

Sexuality Education for Individuals with Autism Spectrum Disorders: Critical Issues and Decision Making Guidelines

Jason Travers
University of Nevada, Las Vegas

Matt Tincani
Temple University

Abstract: Individuals with autism spectrum disorders (ASD) present unique needs regarding sexuality education. While the topic of sexuality has received increased attention in the fields of intellectual and developmental disabilities generally, less consideration has focused on the unique needs of individuals with ASD specifically. This paper presents one position in support of sexuality education for children and adolescents with ASD. The nature of human sexuality is discussed to provide a context for the rights of individuals with ASD to learn about their sexuality. Further justification for providing sexuality education in terms of the unique characteristics of this population is offered in conjunction with potential consequences of failing to provide sexuality education. Lastly, information regarding a decision-making process for sexuality education curriculum is presented, including the responsibilities of families and professionals providing sexuality education.

A large body of research exists regarding specific aspects of intervention and education for individuals with autism spectrum disorders (ASD) (Simpson et al., 2005). Much ASD research focuses on teaching communication (Koegel, Koegel, Frea, & Smith, 1995), as this is a core deficit of ASD (APA, 2000). Despite continual advancements in intervention research, little attention has been given to the issue of sexuality (Konstantareas & Lunsky, 1997; Stokes & Kaur, 2005; Van Bourgondien, Reichle, & Palmer, 1997). Comparisons of available literature on sexuality in people with intellectual disabilities and people with ASD yield significantly more literature in intellectual disabilities and very little in ASD (Bambara & Brantlinger, 2002; Koller, 2000). Nevertheless, the importance of providing quality and individualized sexuality education is substantial because individuals with ASD have unique needs that may not be addressed in sexuality education programs designed for persons with ID (Howlin, 1997).

This paper presents one position regarding sexuality education for individuals with ASD based upon (a) the literature related to hu-

man sexuality in general, (b) the available literature related to sexuality education for this population, and (c) relevant literature on sexuality education for individuals with intellectual disabilities. Attempts to address important specific questions related to ASD sexuality education are included, followed by decision making guidelines. It is hoped that a discussion about this critical but sensitive topic will facilitate dialogue and research representing alternative points of view to further the knowledge base on sexuality education for persons with ASD.

What is Human Sexuality?

Human sexuality is often misperceived as referring only to specific sexual behaviors (NCASH, 1995). Rather, sexuality encompasses a broad variety of physical, emotional, and social interactions, suggesting that a simple and precise definition cannot be written (Bruess & Greenberg, 1994). Thus, many experts and organizations prefer to use general terms to describe human sexuality. The National Commission on Adolescent Sexual Health (NCASH), for example, states:

Sexuality is a natural and healthy part of life. Sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with anatomy,

Correspondence concerning this article should be addressed to Matt Tincani, 1301 Cecil B. Moore Ave., Ritter Hall 367, Temple University, Philadelphia, PA 19122. Email: tincani@temple.edu

physiology, and biochemistry of the sexual response system, as well as with roles, identity, and personality. Sexuality encompasses thoughts, feelings, behaviors, and relationships. (p. 2)

The use of general terms helps deter the common stereotypical association of sexuality exclusively with interpersonal sexual behavior in an attempt to remove the taboo of discussing human sexuality of persons with ASD.

The NCASH (1995) recognizes the stages of sexuality in all human beings and the need for sexual expression regardless of ability. While experts recognize the needs of persons with disabilities to understand and explore their own bodies, build and maintain relationships, and engage in sexual behaviors (Aunos & Feldman, 2002), individuals with ASD may frequently be excluded from the application of this principle. The very nature of their disability may be the primary reason for this occurrence.

