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VOL. 15 NO. 2

Relationships and Sexuality

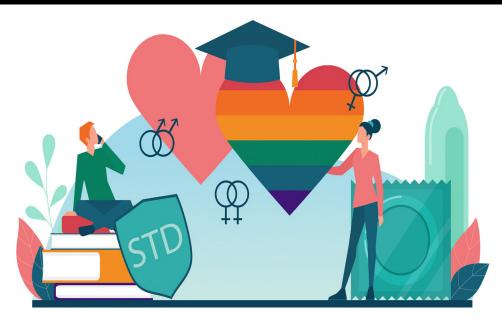
Circles of Sexuality: Creating Inclusive, Comprehensive Sex Education for Autistic Students

By Nellie Galindo, MSW, MSPH Founder & CEO Accessible Sexual Health LLC

FALL 2022

ex education remains a contentious topic in the United States, especially within the public school system. As of October 2020, only 30 states and the District of Columbia require public schools to teach sex education, and only 22 states require that sex education be medically and factually accurate. Despite the development of national standards for sex education for kindergarten through 12th grade, access to comprehensive sex education across the nation is spotty.

Those who stand to lose the most from this patchwork of education are students who receive special education services. Students with disabilities, including autistic students, are often excluded from their school's sex education programs. The reasons for this vary; sometimes it is because of special education teachers' discomfort with the topic, or because schools don't know how to adapt sex education curricula to meet the needs of



students with autism. Regardless of the level of support needs an autistic student has, it is crucial to include them in these conversations.

Lacking access to this information is especially dangerous for autistic individuals, given the incredibly high rates of sexual

abuse within the autism community. Encouraging an understanding of one's own body, bodily autonomy, and appropriate social relationships is an essential way to help prevent abuse. Unfortunately, stigma around sex education creates barriers to accessing this information.

For many, the terms "sex education" or "sexuality" are thought to be topics that only encompass intercourse or other sexual behavior. In reality, sexuality is an incredibly broad topic that encompasses the entire lifespan. It also does not solely include reproductive health; effective sexual health education involves a wide range of knowledge building and skills training.

So, what topics should be included in a comprehensive sex education program? One useful framework for developing or choosing a sex education curricula are the Circles of Sexuality. This framework, based on the work of Dr. Dennis M. Dailey, identifies six topic areas to include within sex education curriculum. The Circles of Sexuality are a core component of existing sexual health programs for youth, and apply to neurotypical students and students with autism.

The Circles of Sexuality

Let's look at each of the Circles of Sexuality in-depth:

see Circles of Sexuality on page 25

Tips for Parents and Teachers to Support Autistic Children in Developing and Maintaining Friendships

By April L. Coleman, PsyD Licensed Psychologist Georgia Autism Center

riendships play an important role in the lives of children and teenagers. These relationships help with childhood social and emotional development in many ways, including: managing emotions, responding to the feelings of others, listening, problem solving, navigating conflicts, sharing and turn-taking, and developing communication skills.6 The importance of friendship increases even more after the transition to adolescence, with adolescents beginning to spend more time with their peers and less time with their families. Not only do friendships promote social and emotional skills, but they also bring a sense of pleasure and comfort. When children are able to develop and maintain friendships, this contributes to increased self-esteem, self-confidence, and social competence, which are pivotal in child development and an overall sense of belonging within a peer group.

Making friends and being a part of a friend group affects overall mental



health, school performance, general behaviors, and self-perception. As humans, we have a fundamental need for social connection, so when those social needs are not met, it can contribute to increased stress in many ways, including anxiety and depressed mood, stemming from rejection, exclusion, and isolation. This

sense of feeling like an outcast can affect a child's overall quality of life, leading to parents and teachers observing noticeable changes that are concerning. It is at that point when help may be sought from a mental health professional to determine the need for therapeutic intervention in some form.

An important part of being able to develop and maintain friendships is having the necessary social tools and skills needed to cultivate those friendships. However, many autistic children and teenagers have social differences that make it harder for them. Therefore, they benefit from support from important adults in their lives, including parents, caregivers, and teachers, to develop various social skills. These include: starting and having conversations, joining in group activities with peers, understanding facial expressions and body language, adjusting to new social environments, addressing differences in opinion, finding and connecting with people with similar interests, being flexible during joint activities, and being able to understand what others may be thinking or feeling.3 Autistic children and teenagers can be successful with making and keeping friends and finding peer acceptance similar to those of their neurotypical peers, but they must be provided with the opportunities to do so. As such, there are strategies that parents, caregivers, and teachers can use to further support the development of these friendships.^{2,3,4,7}

see Friendships on page 28

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Rethinking Non-Compliance as a Skill and Promoting Self-Advocacy

By Alex Kishbaugh, MS, BCBA, Haley M. K. Steinhauser, PhD, BCBA-D, and Frank L. Bird, MEd, BCBA Melmark

early all behavior analysts have come across "non-compliance" within the behavior repertoire of our consumers. Many of us have operationally defined it and targeted it for deceleration. However, how often do we stop to consider the significance of non-compliance? Can non-compliance be adaptive? Can non-compliance have multiple adaptive functions? Can we teach our consumers to discriminate when and how to adaptively communicate "no"?

