

Fact sheet 1: Understanding relationships and sex education in individuals with ASD:

Tips for families.

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The sexual development of individuals diagnosed with ASD is a subject that deserves particular attention. Over the last few years, several authors have become increasingly aware of the importance of this topic, by proposing various intervention strategies, therapeutic tools, and sociosexual educational programs adapted to individuals with ASD. Sexuality constitutes an important factor in the healthy development of individuals and quality of life is partly indicated by how satisfied individuals are with their sexual lifestyle (Holmes, Isler, Bott & Markowitz, 2005).

The sexual development of adolescents with ASD is composed of several aspects, such as; behaviors, intimacy, emotions, communication skills, self-esteem, sexual knowledge and experiences. Despite the difficulties they encounter in communicating, and interacting socially, their interest in sexuality is very similar to adolescents and young adults in the general population. However, the cognitive profile and symptoms associated with ASD must be considered in order to fully understand their sexual development.

Certain inappropriate sexual behaviours are part of the sexual repertoire of individuals with ASD. The majority of these behaviours consist of: sexual acts performed in public, touching or fondling, lack of respect for consent, sexual assault, excessive or inadequate masturbation, sexual obsessions and compulsions (Haracopos & Pedersen, 1999; Ruble & Dalrymple, 1993). The lack of sociosexual knowledge is a major consideration, given that it can contribute to an inappropriate act, due to a lack of understanding or misinterpretations of social and sexual contexts. In addition, many individuals are confused with regards to issues of privacy, especially those which are related to behaviours of an intimate nature. Thus, a detailed and concrete description of sexual acts and intimate areas of the body has to be given to most adolescents and adults. Finally, ASD affects the notion of consent in relation to Theory of Mind skills (i.e. one's ability to recognize different mental states and to recognize the existence of thoughts, beliefs and emotions in others). The individual with ASD may assume that others share the same thoughts and desires without first inquiring. Therefore, many inappropriate sexual acts result from poor judgement, lack of information and limited abilities relating to Theory of Mind.

The objectives of the intervention aim primarily to:

- Acquire better knowledge about social and sexual expectations in the adolescent years
- Cope with changes
- Develop one's own limits and judgment
- Decode situations: interpersonal and intimate contexts
- Improve social and sexual skills
- Decrease problem behaviours and inappropriate sexual conducts
- Empower the adolescent and increase self-esteem

Conclusion

Individuals with ASD must be guided with respect to sexual issues. An extended definition of sexuality takes into account factors linked to sexual development, puberty and symptoms associated with the autism condition. A positive approach that respects the personal and cultural values is favoured over an attitude of condemnation, which risks increasing social stigmas and taboos faced by these individuals. Parents and professionals play a key role in terms of the education and support that they can offer, but also need the necessary tools in order to intervene effectively.

An open and receptive attitude held by parents and professionals will favor an open communication and a possibility for individuals with ASD to share their experiences, questions and express their preoccupations towards sexuality. The sexual education and intervention program not only aims to teach adolescents and young adults to become responsible, but offers them the necessary tools to develop interpersonal relationships. This process will therefore help them develop a healthy and enriching sexual lifestyle.

Fact sheet 2: Sexual Education for adolescents and young adults with ASD: Themes and adapted steps.

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The Sexual Profile

There is remarkably little research and clinical knowledge on the sexual understanding and profile of adults with ASD. One hundred thirty-one subjects living in Canada, Australia, France, Denmark, and the United States completed The Derogatis Sexual Functioning Inventory (DSFI; Derogatis and Melisaratos, 1982). The DSFI examines a range of aspects related to sexuality including knowledge and experience, desire, attitudes, affect, role, fantasies, body image, and general sexual satisfaction. It provides a comprehensive assessment of behavior and attitudes relevant to sexuality.

