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Relationships, Sexuality, and Intimacy in Autism Spectrum Disorders

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1. Introduction

The purpose of this chapter is to provide a brief overview of Autism Spectrum Disorders (ASD) and sexuality, as there is a paucity of this information in the literature. Specific attention is given to sexuality involving the self, others, and interpersonal relationships. Problematic sexual behaviors, legal concerns, and sexual abuse (including victimization and perpetration) are also discussed. Finally, intervention strategies for ASD children, adults, and families are addressed. The overall aim of this chapter is to highlight major themes regarding Autism Spectrum Disorders and sexuality while contributing to the existing literature.

2. Autism overview

Autism Spectrum Disorders, as currently defined by the Diagnostic and Statistical Manual (DSM-IV-TR) criteria, include the diagnoses of Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder NOS. The three major diagnostic categories include the following: 1) language impairment, 2) social impairment, and 3) repetitive behaviors/restricted interests, with the impairments present prior to the age of three. Autism has been conceptualized under this diagnostic rubric as a spectrum of disorders with symptoms ranging from severe to minimally impaired [1]. With the advent of the DSM-5, only two major criteria will be included: 1) social communication impairment, and 2) repetitive behaviors/restricted interests.

The DSM-5 envisions autism as a unitary diagnosis with multiple levels of symptom severity impairing the ability to function [2]. The DSM-5 will use a system of three modifiers to signify level of severity: Level 1 is characterized for patients requiring support as they display difficulty initiating social situations and demonstrate atypical social responses. Rituals and repetitive behaviors cause significant interference for these individuals. They also resist redirection and attempts to be interrupted when involved in restricted interests or repetitive behaviors. Level 2 is characterized for patients “requiring substantial support,” as they have marked deficits in verbal and nonverbal social communication skills, which are apparent even with supports in place. They demonstrate limited ability to initiate social interaction and have a reduced or abnormal response to social overtures from others. Repetitive behaviors and restricted interests are obvious enough to be noticed by a casual observer. These patients become distressed or frustrated when they are interrupted or redirected. Level 3 is characterized for patients requiring very substantial support, as they have severe deficits in verbal and nonverbal social communication skills. Repetitive behaviors or rituals markedly interfere with functioning in all spheres. They demonstrate marked distress when routines are interrupted, and they are very difficult to redirect [2].

Proposed changes to the DSM-5 diagnostic criteria include the creation of a single broad autism spectrum disorder (ASD) diagnosis that encompasses current specific DSM-IV-TR diagnoses. Further, the proposed DSM-5 criteria reflect the tension between considering core symptoms from a dimensional perspective (i.e., symptoms are distributed in the population and patients are distinguished from unaffected persons by the severity of their symptoms), as opposed to the presence of discrete symptoms reflecting categorical distinctions between affected and unaffected persons [3]. A dimensional approach suggests that the core symptoms are quantitative traits which vary along a continuum and reflect the expression of, and interactions between, commonly occurring genetic variations and effects of environmental factors, whereas categorical approaches favor models attributing risk of illness to large effects of single genes, especially genes involved in brain development or maintenance of synaptic architecture [3]. In fact, the DSM-5 diagnostic criteria may be best represented by an empirically-derived hybrid model that merges the dimensional and categorical aspects of symptoms of autism (i.e., there are threshold values for numbers and severity of symptoms that define a categorical diagnosis of an ASD). From a biological perspective, although symptoms may be viewed along a continuum, the diagnosis of autism implies the altered, albeit subtle, architecture of the brain. The two core symptom domains of DSM-5, whose severity can vary along a continuum, were validated independently and include 1) impaired social communication and interaction (SCI), and 2) restricted, repetitive behavior (RRB) [3,4]. There is still work left to be done with respect to determining the number of criteria that must be satisfied in order to assign an ASD diagnosis. The DSM-5 criteria are clearly being shown as superior to the DSM-IV-TR criteria in terms of specificity. However, a balance must be struck between reducing “false positives,” which maximizes specificity, and assuring that criteria are sufficiently sensitive to capture ASD-affected persons that would benefit from intervention and services. This is an especially big concern among caregivers of persons that would have previously received a diagnosis of Asperger’s disorder and for children and adolescents with poor historical information about early-life symptoms (e.g.,

children and youth in foster and juvenile justice settings). Inclusion of “subtler” symptoms, such as those reflected in the following items from the Social Responsiveness Scale (© Western Psychological Services), improved the sensitivity of identifying persons with high-functioning ASD (such as persons diagnosed with Asperger’s disorder): impaired social understanding or awareness, literal or pedantic use of language, difficulties in adjusting behavior to various contexts, unusual prosody, and problems with body orientation or social distance [3]. Additional research must be conducted to determine the discriminative diagnostic value should be placed [4].

Along with the proposed diagnostic criteria, estimates of the prevalence of autism have also changed. Recently, the prevalence estimates of the Autism and Developmental Disabilities Monitoring (ADDM) Network for children aged 8 years utilized a consistent “records-based” surveillance methodology in 14 sites across the United States, examining both health and education records [5]. The overall estimated 2008 prevalence of autism spectrum disorders was 1 in 88 children, demonstrating a steady increase in prevalence since 2002 [6]. Although the ADDM Network sites are not a nationally representative sample, the methodology used in obtaining prevalence estimates of children aged 8 years has been consistent since the monitoring began, so valid comparisons can be made with earlier years. These comparisons show that the estimated prevalence in 2008 increased by 23% in comparison to 2006, and by 78% when compared to 2002. The increase in prevalence may simply reflect greater awareness and better ascertainment of autism spectrum disorders by health agencies and schools, as suggested in a community mental health surveillance study in England [7]. The England study showed that the prevalence of autism in adults, when properly diagnosed, was approximately the same as in children.