Applied behavior analysis, or ABA, has received considerable negative press lately, with some of that criticism being an overemphasis on compliance of autistic clients (Veneziano & Shea, 2022; Wilkenfeld & McCarthy, 2020). However uncomfortable as it may be to receive criticism as someone who is committed to work in a helping profession and adheres to the value of applied behavior analysis and evidence-based practices, the field can benefit from listening to these concerns and care can be improved. There is value in assessing the criticism to understand it and clinically reflect on the extent that it applies to our work. This is the only way we can improve our practices as behavior analysts with the people we serve. We need to acknowledge our own biases and learning history. Only then can we move forward and continue to learn and grow as we remain curious and open to learning more as to how our science can improve the quality of life of

Rethinking Non-Compliance as Withdrawing Assent

Due to ongoing challenges with appropriate funding and the staffing crisis, time is of the essence more than ever when it comes to the importance of skill-building. This can lead well-intentioned behavior analysts, teachers, and caregivers in wanting every moment to be a teaching opportunity, with little time for "non-compliance." Non-compliance, however, might be conceptualized as a withdrawal of assent, or a lack of consent, with instruction or another component of the treatment process. Assent has been promoted within the Ethics Code for Behavior Analysts (Behavior Analyst Certification Board [BACB]®, 2020) and is now an obligation for both practitioners and for researchers. It is imperative to monitor and gain assent, and to respond compassionately and humanely to any withdrawals of assent. There is room for improvement in the integration of assent into clinical and research work in ABA (Morris et al., 2021). More needs to be done to train practitioners to understand assent, to ensure that assent is integrated into care, and to developing assent procedures for individuals who are non-vocal. A related consideration is to rethink our service delivery to alter our instructional approach. Rather than treat escape-maintained behavior, we should think about how our instruction can be reworked into something individuals opt into (e.g., Rajaraman et al., 2022).



Not only is non-compliance a signal that something needs to be modified with our clinical approach; non-compliance is an essential skill. Teaching "no" and respecting it as a means of promoting a healthy, safe, and well-rounded life is critical. Non-compliance is especially valuable in the context of personal sexual safety, in addition to sexuality education, across individuals, diagnoses, and communication skills (Schulman & Gerhardt, 2017). Simply put, an individual cannot be sexually safe if they cannot be non-compliant. As professionals, we need to reflect on how this relates to the work we do. When non-compliance is targeted for decrease, it can send the message that we do not respect an individual's "no." This may further reduce self-advocacy in the form of asking questions, expressing feelings, or engaging in dialogue with us. Unfortunately, we must be mindful of the potential ramifications for harm in this paradigm; it can leave our consumers vulnerable to harm, exploitation, or abuse. For all of these reasons, we need to be thoughtful and re-assess how we can discriminately teach our consumers the value of communicating "no."

Promoting Self-Advocacy

Time is of the essence when it comes to building skills and independence with autistic children and adolescents; helping our clients develop a repertoire that includes self-advocacy is key. Non-compliance with the command of a functional "no" response that others respect is the foundation of self-advocacy, allowing individuals to advocate for themselves and their needs. A popular disability advocacy site, Covey.org, breaks down self-advocacy simply into the following: Knowing oneself, knowing one's needs, and knowing how to get those needs met. Non-compliance is endemic in all three parts; self-advocacy cannot occur without the ability to be non-compliant.

In addition to listening to autistic voices and ensuring we are appreciating the nuance of this topic, we need to write better, more nuanced, and collaborative goals with respect with self-advocacy skills at the forefront. Here are some practical starting points:

 Replace references to "non-compliance" with skills to promote instead.

- Alternatively, frame the goal as cooperation instead of compliance, and ensure that it is targeted only when cooperation is important. Drop references to compliance, as it leads to an over-focus on following commands without consideration of choice, assent, or other contextual factors.
- Get curious about why we are observing "non-compliance." Consider this through a behavior analytic lens and use problem solving to identify elements of intervention that are objectionable to the learner.
- Reflect and reconsider why we value compliance in a particular situation and whether it is even appropriate or necessary to do so in a given context.

A simple first step is to adjust the language we use - both spoken and in written goals. This can be accomplished by replacing "non-compliance" with either cooperation or by focusing on skills to promote and teach while ensuring they align with the individual's personal goals and desires. For instance, rather than targeting decreasing non-compliance, look to increase pragmatic skills such as negotiation, compromise, safe "no" responses, and problem-solving, all which will promote self-advocacy.

Another objective to consider is to assess the function of non-compliance. This can prompt caregivers, teachers, and clinicians to ask several questions. For instance, is the person having difficulty with the task? Are they experiencing a strong emotion that is preventing them from communicating effectively? Could they be feeling unwell? There are countless possibilities, with some being best responded to with individualized accommodations or assistance. By stepping back and considering why we are observing non-compliance, we can more compassionately let the needs of the person guide us in a collaborative approach.

Also, it is crucial to give careful consideration of our own experiences, perspectives, and biases and how they affect our own behavior. As teachers and clinicians, we must self-reflect on why we value compliance in a particular situation or with a specific skill. Rethinking if it is necessary, considering if it can be done differently, or rescheduling it for later might better respect a consumer's personal needs or desires. Everyone has

life experiences that shape our interactions and expectations; self-reflection and adjustment of our own behavior can help us do better for those we serve.

Working with autistic individuals, we want the best outcomes for those we teach and serve. Listening to criticisms, understanding them, and looking to always do better are essential steps for achieving best outcomes and becoming better behavioral clinicians. Small changes in the language we use can have a large impact; it may be time for the field to de-emphasize compliance and to focus instead on cooperation and collaboration. Finally, the integration of assent, and the assessment of monitoring assent, are now ethical mandates and elements of best practice. It is important to explicitly identify how assent will be gained and how it will be ensured throughout the instruction.

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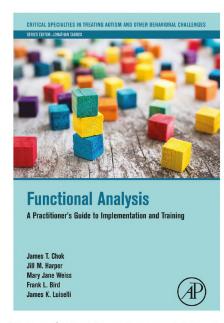
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Sex Education for Autistic People: Why It's Not Too Much to AASK

By Amy Gravino, MA, CAS Relationship Coach and Autism Sexuality Advocate, Rutgers Center for Adult Autism Services

ne of the most vivid memories I have of growing up is when I had my first period. I was 12 years old, and I can still see my mother standing in the bathroom doorway, her face filled with amazement and delight.

"Amy, you're a woman now!"

