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WINTER 2017

VOL. 9 NO. 3

Autism and Sexuality

Healthy Sexuality Education for Individuals with Autism

By Rebecca Schulman, PsyD, BCBA-D
Behavior Therapy Associates
and Peter Gerhardt, EdD
The EPIC School

Sexuality is a central component of socialization for all people and can play a major role in an individual's overall self-identify and quality of life. However, the discussion and promotion of this area of adaptive and social functioning in individuals with autism spectrum disorder (ASD) is often avoided. Historically, children, adolescents, and adults with intellectual or developmental disabilities have been viewed as asexual beings at one end of the spectrum and as sexual deviants at the opposite end (Ailey, Marks, Crisp, & Hahn, 2003). Today, a number of myths continue to exist regarding sexuality and learners with ASD, such as persons with ASD have little or no interest in sexuality; persons with ASD are hypersexual; and persons with ASD are solely heterosexual. However, individuals



with autism are sexual beings, have the same hormones and urges as their typically developing peers, and are faced with the same choices regarding sexuality as their

peers. Therefore, similar to their neurotypical peers, individuals with ASD must receive education and training pertaining to sexuality issues, beginning in infancy and

extending throughout their life span (Ailey et al., 2003).

If healthy sexuality is not promoted and supported, unhealthy and abusive forms of sexuality may result. More specifically, the failure to develop healthy sexuality through appropriate sexuality education can put individuals with ASD at risk for sexual abuse and exploitation, AIDS and other sexually transmitted diseases (STDs), unplanned and unwanted pregnancies, and misinformation (Ailey et al., 2003; McDaniels & Fleming, 2016). Further, individuals may suffer from mental disorders, such as anxiety, depression, and adjustment disorder, as well as impaired self-esteem (Evans & Conine, 1985). Additionally, Stokes, Newton, & Kaur (2007) found that individuals with ASD were more likely than their neurotypical peers to engage in inappropriate courting behaviors; to focus their attention on celebrities, strangers, colleagues, and exes; and to pursue their target for longer lengths of time (i.e., stalking).

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The Risky Road to Adult Sexuality: Know the Unanticipated Dangers

By Lynda Geller, PhD
Founder
Spectrum Services

Growing up and developing socio-sexual skills and knowledge can be difficult for any adolescent or young adult, but when the individual has Asperger Syndrome (AS), it is not only challenging, but also potentially dangerous and life altering if missteps are made. The very characteristics of AS create a vulnerability that most others do not experience and the lack of understanding that the legal system and the public have for this condition further escalates the potential danger and consequences. Most socio-sexual dangers arise from a delayed or different social maturity and generally fall into two categories: those associated with others taking advantage of their social naïveté, and others misunderstanding them and attributing motives they do not have. Unfortunately, there can be personal and financial ramifications when others take advantage of social naïveté and personal and legal ramifications when others misinterpret behaviors the individual exhibits. The purpose of this article is to forewarn young men and women and their families so that honest conversations can be had before undoable circumstances arise. Prevention of these kinds of problems



Lynda Geller, PhD

depends directly on understanding how they can occur and getting a person with AS an education about these devastating, real-world dangers.

There are many underlying skills and bases of knowledge that are important to understanding the subtle, and not so subtle, forms of communication around issues

of developing sexuality. All too often, adolescents with AS who are academically successful do not receive the additional support they need to develop the soft skills necessary for effective social communication. In addition, if sex education was presented before the young person was able to process the information because of a much younger maturity level, it is usually never revisited again and there can be a startling lack of knowledge.

Please take the time to read about each potential danger, the skills needed to avoid it, and what to do to gain those skills.

Harassment and Stalking

Harassment is doing or saying something that another person finds fear inducing or threatening. It is sexual harassment if there is any sexual undertone, such as invading personal space, displaying sexually explicit material and making indecent demands or requests for sexual contact.

Stalking is related to harassment in that it lies in the eye of the beholder as to what constitutes this behavior. If there is any unwelcome nature to the behavior, it may seem like stalking even if the young man or woman did not have that intent. The legal standard in New York State, for example, is that if the person accused of stalking knows or *should know* that his or her conduct is unwanted and fear inducing, it is stalking.

Stalking includes the following:

- pursuing
- waiting for
- showing up uninvited
- non-consensual calling, messaging, or emailing

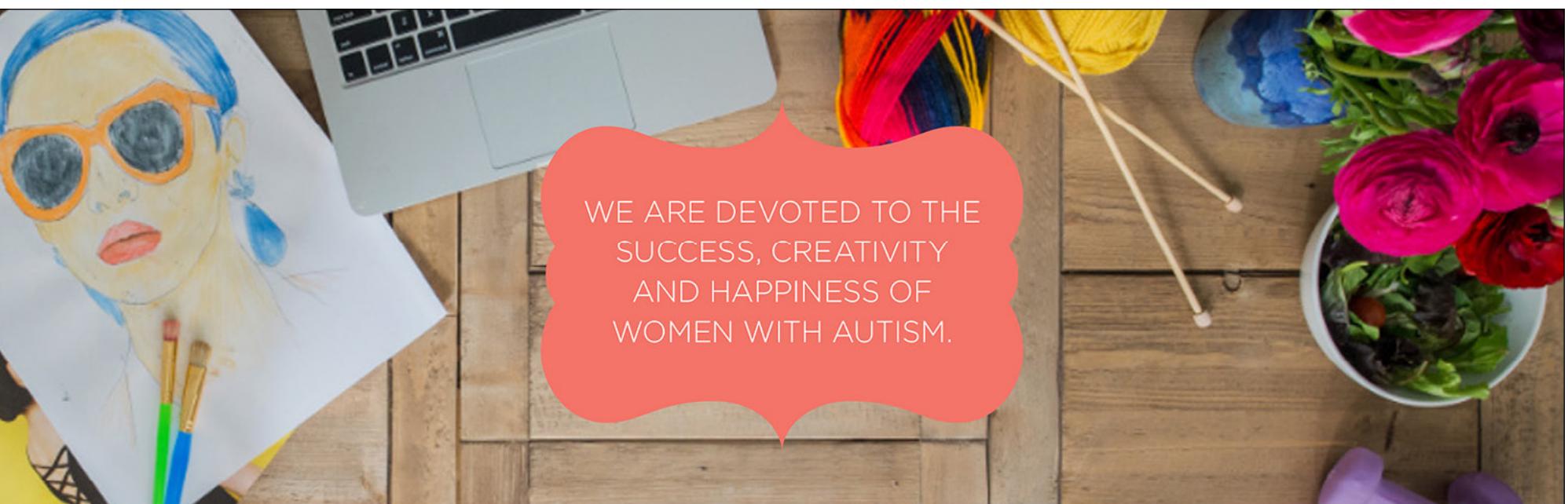
In order to understand the potential crimes of harassment and stalking, a person needs to:

- have good theory of mind skills (understanding others' perspectives)
- possess empathic understanding of others
- appear socially appropriate
- appreciate social subtlety
- understand how they appear to others
- be able to interpret codes of conduct at school or work

All of these skills can be compromised for individuals with AS. If understanding harassment and stalking were simple, there

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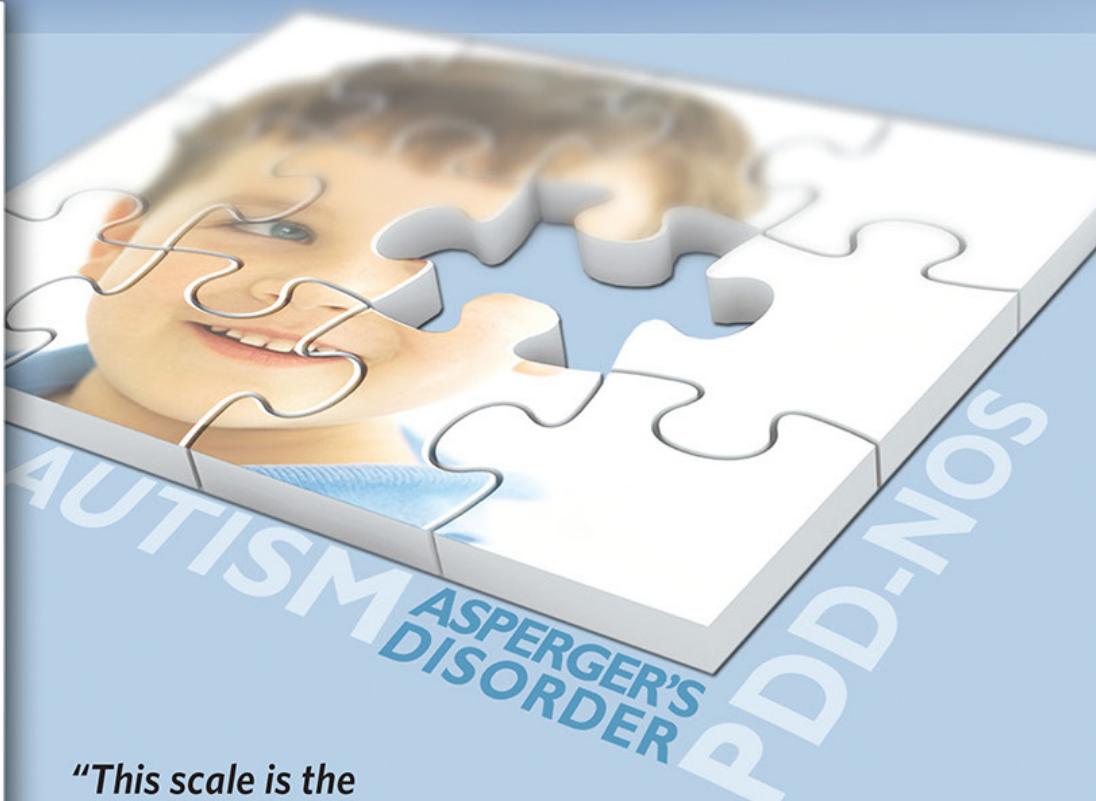
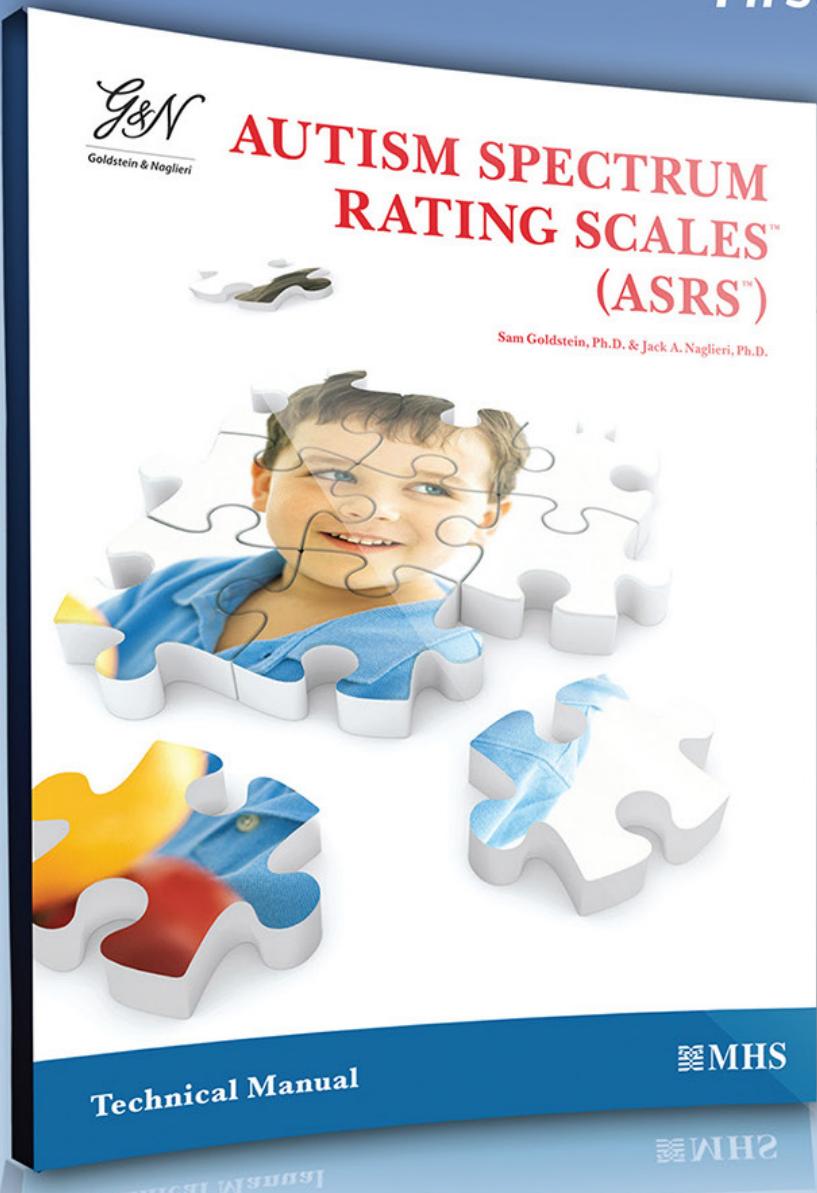
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“Let’s Talk About Sex” with Neurodiverse Couples

By Leslie A. Sickels, LCSW
Clinical Social Worker
Spectrum Services

On a monthly national conference call, a small group of clinicians who specialize in neurodiverse couples’ therapy meet for peer supervision, support and guidance. Clinicians spanning the country, from California to New York, discuss the current need for clinical expertise in providing appropriate supportive services to neurodiverse couples. Neurodiversity in couples is defined as having one or both partners on the autism spectrum (Myhill & Jekel, 2015). While there are a limited number of providers focusing their practices on couples’ services within the autism community, the clinicians presently doing this work see it as a fast growing area of need. While comprehensive work with neurodiverse couples spans all areas of the partnership, this will be a brief review of how some of the core principals of Autism Spectrum Disorder (ASD) impact intimacy and sex within the couple.

Incorporating Neurodiversity

Myhill and Jekel (2015), highlight the importance of bringing neurodiversity to the forefront of couples’ therapy so individuals can better understand their



Leslie A. Sickels, LCSW

partners’, as well as their own, neurological profiles. This is especially true when discussing intimacy and sex within the partnership. Without first acknowledging and understanding the ways in which ASD shapes these intimate interactions, a therapist is unable to provide appropriate tools to address the identified challenges in their sexual relationship. Of the hallmarks of ASD, this article will focus specifically on communication, sensory sensitivities

and past experiences as they relate to sex (American Psychiatric Association, 2013). It should be noted that there are numerous variations and additions to this list that should also be explored when discussing intimacy within a neurodiverse couple.

Communication

Addressing barriers in communication is often one of the first goals in neurodiverse couples’ therapy. However, these communication deficits may be exacerbated when a couple is moving toward intimacy. These intimate interactions, from flirting to engaging in sexual activity, are often communicated through nonverbal cues such as eye contact, body language or micro-movements. This unspoken language adds a layer of challenge for individuals who struggle with nonverbal communication (American Psychiatric Association, 2013). Once the fundamental neurological differences in communication are acknowledged in couples’ work, focus can shift to planning for alternative ways to communicate in a clear and direct manner. Some successful strategies in navigating this may include the use of “code words” to indicate boundaries or triggers, planned breaks for processing during tough interactions or more direct discussions when something does not go as planned or has been upsetting. This shift to using more direct and concrete language may be challenging, es-

pecially for a neurotypical partner, but can offset nonverbal communication mix-ups by clearly stating needs and wants during intimacy. Furthermore, having clear and direct conversations allows couples to be more explicit about consent and what is allowed and appreciated by both partners during sexual interactions.

Sensory

Neurodiverse couples often express variations in sensory experiences as both a benefit and barrier to fulfilling sexual interactions. As a key feature of ASD, sensory sensitivities can be experienced with hypersensitivities, meaning over or more, or hyposensitivities, meaning under or less. Research by Tavassoli, et. al (2014), found that adults with ASD report more “over-responsivity” to sensory stimuli than a non-ASD control group in multiple sensory domains. In neurodiverse couples work, it is critical to understand and educate couples on the ways in which a partner with ASD may be differently impacted by touching and intimate sensory experiences. There are several ways in which neurological differences in sensory sensitivities play out in neurodiverse couples and these should all be examined. Challenges can arise if one partner has a greater need for intimate contact, hugging or touching while the other

see Neurodiverse on page 28

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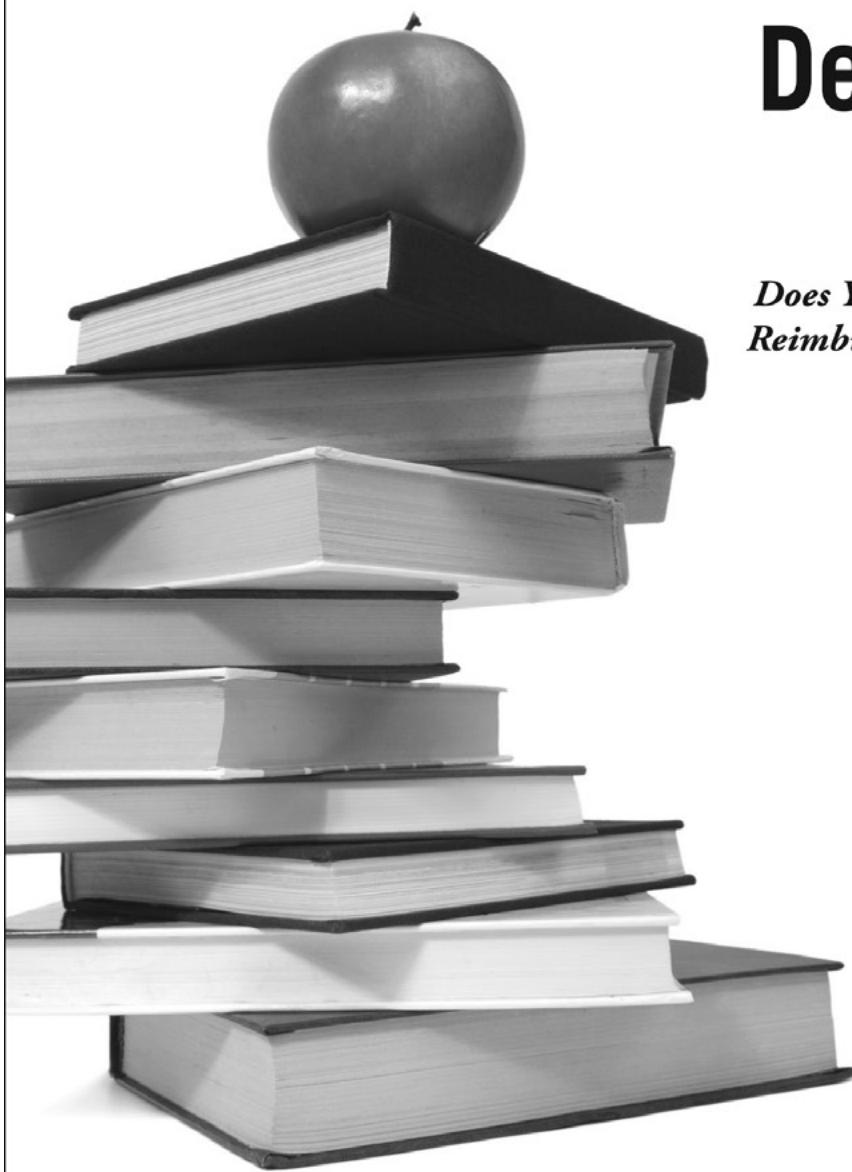
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Supporting Sexual Independence for Individuals on the Autism Spectrum

By Amy Gravino
Autism Consultant

As an individual on the autism spectrum, I have struggled with and achieved many types of independence, such as going to college, living on my own, learning how to cook, and starting my own business. While I did receive varying degrees of assistance with each of these endeavors, sexual independence was something I had to seek out and achieve on my own.

