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# Sexuality and Adolescents with Autism

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*Appropriate education in sexuality is critical to the development of a person's positive self-esteem. The development of a healthy self-image may overcome potential feelings of depression and loneliness for the person with autism. This paper addresses the need for and challenges to providing sexuality education to individuals with autism. It summarizes teaching methods and approaches which have proven to be successful with this population.*

**KEY WORDS:** sexuality education; adolescence; self-pleasuring; sexual abuse.

Sexuality encompasses more than just sexual behavior. It includes self-image, emotions, values, attitudes, beliefs, behaviors, relationships, etc. Our view of sexuality changes constantly in response to interactions, experiences, and formal and informal education. A task force of leading health, education, and sexuality professionals researching sex education for all children determined: (a) nine of ten parents favored sex education, (b) twenty-three states required sex education, (c) thirteen other states encouraged its teaching, (d) over ninety national organizations believed that all children and youth should have sex education, yet (e) only 5% of children in America received sex education (1).

It is reported that 20% to 25% of children without disabilities are sexually abused, and estimated that children with disabilities will experience significantly higher percentages of sexual abuse (2). Although positive sexuality education is important for any population, it should be a priority for people with disabilities.

Unfortunately, incorrect attitudes regarding sexuality and people with developmental disabilities may interfere with sexuality education for this popula-

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tion. Sexuality and people with developmental disabilities has been identified as a "problem, because it is not an issue, or is an issue, because it is seen as a problem" (3). Individuals with developmental disabilities, including autism and/or mental retardation, face barriers to expressing their sexuality. Barriers include "social myths, insufficient knowledge and training opportunities, personal discomfort, and limited access to available and appropriate educational resources" (4). Such barriers may result in a lack of guidance, opportunity, emotional support, education, or acknowledgment of sexuality by caregivers.

Literature on sexuality among individuals with autism is sparse in comparison to information regarding sexuality and people with mental retardation without autism (5,6,7,8). The need to understand individuals with autism, especially as they move through adolescence into adulthood, has increased recently due to the high percentage of adolescents and adults with autism who are experiencing greater opportunities in inclusive educational and community settings.

Adolescents and young adults with autism may have already formed unhealthy opinions and views about sexuality which affect their self-esteem and interactions with others (9,10,11). Informal education about sexuality occurs constantly through interactions with and observations of others and through the media. A sense of belonging is critical especially during the transition period of adolescence since an awareness in differences between individuals with and without autism may occur as inclusion improves (12). This realization may lead to depression and loneliness for the person with autism.

All individuals have the right to instruction regarding sexuality, regardless of their level of functioning. The purposes of this paper are: (1) to discuss issues surrounding sexuality education and individuals with autism, and (2) to describe effective principles and approaches for teaching sexuality found in the literature.

## ISSUES OF SEXUALITY EDUCATION

Education for caregivers of individuals with autism regarding issues of adolescence and self-pleasuring may help alleviate the anxiety of individuals with autism caused by misinformation or the absence of information. Such education, along with information regarding sexual abuse, should be included in a proactive approach to sexuality training for individuals with autism.

### Adolescence

Adolescence may be the most critical of developmental stages which impact the social, physical, and emotional aspects of one's life. Individuals with

autism typically mature physically and sexually according to normal developmental stages (13,14,15). However, a child with autism can develop normally in some areas and have difficulties in social understanding and interactions (13). This inconsistent development can be confusing to both the child and caregivers. Parents and caregivers often express concern over the growing sexual drive since it is generally:

> not accompanied by a corresponding growth in the field of social 'know-how' which often leads to embarrassing behavior. This seems to be particularly true of moderately mentally retarded adolescent boys with autism, who may expose themselves, masturbate in public and touch other people's genital regions. Such behavior can, of course, be very embarrassing to those confronted, including parents and siblings (16).

Classic characteristics of autism, such as failure to develop language or other forms of social communication, continue through adolescence. Though the literature reports that adolescents with autism may improve in some skill areas, "their rate of improvement is not sufficient to accommodate the increasing demands placed upon them as they grow older" (7).