Confusion etched itself in lines across my face, mixed with the acute sense of shame only a preteen girl can feel. As it turned out, I started my period several days previously, but it was only then that I'd become aware of what had happened.

One year earlier, I was diagnosed with autism level 1 (or Asperger's syndrome, as was the label then), and the sense of disconnection I felt from my own body was only amplified by the lack of understanding I had, both about who I was and the physical and emotional changes I was going through. Most of what I learned about sexuality in those middle school years came from my peers, who were less concerned with helping me and providing accurate information and more interested in using my naivete to turn me into a spectacle. I had so many burning questions about sex and puberty and womanhood that no one - not my parents or my teachers - was



willing or able to honestly answer.

Over the past two decades, our understanding of autism has grown significantly, yet there is still a reluctance on the part of both parents and professionals to acknowledge autistic people as sexual beings. Stereotypes of autistic people as asexual have further inhibited this dialogue, with popular cultural preferring to see autistic adults as uninterested in sex. Further, there is a dearth of research in this area, which reinforces societal taboos and stigma around autistic sexuality and perpetuates the idea

of teens and adults on the spectrum as permanent children. It is for all of these reasons and so many others that I became inspired and determined to begin the work of creating a sex education curriculum for adults on the autism spectrum.

In 2020, I started my position as a Relationship Coach in the Rutgers Center for Adult Autism Services. It has become clear to me through my work at Rutgers and as a consultant and mentor through my own business, A.S.C.O.T Consulting, that so many of the struggles I had in my young

adult years - from sexuality to self-esteem to abuse - are still being experienced by autistic young adults today, at Rutgers and beyond. Navigating the social and emotional terrain of relationships and dating remains a tremendous challenge, and the need for a comprehensive, medically accurate sex education curriculum has never been greater.

When NEXT for Autism announced the launch of its Color The Spectrum Community Grants Program in the summer of 2021, it seemed like the perfect opportunity to begin this much-needed work. Together with Dr. Vanessa Bal, Director of the Lifespan ASD Lab in the Graduate School of Professional and Applied Psychology (GSAPP) and the Psychological Services Clinic in the RCAAS, we applied for and received a \$25,000 grant to bring the Adult Autism and Sexuality Kit (AASK) to life.

As we have developed this curriculum, one of the primary goals of the Adult Autism and Sexuality Kit has become building a foundation for future discussions. By adapting existing lesson plans from ANSWER, a national sexuality education organization established at Rutgers University in 1981, and following the guidelines set forth in the National Sexuality Education Standards, Second Edition (NSES), we will create a starting point to ensure that autistic adults receive information and achieve competency in seven main topic areas.

see Sex Education on page 24

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Making Space for Mourning: A Grief Support Session

By Lori Lerner, LMSW, RYT-200 hr. Coordinator of Family and Wellness Services for the UnderServed (S:US)

s the Coordinator of Family and Wellness in the Developmental Disabilities Division at Services for the UnderServed (S:US) and a social worker with extensive experience in providing grief support, I am often requested to administer grief support to people with intellectual/developmental disabilities and our staff in various programs. When going out into the field to provide this type of support, I carry two quotes by seasoned, wise women as a reminder to nurture the qualities that are helpful to people in grief and mourning.

The first quote is from writer and poet Maya Angelou who wrote, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." In a culture and society that has historically shied-away from making space for grief and mourning, it is important to remind people to make space for their feelings and to help people feel their feelings, whatever they may be, in their time of grief.

The second quote is from French philosopher and political activist Simone Weil who wrote, "Attention is the rarest, purest form of generosity." In providing grief support, it is beneficial to embody sensitiv-



ity, patience, an open heart to listen to what a griever needs to share, kind, generous attention, and a compassionate presence to tune into what one may need - even when it may be heavy or raw, especially when a life is cut too short.

In April, a vibrant, lively, and independent woman named Octavia, who was 26 years old and had an intellectual/developmental disability, traveled on a bus from her group home to her day habilitation program in the Bronx, NY, both managed

by S:US, when she died due to a heart condition. Emergency medical technicians arrived at the scene, provided immediate medical attention, and took her to the hospital while a few of her housemates, peers, and staff witnessed her failing health. Soon after Octavia's accident and subsequent death, the management team requested a grief support session for her friends and peers with intellectual/developmental disabilities along with staff at her day habilitation program.

During the grief support session, passages by researchers, writers, and doctors were shared to help them understand the context of their feelings and learn more about symptoms of grief. The emotional, physical, and behavioral responses of grief were shared, some of which included sadness, anger, guilt, anxiety, feeling lonely, helpless, shock or numbness; feeling a hollowness in one's stomach, tightness in one's chest or in one's throat, a sensitivity to noise, breathlessness or muscle weakness; and experiencing changes in sleep, appetite disturbances, feeling absent-mindedness, social withdrawal, crying, sighing, and/or restless overactivity. The symptoms of grief were reviewed along with psychoeducational information to normalize what they may experience or what may arise for them as they mourn their good friend and peer.