When it comes to the subject of sexuality and autism, parents and professionals alike tend to be nervous and uncomfortable. People on the autism spectrum are faced with so many other day-to-day challenges, such as problems at school or with peers, eating issues, disruptive sleep patterns, and sensory overload that talking about sex more often than not ends up on the back burner - if it gets discussed at all.

For me, growing up as an adolescent and now as an adult on the spectrum, learning how to take control of my own sexuality and having the ability to make informed decisions about sex has proved to be as valuable as any other skill I have learned, if not more so. I first began having crushes and developing an interest in boys around age 11, and my curiosity about sex heightened considerably just a few years later, at age 14. But I didn't have my first kiss until I was 17 years



Amy Gravino

old, and I had sex for the first time at 22.

A dearth of learning opportunities combined with a lack of access to information and low self-esteem that I had developed after years of bullying meant that when I did become sexually active, I was not able to fully advocate for myself. I believed that my inexperience meant that I was not allowed to do so, and I deferred to my partner in all circumstances - including assessing my own level of enjoyment. It was only as time went on and my self-confidence grew that this began to change.

As the author of the memoir *The Naughty Autie* and a national speaker on the subject of autism and sexuality, I often hear from parents about their fear, concern, bewilderment, and uncertainty over recognizing and supporting their child's sexuality. Many flat out refuse to see their young adult child as a sexual being, thinking that if they ignore it, it will simply go away. But many others realize that this is not the case and are left struggling with a lack of strategies for how to talk to their child about sexuality.

These three steps can help parents to open a conversation about sexuality with their autistic child:

Get past the “blushing cheek” phase. As I mentioned previously, this is often a difficult topic for parents to broach, but if you are embarrassed or ashamed to speak honestly about sex, your child will feel the same way. Shame is not something that typically comes naturally to individuals with autism, and introducing it in the context of sex can and will cause more harm than good.

Find ways to discuss these issues at an age- and developmentally appropriate level. You don't have to give every piece of information all at once, but waiting until your child is already at the point of wanting to be sexually active is waiting too long. Issues like physical boundaries, consent, and privacy can all be addressed at a young age.

Provide your child with information about sex. Knowledge is empowerment. Parents tend to think that if they give their child information about sex, they will want to have sex. In reality, having accurate, explicit, clear facts will allow individuals with autism to make smart, informed decisions about their sexual desires and well-being. The best way to prevent victimization among autistic people is to give us the opportunity to be empowered adults who have the ability to declare our own sexual independence.

Just as every individual on the spectrum is different, the process of becoming sexually independent is different for each person, and some strategies may be more effective than others. My own journey with sexuality is a continuing one, and though I have been heartbroken and made some questionable choices in my life, it is my mistakes that have helped me the most to grow and learn how to live in this world. Give your child a chance to experience their sexuality, love, and make mistakes, and they will be better for it.

Amy Gravino is a writer, national speaker, autism consultant, and college coach for individuals with autism. Amy is a Certified Autism Specialist and the founder of A.S.C.O.T. Coaching. For more information, please visit www.amygravino.com.

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Healthy from page 1

There is a significant need for individualized, effective instruction for persons with ASD commensurate with each individual's receptive and expressive abilities. Effective sexuality education is complicated for individuals with ASD by language and communication problems, as well as by social deficits associated with the disorder. Additionally, whereas other teens serve as a primary information source available to neurotypical teens, this is not typically the case for individuals with ASD (Volkmar & Wiesner, 2003). As a result, this population is not often taught information related to sexuality in school or by family and friends, thus leading to little, if any, appropriate skill development.

What Topics to Cover

Once it is recognized that individuals with ASD need direct training related to sexuality, it is essential to consider *what* topics should be covered and *how* this information should be taught. Three basic goals for sexuality instruction include providing accurate information, developing individual values, and teaching appropriate social relationship skills. General topics should include public versus private behavior, appropriate versus inappropriate touching, proper names of body parts, personal boundaries/personal space, masturbation/private touching, avoidance of

danger/abuse prevention, social skills and relationship building, dating skills, personal responsibility and values, etc. Specific topics will vary based on the individual's age. When working with families who are reluctant to discuss human sexuality as it pertains to their son or daughter on the spectrum, a helpful topic to start with is that of personal safety/abuse prevention. As there are very few more important areas of intervention, family resistance to addressing safety issues is unusual. Plus, once that discussion starts, the door is (ideally) open to future discussions of more uncomfortable areas of sexuality.

Schwier and Hingsburger (2000) suggest that when a child is in preschool through elementary school, sexuality training may focus on boys versus girls, public versus private behavior and locations, basic facts about body parts, introduction to puberty and one's changing body, introduction to menstrual care, and appropriate versus inappropriate touching. Once an individual is in middle school through high school and adulthood, sexuality education may include the following topics, if not already addressed: puberty and menstruation, hygiene, ejaculation and wet dreams, how to say "no," masturbation, public restroom use, attraction and sexual feelings, relationships and dating, personal responsibility and family values, love versus sex, sexual preference, laws regarding sexuality, pregnancy, safe sex, birth control, STDs, etc. It is also important to discuss different

types of relationships (e.g., friendships, romantic relationships, family relationships) and how one might act in different types of relationships.

When and How to Teach Sexuality Education

Although the topics included in sexuality education for learners with ASD may be very similar to those taught to their neurotypical peers, *how* this information is taught is likely to be quite different. Information should be delivered in a concrete, serious, calm, and supportive manner. Information should also be repeated to ensure mastery of the material. It is often helpful to break information or skills into smaller, more manageable parts (i.e., conduct a tasks analysis), and then essential to teach all steps of the task analysis in the correct order. Further, social rules about specific behaviors need to be explicitly taught (e.g., where and when it is appropriate to masturbate). Many individuals with ASD benefit from the use of behavioral skills training that includes direct instruction, role plays, immediate positive and corrective feedback, and probes for generalization in the natural environment. It is important to take advantage of "real life" to teach as well. For example, it is essential to instill boundaries of privacy and safety during daily routines, such as bath or shower time, getting dressed, family visits, etc. This will help to generalize the idea of privacy and safety within other settings. For instance, it is important that a child gets dressed in his/her private room, rather than in other public places of the house. Skills should also be monitored to make certain they are retained.

Many of the same techniques that are used to teach other skills to individuals with ASD can be used for sexuality education as well. These techniques might include picture schedules, shaping, chaining, cognitive rehearsal, personalized social stories, video-modeling, and discrete trial instruction. Instructors should consider using multiple instructional mediums. It is also essential that parents and educators think ahead and are proactive when teaching sexuality education. In order to ensure that sexuality education is most effective, adults should never wait until something inappropriate happens before teaching a specific skill. For example, training in appropriate menstrual care should start prior to the onset of a young woman's first period, just as providing information about STDs and birth control should be given before an individual has sex for the first time. Communication and consistency are also important for successful sexuality education. An individual's team (e.g., teachers, doctors, parents, therapists) should discuss strategies and progress to ensure consistency with language throughout the individual's life, which can greatly impact the generalization of skills.

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Supporting the Social-Sexual Development of People on the Autism Spectrum

By Consuelo Senior, LMSW
Assistant Coordinator of Sex Education
YAI

Sexuality refers to the total expression of who you are as a human being. Our sexuality begins in the womb and ends at death (Freud, 1986). Everyone is a sexual being, babies, children, teens, adults and the elderly. Sexuality is therefore experienced throughout the developmental lifespan. So why is social-sexual education for people on the autism spectrum and with other developmental disabilities (DD), still taboo?

The American Academy of Pediatrics states, "Sexual development is a multidimensional process, intimately linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings" (2015). This is basic to the human experience. Because of the diagnostic criteria of autism, these are areas that often are challenging for people with autism spectrum disorder (ASD). It is therefore imperative that we provide supports.

Historically we know that people with DD were segregated by sex, forcibly sterilized, seen as either asexual (no interest in sex) or hyper sexual (deviants). There were laws prohibiting marriage, and group homes and families denying privacy and sexual expression. Myths, biases, fears, ig-



Consuelo Senior, LMSW

norance, inexperience, as well as erroneous information have sadly led to the violation of the sexual rights of people with disabilities. Sexual rights are human rights and at YAI, this is the foundation from which all our training, policies and practices evolve.

We explore sexual development in its broad, complete context highlighting the social aspects. The questions posed in many groups include: "How can I get a girlfriend/boyfriend? How do I get a date? What if she says no? How do I get a girl/boy to like me? What do I say to some-

one I like?" These are social skills that are needed and YAI teaches them through its social-sexual curriculum.

Because a person's social-sexual development occurs throughout the developmental lifespan, every significant person along the way has the opportunity to have a negative or positive impact. Sexuality includes values, communication, self-image, gender, socialization, physical expression, body image and personality. If we are committed to helping the people we support to lead person-centered lives, make informed decisions and explore their dreams and wishes, then we absolutely need to actively encourage their social-sexual development.

We need to provide support to change negative messages received from peers (especially in high school), media (lack of representation), unrealistic situations, pornography and abuse.

We expect people with ASD to exhibit skills they were never taught. If we see that the skills are not there, or that the ones displayed are "maladaptive," we need to understand that it's learned behavior and that teaching is needed. Teach the skills to set the person up for success. Be proactive instead of reactive.

I was recently at a residence conducting a staff training on sexuality and values. A staff member shared her experience of supporting one of the residents as he practiced his pick-up lines! Yes, we need to teach. By teaching we are supporting.

Executive functioning and Theory of Mind are two areas where people with ASD have challenges. Executive functioning includes skills such as organizing, planning, sustaining attention, and inhibiting inappropriate responses. Theory of Mind refers to one's ability to perceive how others think and feel, and how that relates to oneself. Both of these issues can impact the behavior of people with ASD, especially their social-sexual lives.

Stephen M. Edelson of the Autism Research Institute states, "By not understanding that other people think differently than themselves, many autistic individuals may have problems relating socially and communicating to other people. That is, they may not be able to anticipate what others will say or do in various situations. In addition, they may have difficulty understanding that their peers or classmates even have thoughts and emotions, and may thus appear to be self-centered, eccentric, or uncaring." So we need to teach.

Parents

Parents are the first sex educators. I have often found that their main concerns are: fear of abuse, fear of their child being taken advantage of, and due to experiencing chronic sorrow, they do not see their child as a sexual being. They are uncomfortable

see Social-Sexual on page 28

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"Both organizations are committed to common core values around excellence, teamwork and compassion for the many families and children we provide exceptional care to," said Jeff Winter, President and Chief Executive Officer of Autism Learning Partners (ALP). Heather Grimaldi, Clinical Director and Founder of Proof Positive, added, "It was my dream to start a company that put families first and to try to help as many people as possible. I'm so proud that we were able to fulfill this and now expand on it. With joining ALP's phenomenal team, we are ecstatic to be able to grow even larger and look forward to helping more families."

AUTISM SPECTRUM NEWS DESK



Fragile X Drug Trial Gets \$11.5 Million in NIH Funding

UC Davis Mind Institute to Research Promising Therapy for Language Learning

By UC Davis Health System

The UC Davis MIND Institute and Rush University Medical Center have been awarded \$11.5 million from the National Institutes of Health to test a new therapy designed to improve language learning for children with fragile X syndrome.

Fragile X syndrome is a single-gene disorder and the most common inherited cause of intellectual disability, which can cause a range of learning disabilities and severe intellectual impairment. Fragile X syndrome is also the most commonly known single-gene cause of autism or autistic-like behaviors. Affecting one in 4,000 people worldwide, fragile X impairs a child's ability to communicate.

"There is a great need to improve cognition early in development in fragile X syndrome, and this unique study combines a targeted treatment for this disorder with intensive language intervention," said Randi Hagerman, the principal investigator for



Randi Hagerman, MD

the study at UC Davis. "The randomized, double-blind study will examine if the drug AFQ056 can enhance neural plasticity in the form of language learning in young children with fragile X syndrome."

Elizabeth Berry-Kravis, a study principal investigator and a pediatric neurologist at Rush, said the drug therapy could potentially improve language learning in young children with fragile X syndrome compared to just speech/language therapy alone.

"The drug targets a specific glutamate signaling problem in the brain of animal models with fragile X that is a direct result of the genetic defect," she said. "In animal models it improves synaptic connections and signaling between neurons, with resultant effects on learning and memory."

In the four-year study participants will either receive the drug therapy or a placebo for the initial period of about a year. Researchers hope to enroll 100 participants with fragile X syndrome between the ages of 32 months to six years.

All participants will be evaluated by speech-language therapists who will analyze and measure change in language skills in response to the intervention as well as deliver language therapy sessions to the family. Participants who receive the placebo and language therapy will be en-

rolled in the extension phase of the trial, in which all participants will be treated with the active drug.

The language therapy involves teaching parents strategies for promoting language growth in their children and delivered to parents in their homes through distance-video technology. Clinicians will support and coach parents in real time as they interact with their sons and daughters with fragile X syndrome.

In addition to determining whether the drug improves communication and learning in children with fragile X syndrome, the study will evaluate the drug's safety and determine the most effective dose.

"The study will be the first of its kind to evaluate whether a treatment aimed at improving a core defect of brain connectivity in the disease can change the ability to learn in young children with fragile X syndrome," said Berry-Kravis. "If successful this study could be a new model for development of medications that work directly

see Fragile X on page 29

Anxiety Measure for Children with Autism Found Reliable

By A.J. Drexel Autism Institute
Drexel University

A new method devised by a Drexel University professor to diagnose children on the spectrum for anxiety symptoms - which tend to be masked by symptoms of autism - was proven effective in a study published today.

"Anxiety is considered an internalizing symptom, in that it is mostly felt by the person inside their bodies and minds and is not always obvious to others," said Connor Kerns, PhD, an assistant research professor in the A.J. Drexel Autism Institute of Drexel University's Dornsife School of Public Health. "For example, a child may avoid a social situation because they are not socially motivated - a symptom of autism spectrum disorder - or because they are afraid of being socially rejected - a symptom of anxiety."

Since children with autism can have difficulties expressing themselves, it is often up to their parents to discern whether their behavior is actually a symptom of autism or of anxiety. But since those symptoms are sometimes difficult to tell apart, even for the child's parent, clear clinical guidelines may greatly improve the ability to reliably diagnose anxiety issues.

Taking that into account, Kerns developed an autism-specific variant for a pre-existing anxiety assessment tool.



Connor Kerns, PhD

Kerns' Autism Spectrum Addendum (ASA) to the Anxiety Disorders Interview Schedule – Child/Parent (ADIS-IV-C/P) adds new questions that are woven into the original interview to help determine what behaviors might be part of the child's autism and what might be related to anxiety.

With a correct diagnosis of anxiety, those children could begin crucial treatment.

"Treating anxiety is important in autism spectrum disorder because anxiety is associated with significantly more impairment for the child and their family," Kerns ex-

plained. "That can include more stress, more self-injurious behavior and depression, and more social difficulties and physical ailments."

She noted that research has shown that the majority of children with autism who received therapy for their diagnosed anxiety disorders were rated as "improved" or "very improved" afterward.

Kerns first developed the ASA method in 2014. She recently tested it in a study of 69 children with autism who had a concern about anxiety, but no prior diagnosis.

"All children interested in the study completed a comprehensive evaluation to determine if they did, in fact, demonstrate clinically significant symptoms of anxiety and autism according to the ADIS/ASA interview," Kerns said. "All ADIS/ASA interviews were video- or audio-recorded and listened to a second time by a blind assessor, who came to their own conclusions about the child's diagnosis."

Those results were also run against other measures of anxiety to check if they came to the same conclusions.

