people with ASD may have internalized negative social stereotypes that they are asexual or incapable of healthy relationships. Nevertheless, although people with ASD may have first relationship and sexual experiences somewhat later in life than their peers, many people with ASD are able to enter and maintain romantic relationships (Byers, Nichols, Voyer, & Reilly, 2013; Gilmour, Melke Scholomon, & Smith, 2013). It is, therefore, important that youth with ASD receive broadly-based sexual health education tailored to their specific learning needs.

Sexual Health Education for Adolescents and Young Adults with ASD

Parents and guardians of typically developing youth may assume that the youth under their care will receive sufficient sexual health education in school or will learn what they need to know about sexuality on their own through other sources of information (e.g., the internet, health care providers) and through experience with minimal parental input. However, parents/guardians and public health professionals cannot make similar assumptions about youth with ASD. For example, most sexual health curricula for youth are implemented with the assumption that adolescents have already acquired basic social skills for interpersonal interactions related to sexuality and relationships.

Key points to consider for developing and implementing sexual health education for youth and young adults with ASD include the following:

Proactive Versus Reactive Sexual Health Education

Parents, educators, and public health professionals should address sexual health education proactively – not only when an issue or problem arises (Ballan, 2012). This will help youth with ASD be prepared, for example, to more successfully meet the biological and emotional/social developmental tasks associated with puberty while at the same time avoid problematic situations that arise due to lack of information (Holmes, & Himle, 2014). Hénault (2013) recommends that sexual

health education for youth and young adults with ASD address the same basic concepts and content areas as other broadly-based sexual health education programs but that they are also specifically designed to accommodate the chronological and developmental age of the participants and place particular emphasis on issues such as communication related to friendship, intimacy and love; qualities of healthy relationships (e.g., sharing, reciprocity, respect, pleasure); boundaries and informed consent; and dangerous relationships (e.g., age differences, bullying, exploitation, aggression).

The Provision of Concrete and Visual Sexual Health Information

A comprehensive overview of appropriate educational methods for teaching sexual health education to youth with ASD is beyond the scope of this Issue Brief. Some basic strategies include the provision of highly concrete factual information and use of concrete visual images. Students with ASD "…often demonstrate relative strengths in concrete thinking, rote memory, and understanding visual-spatial relationships, but have difficulties in abstract thinking, social cognition, communication, and attention" (New Brunswick Department of Education, 2005, p. 24). As a result, students will be more likely to benefit from information that is provided simply, consistently, and with repetition. In addition, providing students with materials that provide factual information in combination with concrete visual images can be helpful.

Social Skills Training

As noted above, youth with ASD may have difficulty reading social cues such as facial expressions and body language, anticipating the emotional responses of others, and developing the ability to initiate and end social Interactions. However, most sexual health education curriculums assume that youth have learned these skills outside the classroom (Gougeon, 2010). It is essential that sexual health education for youth with ASD emphasis social skills development related to sexuality and relationships. In some cases, social skills training and other aspects of sexual health education for youth with ASD will need to be tailored to an individual's developmental level and abilities.

Prevention of Sexual Abuse and Exploitation

Similar to all children with developmental disabilities, youth with ASD are especially vulnerable to sexual abuse and exploitation. Youth with ASD may be targeted for abuse because they are perceived as vulnerable by perpetrators. Additional concerns are that when they have been sexually abused, youth with ASD may have difficulty articulating that they have been abused and that they will exhibit signs of abuse which may be misattributed to unusual or inappropriate behaviours related to their ASD (Edelson, 2010). Sexual health topics that need to be addressed with children with ASD include: learning accurate names for body parts; learning to take care of private parts (e.g., bathing, going to the bathroom); understanding the distinction between "okay" and "not okay" touches; empowerment to say "no" when they do not want to be touched in any way; and telling parents and caregivers If they have been abused (Autism Speaks, n.d.).

Sexual Orientation

Sexual health educators are aware of the importance of providing sexual health education to all audiences that is fully inclusive with respect to sexual orientation and gender identity. For youth and young adults with ASD, providing sexual health education that accounts for the specific educational needs of gay, lesbian, and bisexual individuals is particularly salient. Some research suggests that a high percentage of people with ASD report attraction to multiple genders or identify as gay, lesbian, or bisexual (see Byers, Nichols, & Voyer, 2013). Byers and colleagues suggest that sexual health education for people with ASD "…normalize attraction to both genders and empower individuals to adopt the sexual identity that best fits their self-concept" (p. 2625).