Sexuality and Individuals with ASD

Autism spectrum disorders are neurological developmental disorders that affect language acquisition, social development, and behavior (APA, 2000). While each of these deficit areas can be linked to poor understanding of sexuality and an inability to appropriately express feelings of sexuality, impairment in social development is perhaps the primary contributor. Realmuto and Ruble (1999) suggest that typical children learn about sexuality via casual social experiences. Social experiences include those within the community, family, and educational settings (Suris, Resnick, Cassuto, & Blum, 1996). Individuals with ASD often lack the ability to effectively learn in unstructured social situations regardless of setting. The inability to learn social skills through informal interaction is often misperceived as the individual's preference for being alone (Stokes & Kaur, 2005). In fact, many individuals with ASD report wanting social relationships (Atwood, 1998; Ousley & Mesibov, 1991). Consequently, people with ASD may be viewed as sexually immature or completely asexual and, as a result, the need for sexuality education may be overlooked or ignored by professionals and family members (Konstantareas &

Lunksky, 1997; Ludlow, 1991; Stokes & Kaur, 2005). To the contrary, persons with ASD may be in significant need of sexuality education due to the pervasive nature of their social deficits.

Justification for Providing Sexuality Education to Individuals with ASD

Sexuality education for individuals with ASD is supported by three important factors. First, social deficits common to persons with ASD render them particularly prone to sexual abuse (Mansell, Sobsey, Wilgosh, & Zawallich, 1996). Thus, education to prevent sexual abuse is critical. Second, persons with ASD have the universal right to learn about relationships, marriage, parenthood, and appropriate sexuality. Often, social skills and communication deficits render people with ASD unable to acquire sexuality, relationship, and intimacy skills from the natural environment. Importantly, absence of a clear understanding of appropriate sexuality increases the likelihood of inappropriate sexual behavior among persons with ASD (Stokes & Kaur, 2005). Finally, sexuality education for persons with ASD facilitates good hygiene, promotes health, and prevents unwanted pregnancy. We explore each of these factors below.

Preventing Sexual Abuse

Without individualized education regarding the various facets of sexuality education, individuals with ASD may more likely be victims of sexual abuse. Individuals with ASD are at an increased risk of sexual abuse for at least two reasons: (a) they are often unable to provide reports to parents, professionals, or law enforcement about sexual abuse due to communication deficits; and (b) they may fail to report sexual abuse because they are unaware it is wrong (Howlin & Clements, 1995; Mansell et al., 1996). In addition to the serious personal and physical distress caused by sexual abuse, an individual subjected to abuse may fail to make educational, academic, behavioral, and communicative progress (Howlin & Clements). Moreover, the sex offender may never be caught, charged, or convicted, maintaining a higher prevalence of sexual abuse among this population. An individual with

ASD therefore has the right to sexuality education in order to prevent and/or report incidences of sexual crimes.

Facilitating Relationships, Marriage and Parenthood

It is the generally recognized right of all individuals, including those with ASD, to participate in consensual romantic relationships, marry, and engage in pre-and post-marital consensual sex with their partner. The right of a person to conceive, deliver, and care for his or her own child in conjunction with needed supports is also universally accepted. It has been reported that individuals with mild intellectual disabilities (including autism) often want to marry and have children (Aunos & Feldman, 2002). Intellectual ability should not preclude a person with ASD from learning about his or her own sexuality, or from engaging in consensual, emotionally meaningful romantic and sexual relationships. Therefore, all people with intellectual disabilities, including autism, should be provided with this type of curriculum.

Importantly, access to sexuality curriculum does not imply that the individual should necessarily have a child or engage in interpersonal sexual behaviors such as intercourse. In many cases, the person with ASD may not be able to give consent to sexual behaviors due to limited cognitive ability. Additionally, many individuals with ASD may not be able to effectively care for a child even with substantial supports. Individuals whose cognitive ability (a) limits them from providing sexual consent or (b) prevents them from providing for an infant should be discouraged from engaging in interpersonal sexual behaviors. In the case where two individuals are able to give consent and are able to care for a child should be provided with the supports necessary.

Thompson (2002) cautions against assuming that persons with developmental disabilities are heterosexual simply because heterosexuality is the dominant mode of sexual expression in our culture. In some cases, individuals with ASD may choose to engage in sexual behaviors with members of the same sex or, more broadly, to identify with a gay, lesbian, or bisexual (GLB) lifestyle. While some may disagree with homosexuality on in-

dividual, community, or governmental levels, we should not let personal beliefs interfere with the right of the individual to express his or her sexual identity (Blanchett, 2002). Moreover, we should not dismiss the sexual preferences of an individual on the basis of an intellectual or developmental impairment. Instead, effort should be focused on providing information about safe sex and the potential consequences of engaging in unsafe sex. Similar attention should be given to teaching about romantic relationships and intimacy, affording the GLB person with ASD the same consideration as the heterosexual person with ASD.