Social difficulties do not always mean that young adults do not wish to pursue social relationships, nor do they indicate a lack of emotion. The problem, in fact, may lie in the difficulty of those with autism to acquire and understand the subtle rules of social interaction, and to develop empathy with others (17,18). Social skills training during this time should address difficulties with "empathy, rigidity, and social distance" (7).

Aggressive episodes occurring during adolescence may be motivated by an inability to understand environmental and social expectations. For example, one man with autism characteristically described a feeling of constant "confusion and terror" beginning at the time of adolescence which resulted in anxiety and aggression (7). Behavior management techniques should be modified with the change in increased physical stature of the adolescent with autism. Physical management techniques successful with children may no longer be physically possible or emotionally respectful.

Changes within the central nervous system may also occur during adolescence (9). Studies show that youth with autism between 11–14 years of age are at greater risk of developing seizures. One-fourth to one-third of children with autism and an IQ lower than 70 develop seizures for the first time during this time period (7).

Education for caregivers and the individual with autism concerning the physical changes associated with puberty need to occur shortly before or at its onset depending on the person's need and level of understanding. Caregivers seem especially anxious with the onset of menstruation in the individual with autism and often seek medical intervention to suppress or eliminate it altogether. Hormonal suppression is often sought by caregivers for irregular or painful menstrual cycles, cyclical aggression, or for the prevention of pregnancy. Research and experience demonstrate, however, that girls with autism

generally accept the onset of menstruation in a matter of fact way and rarely need medication for control of menses (16).

## Self-Pleasuring

The Sex Information and Education Council of the United States (SIECUS) states that "sexual self-pleasuring or masturbation is a natural part of sexual behavior for individuals of all ages" (19). Because self-pleasuring is a common occurrence among people with autism, it should be addressed in sexuality training (5). Masturbation in adolescent boys with autism may be accentuated due to "the lack of other outlets for sexual tension and a predisposition for self-stimulating behaviors" (20). Realistically, masturbation may be the only means of appropriate sexual release for those with autism, but is likely completed in an inappropriate or unsafe fashion (2).

Haracopos (1995) found that in a study of 81 people with autism ranging in age from 16 to 40, 74% demonstrated definite signs of sexual behavior either in the form of masturbation or of sexual behavior towards others. Twenty-nine of the eighty-one engaged in masturbation in public areas, and thirty-seven individuals used objects in connection with masturbation. This study identified inappropriate sexual behavior to be the result of social and emotional immaturity rather than a result of sexual deviance (5).

Much of the obsessional ritual behavior of people with autism may be a replacement activity for ineffective masturbation (19). Harmful or inappropriate masturbation may be caused by situations such as: (a) lack of structured routine (b) unresolved sexual problems, (c) punitive attitudes by caregivers, (d) lack of education, (e) lack of opportunity for privacy, and/or (f) the use of medications which suppress libido. Excessive masturbation has also been linked to a lack of tactile stimulation (21).

The literature generally promotes an accepting approach to masturbation training for individuals with autism (2,5,19,22,23). Caregivers will want to address masturbation in a matter-of-fact, individualized manner. It is suggested that instructors teach appropriate time and place and suggest the following interventions when an adult with autism masturbates in public:

1. Interrupt the behavior,
2. Remind the person of the appropriate time and place for the behavior,
3. Redirect the person to another activity or to an activity that requires the use of both hands,
4. Redirect the person to an activity that involves intense focus or high amounts of physical movement,
5. Redirect the person to an appropriate place to have privacy, such as a bathroom, shower, or private bedroom,

6. Reinforce staying in assigned areas and taking breaks as scheduled, to decrease the likelihood that excessive breaks or trips to the bathroom will occur, and
7. Provide visual evidence of scheduled breaks or private leisure time, so the person can anticipate and plan for personal needs (24).