In the end, Kerns' autism-specific addition to the anxiety evaluation aligned with the blind assessors and other measures of anxiety, demonstrating its reliability as a diagnostic tool.

"These findings are extremely important to those who may wish to use the ADIS/ASA in their research or in their clinical work with youth on the spectrum," Kerns

said, "They suggest that the ADIS/ASA is a reliable tool for comprehensively assessing anxiety in children with autism that may reduce the likelihood that anxiety goes undetected and untreated, while also reducing inconsistencies in research."

Her study with this data was published in *Journal of Clinical Child and Adolescent Psychology*.

Ultimately, having a reliable method to diagnose anxiety in children with autism will play an important role in their future.

"While autism may make it difficult for you to know what to do in social situations, anxiety makes it difficult to look at your strengths and challenges in an even way," Kerns said. "This is a particularly pernicious threat, in my opinion, because it can prevent individuals from coping with and, eventually, overcoming real challenges in their lives and seeking out opportunities and experiences, such as education, social interaction and employment, that are crucial to their development."

"Put another way, when your anxiety is high, you are focusing on surviving rather than living, and this has real consequences on your mental, emotional and physical health," she added.

This article is reprinted with permission. You may view the original article, published on December 8th, 2016, at <http://drexel.edu/now/archive/2016/December/Kerns%20ASD%20ASA/>.

In Genetic Diagnosis, a Path Forward

Discovering Their Son's Genetic Diagnosis Helps One Family in Many Ways

By Emily Singer
SPARK

By the time her son Curren was 3 months old, Nerissa Ramsey knew there was something different about him. He had low muscle tone and flapped his hands. Hand-flapping is a repetitive behavior commonly seen in autism.

After consulting with a series of specialists, the Ramsey family was referred to a geneticist. The standard test for developmental delay — chromosomal microarray analysis — looked normal. So did other genetic tests the doctor ordered over the next year and half.

Curren, meanwhile, began to regress. He lost the handful of words he had begun to use at 12 months. He also stopped using the signs he had learned for “more” and “eat.”

When Curren turned two, the Ramseys decided it was time to try whole exome sequencing. This is a genetic test in which scientists decode the portion of the genome that corresponds to proteins. Exome sequencing is often used in genetic research. But it is still fairly new as a tool for clinical diagnosis.

Few families with an autism diagnosis will be referred to a clinical geneticist. Fewer still will be offered exome sequenc-



Photo by Erika Iurcovich Photography

Curren's rare genetic diagnosis causes neurodevelopmental delays and challenges, but he is a happy little boy who loves life!

ing. Curren's severe symptoms and negative results on other tests made him a good candidate.

Four months after submitting their son's DNA sample, the Ramseys finally got the answer they had been searching for. Curren had a mutation in a gene known as HIVEP2.

This gene is involved in brain development.

The condition is incredibly rare. When Curren was diagnosed, only three other children with mutations in HIVEP2 had been reported in the scientific literature. All of them had developmental delay, intellectual disability and muscle weakness.

Scientists know little about the effects of the mutation. And no treatments exist for HIVEP2 mutations. But the diagnosis was a relief to the family. Nerissa said that just knowing about three other children with the same genetic condition was helpful.

The family's geneticist was optimistic when delivering the results. She noted that all three children eventually learned to walk and talk, meaning that Curren might one day as well. “That helped a lot,” Nerissa said.

The diagnosis also gave the boy broader access to certain tests and treatment programs. “If you can put a name or reason behind what is going on with your child, it opens so many more doors,” Nerissa said.

A Growing Network

As soon as the family learned of Curren's mutation, Nerissa reached out for help. She blogged (<http://nerissaramsey.weebly.com/>) about the diagnosis and asked friends and family to share the post. She began researching the gene. She wanted to understand its biology and how the mutation worked.

In April 2016, a new paper on HIVEP2 popped up (<https://www.ncbi.nlm.nih.gov/pubmed/27003583>). It described six

see Genetic on page 29

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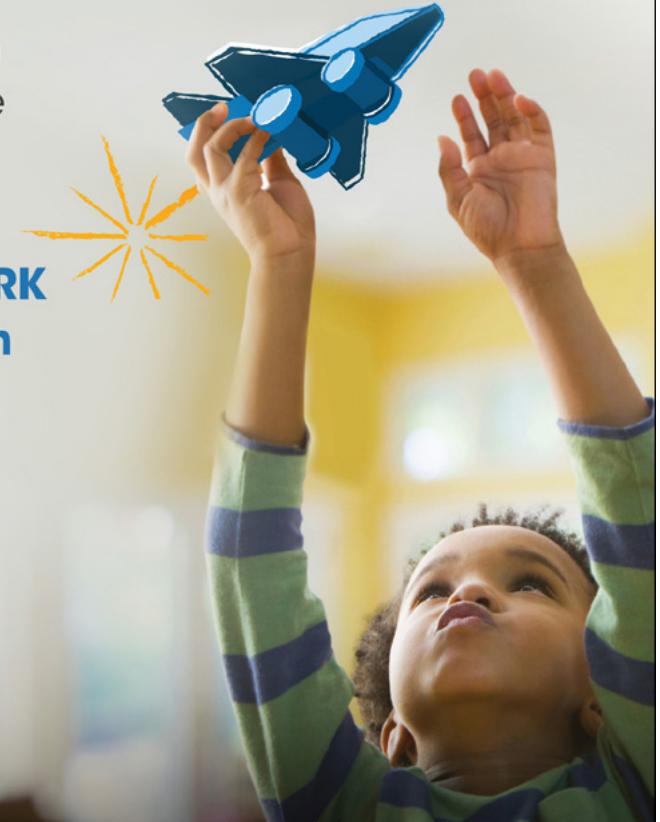


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Human Sexuality and Relationship Training for Individuals with Autism Spectrum Disorders in Applied Settings

By Amy J. Foley, MEd, BCBA, LABA,
Silva Orchanian, MEd, BCBA, LABA,
and Jill Harper, PhD, BCBA-D
Melmark New England

Development is inevitable. All children will change physically, emotionally, and intellectually. Preparation for these changes can assist in the transition from childhood to adulthood. The goals set in preparing individuals with Autism Spectrum Disorder (ASD) for these changes are no different than those set for individuals of typical development (Murphy & Elias, 2006). However, determining where to begin and what to teach individuals with ASD in the realm of sexuality must be met with great planning and consideration of cognitive, social, and communicative deficits. This article aims to outline some of the barriers clinicians and educators face when addressing the needs of their clients in the realm of sexuality and relationship training, and to provide recommendations based on the practice of our organization.

Travers and Tincanci (2010) outlined the importance of human sexuality training for individuals with ASD. The authors remind us of the susceptibility to abuse, the importance of, and right to learn about relationships, as well as facilitation of good



Amy J. Foley, MEd, BCBA, LABA

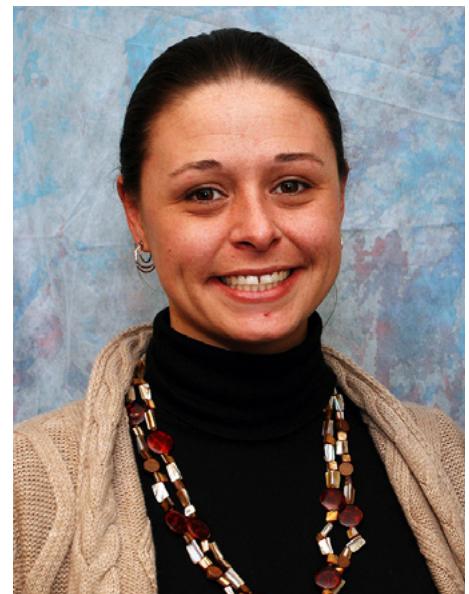
hygiene, health, and safe sexual behaviors. Despite the importance of such training for individuals with ASD, there are limited research-based resources around this topic. One likely reason for limited research in this area is the taboo nature of discussions around sexual development; it is difficult to talk about in any population, nonetheless when discussing the needs of individuals with ASD. This difficulty, in part, arises



Silva Orchanian, MEd, BCBA, LABA

from fear and anxiety of staff and parents training outcomes. For example, the fear of overgeneralization of specific skills taught. Such fear and anxiety often leads to sexuality training for persons with ASD as a reactionary rather than preventative strategy (Gerhardt, 2011).

In an attempt to address the limited research and need of our clients, our organization formed a Human Sexuality Task



Jill Harper, PhD, BCBA-D

Force to guide clinicians and educators. When developing such a task force, it is recommended to include a multidisciplinary team consisting of clinicians, educators, and other professionals in the field (e.g., social workers or psychologists), as well as parents and caregivers that meet regularly to discuss the ongoing needs of

see Training on page 33

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21st Century Sexuality Teaching Resources for Youth with Autism

By Britta Saltonstall, PhD, BCBA
Consultant
Britta Saltonstall, LLC

The twenty first century brought a long-awaited focus to sexuality and ASD. Although a paucity of data still exists regarding sexuality education and ASD (Loftin & Hartlage, 2015), most publications do provide recommendations for the *who*, *what* and *when* components of teaching about sexuality. But finding appropriate informational resources and curriculum is an identified challenge for professionals and parents (Ballan, 2012; Nichols & Blakeley-Smith, 2009; Hatton & Tector, 2010). The good news is that practitioners and advocacy groups have stepped forward over this past decade to meet that challenge and produce specially designed teaching resources.

While the effectiveness of these new sexuality education resources has not yet been a topic of empirical investigation, they do include teaching content and instructional approaches aligned with published recommendations (Koller, 2000; Loftin & Hartlage, 2015; Sullivan & Caterino, 2008; Tarnai & Wolfe, 2008; Travers & Tincani, 2010; Wolfe, Condo & Hardaway, 2009). The purpose of this article is to list and briefly describe new resources. The resources are organized into four broad content areas in sexuality education: self-care,



relationship skills, body awareness and personal safety.

Teaching Resources for Self-Care

Self-care involves the behaviors needed to care for the social and physical health of one's body. Some self-care behaviors directly promote physical health (bathing) and others hold social health as the primary focus (haircare). Self-care and hygiene routines can also provide opportunities to embed instruction about touch and safety for learners with ASD (Ballan, 2012).

1. Mary Wrobel's handbook, *Taking Care of Myself - a healthy hygiene, puberty and personal curriculum for young people with autism*, provides activity ideas and social stories about the body changes and self-care involved in growing up. Social stories and scripts have been suggested as appropriate teaching tools in context of autism and sexuality topics (Tarnai & Wolfe, 2008; Wolfe et al., 2009).
2. Pat Crissey's handbook, *Personal Hygiene, What's it got to do with*

me? is designed to teach a variety of hygiene behaviors to pre-teens and teens. These lessons are brief and each includes a post-test to assess learning.

3. Hot off the press in 2015 were the *Sexuality and Safety with Tom and Ellie* series by Kate Reynolds. The books' straightforward, yet detailed and relatable text reads similar to a social script. *Ellie Needs to Go: A book about how to use public toilets safely for girls and young women with autism and related conditions* walks a reader through the social and hygiene demands of using a public restroom. The corresponding *Tom Needs to Go: A book about how to use public toilets safely for boys and young men with autism and related conditions* tackles topics like urinals, respecting the privacy of others and hygiene. The *Sexuality and Safety with Tom and Ellie* are designed to be read by children and adolescents but can also be used by adults as teaching tools.

Teaching Resources for Relationship Skills

The concept of *socio-sexuality* education involves recognition that sexual health is strongly related to mental health and to social health. This conceptualization is

see Resources on page 25

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Summary of a Systematic Literature Review of Research on Sexuality, Sex Education and Individuals with Autism Spectrum Disorder

By Monica E. Carr, PhD
Autism Specialist and Research Fellow
University of Melbourne, Australia

Individuals diagnosed with Autism spectrum disorder (ASD), currently estimated to occur in one in every 68 births (CDC, 2014), exhibit varying degrees of intellectual ability and social delay. Like other aspects of the diagnosis, typified and challenged by heterogeneity, sexuality is a variable issue. For some, inappropriate behaviors of a sexual nature may limit their ability to engage in education, employment, or social activities. Education addressing appropriate sexual behavior is essential in order to optimise outcomes for all individuals on the autism spectrum. Parents, teachers, caregivers and individuals with ASD are all important stakeholders in the process of sex education.

A systematic review of peer-reviewed literature that explored issues related to sexuality, sex education and individuals with autism spectrum disorder was conducted by Carr & Anderson (*in review*). The authors identified 118 articles for review, however omitted 50 studies that met keyword criteria but did not adhere to the theme of their review. Carr & Anderson developed a final data set of 68 studies for their review.

Publication trend over time (1980 - Oct 2016)

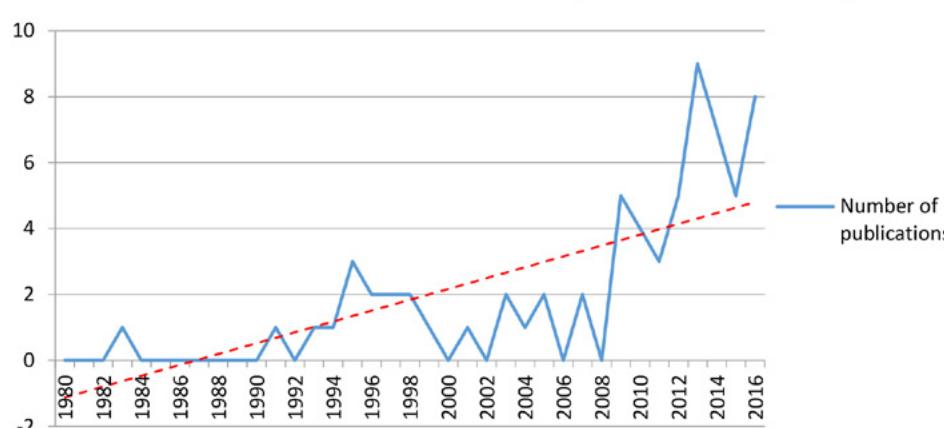


Figure 1. Publication trend of sexuality, sex education and ASD

Figure 1 illustrates the number of peer-reviewed empirical publications addressing the topic of sexuality, sex education, and ASD for the 68 articles published between 1980 and Oct, 2016 (Carr & Anderson, *in review*). While the trend line indicates a steady increase in the number of publications across the time period, the data line illustrates a recent surge in the number of empirical studies published in peer-reviewed journals since 2008.

Carr and Anderson reported that the majority of studies, 60 of 68 (88.3%), adhered to five main research themes. Their review

identified thirty-two studies (47.1%) that examined stakeholder perceptions of sexuality of individuals with ASD, the largest of the five themes. Most encouragingly, individuals themselves have been given a voice, with 14 studies reflecting self-reports of sexuality. Parent-perceptions of sexuality of their child with ASD was explored in 10 studies, and other care-giver perceptions was explored in 8 studies.

Carr and Anderson reported that the second largest theme of their review related to individuals with ASD as sex offenders. Of the nine studies (13.2%) that reported on

this issue, one was published in 2016, two in 2014, three in 2016 and three in 2009. The third and fourth largest themes each reported eight studies (11.8% respectively). A total of eight studies examined issues surrounding the vulnerability of individuals with ASD who have been victims of sexual abuse. The earliest of these studies was published in 1994, the most recent in 2015.

Another eight studies examined training programs, with four studies describing program evaluation and issues relating to capacity building within programmes, and four describing the delivery of training programmes to individuals with ASD.

In the fifth most significant theme of their review, Carr and Anderson noted three studies (4.4%) had examined the use of medications to treat inappropriate sexual behaviour (Coskun, Karakoc, Kircelli, & Mukaddes, 2009; Realmuto & Ruble, 1999; Prasher & Clarke, 1996).

In their systematic review of the literature, Carr and Anderson cite many empirical studies that may be helpful to a wide audience of stakeholders concerned with sexual education for individuals with ASD. A summary of significant studies identified in their review, addressing the themes of perceptions of sexuality, sex offences, sexual victimisation, and training follows.

see Literature on page 31



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Simons Foundation: Funder of Basic Science Research, Early Mover in Autism Science

By Autism Spectrum News

In 2003, [Simons Foundation](#) co-founders Marilyn and Jim Simons set out to understand the state of autism science. Having recently awarded a grant or two to scientists working in autism genetics, they were eager to understand how the field as a whole was faring. They convened a small gathering of autism scientists and others working in the field in New York City that summer for an in-depth discussion of what was happening in autism science, and what might be done to push progress along.

They emerged from that gathering having understood a few things. First, autism science was still in its nascent stage and not much was known about autism's cause, or causes. Second, autism research was not as well funded as other areas of science, so few top investigators were involved in the work. Third, the first autism gene had just been discovered by the French scientist Thomas Bourgeron, and it seemed that the best shot for moving the field forward quickly would be to focus on autism's genetic causes. In the wake of that meeting, they awarded three grants, two of which were in genetics, to autism scientists. They also hired expert staff to begin looking for more grantees.



Simons Foundation co-founders Jim and Marilyn Simons

So began the nation's largest private funding program for autism research. [SFARI](#) (Simons Foundation Autism Research Initiative), is now familiar to people in the autism community. It operates with a budget of approximately \$75 million per year and supports more than 250 investigators at any given time. The initiative has also developed resources for autism scientists, including large databases of genetic and be-

havioral information, a bank of brain tissue, stem cell lines, and mouse and rat models of autism. Its newest effort — [SPARK](#) — SFARI's most ambitious to date — seeks to gather 50,000 families (in which at least one member is diagnosed with autism) in an online research community.