Preventing Challenging Behavior

Stokes and Kaur (2005) report that failure to address the social desires of individuals with ASD can increase inappropriate behavior, including apparent obsession with another individual, inappropriate sexual expression such as public undressing, and aggression. In the absence of understanding how to initiate and maintain appropriate romantic and sexual relationships, adolescents and adults with ASD may be especially prone to sexually inappropriate acts towards others (Ray, Marks, & Bray-Garretson, 2004). In all cases, sexuality education to facilitate one's sexual identity and appropriate sexual behavior can prevent potentially negative outcomes.

Promoting Health and Hygiene

Proper sexuality education for individuals with ASD should not be provided just to prevent and report sexual abuse, promote marriages, preserve parenting rights, or to simply satisfy social desires. Sexuality education is also needed to promote proper health and hygiene, disease prevention, and birth control (NCASH, 1995). Poor health and hygiene can result in physical pain, sickness, and death, but proper health and hygiene can promote a sense of physical well-being and increased self-esteem (Fegan, Rauch, & McCarthy, 1993). Therefore, appropriate sexual education is indicated in all cases to enhance physical well being and promote good health throughout the lifespan.

What Should be Taught in Sexuality Education for Individuals with ASD?

Koller (2000) provides a list of potential topics of instruction that include “body parts, reproduction, birth control, sexual health, the sexual life cycle from birth to death, male and female socio/sexual behavior, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, self-esteem, and assertiveness skills training” (p. 130). Ideally, sexuality education should begin in early childhood with body awareness and social skills development and progress as the individual matures to include building and maintaining friendships, romantic relationships, dating, sexual behavior, partnership, and long-term relationships. Blanchett and Wolfe (2002) present a comprehensive review of published curricula to teach sexuality to individuals with developmental disabilities. The unique needs of individuals with ASD highlight several specific topics for sexuality education.

Body Awareness

Providing individualized education about caring for the human body is an essential component of sexuality education (Fegan et al., 1993). Due to deficits in language, children with ASD may lack basic awareness of their body parts and their functions. Therefore, young children with ASD should be taught to identify all of their body parts. They should also be taught about the importance of protecting themselves from sexual exploitation by (a) learning about private body parts, (b) learning what kind of touching is okay and not okay, and (c) who, when, and how, to report sexual abuse.

When appropriate, individuals with ASD throughout the lifespan should be taught about their body’s functions (e.g. menstruation, ejaculation) and the necessity for regular examinations by themselves and doctors (e.g. Pap and Breast exams, Testes exams). Again, limitations in language ability may preclude adolescents and adults with ASD from attending to health-related sexuality needs. Sexually transmitted disease prevention should also be included in sexuality education. Specific attention should be given to abstinence, safe sex

(e.g., condoms), and symptoms indicating a need for medical treatment.

Social Development

Persons with ASD experience difficulty building and maintaining social relationships (APA, 2000). Teaching social and relationship skills is imperative since sexuality has much to do with human relationships. In the case of a minor, selecting relationship skills to be taught is the responsibility of the student’s individualized education plan (IEP) team. Social skills are a core deficit of ASD and specific social skills instruction should be provided to every individual with ASD, regardless of age or level of functioning (Koller, 2000). Ideally, social deficits should be addressed as early as possible. The IEP team should make decisions regarding social skills instruction based on the individual’s age, cognitive level, skill strengths, and skill deficits. For instance, the IEP team for a younger child may focus on turn-taking, greetings, eye-contact, and play skills. An IEP for an adolescent or adult may focus on the importance of (a) sharing similar interests with others, (b) concepts of love and intimacy, (c) appropriate ways to express emotions and relieve stress, and (d) how to appropriately deal with rejection.

Romantic Relationships and Intimacy

Theory of Mind (ToM) deficits intrinsic to persons with ASD may render individuals unable to understand the actions, feelings, and intentions of others (Baron-Cohen, 1995). Difficulties with ToM become especially problematic as adolescents and young adults with ASD attempt to navigate romantic relationships. For example, a young man with Asperger syndrome interested in dating a young woman might fail to recognize seemingly obvious cues of disinterest (e.g., not returning phone calls, telling him “I’ve got other plans”) and inappropriately persist in romantic or sexual overtures. Therefore, teaching adolescents with ASD the subtle rules of romantic courtship is critical. Specific programmatic content should include how to appropriately initiate romantic relationships, dating, appropriate physical boundaries, listening skills, and the meaning of consensual sexual activity.