Consulting with Parents/Guardians

It is essential for sexual health educators to consult with parents/guardians regarding the provision of sexual health education to youth with ASD. Parents of children with ASD may be especially uncertain or concerned about the appropriateness of the sexual health information their children receive at school. Some parents may have difficulty conceptualizing their children as sexual beings while others are very unclear on which sexuality topics are appropriate to bring up with their children at which time (Holmes & Himle, 2014). Parents should be fully informed about what their children with ASD are learning about sexual health at school and, when appropriate, clear parental consent to the provision of sexual health education should be obtained.

It is important for sexual health educators and parents/guardians to work together in providing sexual health education to youth with ASD. For example, parents/guardians can provide key input on their child's level of social development, level of knowledge of sexuality, and specific issues of concern related to sexuality that enables educators to provide more effective education. Many parents report they wished they had introduced more sophisticated sexuality topics earlier (Ballan, 2012; Holmes & Himle, 2014). Therefore, sexual health educators can help parents/guardians determine how and when to introduce different sexuality topics with their children in a more proactive way rather than only addressing problematic behaviours reactively.

A Positive Approach to Sexual Health Education

In general, sexual health education is often positioned as an exercise in problem prevention, focusing on the prevention of early sexual involvement, unintended pregnancy and sexually transmitted infections. The *Canadian Guidelines for Sexual Health Education* (Public Health Agency of Canada, 2008) emphasizes the importance of a broadly-based approach that includes the health enhancement aspects of sexual health (e.g., development of a positive self-image and mutually satisfying interpersonal relationships). A broadly-based approach may be especially critical for youth with ASD who may not have been provided with education addressing the positive aspects of sexuality and relationships.

As Byers, Nichols, Voyer, and Reilly (2013) suggest,

> By starting early, providing positive messages about sexuality….individuals with ASD will have the opportunity to develop a positive sexual self-view, build confidence and self-knowledge, avoid potentially dangerous situations for themselves and others, and seek the sexual well-being that best meets their needs and desires (p. 13).

Resources

(Disclaimer: note that this resource listing is for informational purposes only and does not represent an endorsement by the Sex Information and Education Council of Canada)

General ASD Website Information

- Autism Society Canada. ASD information, referrals, resources, and training for professionals. http://www.autismsocietycanada.ca/
- About Sick Kids Health. Trusted Answers from the Hospital for Sick Children. Resources for ASD. http://www.aboutkidshealth.ca/En/ResourceCentres/AutismSpectrumDisorder/ResourcesforASD/Pages/default.aspx
- Autism Ontario. ASD information and resources. http://www.autismontario.com/client/aso/ao.nsf/web/Home?OpenDocument

Comprehensive Guide to Teaching Youth ASD

- New Brunswick Department of Education. (2005). Teaching students with autism spectrum disorders: Inclusive programming for ASD students in New Brunswick schools. https://www.gnb.ca/0000/publications/ss/TeachingStudentswithAutismSpectrumDisorders.pdf

Sexual Health Resources and Curricula for Youth with ASD

- Massachusetts Department of Public Health/Developmental Services. (2014). Healthy Relationships, Sexuality, and Disability: Resource Guide 2014 Edition. Description and links to curriculum resources on sexuality and disability including ASD. http://www.mass.gov/eohhs/docs/dph/com-health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf

- Learning and Teaching Scotland. (2008). Relationships, sexual health and parenthood resource for young people with autism spectrum disorder. http://www.educationscotland.gov.uk/Images/Relationships_Sexual_Health_and_Parenthood_Resource_for_Young_People_with_ASD_tcm4-581327.pdf

Training and Workshops

- Autism Society Canada. Training Opportunities for Professionals. http://www.autismsocietycanada.ca/professionals/training-opportunities

- Sexpressions. ABC's of Autism and Sexuality. The Montreal-based organization Sexpressions periodically offers a workshop on autism and sexuality in different parts of Canada designed for teachers, nurses, front line professionals, and parents. http://sexpressions.ca/Autism-and-Teaching-Sexuality.asp

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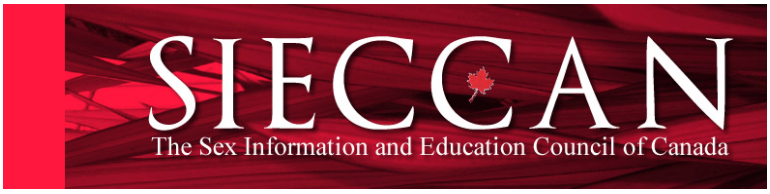

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