Seen through that lens, it is not surprising that few in the autism community realize that the Simons Foundation's mission is

in fact much broader than autism science: Its mission is to advance the frontiers of research in mathematics and basic science. The foundation supports a wide and varied swath of science in the United States and abroad, ranging from mathematics to physics and theoretical computer science, to research on ocean ecology and on the origins of life, from data science to cosmology. Importantly, the foundation exists to support discovery-driven research, research undertaken in pursuit of understanding the phenomena of our world.

The Simons launched their foundation in 1994 in New York City — with no staff — and began with a few larger grants to universities and institutes of higher learning, but also smaller grants to local charitable efforts. As the foundation's endowment grew, however, they determined to hone their mission, committing to support mathematics and basic science. By 2006, they had begun to adopt their central funding model of supporting individual investigators and research organizations, largely selected through open application processes.

The foundation also has a deep investment in the cross-pollination of ideas across disciplines. Jim Simons' own experiences as a mathematician illustrated for him what great strides may be taken when

see Simons on page 28

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Sexual Misconduct on Campus: A Brief Introduction to Title IX Guidelines and Policies for Parents and Caregivers

By William S. Russell III, MA
Teacher/Counselor
New York Institute of Technology
Vocational Independence Program

A young woman waits in line with friends at the counter of a college cafeteria, discussing topics from a class they attended earlier. Nearby, a young man who also attends the class watches the young woman intently, looking for an opportunity to catch her attention. He calls her name a few times, but she either does not hear him over the bustle of cafeteria activity or she chooses not to answer. Perhaps she is made uncomfortable by the fact that he is hovering awkwardly just outside of her small group. She may recognize him from class as a student who asks questions of the instructor that are off topic, has awkward speech patterns, and shares more personal information in class discussion than one would expect. After a few minutes without receiving a response, red-faced and fists clenched tightly at his sides, the young man shouts loudly enough for the entire cafeteria to hear: "I am not invisible, you know!"

What will happen next? There are no special education teachers, school psychologists or guidance counselors present. Will the young woman recognize that she is



William S. Russell III, MA

dealing with someone who struggles with appropriate social behavior due to being on the autism spectrum, and therefore engage in affirmative behavior modification strategies? That outcome is unlikely. If the situation escalates further, it is entirely possible that campus security will be involved.

Although hypothetical, the preceding situation could easily play out at any college or university. Despite recognized challeng-

es, students on the autism spectrum may choose to pursue post-secondary education as part of their life goals (Camarena, 2009; Hart, 2010). In addition to education, many students hope for and expect romantic social experiences to be a part of their college lives, and many individuals with ASD also have these expectations.

The college environment provides individuals with ASD unique opportunities to have a wide range of social experiences including those of romantic natures. Along with these opportunities comes a responsibility to learn and practice behavior that meets the standards of college sexual and gender based policies. While attempting to make romantic connections, individuals with ASD are more likely to exhibit behaviors that fall outside of what is accepted by the mainstream in courting and may be construed as stalking or harassment (Stokes, 2007). Whereas unfortunate encounters similar to our hypothetical may occur in other environments, the situation is further complicated for those on college campuses due to specific policy guidelines for misconduct regarding sexual or gender based harassment under Title IX of the Education Act of 1972. Title IX was clarified by an April 2011 letter issued by the Department of Education's Office for Civil Rights, and further requirements were set in place by the Clery Act. Title IX prohibits discrimination

on the basis of sex, and this prohibition extends to the prevention of sexual misconduct (Know Your Rights, 2011).

Sexual misconduct can be interpreted to encompass a variety of actions, and college and university guidelines include non-exhaustive lists providing examples. Among these are references to unwanted flirtation and advances or propositions of a sexual nature (A Guide to Surviving Sexual Assault, 2016). These examples may fall under a sub category of sexual or gender-based harassment. Furthermore, Title IX does not just apply to sexual misconduct involving heterosexuals. They apply equally to individuals who do not identify as heterosexual, and research indicates that individuals with ASD do not only identify as heterosexual (Hellemans, 2007; Mendes, 2016).

Colleges are required to appoint Title IX Coordinators to ensure compliance with the law. They oversee and facilitate the investigation of complaints, including the establishment of disciplinary proceedings when necessary. Title IX places an obligation on schools to provide a safe place to learn, eliminating conduct that creates a "hostile environment" (Know Your Rights, 2011). The law recognizes that schools can respond more quickly to allegations

see Title IX on page 34

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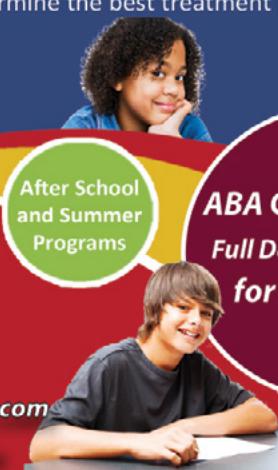
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Helping Students with Asperger's Take the Stage

By Manoli Kouremetis
Beacon Health Options

When I started teaching at a high school for students with learning differences, my first goal was to make my communication as clear as possible. I streamlined my presentations, tried to wipe out any sarcasm that could be taken literally, and crafted obviously clear assignment instructions. These tactics proved apt, but little did I know that my most effective communication would involve neither instruction nor planning.

My first semester included a section of drama. Some students arrived with film monologues memorized, but the majority of them sat huddled around the door ready to bolt as soon as class ended. When I tried to alleviate their fear of reading from a script or learning lines by asking them to improvise scenes, even those who came prepared all readied themselves to dash out of the room.

Though this repellent notion may have branded this new teacher as a villain, I proceeded. But rather than deconstruct episodes of "Whose Line Is It Anyway?" or ask teams of two to stand up and pretend to be kittens or fence posts, I stepped forward myself. Since I'd already started as a villain, I invented a character of a wannabe-meanie teaching applicant. I can't remember the name I chose, but I remember



stating something like, "I'm just like Professor Snape, but without the cape. And the potions. And the menace. And the respect." Those who have taught will recognize the silent chasm that formed between me and the students at that moment, one I'd fall right into: either I'd squandered any semblance of credibility left in my title, or I'd sneaked my way into their trust.

A New Kind of Freedom in Improvisation

It proved to be the latter, and, quite unexpectedly, that trust came most strongly from the students with Asperger's. During each class session, we all got on our feet and improvised scenes. When characters didn't work, they'd stop the scene to fix

it – and to my astonishment the performer was never seen as the problem.

As I prepared for the school year, I learned that students with Asperger's crave parameters established by rules and schedule. However, what I learned on stage was that within those parameters they allowed themselves to take risks and explore scenarios with voices and gestures they'd never tried before. As their fear of making a mistake fell away, their confidence on stage, in the classroom, and in the hallways soared. Teachers and parents and peers all noticed the new swagger in their stride. One student who'd never spoken above a whisper to any teacher became an advocate for new freshmen, and another became the lead prosecutor for that year's mock trial.

Another student gathered up his new confidence and put it toward trying out for the basketball team. He made it.

I had the great fortune of improvising with students for all five years I taught at the school. Each year, we created a sketch comedy show that we performed for their classmates. The students chose black t-shirts and jeans as their costumes, and I proudly wore that costume alongside them.

It was all luck. I asked them to do what at the time seemed impossible and ridiculous, executed teacher folly on the first day, based on a whim. It turns out there is a lot of evidence that shows how improvisation helps students with Asperger's – all of which I read after I'd started our shows. Sometimes we help others by dint of patience and grit, but sometimes we help them by accident. I'm so glad I fell into that one.

Manoli Kouremetis is a Proposal Specialist working with Beacon Health Options' Strategy and Development team to win new business and keep existing clients. Manoli has been teaching since 2000, and continues to teach night classes at a local university. He is also an active playwright whose work has been staged in an area theater. Manoli earned his BFA in Theatre from the University of Colorado at Boulder, and his MFA in Creative Writing from Old Dominion University. For more information on autism spectrum disorders, visit www.beaconhealthoptions.com/category/expertise/autism/.

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Financial Strategies for Your Child with Special Needs

By Liz Kinstlinger
New York Life
Insurance Company

Even the most well-adjusted, optimistic people struggle with being able to communicate how difficult it is to be the parent of a child with special needs. Saying that parenting a child with special needs is daunting is a profound understatement - at least it was for me. During the early years, as parents of children with special needs, we face an especially challenging day-by-day, task-oriented, emotionally and physically draining reality.

That reality is a collection of unique challenges, including navigating the diagnostic landscape; finding proper school or residential placements and developing a strong network of supporters. Even when we have moments of mastery, the underlying truth is that we cannot predict the future, and therefore parents need to put in place a structure to ensure that our children are protected - whether they are diagnosed with a special need at a young age, or they are challenged later in life.

Beyond the idea of protecting our children from the downside of not having enough long-term resources, we also have the responsibility to position them so that they can benefit from the medical advances and potentially game-changing technol-



Liz Kinstlinger

gies that could change their lives, even when we are no longer around to watch them thrive.

Let's Get Started

There are various seamless strategies parents can use in an effort to assure financial security. As a starting point, I believe that a qualified financial professional can help you determine whether your child

qualifies for government benefits, such as Supplemental Security Income (SSI) and Medicaid.¹ These programs are designed to provide funds to supplement basic necessities such as food, clothing and shelter. However, it's important to understand that if a child has more than \$2,000 in assets in his or her name, they will not qualify for these programs. So if someone leaves your child an inheritance or other monetary gift directly in their name, the government could freeze that child's benefits.

Often when I meet with parents, their first reaction is that they cannot afford to fund a trust because their day-to-day expenses are already too high. They are immediately relieved to hear that the trust can be funded by life insurance policies, which are generally a necessity anyway. These policies can be designed to accumulate cash values and generate even more protection for their child.² It is a win-win strategy.

Choosing a Trustee

In addition to choosing a guardian, determining who your child's trustee will be is a critical decision. A legal guardian is a person who is entrusted to make decisions on behalf of a child in the event that the parent is no longer able to make such decisions. The trustee is the person who will be responsible for managing the special needs trust after your death. It can be a family member, a friend, an independent profes-

sional trustee, or even a bank or a lawyer. The trustee ensures that the money in the trust is spent only on your child and only on services that you have specified or that are appropriate to your child's needs. The trustee also supervises how the money in the trust is invested. The guardian - who should not be the same person as the trustee - cannot spend any money in the trust without the trustee's approval.

Preparing a Letter of Intent

A letter of intent is an important planning tool for parents of children with special needs, including adult children, and may also be useful when planning for minor children who are not expected to face special challenges.

No one else knows your child as well as you do, and no one ever could. You are a walking encyclopedia of your child's history, experiences, habits, and wishes. If your child has special needs, the family's history adds a helpful chapter to your child's narrative, one detailing your child's unique medical, behavioral and educational requirements.

What would happen if you suddenly became unable to provide your child with the necessary supports your child needs? Without you, your child would become dependent on other caregivers who simply do

see Financial on page 29

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The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

The Music Within His Body

There's something on my mind lately; a knot I've been trying to untangle. I thought maybe we could talk about it. Stimming. You know, stimming? The way my 12-year old son Jack jumps and hops and grunts at least, oh, I don't know, fifty times a day?

Stimming is short for self-stimulation, or the repetition of certain movements, sounds, or behaviors like rocking, or hand-flapping, or head-banging, or singing A-B-C-D-E-F-G four hundred and ninety-two times in an hour.

(Jack used to do that. The singing thing. It drove me nuts.)

It's considered one of the hallmarks of autism spectrum disorder, although everyone stims occasionally. Some of us run for miles and miles a day, or we twirl our hair, or chew gum, or rub a soft cozy blanket between our fingers while we watch Netflix.

If you were to ask 7-year old Henry what it means when we say his older brother Jack has autism, he would simply say, "Oh, it's because he jumps around a lot."

And he does. He jumps around a lot. Like, a lot a lot.

His jumping is as familiar to me as my own breathing. It's the first thing I hear



Jack Cariello

in the morning before my eyes have even opened, and the last sound I hear before he finally settles into bed at night. We call it his zoomies.

He didn't always jump. When he was a toddler, his movements were more subtle, and quiet.

He would trace the same tile over and over with his pointer finger, or he'd line all of his Little People figures up in a row on the windowsill, stare at them, and then

slowly take them down, one by one, only to line them all up again.

For a while he rubbed hand soap all over the walls, and then he clicked the doors open and shut a billion times. Then we had the singing.

And now, he jumps. He puts two fingers in his mouth and gallops and leaps around the house, or the grocery store, or when we walk down the aisle to choose our pew at church.

If we're somewhere that he has to sit for a long period of time and he can't get up—like on an airplane or squashed into a seat at the movies, he'll bend over at the waist quickly one, two, three times in a row.

Last year we went to a wedding and this huge, gorgeous wedding cake was set out in the middle of the room for almost the entire reception. Jack gyrated and hopped around that thing for hours while Joe and I looked on, horrified. I just knew that at any moment, that cake was going to go crashing to the floor, but no matter how many times we drew him away, he bounced right back like a spectrum moth to the frosted flame.

"We've got to get him to stop doing this," I said to my husband Joe on the ride home.

"I know, but how?"

"I have no idea."

And now, a year later, we haven't made much progress.

See, the thing, Jack is completely unreachable when he stims. It's as if he can't hear you at all. In those few seconds of deregulation, he is lost to us. He doesn't even seem to know he's doing it.

"Jack, try to quiet your body, can you stay still?"

"Quiet how? I am. Quiet."

And yet, I refuse to believe stimming is bad for him. I think he needs it. I think it's a way for him to disappear when the lights and sounds and smells become too much for him to bear. It gives his brain a chance to recharge so it can accept and process the smell of pizza in the restaurant and the sound of falling pins in the bowling alley.

And when words fail him, it's a good way for me to take his emotional temperature; to gauge how fast his brain is racing and his heart is beating, simply by watching how much he's jumping.

I am constantly trying to understand what stimming feels like. The closest I can come to describing it is all of a sudden, it's as though he's stumbled upon an ant hill, and thousands upon thousands of ants start a steady, yet disorganized march up and down his legs and arms and tummy.

see Music on page 29



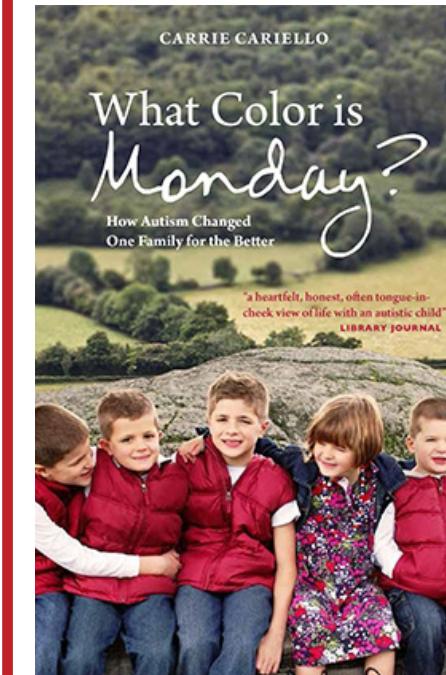
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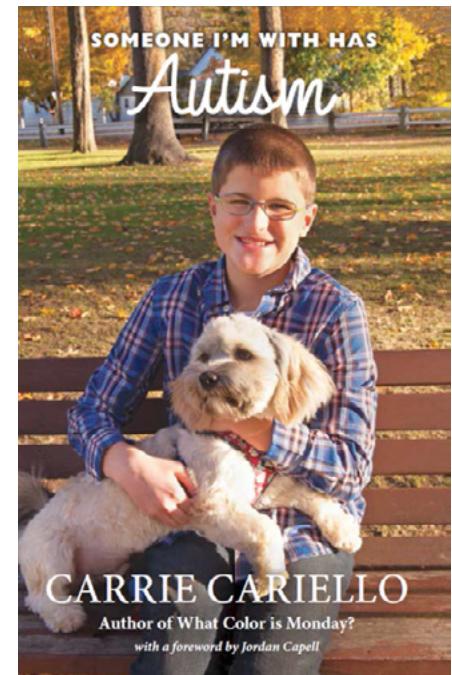
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YAI Approved as Provider for CE Credits for Licensed Social Workers

By Young Adult Institute, Inc. (YAI)

The New York State Education Department's State Board for Social Work has approved YAI as a provider of continuing education credits for licensed social workers. Licensed Master Social Workers (LMSW) and Licensed Clinical Social Workers (LCSW) in New York State can attend select YAI trainings to earn required credits.

YAI brings decades of expertise from training its workforce to providing quality support for people with intellectual and developmental disabilities (IDD). New courses will be available each quarter. Practicing LMSWs and LCSWs are required to complete 36 hours of acceptable formal continuing education during each three-year registration period.

For more information or to register, visit yai.org/training, email connie.senior@yai.org or call 212-273-6202.

Here are some upcoming winter 2017 trainings:

Strategies for Working with People with Profound Disabilities

January 19, 2017, 9:30 am - 4:30 pm
YAI, 460 W. 34th St., Manhattan
6 CE Hours - \$125

Adults needing more supports, who function at the profound range of cognition, are often perceived as primarily needing "care-taking." This training views each person as having the potential for personal growth and skill development. Learn how to provide supports by exploring, listening to understand, and teaching concretely.

Successfully Managing Social-Sexual Issues in Day and Employment Programs

January 20, 2017, 10 am - 4 pm
YAI, 460 W. 34th St., Manhattan
5 CE Hours - \$250

People with intellectual and developmental disabilities, including autism, are transitioning into the workforce. Unfortunately, many are losing or struggling

to maintain jobs due to issues of a social/sexual nature. Learn concrete and practical techniques to begin to address these issues. Attendees will participate in hands-on interactive work that will equip them to develop and run effective groups, and provide better support.