Self-stimulatory behaviors are significantly difficult to modify because of their self-reinforcing nature (Scheuermann & Weber, 2002). This is especially true of masturbation. Masturbation is considered to be a normal component of human development (Bruess & Greenberg, 1994; NCASH, 1995). Despite this, stigma and misconceptions regarding masturbation remain common in our society and, as a result, individuals with ASD are often discouraged from masturbating (Walsh, 2000). Masturbation may be more common in individuals with ASD than nondisabled individuals because of the increased tendency to engage in self-stimulating behaviors (Realmuto & Ruble, 1999). Individuals with ASD are frequently reported to masturbate in inappropriate locations (Koller, 2000). It is important to remember that masturbation may be the individual's only way of appropriately relieving normal sexual urges. Attempting to repress an individual's desire to masturbate in an appropriate situation (e.g., in the privacy of the person's bedroom or bathroom) is therefore discouraged. Providing an individualized sexuality education program to promote appropriate masturbation is suggested. Such programming should include explicit instruction on when and where it is and is not appropriate to masturbate. Those looking for assistance in reducing inappropriate masturbation are directed to Walsh (2000).

Ruble and Dalrymple (1993) found that many parents report other inappropriate sexual behavior such as public disrobing, inappropriate touching of members of the opposite sex, and masturbation with unusual objects. These types of behaviors require behavior modification and teaching that are consistent with social norms and may be the primary focus of sexuality education for some individuals. Ward and Bosek (2002) describe a comprehensive program for treating inappropriate sexual behavior in persons with intellectual disabilities by teaching self-awareness of high risk situations and alternatives to inappropriate responses. Changing inappropriate sexual behavior to meet social norms is essential for the individual to access and participate in the community.

Individuals with ASD have the right to learn about contraception when pregnancy is not desired. They also have the right to learn about the available types of contraception and to be a part of the decision-making process regarding their contraceptive. In some cases, surgery on reproductive organs may be necessary to preserve health, while decreasing or eliminating the possibility of conception. For instance, uterine or ovarian cancer may require hysterectomy to preserve the life of a woman. In men, similar medical circumstances (e.g., testicular cancer) may require testes removal. Nonconsensual or fraudulent sterilization (i.e., forcing, deceiving, or convincing someone to proceed with sterilization who would otherwise choose not to simply for the purpose of preventing the individual from becoming pregnant) is never appropriate. In fact, each state in the U.S. has laws designed to protect the reproductive rights of individuals with intellectual disabilities (Küpper, 1995). Professionals and families should recognize that sterilizing an individual will not eliminate their sexual needs and desires and that sexuality education must be provided even if the individual cannot conceive a child or engage in sexual behaviors. Readers can find more information about reproductive health at the U.S. Centers for Disease Control website on reproductive health at www.cdc.gov/reproductivehealth.

Selecting Sexuality Skills for Individuals with ASD: Decision Making Guidelines

Research regarding sexuality in individuals with ASD, including what skills to teach, is significantly lacking. Nonetheless, the literature on sexuality education for persons with intellectual disabilities provides the following general guidelines for parents and professionals who must make decisions regarding what information about sexuality will be taught. General guidelines include (a) considering the role of the IEP team, including parents, in the design of sexuality education programs; (b) considering the student's involvement in his or her own sexuality education program;

and (c) anticipating disagreements about sexuality education among team members.