### Sexual Abuse

Education regarding sexual abuse should be a component of responsible sexuality education. Increased vulnerability among children with disabilities relates to their inability to understand or communicate what has happened or what will happen (3). Two of the most important issues to address in the area of social-sexual relationships are how to teach appropriate behavior and how to balance risk and opportunity (15). Walcott (1997) reports that "without proper education in the areas of sex, health, and physical education, people with moderate and severe disabilities risk exposure to sexual exploitation, poor health, abuse, and neglect" (25).

Hingsburger (1995) submits that caregivers have inadvertently created a "Prison of Protection" for individuals with disabilities through overprotection. Protection from sexual information, relationships, decision-making, and society have limited and, in many cases, harmed individuals with disabilities. Instead, the person should be seen capable of protecting themselves given proper support and education. Hingsburger describes this support model as "The Ring of Safety" which includes privacy awareness, the ability to non-comply, someone who listens, understanding of personal rights, healthy self-concept and self-confidence, options for healthy sexuality, and sex education (26).

## EFFECTIVE PRINCIPLES AND APPROACHES FOR TEACHING SEXUALITY

This section will address methods that have proven successful in teaching sexuality skills to persons with autism. Before teaching social/sexual skills, however, caregivers will need to assess the person's preferences, strengths, and needs in order to develop an individualized approach. A team approach is also recommended to determine the extent to which the individual can participate in making informed choices relating to social and sexual behaviors.

### Sexuality Curriculum

Three programs and philosophies of sex education for individuals with autism have been suggested in the literature. A review of these viewpoints

highlights specific challenges facing guardians and professionals while offering possible options for consideration.

First, Devereux Centers for children and adults with autism in Massachusetts, New York, New Jersey, Pennsylvania, Florida, Texas, and California follow two fundamental precepts before beginning sexuality instruction:

1. Parents are the best sex educators. If, for whatever reason, parents are unable to do this task, teachers and other staff attempt to fill this role, and
2. It is normal and natural for every person with a body to express their sexuality regardless of their handicap condition or functional ability level. Further, it is normal and natural to express this sexuality within the confines of the individual's social contacts, whomever that may be (22).

Instruction should therefore include all or parts of the following topics depending upon individual need: body parts, reproduction, birth control, sexual health, the sexual life cycle from birth to death, male and female social/sexual behavior, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, self-esteem, and assertiveness skills training. Teachers should assess the client's ability to use abstract thinking in order to determine if audio-visual material and discussions can be used. If not, appropriate, immediate, situational instruction is used (22).

Second, Benhaven is a day and residential school community in New Haven, Connecticut which offers individualized services for children and adults with autism. Melone and Lettick (1985) explain that Benhaven provides sexuality training based on the following policy decisions:

1. We must teach students behavior that will be socially acceptable and appropriate in adulthood as well as in childhood,
2. There is to be no disapproval of masturbation, since it is probably the only kind of sexual satisfaction that will be available to our students during their lifetime. Students must be taught, however, that masturbation is unacceptable behavior in public, and must be informed as to where it is specifically allowable, and
3. We cannot encourage behavior that will lead to frustration and disappointment for the student. Therefore we do not encourage what in normal adolescents would be predating behavior with staff or other students. Romance must be put aside for more realistic social encounters geared to expectations of friendly sharing of activities (23).

Potential students are individually assessed before sexuality training to determine their language ability, social functioning level, behavior, and emotional

maturity. This is not a program for individuals who exhibit or will exhibit high social development, nor is it a program for those who exhibit low social development. Other individualized teaching arrangements need to take place for those not meeting the qualifications of this group-learning setting. Qualified students are taught identification of body parts, menstruation, masturbation, physical examinations, personal hygiene, and social behavior. Topics felt to be "beyond the scope of our students, such as dating, marriage, birth control, and childbirth" were omitted (23).