The results suggest that individuals with ASD have levels of sexual interest and drive comparable to those of the general population. On the other hand, the communication difficulties that they experience combined with their lack of social skills serves to increase the likelihood that symptoms of depression and inappropriate socio-sexual behaviours will appear (Hénault, Attwood & Haracopos, 2010).

Such individuals need understanding and support from their partner, family, friends, and relationship counseling agencies. The support can be in attitude and adapted services. The remedial programs on social cognition, particularly in the areas of friendship skills and empathy that begin in early childhood, continue as the person matures to include information and guidance on puberty, dating, sexual knowledge and identity, and intimacy. The goal is to provide greater knowledge and positive experiences to contribute to better decision-making and self-esteem. The programs must accommodate the person's circumstances and the cognitive profile associated with AS. The first author has developed a socio-sexual program for adolescents and adults with AS (Hénault, 2005).

During adolescence and young adulthood, several subjects need to be addressed. These constitute the basis of sexual education. Here are some examples (Sex Information and Education Council of the U.S., 1992):

- Sexual organs of both sexes: names, functions, and concrete descriptions
- Bodily changes that accompany puberty
- Self-esteem
- Information on nocturnal emissions
- Values and steps to decision-making
- Intimacy: private and public settings
- Sexual health: behaviours and initial examination of sexual organs/gynecological examination
- Communication about dating, love, intimacy, and friendship
- How alcohol and drug use influence decision-making
- Sexual intercourse and other sexual behaviours
- Masturbation
- Sexual orientation and identity
- Birth control, menstruation and the responsibilities of childbearing
- Condoms, contraception, and disease prevention
- Emotions related to sexuality should be included in discussions since they motivate many behaviours.

The first step in intervention and sexual education programs involves teaching general knowledge, which is tailored to the individual's _____ chronological and developmental

age. This information allows the individual to make informed choices. It also enables the person to better understand the limits within his

learned behaviours that can be explored and experienced, while respecting his own values and those of others. The goal of the intervention is to both provide a structure for appropriate sexual behaviours and offer many opportunities for learning and obtaining enriching experiences.

The following themes, which are adapted to the reality of adolescents and adults with Asperger's syndrome cover as a whole, the characteristics linked to their social and sexual development (Hénault, 2006):

- Information on nocturnal emissions
- The value of, and stages involved in making decisions
- Intimacy: both private and non-private parts of the body; different environments
- Sexual health and initial examination of genital organs – or gynecological exam
- Communication: interpersonal, intimate, love, and friendly relationships
- The effect of alcohol and drugs on the ability to make decisions
- Sexual relations and other sexual behaviours
- Self-stimulation (masturbation)
- Sexual orientation and identity
- Planning for pregnancy, menstruation, and parental responsibilities
- Condoms, contraception, and the prevention of sexually transmitted diseases (STD's)
- Hygiene
- Friendship: recognition of abusive/unfriendly relationships
- Dangerous relationships: age difference, intention, bullying, aggression
- Qualities of a healthy relationship: sharing, communication, pleasure, interest, respect
- Intensity of relationships: finding a balance and learning the limits
- Social skills: presentation, interactions, reciprocity, sharing, etc.
- Boundaries and the notion of informed consent

Conclusion

Sexual education has both short and long-term goals. On the short term, it allows adaptive sexual behaviors to emerge with respect to communication, emotions, and interpersonal relationships. Over the longer term, adolescents and adults with ASD will be in a better position to understand what interpersonal relationships consist of and will engage in appropriate behaviors in a variety of relationship contexts. They should also be able to explain what is meant by a sexual relationship, how it unfolds, and the circumstances (time, place, appropriate individuals) under which it is possible for one to take place all while conducting themselves in a manner that is consistent with the situation. Finally, these individuals will understand what is meant by informed consent in the context of a sexual relationship (Tremblay, Desjardins & Gagnon, 1993). The ultimate goal is to allow individuals with ASD to fully experience social integration, healthy sexuality and access a better quality of life.