Role of the IEP Team

First, deciding what to teach should be the decision of the child's or adolescent's IEP team. According to the Individuals with Disabilities Education Improvement Act of 2004 (PL 108-446), the members of the IEP team should consist of educational and related services professionals, family members and friends, advocates, the student (when appropriate), and a representative from the local education agency. The team should decide what to teach the individual based on his or her specific needs. Nevertheless, making decisions about what to teach can be challenging for members of the IEP team. Haracopos and Pederson (1995) provide a framework for decision-making when considering sexuality education for individuals with ASD that may help the IEP team:

1. People have the right and possibility of having a sexual life in accordance with their desires and needs and what they can manage.
2. People with autism have the right to receive guidance and support with regard to unresolved sexual problems.
3. The learning of appropriate social behavior with regard to sexuality should occur in agreement with the social rules and norms of the autistic person's [sic] place of residence.
4. The type of guidance should, first of all, be related to and dependent on how demanding and obvious the sexual problem is for the person with ASD and the environment. It is then important to determine and assess if the sexual signs are definite, indefinite, or not present.
5. Sexuality should be viewed in a global context so that sexual instruction and training do not only consist of helping the person learn to masturbate to achieve orgasm. It is equally important to enhance the person's body awareness and to support him or her in understanding their physical and emotional changes in relation to the sexual drive.
6. When a person with ASD directs his or her

sexual interest towards another person, one should decide how far to go in supporting such contact. Since experiencing sexuality with another person consists of showing tenderness, care, and empathy, one must recognize that the majority of people with autism have extreme difficulty relating to other people. (p. 21)

In addition to these six guidelines it is equally important to consider the religious, ethnic, and cultural beliefs of the family since many families may feel uncomfortable about openly discussing issues related to sexuality (NCASH, 1995). Educators should anticipate that children's sexuality will be a sensitive topic with parents (Aunos & Feldman, 2002). Therefore, it is important to inform the family prior to the IEP meeting using specific language that sexuality education will be discussed. For instance, a family of a five-year-old boy may become upset upon hearing the special educator's intention to discuss sexuality during the IEP meeting, not realizing that sex education, in this case, pertains only to teaching body parts, motor development, and body awareness. Presenting this information before the IEP meeting (a) allows the family to better prepare for the meeting, (b) reduces the likelihood of defensiveness and confrontation, and (c) increases acceptance and participation in deciding what to teach and who should teach it.

Student Involvement

Second, participation of the student with ASD in the IEP process can result in a sense of empowerment, increased willingness to engage in learning, and an IEP that accurately reflects the individual's goals and dreams (Test et al., 2004). Lesseliers and Van Hove (2002) suggest that because individuals with developmental disabilities are viewed as "perpetual children," their voices in decision making about their own sexuality are often ignored. On the other hand, allowing the person to express his or her sexuality interests in the IEP meeting helps the team to make informed, person-centered decisions about sexuality programs. In some cases, students with ASD may not be able to explain their desires for sexuality education. Similarly, stu-

dents with ASD may not be able to provide informed consent to sexuality education. In these circumstances professionals must evaluate the individual using various assessment tools to determine if the individual exhibits a need for sexuality education (Patti, 1995). In such cases, the choice to provide sexuality education should be made on an individual basis and should be supported by assessment results.

Dealing with Disagreement

Finally, because of the contentious nature of human sexuality, disagreements among team members, including parents, should be anticipated. What should happen if the individual wants and/or needs sex education, but the parents do not agree? The ethical questions regarding disagreement about teaching sexuality education are not easy to answer. In the case where the individual is a minor, professionals must exercise respect for the parent's wishes. Providing sexuality education to a minor, or to an adult whose rights have been assigned to a guardian, that has not been approved by the individual's parent or guardian is not advised and may be considered criminal (Gutmacher Institute, 2007).

In cases where some team members (e.g., parents) are resistant, professionals may choose to focus their energy on providing information about the importance of sexuality education as opposed to simply giving up. Professionals often encounter the most challenging ethical decisions when the individual has reached the age of majority and is legally free to make his or her own choices. Providing sexuality education to a legally independent individual with ASD against the parent's wishes will no doubt be a difficult choice for many professionals. In the case where the individual is attending school beyond his/her 18th birthday, the parent may protest by refusing to send his or her child to school, thereby compromising the efforts and educational progress of the individual with ASD.

Despite obvious need, parents may still object to their child receiving sexuality education. In these cases it is not advisable to proceed with sexuality education against the wishes of the parents because the quality of the program may be compromised (i.e. better

results are achieved when families and professionals work together). It may be more efficient to convince the parents about the need for sexuality education than to engage in personal, professional, and legal altercations. If sex education is provided to the individual throughout the school years starting at a young age, and if parents are encouraged and supported throughout their child's education, difficult situations such as these may be avoided and better outcomes can be achieved.