3. Normal sexual development

Sexual development is a complex process that includes sexuality in relation to oneself and others. Sexuality encompasses a broad variety of physical, emotional, and social interactions. It includes sexual beliefs, attitudes, knowledge, values, and behavior and concerns the anatomy, physiology, and biochemistry of the sexual response system. Sexuality involves one’s thoughts, feelings, behaviors, relationships, roles, identity, and personality [8].

As with other individuals, those with ASD grow and mature along many developmental lines [9]. The social developmental line includes the development of sexuality, while the physical line includes that of puberty. Sexuality begins in infancy and progresses through adulthood until death. Each life stage brings about physical changes and psychosocial demands that need to be achieved for sexual health to be attained. The capacity for a sexual response, both male and female, has been found as early as in the 24-hour period after birth. The rhythmic manipulation of genitals similar to adult masturbation begins at 2.5 to 3 years of age and are a natural form of sexual expression [10]. Also during the first three years of life, a child forms an attachment to his or her parents that is facilitated by physical contact. A stable, secure attachment with parents enhances the possibility of such an attachment when an

adult is preparing to meet an intimate partner [10]. Gender identity, i.e. one's sense of maleness or femaleness, also forms in the first three years of life. A clear, secure gender identity allows for satisfying, intimate adult relationships. Children may display masturbatory behaviors and engage in a variety of sexual play activities that coincide with the development of socially expected norms in the context of natural curiosity about themselves and their environment. Between the ages of 3 to 7, children explore their own body parts, recognize them as male or female, and become interested in the genitals of their peers, leading to sexual play [10]. During the latency years, overt sexual play becomes covert, with children beginning to have experience with masturbation, should libidinal urges occur. As latency-age children segregate along sexual lines, any sexual experiences are usually with those of the same gender [10]. More overt behaviors and interests emerge again in adolescence with the onset of puberty. Reports collected by the Centers for Disease Control and Prevention (CDC) in 2000 showed about 52% of males and 48% of females in grades 9 to 12 are engaging in sexual intercourse as reported by Delamater and Friedrich in 2002 [10]. Similar statistics were reported as recently as 2011 by the CDC, with 47.4% of 9-12th graders reporting that they had ever engaged in sexual intercourse [11]. Cultural differences are also apparent among groups regarding premarital intercourse [10].

Pubertal changes can begin as early as 9 years of age or as late as 14 years of age. With the onset of puberty, sexual development moves to the forefront. Puberty, governed by hormonal changes, is defined as the time when a male or female is capable of sexual reproduction. A growth spurt, skeletal changes, increases in muscle and fat tissue, development of breasts, pubic and axillary hair, and the growth of genitalia are all hallmarks of the pubertal process [12]. With the physical maturation of gonads, genitalia and secondary sex characteristics, one's sexual interest increases. Citing a study by Bancroft and colleagues (2003), Delamater and Friedrich noted that many males begin to masturbate between the ages of 13 and 15, whereas the onset for girls is more varied [10]. As older adolescents and young adults develop, more teens engage in sexual intercourse and develop a sexually active heterosexual lifestyle. Between 5 and 10% of adolescent males, and 6% of adolescent females, experiment with homosexual behavior. This exploration may be a transient experience, or it may develop into an adult homosexual identity [10]. One of the major psychological developmental tasks of later adolescence is to develop a firm sense of identity, of which one's gender identity is an important aspect [13]. Achieving sexual maturity continues into adulthood with the ability to make informed decisions about one's partner choice, reproduction, and long-term intimate relationships.

4. Sexuality, disability, and ASD

Sexual development is an intricate process that examines sexuality in regard to oneself and others. This process is often thought of in terms of normal development; however the developmentally disabled also go through sexual stages as they physically mature. This concept can be difficult to accept for some providers and caretakers, due to their tendency to view the developmentally disabled as perennial children [14].

For much of our history, the concept that individuals with any disability as sexual beings was unthinkable [15]. Those with developmental disabilities were frequently subjected to involuntary sterilization in the first half of the 20th century. The sexual nature of those with disabilities has been traditionally denied and/or ignored. It has also been viewed similarly with ASD individuals, whose sexuality is further complicated by social communication and language deficits [15]. Only recently has it been acknowledged that persons with ASD have the universal right to learn about relationships, marriage, parenthood, and appropriate sexuality [8]. A major contribution to the field of autism and sexuality is the TEACCH Report published through the United Kingdom [16]. This article, based on the approach and concepts developed by Mesibov and Schopler [17] in the 1980's, put forth five basic assumptions concerning those with autism and are quoted below.

1. People with autism of all levels of severity experience sexual drives, behaviors, or feelings with which at some point in their lives they need assistance
2. Parent involvement and participation is a crucial ingredient in the area of sexual education
3. Sexual education must be taught in a highly structured, individualized way using concrete strategies with less of an emotional overtone
4. Sexual behaviors must be an important behavioral priority with less tolerance for deviations in this area due to the stringent expectations of society
5. Sexual education must be taught in a specific individualized, developmental manner [16]

This report was one of the first to acknowledge that individuals with autism have the same human sexual urges and behaviors as all humans and that those with ASD have the right to express their sexuality to the greatest level possible. These tenets therefore emphasize the need for sexual education for those with ASD, so they can be integrated into our society's rules concerning what sexual behaviors are considered either appropriate or inappropriate.

Keeping in mind that quite often individuals with ASD may also have an intellectual disability [18], studies of individuals with a disability in general become important for the ASD population as well. The current literature already being conducted for those with disabilities is being applied to the expressed needs for education of those with ASD on how to develop sexual and intimate relationships. One study identified that those under the age of 18 had only limited knowledge about pregnancy and sexual anatomy while most individuals including adults were aspiring to form relationships and marriage [19]. In addition, general reluctance of family members and caregivers to acknowledge and respect the sexual rights of those with an intellectual disability was identified because these concepts created a certain level of anxiety in those family members.