In the article Forgotten Grief: Helping People with Developmental Disabilities Manage Personal Loss, Thomas Holmes writes: "...rather than trying to protect bereaved people with I/DD, counsellors and support staff should provide a supportive presence; offer concrete information; and advocate for the inclusion of the bereaved in decision making, rituals and mourning activities... A person-centered approach to assisting the bereaved has been shown to increase their understanding of their own

see Grief Support on page 27

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- Encouraging good hygiene
- Understanding public/private behaviors
- Handling issues surrounding boundaries and relationships

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- Healthy Bodies Toolkit:
 A Parent's Guide on Puberty for Girls with Disabilities

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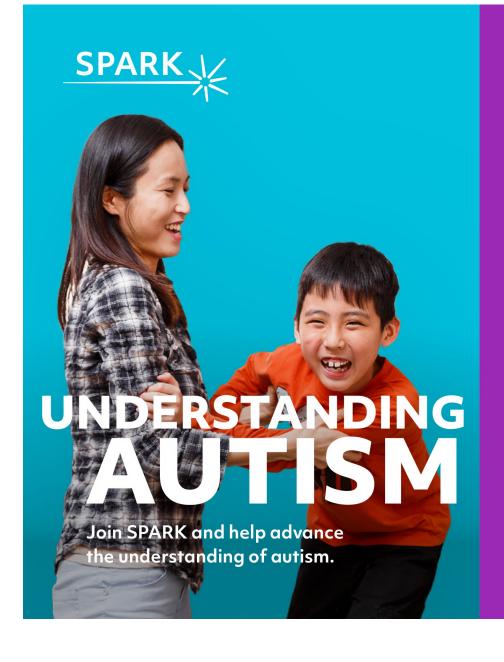




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Cora Taylor, PhD, is a licensed clinical psychologist and researcher at Geisinger's Autism & Developmental Medicine Institute. She completed her doctorate in school psychology at the University of Tennessee and a postdoctoral fellowship at Vanderbilt University Medical Center. Dr. Taylor has experience evaluating children from birth through adulthood for a range of developmental disabilities and providing treatment to children and adolescents with autism spectrum disorder.

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Autism and the Troubling Risk of Suicide

By Marina Sarris SPARK Simons Foundation Autism Research Initiative

This article has information about suicide and suicide prevention. For help 24/7, please call or text the U.S. Suicide and Crisis Lifeline at 988.

ew people used to think about the risk of suicide among people on the autism spectrum. Researchers rarely studied it. Primary care doctors did not routinely ask about it. Most families had no idea that their sons and daughters with autism faced any particular risk of suicide.

But that has changed in the past decade. A growing number of research studies have found that autistic youth and adults appear to have higher rates of suicidal thoughts, plans, or behaviors than other people do. As a group, their suicide risk may be two to seven times higher than the risk for youth and adults who do not have autism.¹⁻⁵

Suicide is a major public health issue in the U.S. population as a whole, according to the U.S. Centers for Disease Control and Prevention. In 2019, suicide was the second leading cause of death for people ages 10 to 34. More than 47,000 people of all ages died by suicide that year. Many, many others thought about it or made an attempt.



"It's an incredibly serious public health threat to our country and worldwide," says clinical psychologist Lisa M. Horowitz, PhD, MPH, who researches suicide prevention at the U.S. National Institute of Mental Health (NIMH). "What we know about people with autism is that they are at higher risk for many other medical conditions, so it follows that they may also be at higher risk for suicide," she explains.

Horowitz notes that research is lagging, especially in children on the spectrum.

As a society, we have been slow to focus upon suicide and suicide prevention, particularly among people with autism and neurodevelopmental conditions, says Paul H. Lipkin, MD, a pediatric neurodevelopmental specialist and director of medical outpatient services at Kennedy Krieger Institute in Maryland. Lipkin is researching suicide prevention in autism and developmental conditions.

Decades ago, people who were diagnosed with autism often also had severe

developmental delays, Lipkin says. Their doctors and families may have believed that they were unlikely to attempt suicide, he says.

"But that thought has been dispelled more recently through public awareness and by research that shows that, in fact, not only can teens and adults on the spectrum have suicidal thoughts and behaviors, but even children can have those same thoughts," Lipkin says. "Suicidal behavior may in fact be a leading cause of injury and death in the autism community, and more needs to be done about this."

What the Research Shows

Several studies published in the last 10 years have examined suicide risk in people on the spectrum. One study published in 2020 stands out for its size. In Sweden, researchers identified 54,000 autistic people using medical records from 1987 through 2013 and compared them to 271,000 people who do not have autism. Researchers use a comparison, or control, group to see if having a particular condition or treatment affects an outcome.

In the Swedish study, researchers also included thousands of people who have a relative with autism, along with more than 1 million people who do not have autistic family members.¹

see Suicide Risk on page 33

Working to Prevent Suicide in Youth with Autism

By Marina Sarris SPARK Simons Foundation Autism Research Initiative

This article contains information about suicide and suicide prevention. For help 24/7, please call or text the U.S. Suicide and Crisis Lifeline at 988.

fter being bullied at school, the preteen boy came to believe that no one would care if he died. His therapist, whom he had been seeing for depression, told his parents to take him to the hospital for his suicidal thoughts. It was the second such hospitalization in his young life.

As his parents learned, their son is not alone. Youth who have autism, as he does, face a higher than average risk of having suicidal thoughts and behaviors. "I think the depression and anxiety cohabitate with autism," says his mother, who participates in the SPARK autism research study. It's true that autistic youth are more likely to have mental health conditions, and be bullied, than others their age.

Could doctors identify autistic youth who are thinking about suicide before a crisis occurs? Some researchers are studying tools that would allow them to do just that.

This is important because several studies have found that people on the autism spectrum have higher rates of suicidal thoughts,



plans, or behaviors than the general population. And healthcare providers have a unique opportunity to help: people often visit doctors shortly before a suicide.²⁻³

"The majority of people who die by suicide have visited a healthcare provider months, and sometimes even weeks, before they die," explains Lisa M. Horowitz, PhD, MPH, who researches suicide prevention for the U.S. National Institute of Mental Health (NIMH). "We think this is an opportunity, and a responsibility, for healthcare providers to identify people at

risk and then bridge them to help."

Horowitz led a team that created a suicide risk screening tool, the Ask Suicide-Screening Questions or ASQ, for typically developing children, teens, and adults. The four-question tool helps doctors quickly find out if someone is thinking about suicide, so they can intervene.