Brief Strategic Therapy

February 9 & 10, 2017, 9:30 am - 4:30 pm
YAI, 460 W. 34th St., Manhattan
12 CE Hours - \$250

This two-day training in the fundamentals of this evidence-based treatment model will incorporate psychotherapy with individuals with developmental disabilities (IDD) and their families, as well as, working with people without disabilities. The training will feature case conceptualization, designing interventions, and increasing motivation in clients to execute interventions. Case examples and role plays will be used to help participants acquire basic competency in the application of the BST model with people with a wide range of challenges and diagnoses.

Supporting End of Life Care, Grief, and Bereavement for People with IDD

Feb. 23-24, 2017, YAI's Tarrytown Day Services; or March 23-24, 2017, 9 a.m.-4:30 pm, YAI, 460 W. 34th St., Manhattan
\$250 - 14 CE Hours

This experiential two-day workshop and conference will explore the supports that are needed to assist people with IDD in understanding and participating in their end of life planning process or the loss of a loved one. In addition to an overview of the forms and processes used to assist planning end of life care, attendees will also explore religions and their rituals for death and mourning.

Young Adult Institute, Inc. (YAI) is recognized by the New York State Education Department's State Board for Social Work as an approved provider of continuing education for licensed social workers #SW-0171.

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Autism and Dating: Practical Tips for Parents

By Heidi Hillman PhD, BCBA-D
Psychology Department
Eastern Washington University



Heidi Hillman PhD, BCBA-D

ASD, with the help of their non-ASD peer, developed a "will you go to prom with me?" card. Third, we discussed appropriate times to ask a person out on a date. Fourth, the teens with ASD and the non-ASD peers role-played on asking someone out on a date. Lastly, all the students in the research group (as one large group with several adult chaperones) went on a "date" to a casual restaurant followed by going to an arcade laser tag fun spot.

What I Learned from the Research Project

The teens with ASD were sensitive about their dates needs, almost more so than the teens without ASD. They wanted to make sure their dates were comfortable, happy, and the date was well planned and organized. They could not go out on a date with only a few hours' notice. The teens with ASD were very sincere, what they said and how they acted was what they meant. With that said, they missed jokes that everyone else understood - one teen was jokingly asked when he found time to sleep when he discussed how many extracurricular activities he was involved in, and the teen responded, "I don't get it." Another example was that a gentle touch of the date's hand on their arm meant their date liked them - rather the teens with ASD actually thought their date bumped into them. Hugging, primarily touching, was a challenge due to sensory issues. At the start of the research the teens did not elaborate on talking. After several sessions of continual prompting on back and forth talking, the teens were more social and could keep a discussion going for a few minutes longer than at the start of the research project.

Six Practical Dating Tips for Teens with ASD

In no order of importance here are the top six practical tips parents can use with their teens with ASD when it comes to dating:

1. Rehearse the date ahead of time - Young adults with ASD are very anxious about

see Dating on page 24

Not as Scary as it May Sound: Getting an Early Start to Sexuality Education for Young Children with ASD

By Krista Nelson, BFA,
and Shana Nichols, PhD
ASPIRE Center for Learning
and Development

After reading the title of this article, you may have taken pause – if so, you are not alone. The idea of providing sexuality education for very young children with ASD is likely to raise questions and may generate uncomfortable feelings; this can be a challenging topic. Despite the difficult aspects of broaching this subject, however, the good news is that the majority of parents of children with ASD do teach at least some sexuality-related concepts (Holmes & Himle, 2014). This is important because the Sexuality Information and Education Council of the United States (SIECUS) recommends sexuality education for *all* children, including children with development disabilities.

So, How Young Is ‘Young’ for Teaching?

It may be surprising that experts recommend starting age-appropriate sexuality education with children as young as three (Schwier & Hingsburger, 2000) and that comprehensive guidelines are available starting at the age of five (see SIECUS). Though this may seem quite young, for



Krista Nelson, BFA

preschool and elementary aged children sexuality education provides foundational skills and knowledge related to understanding the body, touching, affection, and privacy rules.

What Impacts Parents’ Decisions About Teaching?

For children with ASD, recent research suggests that intellectual functioning,



Shana Nichols, PhD

adaptive skills, and parental romantic expectations all influence the amount of sexuality education parents provide (Holmes, Himle, & Strassberg, 2015). Many parents express concerns about safety and a desire for their child to experience meaningful relationships, however they may not be comfortable addressing such topics with their child or they lack confidence in knowing what their child understands (Nichols & Blakeley-Smith, 2009).

Why Is It Important for Parents to Teach About Sexuality and Growing up from a Young Age?

Number one, parents are the best sexuality educators for their children. Though professionals can help, parents know their child best and are their most important and trusted teachers. By providing clear, simple, and proactive instruction, parents create an environment in which it is okay to discuss these topics, and they reduce the possibility of misinformation and confusion. Other important reasons for educating early include:

- Children with ASD follow the same course of psycho-sexual development as their same-aged peers
- Youth with ASD express interest in and experience sexuality (Holmes & Himle, 2014)
- Individuals with ASD are thought to be at higher risk of sexual victimization (Sevlever, Roth, & Gillis, 2013)
- Less knowledge about sexuality is associated with greater vulnerability to abuse (Brown-Lavoie, Viecili, & Weiss, 2014).

see Early Start on page 32

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A Spectrum of Love: When Romantic Love is Not Attained

By New York Collaborates for Autism

Romantic love is a subject with which many in the autism community are preoccupied. They wonder if and how they will find love, and when they do, how they might navigate its occasionally tricky waters. Traditional, romantic relationships can often seem out of reach for a majority of people on the spectrum. Without traditional romance, how can the needs that are typically met in intimate relationships be fulfilled? What alternatives are available to people on the spectrum so that they, too, can find fulfillment?

We spoke to Dr. Mary E. Van Bourgondien, PhD, the Clinical Director of the Chapel Hill TEACCH Center at the University of North Carolina, one of the New York Collaborates for Autism (NYCA) partners in the dissemination of the Project SEARCH Collaborates for Autism’s augmented curriculum for autism-specific



employment training.

NYCA: Dr. Van Bourgondien, what needs are fulfilled by romantic relationships? And how can people on the autism spectrum meet those needs outside of traditional, romantic relationships?

Dr. Van Bourgondien: All of us, whether

or not we’re on the spectrum, have fundamental needs that are met in our romances and partnerships. Three key ones are: *physical intimacy*, *tension release* and *social connection*. When these needs are met, we are happy and fulfilled. People on the spectrum can also find happiness and fulfillment if we help them meet these needs in alternative ways, with strategies that ad-

dress their particular challenges and concrete learning styles.

NYCA: Please explain what you mean by physical intimacy in terms of people on the autism spectrum. How can they find physical intimacy?

Dr. Van Bourgondien: Physical intimacy is about much more than sex. It’s a basic human urge for touch that can include hand holding, hugging, kissing as well as sexual relations. All of this is challenging, if not impossible, for some people on the autism spectrum, but we’ve found alternatives that can be satisfying. For example, therapeutic massage as a form of physical touch works well for some people with ASD. They enjoy the deep pressure of massage, which is unlike the light touching that is intolerable to some people with ASD. When trying massage

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Support and Social Groups: An Essential and Vital Need of the Autistic Community

By Karl Wittig, PE
Advisory Board Chair
Aspies for Social Success (AFSS)

During all of the years since I was first diagnosed on the autism spectrum, support groups have been a constant part of my life in a variety of ways. Having attended, facilitated, and served in organizations that sponsored such groups, I came to appreciate their importance to those on the spectrum and to the autistic community as a whole.

The first autism support groups were exclusively for parents and caregivers of individuals, mainly children, on the autism spectrum who were in what is today considered the most severely impaired population. As the definition of autism was expanded to include a wider range of impairments, support groups for those on the spectrum, particularly adults, began to appear. These were typically facilitated by parents and family members of autistics who were sympathetic to and had direct experience with their challenges. Other groups were run by professionals (psychologists, social workers, speech-language pathologists, etc.) who had expert knowledge of autism and were usually paid for their services. More recently, however, peer-run groups



Karl Wittig, PE

facilitated by people actually on the spectrum have also appeared. The challenges of living with autism are best understood by those who have actually done so their entire lives, making them especially qualified to lead such groups. Also, as these groups expand in size they form a “critical mass” of people whose minds work in a similar manner and are more likely to encounter

the same difficulties in various aspects of their lives. This in turn can lead to the creation of communities for individuals who otherwise have none to speak of.

When I was first diagnosed with Asperger Syndrome in August of 2000 at the age of 44, the first thing I did after receiving the diagnosis was to seek out a local support group in New York that I had found through an online search (the means by which I initially self-diagnosed). Upon arriving at my first meeting, I found myself surrounded by others to whom I immediately noticed uncanny similarities; these included atypical speech patterns, eye contact, mannerisms, and other behaviors. The experience was in many ways similar to that described by members of various racial and ethnic groups when they first visit their ancestral homelands and find a place dominated by people much like themselves. As I continued to attend this group, I found that, in every meeting, at least one thing (sometimes many) would be discussed that deeply resonated with my own life experiences; these ranged from unusual personal occurrences, events, and interests to serious life challenges that I had in common with the person describing them.

Although this group was first created and run by concerned family members of young people on the spectrum, the suggestion was eventually made that meetings

should be facilitated by the Aspies who attended them. In this group, along with (independently) a few others throughout the U.S. (and possibly elsewhere), the notion of peer-run Aspie support was born. As more people were diagnosed, or suspected that they might be on the autism spectrum because of expanding media coverage, meeting attendance increased steadily. There was at least one support meeting every month, and each would center on a discussion topic of interest to adults living with autism. The best-attended were the ones dealing with dating and relationships as well as those concerning employment issues; other topics included disclosure and specialized interests, along with a wide variety of subjects. Also, when someone came to a meeting for the first time, they were given the opportunity to share about themselves and asked to describe their circumstances in regard to living situation (independent or otherwise), employment and occupation, and relationships.

In 2003, a proposal was made to create a network of Aspie support groups throughout the U.S., and even abroad, of the kind that the New York group had evolved into. Thus was born the Global and Regional Asperger Syndrome Partnership (GRASP – www.grasp.org), whose founding I had

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social interactions and how to interact, which can lead to more anxiety. Caregivers are encouraged to rehearse dating behaviors before each date (e.g., how to keep conversations going, how to act) in addition to reassuring the teen the date will go well. A great example is a mom of a teen who was in our research group conducted a practice run with her son before his prom date - driving to the date's house, driving to the restaurant, driving to the school where the dance was being held, and eventually back to the date's house and home - alleviating some of his anxiety.

2. Practice conversation skills - Parents can encourage back and forth talking by having their teen call family or friends on the phone and practicing carrying on a conversation. Another way is having the teen get involved in a hobby or interest group where there are opportunities for making acquaintances. The more teens practice carrying on conversations, the better they will be.

3. Plan ahead and practice flexibility - Parents are encouraged to allow their teens to specifically plan out dates, all the while asking their teens questions such as, “What if this does not work? Then what could you do?” Essentially, this is teaching the teens to have a plan B if plan A fails. I learned from the research study that if allowed, the teens with ASD would perseverate on the details of the date. With respect to the date, the focusing on the details made for a better outing for both the teens and their dates. However, focusing on the details lead to more anxiety for the teens. Flexibility is an

important social behavior when it comes to dating. How many times have you gone out on a date and everything went as planned? One way to teach flexibility is to go on an outing and make an unplanned detour, and ask the teen how to handle the situation. For most of the teens in the research project, the mere thought of a detour would increase their anxiety. Hence, we taught that anxiety is a normal feeling that all people feel; it means you are out of your comfort zone. We asked them, “How can you get back into your comfort zone?” For the four teens in the research study, they found comfort knowing they could call their parents if they found themselves in anxiety provoking situations. The more the teens were put out of their comfort zone in practice, the better they reacted when outside of their comfort zone during a date.

4. Focus on others rather than just on oneself - Since young adults with ASD have a tendency to focus on themselves, teaching how to focus on others is a must. An example was a dad of a teen in our research group who taught his son to bring enough snacks for the four other family members when he got a snack. Rather than teaching his son to ask if others wanted a snack, the dad taught his son to just bring back snacks. According to the dad, at prom when his son went to get a soda his son automatically brought back one for his date. We can see how bringing back just any drink could backfire if the date did not like the drink, but in the prom situation the date was happy with the drink selection.

5. Discuss rejection and emotions - In addition to teaching teens how to focus on oth-

ers, parents are encouraged to also teach that others may have different views and emotions of situations. For example, one of the teens in the research group (we will call him David) asked a girl out to prom and she said no, which sent David into a depressed state for the rest of the day. When I asked David what happened, he said the girl said no because she did not like him. Was that true? I did not think so since David was an extremely likeable person. However, David believed it to be true. We talked about whether David could control what the girl said or did, whether it made him a better or lesser person. The girl had her own reasons for saying no to David and they may have been different from David’s view on why she said no. Rejection is a hard, yet valuable, lesson in how two people can have different viewpoints of one situation. On a positive side, a week later David asked out another girl to prom and she said yes and was excited about going to prom with him.

6. Practice, practice, and more practice on social skills - Unless the social skills are reinforced in daily life, across all situations, they will not maintain. Parent involvement is crucial to social skill development because no one else interacts with teens in varied social settings as much as parents do. Social behaviors we take for granted must be practiced over and over for those on the autism spectrum. The teens in the research project practiced a social behavior an average of five hours before they could perform the behavior automatically (e.g., learning that holding hands is a sign of affection or engaging in small talk with another person). It’s easy to assume teens know certain unwritten rules, but in reality

teens with ASD often need the skill to be explicitly discussed and taught step by step.

When it comes to dating, it is not just the teens that get anxious about dating; parents also become nervous. What parent does not get a twinge of anxiety thinking about their teen going on a date? As intimidating as dating can be for anyone, I encourage parents of teens on the autism spectrum to support their children’s desires in the area of dating. Many teens on the autism spectrum want to date and be in romantic relationships. Learning about dating and romantic relationships is an ongoing process, and one that can be a positive experience for both teens and parents when framed as something that can be a positive experience.

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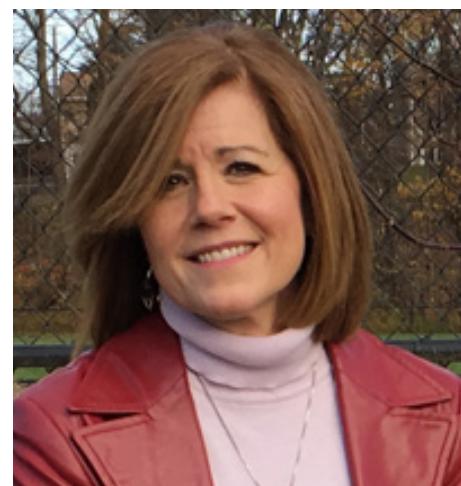
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Autism, Sexuality, and Education

By Laura Albee, MA, BCBA,
Stephen Monroe Tomczak, PhD, LMSW,
Esther Howe, DSW/PhD, LCSW,
and Julie Piepenbring, PhD, LCSW
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Practitioners often construct their programs of research around their clinical practice. Indeed, this is the case with this inquiry. Several years ago, Albee and Piepenbring had the opportunity to work with K, a 19-year-old Caucasian male with a complicated, and well-documented neuropsychiatric history including Autism Spectrum Disorder (ASD). With the onset of puberty, K began to display a pattern of escalating maladaptive behaviors which included inappropriate sexualized behaviors, stealing, agitation, and escalating noncompliance. His poor self-regulation led to compulsive and addictive sexual-seeking gratification, through a wide range of inappropriate behaviors described as touching girls, masturbation in public settings, and stealing cell phones and credit cards to access erotic materials. K had received services at a residential treatment facility that specializes in working with youth with a history of high risk behaviors; specifically sexually problematic behaviors. In working with K, he made stunning gains, successfully participating in a work study program and attending social functions with his peers. Still, his sexuality and his



Laura Albee, MA, BCBA

need to achieve gratification continued to be an obstacle to his wellness. He was unable to access his electronics without direct supervision, and was so intent on accessing pornography, that on a trip to the public library with his peers, he used a library computer to access inappropriate adult content, and openly masturbated. This clinical situation raised many questions about how to best treat sexually problematic behaviors among ASD adolescents.

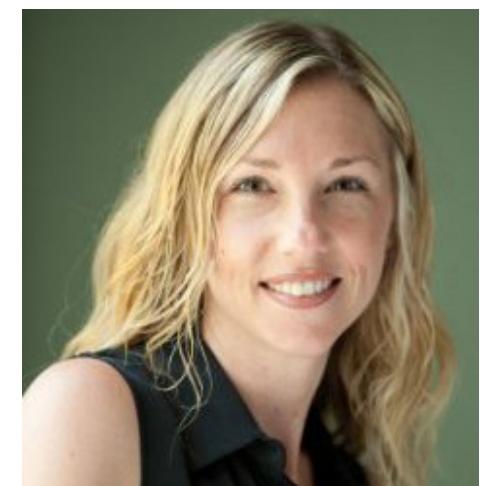
**Psychosocial Problem:
Sexually Problematic Behaviors**

More and more clinicians are encour-



Stephen M. Tomczak, PhD, LMSW

tering individuals with ASD in clinical and educational settings. Their unique profiles, composed of social, cognitive, and communication differences, are augmented by a deep delay in their ability to process social information (Ray, Marks, & Bray-Garretson, 2004; Henault; 2006). Their lack of self-esteem, coupled with their desire for acceptance and belongingness, leave them susceptible to social rejection. From a clinical perspective, the convergence of this neurobiological impairment with the social confusion that accompanies adolescence, provides a unique challenge for untangling the relative contributions of each factor, and for develop-



Julie Piepenbring, PhD, LCSW

ing treatment interventions that are effective (Ray et al., 2004).