As with others individuals who have a disability, those with an Autism Spectrum Disorder diagnosis possess the right to have a relationship, to marry, and/or to have children. Education about legal rights should be provided to those with ASD and extended especially to those whom they encounter, e.g. teachers, family, policemen, community members, etc. Education

and awareness are key factors in the ability to identify violations to individuals' basic human rights.

Although those with an ASD diagnosis have the right to date, marry and have children, there is a paucity of empirical research on family units and relationships for this particular group. Though some evidence does exist anecdotally, e.g. through blogs and books, this evidence is not scientifically sound. Therefore, future research should generate empirical studies that focus on interpersonal relationships within the family unit and examine which factors or skills may contribute to their success.

5. Characteristics common to ASD persons

The overarching confounding factor for individuals with ASD to develop normative sexual identity, sexual orientation, and sexual behaviors is their core social disability [20] that in turn influences the person's opportunity and availability for romantic and intimate relationships. While levels of romantic and sexual functioning typically increase with age, a developmental lag was reported for individuals with ASD [21]. In a survey of parents of 38 neurotypically developing adolescents and young adults and 25 adolescents and young adults with ASD, Stokes and colleagues found support for their research hypotheses that individuals with ASD had less access to peers and friends, engaged in more unacceptable behaviors in attempting to initiate romantic relationships, and persisted in their pursuit of the relationship even when non-mutual interests were evident [21]. In 2012, Shandra and Chowdhury conducted a study on the first sexual experiences of adolescent girls with and without disabilities and reported that social isolation (not the adolescents' impairment) was the primary contributor to difficulties, based on their review of the literature and analyses of a national longitudinal data bank. Results also suggested that having a mild disability increased the likelihood of having sexual intercourse with a stranger for the first time, rather than with a steady dating partner [22].

Several characteristics of those with ASD interfere with the capacity to develop meaningful adult social relationships, which are necessary for developing sexual, intimate relationships. Foremost is the difficulty with social judgment [8], i.e. missing nonverbal communication, poor eye contact, theory of mind problems, and flexibility in response. Lack of experience in peer relationships prevents the development of the common pathway through which adolescents learn about sexuality [23]. Problematic decision-making skills complicate the capacity to maintain the everyday details of a relationship, such as initiating dates, or remembering plans. Lack of flexibility, along with self-absorption, creates significant areas of conflict in a potential relationship. Emotional dysregulation resulting in feelings that are too intense, or perhaps misplaced, together with a lack of awareness of the other's response can quickly end a relationship. Sensory sensitivities, such as inability to tolerate touch or other physical sensations, sound sensitivities, or food texture issues can cause dating to be fraught with problems [24].

Many persons with ASD have little self-awareness and as noted above, do not understand their impact on others. Another dimension of this issue is that persons with ASD may have

little knowledge about themselves. Part of what helps us create a sense of self is the ability to create an internal autobiography [25]. Persons with ASD have difficulty in this area, as they frequently cannot describe their own emotions or are unaware of what they are feeling (i.e. alexithymia) or have difficulty controlling their emotional responses (i.e. emotion dysregulation). As a result, many with ASD lack the ability to insightfully understand themselves or respond to the social climate in a meaningful way. Self-advocacy, a crucial skill for maintaining one's function in daily life, is something that can be very difficult for a person with ASD to learn. The ability to maintain personal safety without awareness of the environment or the behaviors of others can pose a significant danger.

Persons with ASD, either as a result of the above difficulties or due to a true lack of social interest, turn away from others into their own world. Self-absorption fosters another type of social disability. Persons with ASD frequently have restricted areas of interest (e.g. computer animation) and may have little to no desire in sharing this interest with others or attending to the interests of others, since there can be a lack of ability to detach from the area of interest without anxiety or distress. The need for sameness and rigidity in daily routines may supersede one's ability to flexibly respond to another person, e.g. being unable to eat at another restaurant when only two specific restaurants are in that person's repertoire [26]. The need for aloneness or "down time" may be greater than the need to be with others, which may seriously jeopardize an attempt to relate to others in a more than superficial manner. Sensory sensitivities can create intolerance of what may be considered part of the human experience. For example, sensitivity to sound may prevent a person with ASD from engaging in activities where airplanes may be heard overhead or babies may be heard crying. Also, sensitivity to touch can be especially difficult in relation to others, as those with ASD may not tolerate someone touching their skin or attempting to hug them. This particular sensitivity may also affect the choice of clothes for someone with ASD, who may be unable to wear clothes with sleeves or tags that they feel are restrictive and might lead one to wear socially inappropriate apparel.

Executive function impairments, i.e. impairments in decision-making skills, cognitive flexibility, impulse control, organizational skills, and planning, create another layer of social dysfunction [27]. Awareness of the passage of time may be compromised for someone with ASD, perhaps secondary to their self-absorption, and is an essential component of everyday function. Everyday memory problems or the ability to remember to plan and organize daily life activities can create social havoc. The ability to problem solve, make informed choices, or plan for the future becomes problematic in what is called "context blindness" [27].

All of the above challenges are magnified when a person with ASD attempts to have an intimate emotional and perhaps sexual relationship. Intimacy is the sharing of emotional, cognitive, and physical aspects of oneself with those of another. A prerequisite for intimacy is the establishment of a firm sense of self-identity. Intimacy requires the flexibility to loosen one's identity in order to feel the pleasure of merging with one's partner in an emotional and physical connection. For all of the reasons above, a person with ASD may be unable to share with another or may be limited in his or her ability to do so.