But what about autistic youth, who may have language and communication problems that could affect how they respond to such questions? Would the ASQ work with them? Testing a Suicide Risk Screening Tool for Youth with Autism

In consultation with the NIMH, researchers are testing the ASQ, along with new questions, with youth who have autism and other developmental conditions. The study is underway at Kennedy Krieger Institute in Maryland and will soon include Nationwide Children's Hospital in Ohio, says the lead researcher, Paul H. Lipkin, MD, a neurodevelopmental specialist who directs medical outpatient services at Kennedy Krieger. Researchers are comparing the ASQ to a longer, "gold standard" suicide assessment by a clinician, to see how well the ASQ identifies children at risk, he explains.

During a screening, a doctor or nurse asks youth four very direct questions about whether they have thoughts about dying or killing themselves. If they answer "yes" to any of those questions, the clinician then asks if they are having thoughts of suicide "right now." Anyone who answers "yes" to any of the screening questions receives a suicide safety assessment to determine next steps.

To take part in the study, a child must be ages 8 to 17 and able to speak, although a communication device can be used to assist.

This current study builds upon previous work at Kennedy Krieger in 2017, when clinicians used the ASQ to conduct 3,800 screenings of youth visiting their clinics

see Suicide Prevention on page 26

Autism Without Fear: Reframing Our Conversations About "Sex"

By Michael John Carley Facilitator, New York University Connections ASD Program

A quick thank you to Autism Spectrum News and Publisher, David Minot. I've known David and the publication for almost two decades, wrote for it more than once, and am thrilled to herein move my column, "Autism Without Fear," with the hopes of many years of collaboration. Now, David also deserves a special "trooper" award, as in my first submission, I am openly disagreeing with the popular notion (celebrated by this entire issue's theme) that sex should be taught in conjunction with relationships. I believe this is harmful (read on!), so... Thank you, David!

t's hard to admit when, by most people's definitions, you might be actually sex-negative. Gasp! You thought you had a positive attitude, right? And then - doggone it - you read a little, or you listened once to Dan Savage...It's tough, right? Well, take heart in that (I assume) you live in the US, a country that despite its relative economic and educational advances, is *ridiculously* sex-negative. You (and the autism world) didn't have a chance!

Ok. So we may not be the French or Dutch who allow underage "sleepovers"

Autistic Sex Education

1. Sex can be really wonderful. BUT...

2. Unwanted STDs

3. Unwanted pregnancies

4. Sexual assault/rape prevention

5. Sex Offender Registry

6. BE AFRAID!

7. Don't you feel great about sex now?

or give free birth control in public schools. But because of those aforementioned economic and educational advantages, we should know better - we do know better! But we consciously give in to insecurities that turn us into inordinately draconian, and frankly, punitive people. Whether it's...

- Religious-based abstinence programs in public schools
- Feeling the obligation to be critical of people that want to have sex 5 times a day...when you want to do it 5 times in your whole life (and vice versa)
- The false premise that Americans are against rape; when we so blatantly use it as a strategic tool in our prison system.
 And how in our façade of disgust at rapists we go out of our way to convince the survivor that they are incapable of ever

having a healthy sex life again

- How we lie about "trafficking" statistics or drive sex workers off the internet in the ruse of protecting them...when we are sending them back on the street where they are infinitely more susceptible to assault, and worse (psst...most sex workers aren't "trafficked." They're immigrants and single mothers who do this by choice)
- Our offense over porn, when given our reluctance to teach our young about how to actually have sex - porn has long since been embraced as our default sex education whether we like it or not
- How we love to laugh at the CEO we see in movies and TV caught naked with an apple in their mouth getting whipped by the dominatrix from behind...when the BDSM community is maybe the most honest and safe-sex-abiding community we have

Stop me now!

Why? Why do we do this to ourselves? Sex is about *pleasure*!...(and in the autism world, which I'm getting to, our messaging is even worse).

see Reframing on page 29



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AUTISM SPECTRUM NEWS ~ FALL 2022

The Importance of Proactive Sexuality Education for the Autistic Population

By Kate Langston-Rooney, MEd, BCBA, Kara L. Constantine, PhD, NCSP, BCBA, and Todd Harris, PhD Devereux Advanced Behavioral Health

or most adults, an important quality of life factor is romantic/sexual relationships. Autistic individuals are no different. However, they are less likely to receive sexual education in a proactive framework than their neurotypical peers (e.g., Sala et al., 2019). When sexual education is provided to autistic individuals, it is often in response to a problematic behavior, such as public masturbation, disrobing, non-consensual touch, etc., rather than proactively (Tullis & Zangrillo, 2013). Thus, the information Autistic individuals receive on sexuality focuses primarily on biological content and self-awareness/safety rather than helping them understand their own personal sexuality and how to have meaningful relationships (Sala et al., 2019). Stereotypes of autistic individuals' sexual awareness, such as asexuality or sexual immaturity, create additional barriers to accessing proactive sexuality education (MacKenzie, 2018). What research clearly indicates, however, is that autistic individuals are sexual beings and need education to understand their sexuality and support their quality of life (Hamrick et al., 2020).

Autistic individuals are incarcerated for sexually based offenses more frequently than their neurotypical peers, which can partially be attributed to a lack of proper sexuality education and a manifestation of their autism (Mogavero, 2016). Sexuality education offers vital safety skills that can help prevent abuse, teach advocacy, and offer positive avenues for sexual expression (Tullis & Zangrillo, 2013). Despite the demonstrated need, few available materials and resources are designed for teaching autistic individuals about sexuality. Of those materials, there is a paucity of research on their effectiveness (Sala et al., 2019). However, reviewing existing evidenced-based strategies offers insight into addressing the question of when and how to proactively teach comprehensive sexuality education to autistic individuals and how to respond to challenging sexual behaviors.