Finally, Haracopos (1995) outlined the following general policies for addressing sexuality for children and young adults with autism in Denmark:

1. People with autism should have the right and possibility to have a sexual life in accordance with their desires, needs and what they can manage,
2. People with autism have the right to receive guidance and support with regard to unresolved sexual problem(s),
3. The learning of appropriate social behavior with regard to sexuality should occur in agreement with the social rules and norms of the person's place of residence,
4. The type of guidance should first be dependent on how demanding and obvious the sexual problem is for the person and the environment,
5. Sexuality should be viewed in a global context so that sexual instruction and training do not consist only of the person learning how to masturbate to orgasm, but also enhancing the person's awareness of self, and supporting him or her in understanding the physical and emotional changes in relation to the sexual desire, and
6. When an autistic person directs his or her sexual interest to another person, one should decide how far to go in supporting such a contact, since to experience sexuality with another person consists of showing tenderness, care, and empathy, one must recognize that the majority of people with autism have extreme difficulty in relating to other people (5).

Haracopos (1995) further advocates for systematic individualized instruction which has been approved by a professional team before implementation. He also submits that instruction should be approved by the person with autism by verbal and/or non-verbal reactions (5).

The goal of sexuality education should be to protect the individual from sexual exploitation, teach healthy sex habits, and increase self-esteem through systematic, individualized approaches. Education needs to be provided with consistency and common-sense. It will need to be on-going, and will need to constantly reinforce appropriate behaviors.

## Teaching Strategies

"Being autistic does not mean being unable to learn" (27). Teaching methods need to be adapted, however, to accommodate an individual's learning style, interest, and need. The student's values and motives must also be taken into consideration since "there is invariably a personality constructed over the handicap" (28). An emphasis should be placed on facilitating "personally meaningful experiences" rather than on teaching skills simply because they are "normal" (29).

The learning environment should be arranged in advance in order to minimize the potential for stress and possible behavioral difficulties. The individual with autism should not be exposed to situations longer than can be tolerated and rules should be emphasized before engaging in social encounters, e.g. turn-taking and proximity to others (17). Periods of regularly scheduled vigorous exercise might be provided to help reduce stress, anxiety, and the potential of problematic behavior (30).

Generally, individualized instruction should: (a) be concrete rather than abstract, (b) be brief, specific, and clear, (c) be visual, (d) utilize imitation and role-play, (e) be taught in real-life settings, and (f) be repeated frequently (19). Several effective methods for teaching social skills to individuals with autism include: (a) video taping real or acted situations for playback and discussion, (b) individual counseling coupled with social skills training, (c) peer-initiated interactions, and (d) developing books that depict social situations (18,24,30,31,32,34).

Increasing the predictability and organization of events and interactions may also help individuals with autism develop flexibility and independence. Quill (1995) describes four environmental strategies which enhance a sense of their world:

(1) Temporal supports used to organize sequences of time such as schedules, completion guidelines, waiting supports, and strategies for accepting changes,
(2) Procedural supports used to clarify the relationship between steps of an activity or relationships between objects and people which can include clarification about routines, personal possessions, or privacy,
(3) Spatial supports used to provide specific information regarding the organization of the environment which include information about the location of objects, and
(4) Assertion supports used to help the individual initiate and exert control such as in making choices and maintaining self-control (30).

### Fostering Opportunities

Individuals with autism "must be exposed to everyday situations and responsibilities that will challenge, and sometimes exceed, their capabilities" (12). In addition to fostering rules of social interaction, it is also valuable to encourage the individual with autism to participate in sports, games, or organized clubs which are of interest to the person (18). Quill (1995) suggests directing and broadening fixations into useful activities, and motivating interactions with others (30).

## CONCLUSION

Sexuality education for individuals with developmental disabilities, and especially autism, is an emotional issue. These emotions often create barriers for the very people that caregivers want to protect. Those wishing to provide sexuality education for this population must first examine their own attitudes, values, and motives. Mesibov (1985) cautions that "because most autistic people will not form our society's traditional sexual unions consisting of marriage and a family, we must evaluate our feelings about possible alternatives, weighing the needs of autistic people for appropriate sexual outlets against the values and morals of society" (7).

The question for caregivers then, is not *if* sexuality education can or should be provided for individuals with autism, but how will it be offered. Though the literature concerning sexuality education for people with autism is relatively small, there is growing evidence that an individual with autism can learn and benefit from instruction that is respectful of the person and their autism.

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