Case example: RJ

RJ is a 28 year-old female with ASD who was attempting to negotiate an intimate relationship with another woman her age that did not have ASD. First of all, RJ explained that a homosexual relationship was better for her than a heterosexual relationship because her partner was more like her than another man would be, and it was already very difficult to consider an intimate relationship, let alone try to understand someone of a different gender. RJ was absorbed in her interest in drawing and hoped to get a job at some point in computer animation. She spent most of the hours in a day drawing when she was not at her part time job at the local animal shelter. When she was drawing, it was fine for her partner to sit next to her, but she didn't want to be disturbed or touched. She was unable to do something other than drawing in the evening except on Saturdays, when she was able to include her partner in her schedule. Even on Saturday, she needed to find some time to herself because it took too much energy to be with her partner for a full day. When she attempted to do so, she would experience anxiety and frustration which would frequently culminate in an episode of yelling, stamping her feet, and retreating to her room. On Saturdays, when she was attempting to spend time with her partner, RJ was only able to engage in certain activities. Her partner would frequently ask her to go to the movies, while RJ was unable to tolerate the feel of the seat cushions on her skin, the smell of the popcorn, and the loudness of the sound track. RJ could only eat at two restaurants in the neighboring area but preferred to eat at home. RJ could not understand her partner's frustration with her or her partner's need for physical affectionate contact. RJ was able to tolerate some sexual contact but avoided it whenever possible, as it was adverse to her but she understood from reading that it was an expected part of a relationship. After several months, RJ's partner terminated the relationship, much to RJ's relief. She was very happy to return home to her parents' house where she could have conversation with them at her initiative, and the expectations for social interaction or disruption of her schedule were minimal. It was comforting to return to her family's schedule, which she knew well. She did have the insight to know that her parents wouldn't always be there and knew that she needed to work earnestly to maintain at least some relationship with friends. She understood that even though it may be difficult to do so, she would have to initiate contact and not rely on her friends solely to initiate such contact.

The only significant predictor of romantic functioning among those with ASD is level of social functioning [21]. When meeting someone with ASD, several irregularities are noticeable. Persons with ASD frequently will not look into the eyes of the person with whom they are interacting; instead they may look at their mouths or perhaps even another object in the room [20]. Some of those with ASD would state that looking directly at another's person's eyes is extremely anxiety provoking, whereas others with ASD may be disinterested. Personal physical spatial boundaries, which many people take as second nature, are not part of the social make-up in persons with ASD. They may stand too close to a person with whom they may be interacting, or they may seem distant and uninvolved. Those with ASD may not pay attention to socially acceptable standards of personal appearance and may appear unkempt or inappropriately dressed for an occasion, e.g. wearing a casual, comfortable outfit to a formal event. Persons with ASD have a very difficult time en-

gaging another person in conversation, i.e. they have difficulty initiating conversation or maintaining conversation through reciprocal social interaction [26]. A person with ASD may answer questions when asked or begin a scripted monologue that is repetitive in nature about an area of interest, with little to no awareness of the reaction of the person with whom they are interacting. Part of the reason for this lack of awareness is that a person with ASD is frequently unaware of the meaning of nonverbal behavior as a means of communication. The concept of theory of mind states that a person cannot understand the thoughts, intentions, and feelings of others or what another person means during an interaction, other than the concrete nature of the words stated [28]. For example, when a mother asked her child to “go sit in the tub”, the child sat in the tub with all of her clothes on, when the mother of course meant to prepare for a bath. This may seem obvious to most people but might not be so obvious to a person with ASD. As a corollary, a person with ASD frequently cannot read the emotional meaning behind a verbal or nonverbal communication, i.e. interpret social cues [29]. A study by Izuma supports that people with autism lack the ability to take into consideration what others think of them [30]. Partially due to this lack of awareness, someone with ASD may respond in a very blunt or honest way to a statement of another person with whom they are interacting. For example, when asked a question such as “Do you like my new dress?”, the person with ASD might say all the reasons they feel the dress is unattractive, being unaware of the emotional impact such statements might have on the person to whom they are making such comments [31].

6. Gender identity and sexual orientation

Gender identity usually develops in neurotypical children by the age of three [10] with ranges of 3-5 years of age [32]. Gender identity may be more rigid in individuals with ASD [33]. For children with developmental disabilities, gender identity in general likely develops in synchrony with many other developmental delays, especially in language, communication and social relatedness, which in turn influences the child’s ability to mentally represent their own gender either in images or language. There is no current established literature about gender identity development in children with ASD; however, a recent article on gender dysphoria and identity difficulty found that clinics are reporting an overrepresentation of individuals with ASD in their gender identity referrals [33].

Sexual orientation refers to a person’s established patterns of overall attraction to another person, including emotional, romantic, sexual, and behavioral attractions [34] regardless of whether this pattern results in sexual behavior. Research in the last several decades established sexual orientation on a continuum from entirely heterosexual, bisexual, and homosexual to asexual [35-37]. The relatively novel term “sexual fluidity” refers to the situation-dependent flexibility in someone’s sexual responsiveness and may include both hetero- and same-sex experiences [37]. Same-sex behaviors among adolescents are reported between 5-10%, with similar percentages observed in adults [10].

Sexual identity develops normatively in adolescence related to puberty and overall body changes in the context of societal expectations about partner choices. For most adolescents

with ASD, this development may occur later than that of their typically developing peers [38] and may include higher percentages of asexuality, but in most aspects of sexual development, the literature identifies similar desires and fantasies [21]. In fact, the literature on sexuality of children and adolescents with developmental disabilities cautions to not erroneously regard people with disabilities as childlike, asexual or as inappropriately sexual [39].

At the same time, several studies were identified by Healy and colleagues [19] that show that people with a disability may hold rather conservative views about their own sexuality related to negative caregiver attitudes toward certain sexual behaviors, including pre-marital sex and homosexual activity. Still, in comparison to caregiving staff, family members may altogether be less inclined to openly discuss issues of sexuality. Family members seemed to prefer low levels of intimacy in the relationships of their child amidst a high acceptance of platonic and non-intimate relationships [40].