Who Teaches Sexuality Skills to Individuals with ASD? Decision Making Guidelines

Role of Parents and Caregivers

Deciding who will be responsible for teaching sexuality should also be determined during the IEP team meeting. Traditionally, parents and caregivers have been the primary providers of sexuality education (Fegan et al., 1993). Parents and caregivers provide the foundation for sexual development by demonstrating and modeling appropriate relationships within the home (NCASH, 1995), and are responsible for explaining their moral standards to their children (Fegan et al.). Additionally, they are more likely to know their child's needs than professionals and, as a result, are better equipped to teach their child about sexuality. Therefore, where appropriate, parents should be encouraged to participate fully in their children's sexuality education.

Despite these advantages, parents may not be comfortable addressing their child's sexuality (Aunos & Feldman, 2002). Sexuality may be a particularly sore topic for parents of adolescents with autism or other developmental disabilities because they perceive sexuality to be an extra burden for their child, and because they view their child to be asexual or unable to make independent decisions about sexuality (Lesseliers & Van Hove, 2002). Consequently, parents may suggest that it is the school's responsibility to provide sexuality education, or they may ignore the issue of sexuality altogether. Parents' decision not to participate in their child's sexuality education, or any aspect of their educational curriculum, should not lessen the team's willingness to incorporate parents' values and desires into

their child's sexuality education program (Vaughn, White, Johnston, & Dunlap, 2005).

Role of Professionals

The professional who has been designated to be the provider of the individual's sexuality education may feel inadequate or hesitant for several reasons. He or she may feel uncomfortable discussing various aspects of sexuality with students. He or she may have religious, cultural, or personal beliefs that conflict with the situation. Despite such conflicts, professionals must remember their obligation to provide individuals with disabilities, including ASD, appropriate sexuality education. The professional who feels that they are unable to provide quality instruction due to personal beliefs should be replaced in favor of someone who can remain objective.

Objectivity is not the only quality that the professional should exhibit. Fegan et al. (1993) outlines several characteristics of professionals who provide optimal sexuality education. They suggest that the professional:

- (a) feel confident and at ease, (b) be open and direct about the topic, (c) be aware of your own attitudes to reduce bias, (d) learn and understand current information so that it can be presented accurately, (e) maintain open relationships and communicate frequently with parents, (f) ask for help from a qualified individual (e.g., sex therapist) when needed, (g) repeat, reinforce, and generalize instruction, and (h) use multi-sensory tools (e.g., videos, pictures, models, charts, etc.) (pp. 15-16).

A Collaborative Effort

Collaboration is the ideal context to provide sexuality education to individuals with ASD. Parents and professionals may find comfort in working together to provide quality sexuality education. Through collaboration parents can be designated as the responsible party for providing explicit sexuality education that is consistent with their family's culture, religion, and/or other beliefs, while professionals are responsible for teaching skills for social development in the school and community settings. In combining efforts, maintaining communi-

cation, and building relationships with the family, positive outcomes are more likely.

Conclusion

This paper presents one position supporting sexuality education for individuals with ASD. The limited amount of available research supports the need for further study of sexuality in the ASD population. Specifically, future research should explore (a) the unique skill needs of children, adolescents, and young adults with ASD regarding their sexuality and (b) the most effective ways to deliver sexuality instruction considering the unique needs of this population.

It is clear that every person with ASD has the right to sexuality education regardless of intellectual functioning (Koller, 2000). However, this entitlement accompanies ethical questions. Some of these questions are discussed here (e.g., How do we provide sexuality education when team members are resistant or disagree?), but considerably more specific questions exist based on circumstances of the individual's societal, cultural, local, and familial conditions. Society is becoming more accepting of individuals with disabilities (Aunos & Feldman, 2002); however, without individualized instruction, individuals with ASD are less likely to participate in meaningful relationships and are more prone to sexual abuse. Additionally, without proper training in sexuality, individuals with ASD may become more socially isolated. These factors support the critical need to provide sexuality education to children and adults with ASD. Effective collaboration in sexuality education can result in better outcomes for the individual with ASD, his or her family, and society.

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