Autism Spectrum Disorders and Sexuality Information Sheet

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The frequency of assigning an *autism spectrum disorder* (ASD) diagnosis has significantly increased in recent decades. In 2013 the diagnostic criteria were changed by the American Psychiatric Association (APA). They now reflect that ASD symptoms and challenges exist on a continuum ranging from low to high levels of impairment. ASD is a neurodevelopmental, brain-based, condition that affects the person in different ways across their lifespan. ASDs are lifelong conditions although the symptom presentations may change over time.

In early childhood language delays and limited interest in social interaction are often the first indications that parents notice. Individuals with ASD often exhibit a limited range of interests and seemingly obsess on the things they are interested in. Individuals with ASD also do not do well with sudden changes in their environment or schedule. Variations of these ASD-related challenges endure well into adulthood.

Only a small percentage of adults with ASD live and work independently. Those who do usually have better language skills and intellectual functioning. They also tend to find jobs that match their special interests.

Most adults with ASD require some level of professional supports and services. This is especially true for those who also have intellectual disability (ID; Blasingame, 2005). They often struggle to effectively manage their lives without assistance from other people. Higher functioning individuals with ASD tend to find ways to cover or disguise having ASD in effort to compensate for the condition and to fit in. This is also known as ‘masking’ and often causes serious anxiety and depression symptoms.

Adults with ASD often experience more than the one form of neurodevelopmental disorder. Intellectual disability and attention deficit hyperactivity disorder (ADHD) are the most common co-occurring conditions, both of which are lifelong. About 70% of individuals with ASD also have at least one co-occurring mental health condition. About 40% have two or more (APA, 2013). An adult who has ASD plus another mental health condition will likely have much greater challenges with social interactions and behavioral issues.

When ID or ADHD are present, the adult with ASD is likely to struggle with planning, organization, problem solving, academic achievement, and acquiring adaptive life skills. Many adults with ASD continue to have rigid patterns of social interaction making them appear uninterested or unable to have friendships. This can lead to social isolation. These social inabilities get in the way of knowing how to effectively reach out to get help or support. Some adults with ASD have difficulty accepting help from others.

Adults with ASD tend to be socially naïve and immature. They may try to fit in socially, although this is a huge challenge. They frequently struggle with the back-and-forth of social communication, showing interest in other people’s interests rather than just their

own, and carrying their side of a conversation. These challenges can undermine relationships with family, peers, coworkers, and staff persons.

Sexual Development

As noted, many adults with ASD are socially naïve and immature. This is also true regarding their sexual self-expression. The physical and hormonal aspects of sexual development are the same as with their non-ASD peers. In typical adolescence, sexual feelings and desires become more prominent, and social interactions may become intertwined with sexual overtones (Blasingame, 2011). These new sensations can be a social mystery for a person with ASD.

Many adults with ASD have difficulty knowing how to read social cues and body language from other people. The nuances of social correctness are often misunderstood or overlooked. Many with ASD are greatly challenged when it comes to being sensitive to how their behavior affects others. These social communication issues are major challenges for people who have ASD.

Another challenge is to understand the changes of the social rules or expectations that occur in adolescence and adulthood. These can become more confused when it comes to sexual self-expression. In addition, some individuals with ASD develop an over-focus on sexual themes due to social mystery or novelty. The combination of ASD-caused social communication challenges and the complications with new social rules and strong sexual sensations can get very confusing -and at times frightening- for adolescents and adults with ASD.

Sexual behaviors, such as touching one's own private parts for whatever reason, are expected to be done in private. Masturbation is considered a normal human behavior when done in the right place and at the right time. Some people with ASD do not have interest in sexual intercourse with another person, making masturbation their only form of sexual expression. This is also true for people in placement settings.

In the ever-changing landscape of social expectations, sexual self-expression is expected to adapt to new nuances and degrees of social acceptance. Keeping up nowadays with these new social-sexual nuances is a challenge for everyone, whether for a person with or without ASD.

As with other people with developmental disabilities, many people with ASD conditions have experienced abuses in their childhood and adulthood years. These trauma causing events can have a negative impact on any person's social and sexual development. These abuses and household dysfunctions can have lifelong implications on a person's identity and personality and often influence sexual decision making.

Uncommon Sexual Behaviors

Some individuals with ASD engage in uncommon sexual behaviors. These may be due to sensory issues, inadequate training, or a lack of knowledge about sexual matters.

Sometimes these are described as sexual “quirks.” Examples of uncommon sexual behaviors include the following:

- Saving one’s ejaculate in a bottle or bag and placing it in a freezer.
- Masturbating by laying on the floor nude and making hip thrusting motions to rub one’s penis on the floor until ejaculation.
- Using soiled diapers found in trashcans around the neighborhood.
- Using stuffed animals, unusual objects, or fabric pieces with preferred textures.
- Inserting objects into one’s urethra or other orifices such as sticks or wires during masturbation.
- Poking needles or sharp pins into one’s penis for sexual arousal.
- Behaviors that help the person avoid touching their penis with their hands.