7. ASD and intimacy

Individuals growing up with ASD have the same human needs for intimacy and relationships as anyone [41]. However, the self-identification of these needs may develop later than same age neurotypically developing peers and become expressed differently depending upon the individual's sexual knowledge, beliefs and values. Understanding of implicit dating rules and the hierarchy of sexual intimacies may become potential barriers for individuals with disabilities in general and particularly for adolescents and adults with ASD. Focus groups have been shown to make a difference in an individual's understanding, especially with involvement of his or her family and caregivers [19].

Intimacy is the sharing of emotional, cognitive and physical aspects of oneself with those of another. Individuals with ASD often have problems with rigidity and the need for repetition, which may limit the spontaneity and playfulness of sexual contact. Sensitivity to physical contact and inability to tolerate internal sensations created by physical intimacy may also create significant anxiety. The inability to read the thoughts, feelings, or expressed sensations of one's partner can lead to miscommunication, emotionally or physically painful experiences, and/or shame and guilt. In the context of navigating intimacy, by adulthood there are several options for types of relationships, typically to include living single, cohabitating with one or several others, and living in a marriage/partnership. Currently, many adult individuals with ASD continue to reside with their family of origin. Due to poor social relationships and lack of employment, living with family provides a comfortable social situation, as observed in the case of RJ. There is no need for continual social contact or concern for others, as family already exists as a group.

When even possible, marital relationships can be very strained, as the ASD spouse (usually a male) frequently has difficulty interpreting the spouse's need for emotional attention. Little to no research has been done on the adult lifestyles of higher functioning persons with ASD other than to say that most of them remain in their parents' home. Most previous research has been with those living in a residential setting. One study whose focus was to sur-

vey the gender identity of ASD subjects did ask a question pertaining to marital status. Gilmour and colleagues found that the group, which was atypically more female, did not differ from the control group on the basis of marital status. This result was unexpected and may be specific to the group surveyed of 82 persons with ASD [42]. More research is clearly needed in this area, but attaining accurate statistical data will be difficult, as many high functioning individuals with ASD are undiagnosed or misdiagnosed.

Case example: L

Patient, L is a 35-year-old male engineering student, who was accompanied by his wife for an initial assessment. L's wife believed that he had Asperger's disorder. He did not understand why this potential diagnosis would even matter to his wife. A major concern in their marriage was L's dislike for social situations. His wife worked at a bookstore and was frequently invited to her coworkers' houses to play games, watch movies, or perhaps have dinner. L would begrudgingly attend but would then sit quietly and not interact with anyone. His wife's friends would attempt to include him in conversations, but L would frequently give one-word answers and not reciprocate or would engage in a long monologue about his most recent engineering project. He did not understand his wife's distress at these situations. As a couple, it was their usual routine to have a date on Saturday night consisting of time spent together in an activity, followed by a sexual encounter. L did not understand why his wife would break this routine when she was upset by his lack of social interaction at her co-worker's home. He would become very angry and frustrated, slamming the door, and breaking small nearby items. His wife encouraged him to come to the appointment as a way for her to begin to understand his behavior and to find ways to cope with him.

8. Potential for abuse

For all individuals with disabilities, including ASD, there is an increased risk for physical and sexual abuse. In 2006, Murphy and Elias reported a sexual abuse rate that was 2.2 times higher than that of children without disabilities [39]. In a recent study, caregivers of individuals with autism reported that 16.6% had been sexually abused. Individuals with ASD can be subject to sexual victimization due to their trusting natures, desire to be socially accepted, lack of understanding of the meaning or possible consequences of their behavior, or exposure through internet contacts. Children who experienced sexual abuse were more likely to act out sexually or be sexually abusive toward others [43]. This mindset, although with seemingly honest intentions, places the ASD individual(s) at risk for sexual abuse, due to the lack of available sexual knowledge. Lack of knowledge can contribute to an individual not understanding appropriate boundaries and therefore they may not be able to distinguish when someone is touching them inappropriately. This, coupled with existing social deficits, has resulted in underreported sexual abuse in this population. Therefore, sexual education and public intervention strategies (which will be discussed later in this chapter) are key protective factors and could contribute to healthy sexual development.

Case example: M

A 17-year-old female patient, M, presented for diagnostic evaluation and was diagnosed with ASD. Her cognitive ability was in the low average IQ range. As a student in high school, she was very invested in making friends. She had difficulty managing the intricacies of relationships with other girls in her class, as her hygiene was below average and her clothing choices were not fashionable. M didn't belong to a specific social group of girls, such as cheerleaders, athletes, "Goths," etc. and therefore frequently sat by herself in the lunchroom. As she was failing in her social relationships with girls, she thought she would attempt to make friends with some of the boys in her class. She was coached by her younger sister at home (age 15 without ASD). Her sister was actually aware of M's poor social standing with other girls, as she was frequently asked what was wrong with her older sister by peers. M had previously made positive contact with a boy in her art class, who was drawing a video game character. The art teacher supported this interaction and facilitated their conversations in class. Her contact with another boy, however, was less than positive. He told M that the best way to make friends was to spend time together after school at the park. The boy then made sexual advances, kissing the patient. She was very confused and did not stop his behavior, which led him to attempt to fondle her genital area. The encounter stopped at that point. M did not bring this event to the attention of her parents or sister. Fortunately, in her therapy session, she was able to ask if it was OK for a boy to put his hand in her pants. Clearly, M had not received instruction from her parents about "appropriate touch." The parents brought this situation to the attention of the school administrators, who reprimanded the boy but could not address it further, as M was older than 16 and it was deemed that she consented to the behavior by not stopping him.