Autism and Sexuality

Currently, there is limited research that explores the impact of sexuality education and high functioning adolescents with ASD. Most literature pertaining to sexuality applies to the typically developing adolescent, or those affected by an intellectual disability. Although no one instructional methodology has proven to be best, 50 years of clinical research has

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instruction about social behaviors and relationship interactions. These include skill-sets such as discriminating between types of relationships (friends versus coworkers), appropriate behavior for relationships (flirting), safety in relationships (cell phone etiquette), and contexts influencing relationships (private versus public locations). The following resources focus on teaching social behaviors and relationships.

1. *Teaching and Learning Scotland* produced a free, downloadable pdf entitled *Relationships, Sexual Health and Parenthood Resource for Young People with Autism Spectrum Disorder*. It offers lessons about friendship, appropriate behavior in relationships, reproductive health and sexual intimacy.
2. Davida Hartman's book *Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Professional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Responding to Inappropriate Behaviour* has more than just the charm of a detailed title. This resource is unique in that it provides a curriculum based assessment that allows a professional to document, teach and track a learner's sexual knowledge in key areas.
3. *Mike's Crush: Understanding High School Relationships for Youth with Autism and Learning Disabilities* is

a curriculum with lessons and DVD instruction intended for adolescent to young adult viewers. There is also an available *Mike's Crush for Families* which includes the DVDs and a related booklet. For a review of *Mike's Crush* see Mitelman & Von Kohorn (2012).

4. Another resource designed for high school and beyond is *Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/ Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges* by Catherine Davies and Melissa Dubie.

Teaching Resources for Body Awareness

Body awareness includes knowledge about one's body and body parts, knowledge about the changes that occur in the body and the corresponding behaviors associated with sexual maturation of the human body. The following resources address the knowledge and behaviors needed for body awareness.

1. *Charting the Course: A Family Toolkit to Help Youth with Autism Navigate Sexuality and Relationships* is a comprehensive curriculum manual designed for parents and caregivers of growing youth with autism. It includes a number of scripted activities alongside tips and information. *Charting the Course* provides guidance on the potentially uncomfortable realities of sexual maturation such as making

plans for erections at school or dealing with stained underwear during menstruation. A related online game called *Boardwalk Adventure* is included in the purchase of *Charting the Course*. Although this resource is intended for parents, it is also a valuable addition to any practitioner library.

2. Another resource for parents is *ATN/AIR-P Puberty and Adolescence Resource: A Guide for Parents*, a recent addition to the library of free toolkits available through Autism Speaks Inc.

3. Two resources for puberty and body changes by Davida Hartman are *The Growing Up Book for Boys: What Boys on the Autism Spectrum Need to Know!* and *The Growing Up Guide for Girls: What Girls on the Autism Spectrum Need to Know!* These two books are designed to be read by children and adolescents but can also be used as adult teaching tools.

4. The *Sexuality and Safety with Tom and Ellie* series by Kate Reynolds includes books about body awareness and puberty: *What's Happening to Ellie? A book about puberty for girls and young women with autism and related conditions* and *What's Happening to Tom? A book about puberty for boys and young men with autism and related conditions*.

5. Body awareness involves sexual self-awareness. Sexual self-aware-

ness includes touch and stimulation. Both are addressed by Kate Reynolds and illustrator Jonathon Powell in the last of the three Tom and Ellie books. *Things Tom Likes: A book about sexuality and masturbation for boys and young men with autism and related conditions* and *Things Ellie Likes: A book about sexuality and masturbation for girls and young women with autism* take a pro-active, instructive approach to often ignored topics.

Teaching Resources for Personal Safety

Personal safety includes sexual safety. Although the data on incidence and risk of maltreatment vary, it is generally accepted that individuals with ASD are vulnerable to sexual abuse (Brown-Lavoie, Viecili & Weiss, 2014; Edelson, 2010). The following two resources focus specifically on guidance for personal safety.

1. *Life Journey through Autism: A Guide to Safety* produced by OAR (Organization for Autism Research)
2. For this crucial topic I will share one resource that is not specifically designed for ASD. Frieda Briggs' *Developing Personal Safety Skills in Children with Disabilities* is a rare resource for individuals with special needs. It provides information, guidance and activity suggestions for teaching children through young adults.

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would not be so many trainings about it at universities and workplaces. However, the consequences for exhibiting these behaviors can include suspension or expulsion, being fired, and being arrested.

The Internet

Individuals who struggle socially may be particularly vulnerable to many dangers on the Internet. They may gravitate toward Internet communication because it allows them more time to process conversation than live speaking does. They may feel lonesome and search for company online, and they may be curious about sexuality and seek information there.

Anyone may be susceptible to unscrupulous predators on the Internet, but individuals who are socially unsophisticated, as many with AS are, are particularly vulnerable.

Dangers to consider include:

- people who pretend to be in love as a ruse to extract money
- supposed dating sites which are really the entrée into the world of pornography
- gambling sites that seem to be too good to be true
- requests to post personal information or compromising pictures
- sexual meet-ups which may be police stings, ambushes, or introductions into drug cultures.

Generally, whenever sexuality is an element, judgment can be compromised more easily.

In addition to various kinds of victimization, there are also unanticipated risks. Underage teenagers inhabit Internet sites and present particular dangers. Their motives are many, but the consequences can be devastating. Many claim to be of age and lure the inexperienced to a sexual meet-up where all sorts of personal and legal difficulties may result. Whether a troubled adolescent or law enforcement professional communicates with a young man or woman of legal age, meeting for a purpose of a planned sexual encounter can result in arrest.

Pornography

Of all Internet perils, viewing pornography may be the most dangerous. While viewing adult pornography is perfectly legal, the methods of obtaining pornographic images may quickly lead someone to also receive child pornography. Arrests for child pornography have increased by 2,500% in the past ten years! The primary spread of both viewing and being arrested stems from the use of file-to-file sharing in concert with law enforcement's growing sophistication in finding such use. Punishments have also increased in severity as the public becomes increasingly alarmed about dangerous men and women in their neighborhoods as the sex crime registries explode in numbers in every state. **The aggressive prosecution for child pornography via Internet is the prime reason for this explosion.**

There are various explanations as to why someone with Asperger Syndrome may come in contact with such material. They may not even be looking for pornography at first, but may have been Internet crawling on various topics. Pornography does pop up in unexpected places, which starts a dangerous pathway for the unsophisticated. Some are seeking sexual information they never internalized during adolescent years when they were either unready to hear it or were presented with only the sketchy information schools are willing to provide. Many people learn about sex through a peer group, but those with AS often do not have such a group and may be friends only with other socially inexperienced individuals. As their social age generally lags significantly behind actual age during adolescence, dating experience probably did not occur in high school. Seeking sexual information privately on the Internet is entirely understandable if you have nowhere to turn when physical maturity develops and hormones increase. Unfortunately, pornography is hardly an appropriate sexual education (although increasing numbers of adolescents utilize it as such). In addition to gaining a very unrealistic impression of adult sexuality, it is opening the rabbit hole to a very dangerous Internet world. Many young men with AS report that they were looking at legal adult pornography when child or young teenage images popped up. Once it is seen, the illegality may not register as curiosity increases.

Why are individuals with AS more vulnerable than others to child pornography? It certainly is not that they are more sexually deviant or more likely to cause harm to children. The Asperger community has been correct in rejecting that their members should be viewed this way. However, they may have more vulnerability to it than most. There are various reasons for this, including:

- They may feel rejected by age-mates, lonely and isolated and retreat to their rooms and their computers.
- They may perceive a similarity in social age between themselves and the victims.
- They may have difficulty putting themselves in the victim's perspective.
- They may have believed that the victim was a paid actress or actor or was of legal age.
- They may simply not understand that it was illegal to view something so easily obtainable that clearly already existed.
- They may have a poor ability to imagine potential consequences, and may keep looking rather than close down the site and the computer.
- The moral and legal issues may never have been discussed and they are too abstract to really understand.

Parents often think that a son with no expression of sexual interest does not yet need to be exposed to such deviant thoughts. They also may have little understanding of the current Internet sophistica-

tion and the concept of file-to-file sharing, the main road for obtaining pornography in general. Thus their sons may not have received appropriate sexual information at home and may not have been schooled about rules for sexual or other Internet use. Once someone enters the world of file sharing, law enforcement can easily find them and the proof for prosecution is right on their own computers.

The seriousness of such an arrest for child pornography viewing cannot be overstated. Federal prosecution carries a five-year minimum jail sentence and listing as a Sexual Offender for decades or life. Punishments are often meted out based on numbers of images, and videos have thousands. In addition, jail is often an especially dangerous place for those with AS. Later, the chances for living an independent life are virtually upended as convicted sex offenders are limited to where they can live and if they will ever work, as employers must be informed. In addition, it is not uncommon to forbid computer and smart phone use for years, making normal life almost impossible. Probation may require mandated sex therapy, often in groups with more active offenders. Participation in such groups can be traumatic for individuals with AS and creates its own problems when they are viewed as uncooperative.

Individuals with AS are often easy marks for law enforcement. They may be persuaded to waive the right to an attorney and can be manipulated into confession. Attorneys who specialize in sex offender cases generally have no idea what AS is and consider it a given that there is no hope once someone is arrested. It is critical that prosecutors understand the contribution AS has made and be persuaded to show some understanding. Equally critical is to prevent this crime from happening in the first place through family education and effective intervention for those with AS.

Appropriate Sexual Education

Appropriate sexual education is vital for all maturing young adults and equally critical is an understanding of the social and cultural context of sexuality. A characteristic of AS is social immaturity or difference, so the typical concurrent development of social maturity and sexual understanding often does not occur. Yet as time marches by, legal majority and opportunities for greater freedom occur whether the family and individual are ready or not. To be prepared for this, education and intervention in both realms of social development and sexuality are necessary. Early on in young adolescence the family needs to identify how this intertwined learning is going to occur. In some cases parents may be able to fulfill some of this role, but finding an informed therapist or trusted adult outside of the family, with a clear understanding of AS, may be more effective as the young person matures. Communication and social skills curricula exist that can help young people develop socially, especially if utilized in a group format. Development of a set of rules for understanding and handling the risks of entering new cultures (college, work life, apartment living, internet use) can help the young person have default rules for a wide variety of typical risks.

Of particular importance, in light of the dangers described above, it is advisable to:

- Have rules for Internet safety.
- Discuss with the school district how they are handling sex education in general, and in particular for your son or daughter, making sure it is being presented in a way and at a time it can be internalized.
- Go over scenarios so that rules can be developed and problem solving can be practiced.
- Be an activist. Convince your school district, counseling center, community agency to do something.
- Get together with other parents and ask a therapist to start a group.
- Be creative in finding someone to help who the individual will listen to.
- Go over together definitions of harassment and stalking as they are written in codes of conduct of colleges and workplaces. They are often written in legal-ese or abstract language that a person with AS may not fully understand.
- Identify therapeutic resources, including those on the Internet, regarding:
 1. Sex education at the appropriate time and level: *100 Questions You'd Never Ask Your Parents: Straight Answers to Teens' Questions About Sex, Sexuality, and Health*, by Henderson & Armstrong; *Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome*, by Sarah Attwood
 2. There is a blog by an adult with Asperger syndrome entitled 9 Things You Must Include in Sex Education for Individuals with ASD at: <http://aspergersissues.tumblr.com/post/51326015960/9-things-you-must-include-in-sex-education-for>
 3. Social thinking curricula: www.social-thinking.com
 4. Problem solving curricula: e.g., *Critical Thinking*, by Gerard Johnson)
 5. Interpersonal Effectiveness training: Dialectical Behavior Training books and courses
 6. Interpersonal Communication training: *Interpersonal Communication: Everyday Encounters*, by Julia T. Wood or any of a number of such texts or take a college course with Communications 101 type of content

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What to teach and *how* to teach this information should be individualized as much as possible. It is essential to identify what the child knows when determining where to start sexuality education. For example, one would want to know if the child has a good understanding of where each of his/her body parts are before starting to talk about what constitutes an "okay touch" versus what is considered a "not okay touch." Another common example is when trying to teach the concept of public versus private. It is important to make sure the child understands the meaning of these words, public and private, before starting to use them in one's teachings. Further, an understanding of a child's expressive and receptive communication is essential in guiding instruction. Many times, children have stronger receptive language, meaning that they understand and comprehend what one is trying to convey, yet are not able to express his/her understanding to others. Of course this is not the case for all learners with ASD though. Additionally, it is helpful to consider what strategies have been the most successful previously to teach other skills and then use those strategies as a starting point (e.g., pictures, conversation, play, etc.).

It is also important for the instructor, whether a parent or professional, to consid-



Rebecca Schulman, PsyD, BCBA-D

er how he/she feels about each of the topics surrounding healthy sexuality. For example, some adults have uncomfortable feelings when saying certain words or phrases. Additionally, many adults may not have had these types of conversations with their own parents, and thus, may struggle with what to say or how to say it. Each family should also consider their own values when exploring these topics with a child and help the child develop his/her own values as they grow up.



Peter Gerhardt, EdD

When taught proactively and effectively, sexuality education allows individuals with ASD to be safer, more independent, and more integrated into their own communities. Together, this results in a more positive quality of life for this population.

For more information contact Dr. Schulman at rschulman@behaviortherapyassociates.com or Dr. Gerhardt at PGerhardt@epicschool.org.

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for the first time, we recommend that therapists start with a social story or with pictures showing what is going to happen with which parts of the body. It helps to have a clear beginning and end. As long as it's presented as a predictable activity, massage can be a soothing form of physical touch.

We encourage families to educate their children about sex as well as appropriate and safe behaviors. How sex education is addressed depends on the family's values. With ASD learners, it's important to be concrete and use explicit vocabulary, not the euphemistic language that we tend to use when talking about sex. Try to explain when and where certain behaviors are okay or not okay. For example, when might a handshake be preferred to a hug, or a tap on the shoulder be better than a hand on the thigh when seeking someone's attention. Also, try to teach the concept of privacy, using visual aids such as picture books, symbols, and schedules to reinforce lessons. With clear parameters, people on the spectrum can meet their basic need for intimate touch in healthy, appropriate ways.

NYCA: What activities would you suggest for tension release when intimate relations are not possible?

Dr. Van Bourgondien: Regular exercise and relaxation activities are healthy substitutes. Aerobic exercise, in particular, is highly effective and has been proven to reduce aggression, self-harming and self-stimulating behaviors among people on the spectrum. Activities such as running, swimming, dancing, biking, walking, or hiking can be built into a regular schedule and encouraged as a lifelong practice. Yoga, too, has been used and appears to be an effective relaxation technique for people on the spectrum as young as three years old. The key is to tailor the activity to the individual's interests and age, and to develop structured methods for implementation. For example, we might preview an activity such as running by describing clear beginning, middle and end points, and by using a counting system for laps. Motivators are helpful, too, as long as we don't always use food.

NYCA: And finally, an important key to happiness is to enjoy close, interpersonal connections. Without traditional romantic options, what are alternative social strategies for people on the autism spectrum?

Dr. Van Bourgondien: People on the spectrum may develop connections with colleagues or acquaintances whom they meet when they're encouraged to participate in volunteer activities, sports, or special clubs organized around movie watching,

computer games, hiking or eating dinner together weekly. Attending such activities helps them to foster predictable connections, so that a swim or dinner buddy whom they see on a regular basis can become an enriching presence in their lives. It's important also to recognize that young people with ASD, just like their typically developing peers, need to form connections outside of the family and get out in society. For them, as for us, one relationship does not necessarily satisfy all of their physical, emotional and social needs. They, too, become bored and require variety in their relationships and activities.

NYCA: Thank you. For so many on the spectrum, it will be encouraging to know that fulfillment and happiness through activities and relationships are real possibilities.

Dr. Van Bourgondien: Yes, with creativity and attention to the individual's interests, and as long as each effort is undertaken in predictable, scheduled ways. Breaking routine, trying new activities or meeting new people can be challenging for people on the spectrum, so we recommend that families consider making a rule that new activities should be tried at least three times before saying no, or introducing new activities in stages and increasing exposure over time. With a thoughtful, concrete approach, people on the spectrum can certainly live lives with enriched and fulfilling relationships.

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New York Collaborates for Autism (NYCA) is a non-profit organization founded in 2003 dedicated to addressing the needs of individuals and families who are living with autism spectrum disorder (ASD). For more information, visit <http://nyc4a.org/>.

Neurodiverse from page 6

partner has a lesser need for physical contact or may struggle with it altogether. In regards to sexual activity, hypersensitivities may heighten sexual enjoyment for a partner with ASD, while simultaneously leaving the partner with more typical sensory experiences, or one with hyposensitivities, feeling sexually unsatisfied. An example of this in clinical practice was seen with a couple in which the partner with ASD experienced hyposensitivities, which caused a lack of awareness and understanding of the need to use different parts of his hand (ie. front versus back) and alter the pressure of his touch, when stimulating his partner's body. This caused significant distress for the neurotypical partner who was frustrated by these interactions because she did not understand how her husband's sensory experiences led to touching in a way that was more in line with his own experience of sensation versus her sensory needs. By educating neurodiverse couples on the ways in which sensory input is different for individuals with ASD, couples are able to identify how they each experience sensations and what they need from their partner to feel gratified during sex.