These uncommon sexual behaviors likely will not lead to law enforcement involvement. They are, however, concerning and could lead to a referral to the PRSC program.

Sexual Problems and Offending Behaviors

Some individuals with ASD engage in less socially acceptable behaviors including what may be referred to as having sexual problems and sexually offending behaviors (SPOB).

Some individuals with ASD engage in sexual behaviors that are considered problematic due to the potential for self-injury, poor hygiene, or offensiveness toward others. Examples might include:

- Sneaking female’s undergarments from the laundry to masturbate with.
- Using urine or feces during masturbation.
- Making sexually lewd comments toward family members, peers. or staff.
- Masturbating inside one’s pants in front of others.
- Disrobing in front of peers and staff in the care home setting.
- Some of the examples of uncommon sexual behaviors listed above.

Other sexual problem behaviors involve engaging in impersonal sexual activity or having an elevated sex drive. These may include:

- Viewing adult pornography for hours on end each day.
- Masturbating more than twice a day.
- Viewing pornography that involves violence, use of weapons, or coercion.
- Engaging in sex acts with strangers.
- Making repeated unwanted sexual solicitations to staff, family members, or strangers.

While the above sexual behaviors are not illegal, these behaviors can be problematic and may come to the attention of law enforcement. They also can lead to a referral to the PRSC program.

A small number of people with ASD engage in illegal sexual behavior, i.e., sexual offending. While not all with ASD who commit illegal sexual behavior are convicted due to the person having a developmental disability, these behaviors are nonetheless unhealthy and problematic. Examples can include:

- Engaging in sexual acts with a child or teen who is an underage person.
- Using, or attempting to use, force to gain access to sex from another person.
- Soliciting sex with a minor via social media apps over the Internet.
- Exposing one's genitals publicly or disrobing in public.
- Grabbing or groping another person's sexual areas.
- Seeking or possessing child pornography via the Internet.
- Sending photos of one's genitals over the Internet when uninvited to do so.
- Having sexual activity with a person who cannot legally give consent.
- Other behaviors deemed illegal in the State of New Mexico.

Behavioral Intervention and Support

Some people with ASD, and those with other developmental disabilities, who engage in sexual problems or offending behaviors (SPOB) find themselves living with family members, incarcerated, or homeless, and others in board and care facilities as adults. It is not uncommon for families to find these and other behaviors to be a greater challenge than they can manage. Residential service providers also find some of the individuals with ASD who have engaged in these SPOB to have additional challenging behaviors which make it very difficult to provide long term care and support even for their professionally trained staff members.

Service providers are commonly guided by Positive Behavior Support Plans (PBSP) that are developed to address the various needs of the persons in their care. After a detailed assessment is completed, PBSPs identify areas of need and challenge, and the supports and interventions needed to address those needs and challenges. The assessments commonly draw from a review of file information, interviews with care providers and family members, as well as interviews and testing with the individual.

Many times, the PBSP needs to address the ASD condition itself. Examples of this might include teaching the person to use words or pictures to communicate with others. Another example might be to support the person to develop more effective social skills or coping skills. Some adults with ASD need to learn to develop socially pragmatic relationship skills to enable them becoming comfortable communication with adult peers. It may be necessary to treat some of the ASD issues before being able to address challenging or problematic sexual behaviors.

For those individuals who have exhibited SPOB, their PBSPs need to address the sexual issues directly. This should include identifying the individual's level of risk to re-engage in the SPOB in different settings, the level of staff supervision and support needed to prevent opportunities for a recurrence, and the support interventions needed to help the person develop healthy sexual self-expression.

Supports and interventions needed to assist individuals with ASD who have exhibited SPOB can be more complicated by the presence of intellectual disability and other mental health concerns. It is often necessary to help the person get a referral for psychiatry services for the mental health concerns and sometimes for medication evaluations to possibly address the problematic sexual behaviors.

The PBSPs themselves should address the sexual issues and instruct how the direct care providers should intervene and support the individual if problem behaviors occur in their presence. This should include discussion of the level of staff supervision as well as the types of interventions staff members should use when supporting the person.

In many regions there is a shortage of licensed mental health professionals who are accustomed to working with people with ASD much less those who have exhibited SPOB. This being the case, the treatment teams supporting the individuals will need to determine who, when, and how the sexual issues will be addressed. This often comes back to the Behavior Support Consultant (BSC).

One frequent area of sexual concern is that many individuals with ASD have a poor knowledge and understanding of typical and healthy sexuality. These individuals should be provided age and maturity-appropriate education in formats that they understand, e.g., words, graphics, pictures, etc. They should be given clear messages in plain language as to what behaviors are okay and which are not; what behaviors are illegal; and how to maintain privacy when engaging in sexual behavior in their home given other people are present.

BSCs are the usual team members who write the PBSPs. In most circumstances the BSC will make recommendations for direct care and day program providers to use the following general teaching strategies:

- Know the person's history and reasons for the recommendations.
- Be concrete, using plain language and simple terminology.
- Use role play and visual aids in addition to words.
- Be straightforward about sexual and personal boundaries.
- Be selective of who will address gender and health and hygiene issues.
- Reinforce appropriate behavior frequently.
- Redirect inappropriate behavior consistently.
- Provide clear instructions and expectations.
- Read printed educational materials aloud with the individual.
- Adjust the pace of training based on the individual's cognitive abilities.
- Review, discuss and reinforce previously trained information and skills.
- Reinforce efforts to learn, change, and stay changed.