9. Inappropriate sexual behavior

Along with the concerns of interpersonal intimacy and delayed maturity of sexuality, individuals with ASD may have difficulty determining what and where sexual behaviors are appropriate. Permitted behavior is governed by social appropriateness, which is gathered through social cues. With the limited ability to read and understand social cues, those with an ASD diagnosis can fail to discern between acceptable public behavior and acceptable private behavior [44]. A review article by Stokes and Kaur included masturbatory behaviors in public, removing clothing in public, and touching members of the opposite sex, as reported in previous studies, followed sometimes by the rejection of others due to these problematic behaviors [45]. For example, masturbatory activities are often seen in public when anxiety levels have increased. This in turn could potentially lead to legal implications. Among adolescents with ASD, some concerns include inappropriate courting behaviors, such as stalking or touching the person of interest inappropriately, making inappropriate comments, not always understanding the need for privacy such as knocking on doors [45], making threats against the person of interest, or exhibiting obsessive interest in a person [21], which can lead to both interpersonal and legal consequences. Behavioral and educational interventions must be considered in order to serve as a protective buffer against undesired outcomes.

Case example: C

Patient C is a 14-year-old boy diagnosed with autism who had minimal verbal skills. At age 14, he was 6'2" tall. Cognitively, he was functioning at the mild intellectual disability range (IQ ~70). C had no friends. His social judgment was poor, so his parents encouraged his interactions and visits with extended family in an effort to improve his social communication. One of the patient's areas of interest was wrestling. He would frequently roughhouse with his other male cousins, who were teenagers as well. On one visit, C was watching a wrestling program with his younger cousin, age 4, as the older boys had gone to the movies and C refused to attend. C, not understanding the social implications of his behavior, began to roughhouse with his young cousin. When his mother and aunt entered the room, C was laying on top of his 4-year-old cousin in what was judged to be an attempt by the patient to molest this young child, whereas C thought he had won the wrestling match like the man on television. When asked, C could not adequately explain his behavior, due to his limited verbal skills. His mother was able to reassure the young boy's mother that C had no sexual intent. However, C and his mother no longer received invitations to visit the home of those relatives.

Masturbation especially in public settings has been the central focus within the developmental disorder literature due to the concerns and personal views of the general public and legal officials. In particular, these groups possess a tendency to label public masturbation as sexual deviancy. This predisposition was greatly reduced when both groups received training on the behaviors of individuals with ASD.

10. Sexual education

Sexual education is a core ingredient of successful intervention beginning with body anatomy, physiology and personal hygiene, taught in childhood. As the individual with ASD reaches older adolescence and adulthood, social dictates of what is appropriate sexual behavior in public must be carefully taught with video modeling and social stories [23] to prevent problematic outcomes for the person with ASD and those around him or her [21]. As with all stages of development, sexual development may be delayed, while pubertal development may be chronologically on time. The family needs to be educated about teaching sexuality as well in order to facilitate the knowledge of the individual with ASD throughout his or her development [8,44]. Sexual education can also prevent sexual abuse, unwanted pregnancies, and sexually transmitted infections, or STI [8]. A recent article on the sexuality of children and adolescents identified educational needs in the context of parent and health care professionals' expectations [39]. Likewise, a greater educational need was identified for caregivers of individuals with disabilities to help individual better navigate their social environment with implemented help on a societal and political level [44,46,47]. DeLamater and Friedrich cited the Kaiser Family Foundation (1997), noting that young people especially name mass media as a primary source of information about sex and intimacy over information and education provided by parents or professionals [10].

This is likely even more true currently, with youth having increased access to information via the Internet and the use of personal electronics. In this sense, the use of electronics may become a useful educational medium and perhaps even an interactive tool to facilitate development of socially expected courting and dating behaviors, with the goal of becoming able to establish longer term romantic relationships.

Education about sexuality is critical for the ASD population. Many persons with ASD have the desire to have friendships and intimate relationships; however it is very difficult for them to make the complex emotional distinctions between friendship, kindness, and romantic interest. In a study by Hellems, the majority of subjects with ASD expressed sexual interest but lacked the appropriate skills and knowledge to have a successful relationship [48]. Their misinterpretations can lead to emotional pain for themselves and possibly inappropriate behaviors toward others [26]. The most common forms of sexuality education for adolescents and young adults occur through conversations with their peers and/or their families. A study by Realmuto and Ruble suggested that typical children learn about sexuality via casual social experiences, including those in the community, family and school settings [49]. Persons with ASD are at a unique disadvantage as they do not initiate or maintain social contacts to acquire such education. Family members approach sexuality in their children with ASD by denying it and not teaching sexuality at all, or by considering that their ASD children can approach sexuality as any other adolescent would [21]. In a study by Stokes and colleagues, 25 subjects with ASD aged 13-36 were compared to a normal control group of the same age; the study found that persons with ASD relied less upon peers and friends for knowledge but relied more on information they learned through reading and other similar activities [21].

When considering education about sexuality, three content areas need to be included: 1) basic facts and accurate information, 2) formation of individual values with consideration of family values, and 3) application of sexuality to relationships and social situations [15]. More specifically, basic biology of the sexual organs and how they function for males and females, maintenance of hygiene, prevention of pregnancy and sexually transmitted diseases, methods of birth control, how to initiate and maintain intimate sexual relationships, how to prevent unwanted sexual contact, the role of masturbation as a normal sexual bodily function and its social implications, as well as reproductive and parenting rights. What is most essential is to maintain a consistent focus on the social component of sexual behavior [8]. Due to theory of mind deficits, a person with ASD may be unable to understand the actions, feelings and intentions of others, such as not recognizing obvious clues of disinterest and being inappropriately persistent in pursuing a desired person. The person with ASD must learn how to initiate romantic relationships, understand dating behaviors, know appropriate physical boundaries, develop listening skills, and understand the meaning of consensual sexual activity [8]. Frequently, booster sessions are recommended as an individual grows and develops and has the need for additional information and skills or reinforcement of principles already learned that may have been forgotten [8].