Unfortunately, when autistic individuals do not receive proper sexuality education, they may not be aware that their behaviors are contextually inappropriate. Further, the behavior observed may not even be based on fulfilling a sexual need. When sexual behaviors occur that are identified as dangerous, harmful to self or others, or contextually inappropriate, it is important to understand why the behavior is occurring so that an appropriate treatment plan can be designed. The first step in developing the plan is conducting a functional behavior assessment to understand the maintaining function. What may appear to be a sexual behavior (e.g., hands in pants), may be a behavior that a student has learned that allows him to escape from a task to go to the bathroom (Hamrick et al., 2020). Once



a function has been identified, a behavior plan can be developed to address the behavior based on the function rather than the topography. If the function of putting hands in pants is to escape, the student might be taught to request a break from class. If the function is sensory and the student is attempting to masturbate, they may be provided with socio-sexual education that would teach appropriate public versus private behavior.

What is the appropriate age to begin sexuality education for autistic individuals? Parents/caregivers and educators often focus on the limitations of the individual's developmental age as opposed to teaching to chronological age when considering sexuality education. Furthermore, perceptions that talking about sex will increase the likelihood of sexual behavior occurring is an additional barrier to early awareness. Research, however, suggests that autistic individuals who are not provided with proactive sexuality education are at increased risk for unplanned pregnancy, sexually transmitted infections, and sexual abuse (Hamrick et al., 2020).

According to the National Sexuality Education Standards (NSES), by second grade children should be able to label the proper names for body parts and by eighth grade adolescents should be able to understand and describe male and female reproductive systems. Travers, (2018) suggested that professionals and caregivers utilize Guidelines for Comprehensive Sexuality Education (CSE) developed by the Sexuality Information and Education Council of the United States (SIECUS, 2004) as a framework for teaching sexuality education for autistic students. Guidelines can be tailored to the needs of each individual and implemented proactively rather than as a response to problematic behaviors.

Although there are a variety of evidence-informed materials tailored to individuals with developmental disabilities and autism, little attention is given to how to teach these skills using effective evidence-based strategies (Travers et al., 2018). A generic curriculum is not sufficient for a population with such diverse

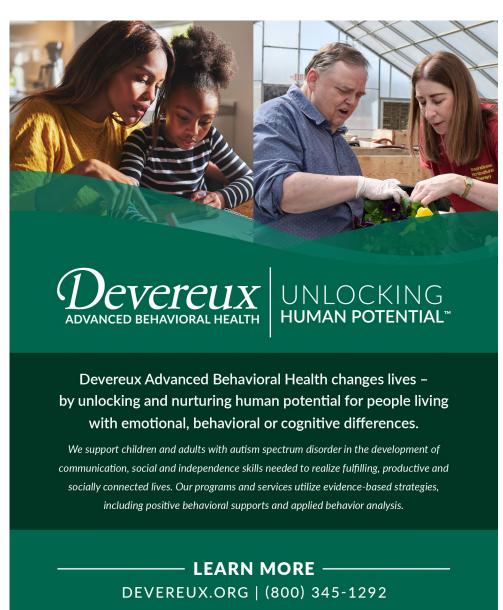
needs. Not only must curriculum be individualized, but the teaching style must be tailored to individual needs as well.

In 2017, The National Professional Development Center (NPDC), systematically reviewed research studies to determine the 27 most effective evidence-based interventions for professionals to use with autistic individuals. Many of these strategies are rooted in Applied Behavior Analysis.

Wolf et al., (2019) systematically reviewed nine commercially available socio-sexuality curricula to evaluate the use of 12 of these evidence-based teaching strategies. These included, modeling, visual strategies, task analyses, social problem solving, role-playing, strategies for generalization, story-based interventions, direct instruction, and scripting. Across the nine curricula, only three evidence-based interventions were consistently implemented (visual strategies, social problem solving and role-playing). This suggests that learners may not be accessing the information necessary and that a more individualized approach may be necessary when teaching autistic individuals.

Devereux's Community Adult Autism Partnership Program (CAAPP) recently piloted a commercially available sexuality and relationships education curriculum with a small cohort of autistic adults. Significant modifications to the standard curriculum were necessary to address individual needs. By adding additional visual supports, teaching at a slower pace, offering additional opportunities for role playing and regularly incorporating behavior skills training (BST) into the didactic instruction, teachers were able to deliver an

see Proactive on page 27



PAGE 12 AUTISM SPECTRUM NEWS ~ FALL 2022

Marriage Proposal Carries Consequences

By AHRC New York City

ayson Valles recalls the first time he saw Cecilia Primera. That was 12 years ago during AHRC New York City's Sunday Trip program for individuals with intellectual and developmental disabilities. He knew immediately that Cecilia was different than other women. He introduced himself to her and asked her name. "She is one of a kind. I'm always thinking about her and she's thinking about me."

Today, Jayson and Cecilia are engaged.

Engagement Surprises Parents

"Jayson loves Cecilia and he wanted to buy her a ring; a good ring," said Gloria Pizarro, his mother. However, she didn't realize that Jayson, who has autism, would propose on Feb. 19th, and post a video on Facebook Live and Instagram after Cecilia accepted. Family and friends began calling Pizarro, offering congratulations. The video was also shown during AHRC NYC Foundations Annual Thurman Munson Awards Dinner in March.

After walking across the Brooklyn Bridge with Cecilia, he proposed to her at Brooklyn Bridge Park. "We are going to be happily married," Jayson said.

While Cecilia did not wish to be inter-



Jayson Valles and his fiancé, Cecilia Primera, love walking across the Brooklyn Bridge and exploring New York City together

viewed, her mother, Myrian, said she was surprised to learn about the couple's engagement. "With the video, it was much more official," Primera said.

The more they learn about Jayson, the more impressed Cecilia's parents grow. "As long as she's happy, they treat each other well, and they respect one another, we're happy," Primera said.