Addressing many of these issues is likely to fall to the BSC. Specifically, issues of private sexual functioning, masturbation, sexual fantasies, etc. are topics that direct care providers should not discuss with the individual in care. Doing so could impede the relationship between the staff member and the person in care, and in some cases could

sexualize their relationship in ways that become problematic. Given these concerns, a BSC, or other professional resource, is the likely candidate.

There are behavioral interventions that are proven strategies for individuals with ASD conditions: video modeling, visual strategies, social stories, script fading, task analysis, and peer tutoring and modeling (Wolfe et al., 2009). These are commonly known by trained behavior specialists who work with people with intellectual and other developmental disabilities among other conditions.

Video modeling involves the person observing a video presentation of another person performing the desired behavior. The person is then to imitate the appropriate behavior. The process involves developing a script to address the target behavior. Models are selected based on similarity to the person being trained, as those who are like the person will evoke the most effective learning. The model enacts the script. The video is shown to the person several times before attempting to replicate the behavior. Imitation and practice of the target skills lead to feedback and are reinforced. This process applied to socio-sexual behaviors has been effective for teaching people with ASD conditions to label emotions, use spontaneous greetings, engage in conversational speech, and employ self-help and social skills.

Visual strategies involve use of a visual cue or stimulus to prompt or remind the person to engage in the desired behavior. Visual cues are useful in teaching sequences of behaviors or activities, schedules, and materials needed for activities. Applied to teaching socio-sexual behavior, visual strategies can be used to teach behaviors such as changing clothes in appropriate locations, prompts for social interaction sequences, discussion of condom or other contraceptive use, or teaching human anatomy.

Social stories involve an individualized short story (about a paragraph in length) that focuses on aspects of social situations and includes an appropriate outcome or behavior. The characters in the story serve as role models. The story can include social cue and feedback information that the person with an ASD condition might not otherwise notice. Social stories can be developed to teach a variety of pro-social behaviors and provide directions or affirmations for the reader. Stories can also be written in the first person, whereby the reader is providing self-instruction by reading the story. The person with the ASD condition is involved in writing the social story. After the first draft is written, it is read aloud, then revised as needed for clarity. The social story is reviewed and reread for self-instructive training purposes. Social stories applied to socio-sexual behavior training include self-instruction about how to manage sexual thoughts or feelings, cognitively rehearsing gaining consent for sexual involvement, or rehearsing refusal skills regarding unwanted touching by others.

Social script fading involves use of written scripts to guide social and communication skills. The script tells the reader what to say or do in given situations. Once the skills are acquired, the use of the script is faded, i.e., its use is gradually reduced. Social scripts can include all forms of visual cues such as pictures, graphics, or words. After the target behavior is identified, a short script is written. The person then learns the script and

implements the instruction during prescribed situations. Applied to socio-sexual behavior training, social script fading can be used to teach appropriate initiation skills such as talking to another person appropriately, asking for a phone number, or other conversational skills. One program for individuals with intellectual disabilities who had sexual behavior problems integrated this strategy in developing Smart Cards. The Smart Card is a written script of appropriate behavior or self-instruction to manage one's self-talk when having inappropriate sexual thoughts (Blasingame, 2005).

Task analysis involves breaking down larger tasks into smaller ones. The small tasks are trained independently, and then chained together in sequence. Task analysis has been used to teach personal hygiene skills, recreational activities, and table setting. Applied to socio-sexual behavior, task analysis can be applied to condom-use training, conversation skills, or masturbation training.

Peer tutoring and modeling is used in academic settings on a regular basis. Using socially competent peers to teach various skills enhances social interaction competencies as well as skill acquisition. This approach can be applied to a number of life skills. Peer tutors need to be same-aged or older than the person being trained, including perhaps siblings or cousins. Tutors can be trained in the skill sequence to be taught, and then they implement a training sequence up to three times per week for up to 30 minutes each session. Positive reinforcement is given to both the tutor and the learner. Applied to socio-sexual behavior training, peer tutoring and modeling can be used to train social communication, rehearse initiating greetings, appropriate non-sexual social touch, or handling social rejection if turned down for a date.

These behavioral strategies are well supported in the literature. However not every strategy listed here can be applied in every case. Thoughtful supports planning will involve treatment team members who can provide helpful input and guidance on what strategies fit best with the individual.

Summary Comments

People with ASD conditions sometimes develop in a void of accurate information about healthy sexuality. Sometimes there are other mental health or developmental disabilities present which further complicate their lives. Most people with ASD conditions do not exhibit sexual problems or offending behaviors. That said, some do engage in uncommon sexual behaviors and ones that gain the attention of care providers or the legal authorities.

Supports and services can and should be tailored to help individuals with ASD who engage in these problematic sexual behaviors.

References

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