Deciding who should teach a person with ASD about sexuality can be confusing. A team approach may be most successful. Parents and caregivers usually provide primary instruction

but may need the support of a formal sexual education program provided by the school system. Parents provide the foundation for the development of the child's sexuality by modeling relationships in the home. The family's moral values, culture, religion, and other beliefs are clearly a major part of sexuality education. An IEP team can designate a specific component of the health curriculum to sexuality that must be geared to the child's cognitive, emotional, and social level of development. Such a plan should be revisited and revised as a child/adolescent matures with the need for more information, skills, and attitudes [8].

11. Model programs

Several models and approaches to sexuality education for those with ASD have been published. One model from a research study in Israel provided treatment through ten bi-weekly sessions, each devoted to topics that included establishment of self-identity, acceptance of one's disability, independence in social life, establishment of friendship and intimate relationships, sexual knowledge and development, and safety skills [50]. The aims of the group were to 1) discuss attitudes and feelings, 2) provide information, 3) advise parents on how to help children manage their sexuality, and 4) encourage independence in their children. The overarching principles of this group treatment were to 1) develop an appropriate self-concept, 2) find a similar social group, 3) develop relations based on equality and reciprocity, and 4) prevent abusive relations, with all of these aims potentially leading to satisfactory intimate romantic relationships. The most improvement in this study was shown in social development and the development of a clearer concept of friendship.

Case example: H

H is a 19-year-old female who recently began attending community college. She has an above average IQ and good facility with language. She was able to manage some friendships in high school by being the manager of one of the girls' sports teams. The girls on the team were kind to her and included her in team activities, encouraged by the team's coach. H also belonged to the Anime club and had some friends there. The structured schedule of high school, along with the academic supports provided by her Individualized education plan, coaching and encouragement from her parents, enabled her success. H was having a difficult transition to college with no friends, no academic supports, and a less structured schedule. She attended a session provided by the disability services department and sat next to a boy several years older than she with a similar disability, who initiated and maintained a conversation. H was aware that he was a stranger and was careful in the information she provided. He asked her to meet for lunch at the cafeteria several times. H's mother wanted to meet him because she was unsure of her daughter's social judgment. With her parent's approval and her mother's coaching about dating, they went to a movie. Their relationship slowly progressed over the last six months beyond the handholding stage to the first kiss. H's boyfriend was able to allow her to manage the relationship to assist H in dealing with the anxiety that this relationship had created for her, though she was beginning to increasingly enjoy their time together.

Another intervention that shows promise is the development of Social Stories™ by Carol Gray [51] which can be tailored to each child or adult and written in the person's perspective, so it can be used to prepare persons for dealing with friendships, managing intimacy, and improving safety [23]. Video modeling is another technique where a student watches a video where peers or others demonstrate appropriate behavior. The student then models the behavior he or she just viewed. Video modeling, by providing some distance, helps relieve some anxiety during a practice phase before trying a real time interaction [23].

Concepts from other treatment centers have added to sexuality education. Two precepts from the Devereaux Centers for Autism emphasize that 1) parents are the best sexual educators and 2) it is normal and natural for every person with a body to express their sexuality regardless of their disability [44]. The Benhaven residential program for those with autism emphasizes 1) the need to teach students socially acceptable sexual behavior appropriate for both childhood and adulthood 2) no disapproval of masturbation when done in socially appropriate situations as it may be the only sexual satisfaction some individuals with autism may experience and 3) do not encourage behavior beyond which an individual is capable or that will lead to frustration and disappointment [44].

It is helpful to consider the basic learning needs of those with ASD in general and apply them to sexuality education [26].

1. Use of visual aids, role play
2. Use of concrete, specific examples instead of abstract concepts
3. Dividing large blocks of information into smaller, sequential segments
4. Allowing time for comments and questions
5. Keeping brief any discussions of feelings so as not to confuse or overwhelm
6. Provide overviews and structure to the lesson
7. Include specific problem solving strategies and examples

Especially when considering sexuality education in those with lower functioning ASD, the capacity to make sexually-related decisions must be considered. A study of four adults with moderate intellectual disability (not autism) focused on improving capacity to make sexuality related decisions [52]. Treatment was rendered on a 1:1 basis for 20 sessions. The article by Dukes and colleagues emphasizes that in order to provide valid consent to sexual contact, the person with a disability requires knowledge about sexuality and the understanding of the concept of what is and is not voluntary [52]. Consent must also be individualized and situation specific for decision-making associated with sexual contact. This intervention focused on sexual safety practices, knowledge of the physical self, knowledge of sexual functioning, and knowledge of choices and consequences in sexual matters. The study noted the need for booster sessions, as the memory of topics covered waned with time, perhaps secondary to little opportunity to utilize the information learned [52]. A survey of the sexual behavior of 89 adults with autism living in group homes in North Carolina found that the majority of individuals were engaging in some

form of sexual behavior [53], with masturbation being the most common sexual behavior. One third of the residents did have other oriented sexual behavior, which mostly consisted of holding hands, touching, and kissing. One third of the residents did not masturbate at all. A major concern with lower functioning individuals is the inappropriate expression of sexual behaviors in a socially unacceptable manner [53].

To improve decision-making related to sexuality in individuals with an intellectual disability, Dukes and McGuire adapted successfully a sexual education program for individuals with special needs called *Living Your Life* [52]. Possibly such a program could also further be adapted to the specific knowledge and needs of individuals with ASD. In their 2010 article, Travers and Tincani identified Body Awareness, Social Development, Romantic Relationships and Intimacy, Masturbation and Modifying Behavior to Meet Social Norms, and Reproductive and Parenting Rights of Individuals with ASD as crucial components of sexuality education for individuals with ASD [8]. These authors also identified the need for professionals to address sexuality education in an open, confident, and objective manner in a collaborative effort with the individual with ASD and their family.