Cecilia's mother admires Jayson's independence. She has seen her daughter's travel skills improving since she and Jayson began dating. They go out every Saturday, usually venturing to various parts of New York City - walking across the Brooklyn Bridge, visiting Times Square, or taking the Staten Island Ferry. They still meet during AHRC NYC's Sunday Trips.

Primera recalls escorting Cecilia to her first Sunday Trip program. "Jayson was the only one there who introduced himself and welcomed Cecilia to the group. From there on, they became friends," Primera said.

"It would be nice if they eventually married, but I'm not sure how that would look," she said, adding that Cecilia, who has an intellectual disability, requires a lot of support at home. "What I really want for her is to become more independent."

Jayson is a talented artist who participates in AHRC NYC's ArTech Collective program. He also participates in AHRC NYC's Bronx Day Habilitation Without Walls program. He lives with his family in the Bronx and has many relatives and friends in the borough.

Kecha Perrin, now a Certified Support Specialist (CSS) with Bronx Day Habilitation Without Walls, has known Jayson for four years. "Jayson is very welcoming," she said. "He's easy to get along with and extremely respectful. And, with every opportunity, he talks about his fiancé."

Cecilia lives with her parents in Manhattan. With only one cousin in the city, Primera said they have relatives in Venezuela. "I worry about that," Primera said. "I want to make sure she has something in the future that's stable for her."

Marriage Penalty

Between 5-9% of people with autism marry, according to a study.¹ One of the biggest challenges they and others with intellectual and developmental disabilities (IDD) face is what's known as the marriage penalty. People with disabilities can lose some of their benefits if they marry someone without a disability who earns a typical income. If two people with disabilities marry, they both could lose 25% of their SSI benefits.

Earlier this year, U.S. Rep. Jimmy Panetta (CA-20) introduced a bill² which would allow people with disabilities to marry without penalties.

U.S. Sen. Sherrod Brown (D-OH) introduced a bill³ in June of 2021 that also would allow people with disabilities to marry without losing critical benefits.

"The marriage penalty comes up a lot because people's rights are being violated," said Matthew Estep, AHRC NYC's Self-Advocacy Advisor. "No one wants to be told you can't get married (without risk to his/her benefits)."

When Estep raises the topic with students in AHRC NYC's Melissa Riggio Higher Education Program, the first reaction is "why?"

"The fundamental limiting factor in the lives of the people we support is not their disability, as much as it is a benefits-support system that is based on poverty," he said.

To get around the marriage penalty, many people with disabilities hold a celebration of love or commitment ceremony.

It may look and feel the same, but in the eyes of the law it is not a marriage.

Learning Opportunities Continue

Pizarro is trying to explain budgeting and social security to Jayson. While her son likes to get coffee and a sandwich at Dunkin Donuts on a regular basis, she explains that making the coffee and sandwich at home is much less expensive. With a background in social work, she's accustomed to working on these and other skills. Pizarro and her husband have helped Jayson develop life skills, such as cleaning the apartment, doing laundry, making his bed, and cooking.

Jayson is fluent in social media, posting cooking videos on Facebook Live. Calling himself "Mr. Hollywood J," he recently described the teriyaki rice and fried dumplings he had made. "I made them myself," he says proudly on the video. "Nobody's here. It's only me. I'm a grown man and I'm independent. I'm fine by myself and I'm happy." As he continues to eat his meal, he speaks his native Spanish at times. Cecilia posts a message, "I love you, my fiancé." Jayson responds on video, "I love you, too, my fiancé."

Recognizing boundaries is another area Pizarro is trying to explain to her son. On social media, not everyone watching is a friend, she said. She wants Jayson to understand that privacy is important.

Pizarro sees marriage as a long-term goal for Jayson. "Adults with intellectual and developmental disabilities have a right to live together and can live independently with some support," Pizarro said. "They have a right to be together with someone they love. He loves her very much."

"Jayson is very sweet," Primera said.
"He has a good heart and he's very careful with her"

AHRC New York City is the largest organization supporting children and adults with intellectual and developmental disabilities (I/DD) in New York State. Its mission is to advocate for people who are neurodiverse to lead full and equitable lives. Its vision is to help create a socially just world where the power of difference is embraced, valued, and celebrated. AHRC NYC was founded by parents of children with disabilities more than 70 years ago, when supports and services were unavailable to meet their children's needs. For more information, visit AHRCNYC.org.

Footnotes

1. International Journal of Culture and Mental Health. (2021). Marriage and family life in people with developmental disability. [online] Available at: www.tandfonline. com/doi/abs/10.1080/17447140903205317

- 2. panetta.house.gov/media/press-releases/ rep-panetta-introduces-marriage-equality-disabled-adults-act
- 3. www.brown.senate.gov/newsroom/press/release/sherrod-brown-portman-bipartisan-leg-islation-reform-supplemental-security-income-program-americans-saving-emergencies









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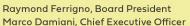
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Tips for Women in Relationships with Partners on the Autism Spectrum

By Marci Wheeler, MSW Indiana Resource Center for Autism Indiana University - Bloomington

t is a challenge for most couples to find a balance between their needs and expectations and their partner's needs and expectations. In a relationship where one individual is on the autism spectrum, there are likely many more opportunities for misunderstandings and frustration. Finding a path to a respectful, loving, and fulfilling long lasting relationship is every committed couple's desire.

In recent years, it has been helpful that there is more information and resources focused on neurodiverse relationships. More is available for couples and individuals, including more for women, in relationships with men on the autism spectrum.

This article is a brief summary highlighting information gathered from my experience as well as many women who have shared their stories with me over the years. A listing of resources is available at the end of this article to assist you in locating other information related to this subject.

1. Learn about Autism Spectrum Disorders (and how ASD affects your partner)

Autism is a neurobiological disorder that affects perception, communication, social skills, learning, and behavior. Informa-



tion processed by the senses can easily overstimulate an individual on the autism spectrum. On the other hand, an individual with autism can also have difficulty processing input from their senses and be under-responsive, unresponsive and/or have a unique response to sensory input.