Experiences

Lastly, an important lens to use when working with neurodiverse couples is their past experiences in both social and intimate relationships. While many individuals with ASD have a significant history of dating and sex, many have lesser or more limited experiences than their neurotypical counterparts. As an important note, while pubertal physical and hormonal development are the same for adolescents not on the spectrum, individuals with ASD often experience a delay in developing intimate relationships. This may stem from challenges in relationship building, disinterest in dating during adolescence due to other interests or goals, lack of sex education and so on (Aston & Attwood, 2014). Using this lens when working with neurodiverse couples helps us understand the breadth of an individual's' dating experience compared to their partner, who may or may not be on the spectrum. In practice, this can be seen as someone having unrealistic views of a relationship or misunderstanding the roles and responsibilities of each partner in this dynamic. Discussing the differences in experience as well as beliefs and expectations of romantic relationships are important in the foundation of couples' therapy. This allows individuals to hear their partner's viewpoint and expectations of sex and intimacy in the relationship. Often times,

this is helpful for both ASD and non-ASD partners to begin to understand the frustrations or disappointments in these sexual interactions. This also normalizes the concept that individuals enter a partnership with a wide range of expectations, needs and desires of intimacy, which often stems from past experiences or a lack thereof.

Striking a Balance

Using a strengths-based lens, we often find that neurodiverse couples can pool their strengths within the partnership and find ways to be stronger and more effective together. Neurodiverse couples who seek counseling need therapists who understand their neurology and the importance of integrating this understanding of ASD into the clinical work (Myhill & Jekel, 2015). It is imperative that in couples' therapy there is a specific and concrete focus on intimacy and sex. As noted throughout this article, there are often challenges faced in intimacy of neurodiverse partners, but through identification of neurological difference and directed clinical work, couples can strike a balance and identify ways to have rich and fulfilling intimacy within their partnership.

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Social-Sexual from page 9

having these discussions and they tend not to see sexuality in its broad definition; instead, seeing/hearing S-E-X in the word "sexuality." An example is proactively preparing children for puberty.

Many parents do not realize that children with DD generally mature biologically the same as those without DD. So parents need to concretely, and in a multisensory manner, teach children about the physical changes that their body will go through. This needs to begin a few years before the onset of puberty so that the child can have time to learn. At YAI, we offer parent workshops that help them to prepare for and better support their child through what can be a very confusing, socially awkward and scary time. We help parents understand how social-sexual training teaches their child how to let love in and keep abuse out.

Educators

People with ASD have challenges with executive functioning. This is important for educators to keep in mind, as they support students in social sexual development. From elementary through high school, elements of sexuality can be taught and reinforced by incorporating them in various subjects. Topics such as a positive self-image, personal pride, celebrating differences and building self-confidence are helpful to the social sexual development of a child.

Service Providers

Develop a comprehensive social-sexual policy to serve as a guide for everyone in the agency. This should include the commitment of the agency and responsibilities of its staff members. There should also be a plan of how the policy will be implemented. At YAI, this is addressed through the agency's Relationships and Sexuality Policy and its Sexuality Rights and Advocacy Committee. An approved social-sexual curriculum should be taught by trained staff. This curriculum needs to be fluid and adapt to the time and needs of the people being supported.

YAI holds a monthly networking and social skills group called the YOU & I Program. The focus is on skill development. Some of the requested group topics are: How to deal with rejection or anxiety for that initial conversation, Social etiquette around dating - who calls or pays? Where do you go? How long should a date be? What's OK and what's not? Some other topics are: How to make a friend; what is flirting; how and where to flirt; navigating levels of intimacy; using dating sites; safe use of social media; how to make small talk; or deepen and maintain a relationship.

Self-advocates were asked what they wish they had known about sex. One person wished that they were given more of an explanation. Another wished that they were given an introduction to puberty. One young lady said, "If I had known everything that I know now, I probably would have waited" (IMPACT, Spring/Summer 2010).

If we do not support the social-sexual development of people with ASD (from babies to seniors), then we are failing to provide person-centered services. We are not helping them to make *informed* decisions in their social lives and, in fact, we are promoting keeping them in social darkness. We are in essence continuing to deny them the opportunity to experience a basic biological need - to love and be loved, safely.

The overall goal of social-sexual education is to foster the growth of *knowledge, skills, attitudes and lifelong behaviors* that will enable the individual to make informed decisions and to assume responsibility for healthy living and personal well-being. For this to be achieved, there must be collaboration among parents, schools, service providers, and communities (places of worship, businesses, governments) to develop healthy relationships and provide a safe environment in which people with disabilities feel free to practice these skills. By ignoring this topic, we are doing a disservice to people with autism and other developmental disabilities.

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Simons from page 15

collaborators work together. He and the legendary mathematician Shiing-Shen Chern together developed the Chern-Simons invariant in 1974, which serendipitously turned out to be important in physics, a field in which neither of them was an expert. Simons also founded a successful quantitative hedge fund, Renaissance Technologies, where collabo-

rative working among employees was a first principle. So in 2012, the foundation extended its support for basic science, funding not only individuals' projects, but also large research collaborations of scientists. The foundation now provides funding for 10 such research collaborations, which are probing everything from large-scale brain activity to ocean ecology to electron interactions.

Most recently, the Simons Foundation

has undertaken to boost basic science more directly by launching a research organization within its own walls. In 2013, the foundation launched the Simons Center for Data Analysis, now called the Center for Computational Biology. And, in early 2016, an additional internal unit called the Center for Computational Astrophysics was launched. These centers, together with two others in the planning stage, form the Flatiron Institute, a new

organization devoted to computational science. Additional centers within the Flatiron Institute, along with Simons Foundation-supported collaborations, may be added in the future.

For more information on the Simons Foundation and its programs, visit simons-foundation.org. For more information on SFARI or SPARK, please visit SFARI.org or SPARKforAutism.org.

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on brain mechanisms in other genetic disorders affecting development and learning."

Leonard Abbeduto, director of the UC Davis MIND Institute and co-leader of the research at UC Davis, said it will not only help participating families, but also change how the field conducts clinical trials of new drugs for people with intellectual and developmental disabilities.

"We hope future trials will try to pair drugs with behavioral and education programs to produce larger synergistic benefits for families," Abbeduto added.

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The study was funded by the National

Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health under award number U01NS096767.

The UC Davis MIND Institute in Sacramento, Calif., was founded in 1998 as a unique interdisciplinary research center where families, community leaders, researchers, clinicians and volunteers work together toward a common goal: researching causes, treatments and even-

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additional children with mutations in HIVEP2, including Curren. (The Ramseys had given their geneticist permission to publish his information.)

Nerissa was thrilled to learn about the additional families with the same disorder. And she reached out to the study's senior author, Dr. Wendy Chung. Chung is a clinical geneticist and scientist who leads SPARK (<https://sparkforautism.org/portal/page/meet-the-staff/>).

At Chung's suggestion, Nerissa enrolled in the Simons Variation in Individuals Project (VIP) (<https://simonsvipconnect.org/>). This is an online community that supports families with rare genetic changes linked to autism and developmental delay.

Through the VIP, Nerissa and Chung set up a virtual conference for HIVEP2 families, which took place in December 2016.

Connecting with other families has been extremely helpful. "When dealing with such an ultra-rare diagnosis, most doctors have never heard of it and are not that interested in learning more about it," Nerissa

said. "The family community is probably the strongest resource we have, short of Dr. Chung, who has taken us under her wing."

Nerissa and some of the other parents formed a family support group. "So far, three families found me through social media and my blog, outside of the families that have currently been published," Nerissa said.

Most of the children in the group are older than Curren. So the Ramseys can learn from them about what to expect. For example, more than half of the children in the group have severe vision problems. "So I am monitoring Curren's vision and taking him to see an ophthalmologist more often than I would have, had I not had that information," Nerissa said.

SPARK hopes to provide other people with autism and their families with a similar chance to learn about genetics and connect with other families. People who enroll in the project will have the chance to have their exome sequenced.

However, SPARK's genetic analysis differs from that of commercial sequencing services, such as the company that ana-

lyzed Curren's exome. SPARK is starting by focusing on a fairly narrow set of genes — including HIVEP2 — and mutations. The ones the project is looking at have strong evidence of a link to autism. These genes have been identified in multiple studies, all in more than one family.

One of SPARK's goals is to aid in the discovery of additional autism-linked genes and then add those genes to the list of results to return to families who wish to see them.

Chung cautions that not everyone who has his or her exome analyzed will get an answer to the cause of autism in their family. SPARK scientists estimate that sequencing will detect an autism-linked mutation in roughly 10 to 15 percent of participants.

In the meantime, SPARK provides many other chances to participate in important research that will enhance the understanding of autism. Indeed, Chung's goal for SPARK is to create a community where researchers and families can connect in useful ways.

"This is about trying to make the pro-

cess more efficient and more inclusive, so that people who have historically been left out of the research process can become involved," Chung said.

For the Ramseys, getting a genetic diagnosis and connecting with other families has had a powerful impact. "My ultimate goal is to accelerate research," Nerissa said. "If you can find a community, whether it's two or three families or thousands of people with the same diagnosis, there is strength in numbers."

About SPARK

Today we simply don't know enough about autism. SPARK—a landmark autism research project—aims to make important progress possible. SPARK stands for "Simons Foundation Powering Autism Research for Knowledge," and the mission is simple: we want to speed up research and advance our understanding of autism to help improve lives. If you or your child has a professional diagnosis of autism spectrum disorder, learn more about SPARK by visiting <https://sparkforautism.org/>.

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not possess all of your personal knowledge and insight. However, there are steps you can take now to help minimize the natural disruption and disorientation that will occur upon your death, or if you become unable to care for your child during your lifetime.

Some of the Nuts and Bolts

The letter of intent may be addressed to anyone you wish – for example "To Whom it May Concern," "To my Guardian(s), Trustee(s) and Executor." At minimum, the letter should address the following points:

general overview, daily schedule, food, medical care, education, benefits received and employment.

In addition, there should be information included about your child's residential environment, social environment, religious environment, as well as behavioral management plans and final arrangements.

Once you prepare, sign and date the letter of intent, you should review the document annually and update it as necessary. It is important that you let both the legal guardian and trustee, as well as the caregiver know that the letter of intent exists and where it can be accessed. Even better, you can review the document with the caregiver on an annual basis. The letter of

intent should be placed with all of your other relevant legal and personal documents concerning your child.

Paving the Road Towards a Secure Future

Understanding these four essential tools can help start your child on the road to security, while also possibly providing some peace of mind for you as parents, because you have addressed the uncertainty of the future.

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2. Provided the premium requirements are met and paid.

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They tickle him with their tiny feet, and he jumps suddenly to try and shake himself free of their miniature stampede.

That's what I imagine, anyway.

Or maybe it's like a song in his head that only he can hear, and he cannot rest until he performs his own private dance to the silent notes.

It is the symphony of my day, the orchestra of my background, this music that plays within my boy. Like the moon to the tide's cool waters, again and again he surrenders to the quiet retreat of his heart's song.

Who am I to take that away from him? A long time ago I got used to looking at

everything through a continually shifting spectrum lens, as a way to decide what to change about this boy, and what to keep—what to let him have, and what to alter, to remove, to take away and replace. It is exhausting and frustrating.

Stimming sets him apart. It makes him look very, very different.

It's the first thing people notice about him. It's the reason kids stare and grown-ups drop their eyes when we're in the mall.

It is the proverbial sign on his back. Hello I am not like the others.

I don't care if he's different. I don't care one tiny-little-marching-ant-bit if people stare or point or giggle or chatter. But he does.

He cares about the proverbial sign even though he would have a hard time explaining what the word proverbial means. He cares that he's different. He cares very much.

"When for will I. Be normal."

The other day we had to pick out new glasses. After a busy school day, I knew it would be hard for him to focus long enough to try on new frames and to sit still while the doctor measures the lenses.

Driving in the car together, it occurred to me that maybe I'm just over thinking this stimming thing. Maybe it doesn't have to be so hard. Maybe there's a way to quiet the music and still the ants without upsetting the tender balance of autism and boy.

"Jack, buddy, listen. I have an idea."

"What. What for this idea."

"Before we go in to get your glasses, let's do some jumping in the parking lot. To get your zoomies out."

"Ok. Yes."

So I parked in a spot that was away from all the other cars. We both unbuckled our seat belts and opened the door. And underneath the dusky autumn sky, we looked at one another. He smiled a slow smile, and together, we jumped.

"What Color Is Monday?" is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: www.CarrieCariello.com and Facebook.com/WhatColorIsMonday.

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demonstrated that denying access to sexuality knowledge is not an effective strategy to promote adolescent sexual health (Davies & Dubie, 2012).

Due to their unique profile, research has suggested that ASD adolescents are better served by instructional methodologies that focus on socio-sexuality education (Gougeon, 2010). ASD adolescents often require a comprehensive and personalized curriculum that provides direct instruction with what is often learned incidentally, or acquired naturally by their typically developing counterparts (Gougeon, 2010). For example, individuals with ASD frequently necessitate overt teaching of facial expressions, emotions, and other non-verbal decoding skills, as well as training in initiating, maintaining and ending social interactions with peers, and the ability to discriminate between public versus private settings (e.g., Attwood, 2004; Chin & Bernard-Opitz, 2000; Gerhardt, 2006; Rogers, 2000; Travers & Tincani, 2010; Gougeon, 2010).

As the ASD youth matures, their social and sexual deficits may present as significant and problematic for procuring and maintaining intimate relationships, engaging in socially appropriate behaviors, gaining and retaining employment, and being accepted as a valued member within their community (Gougeon, 2010; Sullivan & Caterino, 2008; Travers & Tincani, 2010; Tremblay & Pigeon, 2004). These problems may prevent individuals with ASD from fully integrating with their respective communities as social and sexual beings resulting in depression, anxiety, low self-esteem, isolation and other mental health concerns (Aylott, 2000; Ozonoff, Garcia, Clark, & Lainhart, 2005; Gougeon, 2010). As a result, their needs must be addressed through the visionary methods of appropriate, relevant, and effective socio-sexuality education (Gougeon, 2010).

Sexuality Education Interventions

Research indicates common themes for teaching socio-sexuality education to individuals on the spectrum. Here, four evidence-based interventions designed to provide sexual education programming to ASD adolescents will be presented.

TEACCH: Treatment and Education of Autistic related Communication-handicapped Children (TEACCH) began as a comprehensive public program for children with autism in the state of North Carolina (Schopler, 1997; Sullivan & Caterino, 2008). TEACCH covers all areas of functioning, including academics, social skills, and sexuality (Sullivan & Caterino, 2008). TEACCH features four developmentally sequenced levels, which are presented to students based on their level of cognitive functioning (as cited in Sullivan & Caterino, 2008, p. 387). Those with strong cognition are exposed to all four levels, while those presenting with cognitive deficits will only complete level one (Sullivan & Caterino, 2008). From a social learning perspective, TEACCH applies the principles of discriminative training, overcorrection, restitution, and positive practice through education and role play (Sullivan & Caterino, 2008).

The Devereux Center Model: Equally sig-

nificant is the Devereux Center Model; a multi-tiered sexual education program, which includes topics focused on the body, anatomy and function, social/sexual behavior, sexual life-cycle, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, assertiveness, and self-esteem (Sullivan & Caterino, 2008; Koller, 2000). The Devereux philosophy utilizes parents as teachers whenever possible (Sullivan & Caterino, 2008). Devereux promotes sexual expression, as it is regarded as normal and natural and can be individualized in order to meet the specific needs of all recipients, including situational instruction, audio-visual materials and discussion (Sullivan & Caterino, 2008).

Social Stories and Video Modeling: Additional strategies used to personalize instruction include Social Stories (Gray, 2002; Ray et al. 2004; Tarnai and Wolfe, 2008), comic strip conversations (Gray, 2002; Ray et al. 2004), and video modeling and task analysis (Wolfe & Blanchett, 2003; Wolfe et al. 2009), many of which are Applied Behavior Analysis (ABA) based (Gougeon, 2010). Developed by Gray and Garand (1993), social stories are excellent for placing emphasis on "hidden rules" of engagement, which can best benefit the adolescent. Social stories facilitate expectations without being punitive.

Groups: Groups can provide the perfect platform for education, friendship, community, and engagement. Groups provide a natural laboratory where members can experiment with new ways of being (Corey, Corey, & Corey, 2014). A well-defined group can provide a perfect venue to create acceptance, and a willingness to offer each member security and guidance, so that they feel socially accepted and included.

Additional Educational Resources

Many school districts and private institutions are adopting curriculums that inform, educate, and support healthy relationships so that adolescents with ASD can successfully transition into adulthood and society. The literature cited three such educational programs.

1) *The Healthy Relationships & Autism Curriculum* (Sutton & Wesley Spectrum Services, 2013) has been proven to be an effective intervention for increased knowledge and acquisition with topics including personal hygiene, biologically-based sexuality education, and relationships (Pask, 2015; Greiert, 2016).

2) The Tackling Teenage Training (TTT) program is another successful curriculum distinguished for promoting psychosexual knowledge in a sample of thirty 11-19 year-old adolescents with ASD (Deckker, van der Vegt, Visser, Tick, Boudestijn, Verhulst, Maras, & Graves-Lord, 2014; Greiert, 2016). Although the results of the TTT study are not yet published, this 18 session format utilizing one-on-one psycho-educational instruction is receiving notoriety due to the implementation of an instructional protocol that can monitor the efficacy of each ASD participant (Deckker et al. 2014; Greiert, 2016).

3) Finally, *Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents / Adults with High-Function-*

ing Autism Spectrum Disorders and Other Social Challenges created by Davis and Dubie (2012) is perhaps one of the most comprehensive sexuality curriculums to date (Greiert, 2016). This highly structured 11 unit curriculum addresses sexuality and relationships using video modeling, role-play, exercises, and discussions. Each intervention will begin with a pre-assessment and conclude with a post-test assessment. Topics include sexual responses and partnered sex; sexual anatomy; reproductive health; contraception and sexually transmitted infections; dating; stages of relationships; attitudes, values, and differences; and sexual harassment, aggression, and abuse (Davies & Dubie, 2012).