The TEACCH program [54] has explicit guidelines for teaching sexuality education to the lower functioning person with ASD [16]. An important component is taking an individualized developmental approach, with the goal of matching teaching programs to level of function and development of long range goals (e.g. capacity to have a romantic relationship versus ability to enjoy masturbation in a socially acceptable manner). Another concept is that sexuality cannot be taught in isolation but must be considered in the context of other skills, such as one's ability to verbally communicate or one's cognitive ability. The most basic skill is the ability to have discriminate learning, for example, knowing where and when to touch others or masturbate, and can be taught from a behavioral perspective, with rewards for appropriate behavior. Environmental supports to reinforce appropriate behaviors can be very useful, and environmental changes (e.g. wearing a belt to help prevent a young man from masturbating in public) may allow for intervention prior to a behavior occurring, as slowing down the behavior provides more time to intervene. The next level beyond discriminate learning is managing personal hygiene, followed by understanding body parts and their functions. The highest level is a complete sex education program, including development of sexual relationships with others.

Social skills groups and meet-ups for older adolescents and young adults are essential to continue to build on social skills and allow for facilitated interaction [55]. A recent study with adolescents and young adults with ASD by Stokes and colleagues found that one's level of social functioning predicted romantic functioning [21]. The development of social interaction skills will help promote interest in developing meaningful relationships with others that in turn may lead to intimate relationships and ultimately more independent living arrangements. Equally important are the development of emotion regulation and self-esteem skills that will help to navigate difficulties and changes within significant relationships. In their 2006 article, Murphy and Elias [39] described how children and adolescents with disabilities generally have fewer skills and opportunities to engage in social interactions that could lead potentially into intimate relationships. In particular, this im-

portant article emphasizes particular skills that are often amiss for individuals with disabilities, Abilities, especially the ability to make eye contact, develop appropriate greetings, recognize personal space, and interpret nonverbal communication, that apply to individuals with ASD [39].

Based on previous studies, and addressing the gap in identified interventions specific to the sexual development of individuals with ASD, a current intervention program called Growing Up Aware is in the process of being developed at Columbia University [14]. The first research component attempted to better understand how parents teach their children with ASD about sexuality. Results of the study showed that the majority of parents indicated a strong interest in learning how to better communicate with their children about sexual and reproductive health [14]. This is met currently by insufficient availability of materials for parents. Many clinical providers appear under-equipped, with normative knowledge and skills themselves about how to address questions of parents regarding their child's changing sexual development based on parental perception. Clinicians need to become better equipped to help families with unusual or inappropriate sexual development.

12. Medication concerns

Medication side effects that were not troubling to a child with ASD may cause significant distress in an adult with ASD by decreasing sexual desire or interfering with sexual potency [56]. Self-injury may result if appropriate instruction about masturbation is not provided. Medications such as fluoxetine or sertraline (selective serotonin reuptake inhibitors) are frequently prescribed for persons with ASD to help with anxiety or repetitive behaviors. This group of medications can cause a decrease in sexual desire or make it much more difficult to attain an orgasm. Since masturbation is one of the most frequent sexual behaviors within the ASD population, unintentional self-injury may result from prolonged attempts to reach orgasm. Appropriate instruction in masturbatory behaviors may be necessary in order to prevent self-injury [46]. Alternately, a medication with sexual side effects may be beneficial for a patient who has anxiety and/or excessive inappropriate sexual behaviors by decreasing sexual desire [57] and enhancing the effectiveness of behavioral interventions.

13. Public intervention

There are many important reasons for promoting sexuality education for those with ASD including the following: 1) prevention of sexual abuse, 2) preventing inappropriate sexual behavior toward others, 3) promoting health and hygiene and preventing sexually transmitted disease and pregnancy, 4) facilitating the development of intimate relationships, and 5) pre-

venting self-injury [8]. A basic tenet is that sexuality education for persons with ASD must be geared to their particular level of cognitive, emotional, and social functioning and is most effective when it is highly individualized. Those with ASD have a right to have a sexual life, a right to receive guidance and support, and they need assistance in expressing sexuality in an acceptable way to those in their environment [8].

Public intervention strategies should primarily focus on educating the community about the behaviors and traits common to persons with Autism Spectrum Disorders. Education has been shown to foster tolerance and understanding. In addition to this, education tends to spawn advocacy, thereby facilitating the needed changes in existing policies and law. In particular, advocates of those with ASD have the greatest opportunity to teach others about this population by modeling how best to support persons with ASD in the community.

Particular attention should be given to law enforcement, judicial systems and other populations that traditionally have minimal contact with individuals with ASD [7]. Educational efforts should include a discussion of basic symptomatology, behavioral interventions and treatments. Efforts should also be made to dispel myths, misconceptions and assumptions about those with ASD [58]. In addition, education should include information about potential risks to this population and the available programs and systems that are in place to provide protection for the ASD population [44].

14. Conclusion

In summary, our literature review and ample experiences of the families in our clinical practice show that, while every person has the innate basis for developing sexuality in a multitude of expressions and experiences, individuals with disabilities (and especially individuals with an Autism Spectrum Disorder) most often require additional education and help to become able to express their sexuality in a socially appropriate way. While most neurotypically developing peers form intimate relationships beginning in adolescence and into adulthood, along a variety of experiences from dating to partnering in committed relationships, many individuals with an Autism Spectrum Disorder remain living with their family of origin into their adulthood and have significant difficulty navigating the social expectations surrounding relationships. Their difficulty may pertain to recognizing their own needs and wants, as well as to recognizing their partner's wishes coupled with more inexperience than their peers in this arena. Individuals with ASD and their parents and caregivers frequently identify this difficulty when directly asked about it. Sexuality education in a supportive format that includes the individual's family and their particular values and background will be most effective. Interventions need to be individualized with a long-range goal that matches the cognitive, social, and emotional developmental level of the person with ASD. As the prevalence of persons with ASD increases in our society, we are more than ever called to support their ability to mature into adults capable of functioning in all areas of life, including sexuality and intimacy.

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