Taken together, this research suggests several key components that are critical to the success of autism specific sexuality education. First, the intervention must be flexible in order to adapt to the various cognitive abilities of the ASD population. Second, training parents to be partners in this educational endeavor is essential. Third, by incorporating social stories and other instructional ancillaries the learner will gain practice in healthy scripts and behaviors. Finally, group interventions can offer a welcome source of community and friendship to guide the adolescent through these challenging topics.

In summary, adolescents with ASD are sexual beings who can and should be educated on how best to handle their own sexuality (Koller, 2000; Sullivan & Caterino, 2008; Tullis & Zangrillo, 2013). Existing research supports the use of sexuality education, however no one methodology can be determined the most appropriate. While empirically derived sexuality education for adolescents and adults with ASD is limited, the current body of literature does provide support for direct and measured teaching methodologies for self-care and programs based on social interaction (Mason-Jones et al. 2012; Klett & Turan, 2012; Tullis & Zangrillo, 2013).

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Byers, Nichols, and Voyer (2013) explored the sexuality of single adults with high functioning autism or Asperger's syndrome using an online questionnaire. Byers et al. reported that in general, positive experiences were described and further noted that men reported better sexual function than women. In addition, Byers et al. noted that their findings are useful in countering negative societal perceptions about the sexuality of high functioning individuals on the spectrum.

Gilmour, Schalomon, & Smith (2012) administered an online survey of sexual knowledge and experiences. Reporting on responses drawn from 82 adults with autism and 282 adults drawn from the general population, Gilmour et al. found no significant differences in breadth and strength of sexual behaviors and comprehension of sexual language when compared to participants without ASD.

Holmes & Hilme (2014) explored communication regarding sexuality between parents and their children with ASD, and noted that experts recommend that parents be the primary source of sex education for adolescents with ASD. In particular, Holmes & Hilme emphasised the importance of tailoring sex education to the individual child's level of development.

Lindsay et al. (2014) examined 477 sexual offence case referrals to forensic intellectual disability services. Lindsay et al reported that individuals with ASD showed a lower prevalence of contact sexual offences when compared to those without ASD, and concluded that there is no persuasive evidence that ASD is a risk factor for offending behaviours.

In other research, a questionnaire was given to 95 adults with ASD and 117 adults without ASD to gather data on sexual knowledge sources, actual knowledge, perceived knowledge, and sexual victimisation (Brown-Lavoie, Viecili, & Weiss, 2014). Brown-Lavoie et al. reported that the individuals with ASD acquired their sexual information less from social resources, more from non-social sources, had less perceived and actual knowledge, and were subjected to more sexual victimisation than the control group. Brown-Lavoie et al. noted that sexual victimisation

**Monica E. Carr, PhD**

of individuals with ASD was partially mediated by their actual knowledge.

A research team in India developed a sex and health curriculum, reflective of Indian cultural values, in effort to reduce problem and odd sexual behaviors in individuals with ASD (Banerjee, Ray, & Panda, 2013). A sample of 45 individuals drawn from special education schools received 40 Sex and Health Education lessons, once per week, that lasted 40-60 minutes. Five domains were included in the curricula: biology and personal appearance; privacy/modesty regarding sexual expression; health/hygiene and personal care; recognition of emotion; and social behaviour. Banerjee et al. reported that the program had a positive effect in handling the expression of sexual urge in a socially acceptable manner, and had positive effects on both odd sexual and problem behaviours.

Klett and Turan (2012) conducted a pilot study with three girls with ASD, in which parents implemented a Social Story based intervention, embedded with a visual task analysis, to teach their daughters menstrual care. Klett and Turan reported that the participants were more knowledgeable about reproductive development, and were able to independently care for themselves.

Dozier et al. (2011) used a single-sub-

ject research design, and conducted a functional analysis of an inappropriate sexual behavior (ISB) that had prevailed for 20 years, for a 36 year old participant with little expressive language. The participant was known to drop to the floor and engage in ISB when in the presence of a woman wearing sandals. Dozier et al. describe the implementation of a response interruption (to the target behaviour) followed by a time out procedure (RI/TO), and reported that the RI/TO procedure quickly eliminated the problem behaviour in multiple settings.

Carr and Anderson provide additional information on the topic of sexuality, sex education and amelioration of inappropriate behaviours, for individuals with ASD in their forthcoming systematic literature review.

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Education from page 30

Schopler, E. (1997). Implementation of TEACH philosophy. In D.J. Cohen & F. R. Volkmar (Eds.) *Handbook of Autism and Pervasive Developmental Disorders* (pp. 767-795). New York: John Wiley.

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Early Start from page 23**We Know It's Important,
Now What Do We Teach?**

A child's *chronological age* should guide *WHAT* to teach as part of socio-sexual education (Nichols, 2007). Two important considerations for children with ASD are that: (1) they will benefit from learning about some things, such as body changes, ahead of time; and (2) integrating sexuality education with social education is essential. The social element connects the dots about *why* certain behaviors are appropriate or not, given the context.

Ages 3-5

At this young age, children learn about their own and others' body parts, differences between boys and girls, touch and affection, and privacy. Foundational social skills are a critical part of any curriculum. Teach the correct names for body parts (e.g., vagina, penis) and provide clear guidance about the concepts 'public' and 'private.'

Ages 5-9

As children enter school, instruction should become more comprehensive and introduce the fact that bodies change as we grow up. Change can be difficult for children with ASD: discussing puberty will help kids know what to expect ahead of time. At this age, it is important to talk about friendships, communication, assertiveness and

saying 'no,' and asking for help.

Ages 9-12

In the pre-teen years, discussions about puberty and safety become more specific (e.g., body hair) and skill-focused (e.g., hygiene). Personal values and decision-making become important, as does understanding of different social relationships. An emphasis on emotional development is critical, and teaching about romantic feelings may be relevant.

How to Teach – Tips and Resources

Together, a child's developmental (cognitive) age and their learning style will guide *HOW* you teach (Nichols, 2007). In general, it is important to be clear, simple, and concrete. Use the child's language when appropriate and avoid using euphemisms. Give specific examples across a range of situations and repeat. Get creative and integrate multi-sensory methods such as role plays and demonstrations, as well as individual and group experiences. For all children with ASD, but in particular for youth with cognitive and language challenges, it is particularly necessary to use visual strategies when teaching: pictures, schedules, videos, charts, books, dolls. Provide opportunities to practice skills (e.g., role play) or apply new knowledge. Remember to LISTEN as well as teach – understanding the child's perspective and checking comprehension is crucial to effective teaching.

Want to learn more? Some books on sexuality education for youth with ASD are listed below.

Resources

Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Professional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Responding to Inappropriate Behaviours. By D. Hartman

When Young People with Intellectual Disabilities and Autism Hit Puberty: A Parents' Q&A Guide to Health, Sexuality and Relationships. By F.J. Brown & S. Brown

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism By Mary Wrobel

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Support from page 24

a role in along with Michael John Carley (who served as its executive director for many years) and three other members of our group. Similar groups were formed, one by one, in various parts of the U.S. The New York group continued to thrive, and at times even played a role in enhancing public awareness about Asperger Syndrome and the autism spectrum. Meetings were actually featured in two documentaries (one of which was nationally broadcast on public television), filmed by a crew from Japanese television, and even visited by a major movie star (I am not kidding!) who was preparing to play the role of an autistic person on the screen. We also hosted a number of journalists as well as journalism students (print and radio) who helped to spread the message about autism and our community. The most significant aspect of support groups, however, lies in providing an environment where people on the spectrum can share about their issues and challenges among others who can appreciate them, and feel comfortable doing so. In particular, they are often the first place outside of a clinical setting where a newly-diagnosed autistic person can go.

In 2009, after several years of regular attendance, I became a facilitator of the New York group, and did this for several years. Having no background whatsoever in psychology, medicine, or social services (I am an electronics engineer by education and profession), this was hardly a natural thing for me to do. Nevertheless, having

lived a lifetime on the autism spectrum and come to understand its characteristics and challenges, I was able to be effective in that capacity; had I attempted this in any environment outside of the autism community, I am certain that I would have failed miserably. All of this convinced me that there is no substitute for life experience when it comes to understanding and appreciating what it means to live on the spectrum. As such, an autistic person is in a unique position to facilitate a group for other autistics.

Around this same time, a few enterprising members of the New York group decided to form a separate group that addressed the employment-related issues faced by so many in our community. After a while, however, its members realized that there was even greater interest in matters relating to socialization, to which the focus of the group was changed. Over time, the number of people attending this group continued to rise, which in turn helped foster a sense of community among Aspies in the New York area. Eventually, it evolved into a social group. Within a few years, a new organization emerged from the group, Aspies for Social Success (AFSS – www.nyautismcommunity.org). Its objective is to provide support and social groups, as well as cultural and recreational activities, for adults on the autism spectrum. Activities have included visits to museums, theatrical performances, films, renaissance festivals, and other events. These can cater to the specialized interests and preferences of Aspies, or else serve to broaden their cultural horizons (which can in turn help

enlarge social circles).

Socialization issues include getting along with others, being part of a group, meeting people, making friends, and finding and maintaining romantic relationships. As such, these constitute the most important challenges faced by many autistics because they are at the root of so many difficulties, most notably those concerning employment (the original focus of this group) and relationships. It is well-known that people on the autism spectrum have difficulties finding and keeping jobs mainly because of social deficits rather than lack of competence, poor attendance, theft, or other common workplace infractions.

Another area of concern in the autism community involves matters of sexuality. One misconception that unfortunately is far too common (even among professionals) is that autistics are asexual and not interested in romantic relationships. While there may be a small minority of autistics for whom this is true, I can assure you that it is generally not the case. Based on my experiences over the years, I am convinced that autistics face essentially the same issues regarding sexuality as any other population; in other words, we are as a group no different from everyone else. Where we do have considerable difficulty, however, is in finding and maintaining relationships. It is here that social deficits can present significant and even formidable challenges. This is probably the one aspect of life where the ability to read nonverbal social cues and to discern hidden curricula, not to mention hidden agendas, is of greatest importance. Autistics who have deficits in these areas

will inevitably be at a great disadvantage.

All of these challenges are much easier to address in an environment where everyone has faced them, and Aspie support and social groups provide just this kind of environment. One problem that sometimes arises, however, is inappropriate behavior on the part of group members. There is a delicate balance between tolerance of such behaviors, the inappropriateness of which is either not understood or else an expression of anger at being mistreated and not accepted, while still maintaining an environment in which others are not made uncomfortable. These groups need to be a haven from the intolerance that Aspies so often encounter, but must also provide one in which they can all feel safe.

Groups like these are desperately needed by our community. Given the large numbers of undiagnosed autistics, this need will only become greater as public awareness of autism continues to grow and more adults are diagnosed. Organizing groups for autistics can present substantial challenges to a population that, in spite of a few notable exceptions, is generally not well-suited to such activities. Just as we benefit from the assistance and services of autism professionals, family members, friends, and others not on the spectrum, we will need help with some aspects of organizing communities for our people. Nevertheless, we should try to do as much for ourselves as we can. There is still much to be done.

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Training from page 12

their clients. The first step of the task force is assessing the needs of our clients, and then developing curriculum tailored to address those needs utilizing literature and available resources.

It is essential to obtain consent from parent or caregivers and, at times the individual themselves, prior to conducting assessment. If request for consent is met with hesitation, additional discussions and training should take place as the client continues to grow and develop. Initiation of assessment and training should not occur until consent is provided. Above and beyond initial consent, we at Melmark New England, make every effort to involve families throughout the entire process. When communication with families it is important to take into account the family's perspective and wishes into account.

Depending on the nature of the need, assessment may include formal tools such as the Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised (Griffiths & Lunsky, 2003) and the Checklist of Adaptive Living Skills (Morreau & Bruininks, 1991). Such tools may need to be modified to fit the needs of the clients with whom you work. A more individualized assessment process consists of functional and descriptive assessments which allow the team to directly observe conditions under which the behavior is, or is not, currently displayed. Hartman (2014) provides one example of a Functional Behavior Assessment tool in the Appendix E of his book "Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Professional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Responding to Inappropriate Behaviors." This tool follows the conceptual outline of any functional assessment: define the behavior and establish a baseline measure, evaluate current skills related to the target behavior and condi-

tions under which these behaviors occur, analyze data from the initial assessment and plan for the next steps.

A general scope and sequence of topics related to human sexuality development, from childhood to adulthood, guides the recommendations set forth by the task force. It is important to note that human sexuality training covers a wide range of topics, some of which are important to consider teaching during early childhood. For example, labeling body parts are crucial prerequisite skills that can be taught within the context of a grooming routine. During adolescent years, teaching about changes to one's body prepares individuals for the transition to adulthood. In addition to gender-specific skills, it is also important to consider other skill sets such as self-advocacy and social skills as part of the larger curriculum. Factors to consider when teaching any skill include prerequisite skills, context of teaching, individual versus group formats, and accessibility to appropriate peer groups. Specific teaching strategies should be empirically-based (e.g., behavioral skills training, discrimination training, chaining, and shaping).

Some skills are more appropriately taught within an individualized format. For example, many of our clients display self-exploratory behaviors around the time of puberty. Upon determining that the behavior may be sexual in nature (i.e. an attempt at masturbation), assessment is conducted and the results are summarized to develop the lesson plan and data sheet. When such a need is identified for a particular client, we must return the scope and sequence to ensure that all prerequisite and related skills are also established (e.g., requesting, appropriate context, and safety). Skills that are private in nature should be taught by parents, caregivers, or staff of the same gender. Other skills might be best taught within a group format; one example of such a curriculum is the Circles curriculum (Walker-Hirsch & Champagne, 1991). This curriculum

aims to teach individuals to identify people and appropriate interactions based on categories. We recently implemented this curriculum for our clients because it provides concrete categories (e.g., individual, family, friends, and community members) associated with specific visual stimuli (e.g., colors) to promote learning and application.

We, as clinicians and educators, are responsible for teaching these skills to our clients to promote independence and successful transition into adulthood. Our hope is this article provides one example of how an organization can systematically address such an important area of need within the ASD population. The Sexuality Information and Education Council of the United States, "believes that individuals with physical, cognitive, or emotional disabilities have a right to education about sexuality, sexual health care, and opportunities for socialization and sexual expression" (n.d.). We agree, encouraging and challenging clinicians and educators to pursue topics related to human sexuality training, conduct systematic evaluations of assessments and teaching procedures, and to share the results with the greater community. Through the development of an empirical literature base, the fear and anxiety around human sexuality training will cease to be a barrier and the independence and successful life transitions of our clients, our children will be realized.

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clinical, residential, healthcare and rehabilitative services, personally designed for each individual in a safe environment of warmth, care and respect. For more information, please visit www.melmark.org and www.melmarkne.org.

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Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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Title IX from page 16

of sexual misconduct than law enforcement, and due to the mandate to provide safe environments, institutions may choose to err on the side of caution. Parents and caregivers need to understand that the unstructured nature of social interaction on a college campus will create challenges students did not have to grapple with in high school. Individuals with ASD who engage in behavior interpreted as stalking or other types of sexual misconduct may find themselves subject to investigations and disciplinary action. According to Title IX guidelines, colleges follow a preponderance of evidence standard. With a preponderance of evidence standard it only has to be found that the behavior in question was more likely than not to have occurred for an individual to be held accountable for the behavior. Infractions may have a negative impact on the individuals subject to them, regardless of the accused's intent or understanding of the nature of the violation (Gordon, 2016). In some instances, consequences may be imposed in the interest of safety that precludes findings by the criminal justice system, without due process as typically understood. For example, the accused may not have the opportunity to face the accuser. When time and diligence clarify that an individual accused of sexual

misconduct on campus has impaired social skills development due to ASD, the clarification will not alleviate lost academic time or emotional stress resulting from disciplinary action enacted to ensure the safety of the accuser.

In addition, individuals with ASD may become victims of sexual misconduct themselves, possibly as a result of inexperience with romantic relationships, or taking risks in order to be socially accepted. Consequences of poor decisions are amplified in college settings for many reasons, including reduced supervision and the presence of alcohol. Individuals with ASD attending college and their parents or caregivers need to be aware of Title IX policies so that they have an understanding of their rights and can seek help should they need it.

Transition plans often focus on continued academic and vocational skills development. If studying on a college campus is a goal for individuals with ASD, social skills training including familiarity with college campus Title IX policies should be an important part of their transition plans. Parents, families and students themselves can advocate for specific training to be included in a student's transition plan. In addition, when applying for college or college-based post-secondary programs it will be important to ensure that orientations programs and/or freshmen year campus

orientation courses adequately address these concerns.

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Resources from page 25**Conclusion**

This article lists resources that provide guidance and scripted activities for teaching youth with ASD about sexuality. In addition to these resources, professional settings that offer socio-sexuality education for individuals with ASD should consider (1) State regulations and guidelines for sexual health education, (2) guidelines and resources for sexuality education and disability and (3) national guidelines for sexuality education and typical development. Also informative are the variety of 21st century books which explore sexuality and autism but are not structured teaching resources. A parent or professional approaching the topic of sexuality will likely use a combination of resources to individualize education for their child, student or client. One current challenge to individualization is the lack of investigation, discussion and resources addressing the role of culture when providing sexuality instruction in context of ASD.

In her extensive review of literature on sexuality and ASD, Gougen (2010) states, "As it currently stands, a gap exists between the perceived need for socio-sexuality education and its actual provision" (p.331). The resources listed in this article can be tools for practitioners, parents and individuals with autism to start bridging that identified gap between need and provision of instruction about socio-sexuality.

Britta Saltonstall, PhD, BCBA, provides private consulting and professional development trainings in the areas of specialized instruction and ethical practices in sexuality and behavior support. She can be reached at brittasali@comcast.net.

**Teaching Resource List
(In order of appearance in the article)**

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