Communication is frequently processed and interpreted differently for someone on the autism spectrum. Verbal communication is often processed more slowly and words interpreted literally. Persons on the autism spectrum often have trouble staying on topic and maintaining a conversation. Social skills are also affected. Eye contact may be difficult and sometimes facial expressions may not reflect an individual's true feelings. Social cues are often missed or misread. Individuals on the autism spectrum are not sure how to connect with others. Each person presents differently with his or her challenges. Many on the autism spectrum suffer from anxiety as well.

Your partner likely has executive func-

tion deficits. Executive function tasks include planning, organizing, prioritizing, time management, emotional regulation, and impulse control. Inertia, both starting and stopping tasks, can be a challenge for people on the autism spectrum. These executive function deficits may be mistakenly attributed to lack of motivation, and/or behavior or personality problems. Non-spectrum partners are often relied upon to perform many executive function tasks within the relationship.

There is now a variety of books, written about relationships when one partner is on the autism spectrum. There are books written by professionals as well as those written by women married to men on the autism spectrum. There are also some written by couples together. Some of these books are listed at the end of this article. Reading stories from others can be very validating of your feelings and experiences. Keep in mind that each relationship is unique. Some of the books are quite negative. Your partner on the autism spectrum will have their own autistic characteristics as well as a unique profile of experiences, personality, and possibly other co-occurring diagnoses that are a part of what makes them unique.

If this is a new diagnosis, you and/or your partner may be working on accepting the diagnosis. Getting to acceptance may be hard for one or both of you. As you

see Tips for Women on page 30



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PAGE 14 AUTISM SPECTRUM NEWS ~ FALL 2022

A Brief Guide to Discussing Intimacy and Sex in Neurodiverse Couples Therapy

By Leslie A. Sickels, LCSW Clinical Social Worker

ntimacy and sex are healthy, natural aspects of human relationships. Yet, this topic is often unaddressed by both therapists and couples seeking support. While differences and challenges related to intimate connections are not unique to neurodiverse couples, there are core areas of neurodiversity that frequently arise and can be effectively identified, addressed, and managed in neurodiverse couples therapy. This article aims to normalize challenges related to intimacy and sex in neurodiverse partnerships and assist both therapists and couples in identifying strategies to begin speaking more openly about these areas.

Intimacy and Sex

As a neurodiverse couples therapist, I begin all therapeutic work by having couples establish concrete goals to address throughout our sessions. Sex and intimacy are among the most frequent topics brought up by one or both partners. For neurodiverse couples therapists, it is useful to acknowledge to couples the normalcy of this topic so that it is "on the table" for couples to address. While there are therapists who spe-



cialize in talking about sex, all therapists should be able to address this fundamental piece of identity, as every person has a sexuality. Growing research shows "reduced heterosexuality and increased diversity and dysphoria in gender identity in autistic people" (Sala et al, 2020). It is important to recognize that sexual identity falls on a wide spectrum and can be personally identified in many ways, such as gay, straight, asexual, demisexual, and a multitude of others.

In neurodiverse relationships, partners brains are wired differently, which impacts beliefs, thoughts, and opinions. These differences in neurodevelopment can result in varying needs in intimacy and sex within a partnership. For many, intimacy tends to refer to an emotional closeness and connectedness between partners. Sex within a partnership is one way of cultivating intimacy. It often involves sexual contact or an exploration of physical sexuality, which

varies greatly from person to person based on preferences, desires, and sexual identity.

Often neurotypical partners express an un/under met need for emotional intimacy when they are looking for communication about emotions and interpersonal experiences. This is rarely a reflection of a neurodiverse partner not wanting, or trying, to meet those needs, but due to neurodiverse couples "speaking different languages" (Myhill & Jekel, 2015). In some partnerships, couples may attempt to achieve closeness by taking opposing routes. One wants emotional intimacy as a way to feel close enough to have sex, and another to use sex to feel connected and derive intimacy from that experience. Regardless of the approach, these areas are distinct and can both come up in a myriad of ways for neurodiverse couples.

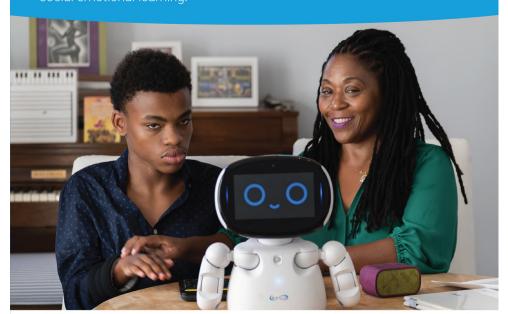
Strengthening Communication and Trust

Before a couples therapist can begin working on intimacy and sex, they must address other key neurodiverse couples challenges first. For many couples this is addressing both communication and working to rebuild trust. This requires couples to acknowledge and understand how neurodiversity is impacting their relationship

see Intimacy and Sex on page 20

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Recognizing and Understanding Neurodiversity in Couples

By Pat Schissel, LMSW and Grace Myhill, MSW AANE

any couples come to the realization they are in a neurodiverse relationship decades into their relationship, after listening to a podcast, reading a book, or watching a movie that includes an autistic character. But recognizing neurodiversity is just the beginning... Then what? How does neurodiversity impact an intimate relationship? What is the effect on the couple together and on each partner separately? Comments from couples often include remarks such as, "we speak different languages," "we feel disconnected," and "we want to develop emotional understanding."

AANE's Services for Neurodiverse Couples

Neurodiverse couples often have difficulty finding therapists trained in neurodiversity or they may struggle with therapists who don't understand their complex issues. Our research has shown that working with untrained therapists can create even more problems for them. To support the need for trained therapists, AANE created the Peter M. Friedman Neurodiverse Couples Institute in 2017.

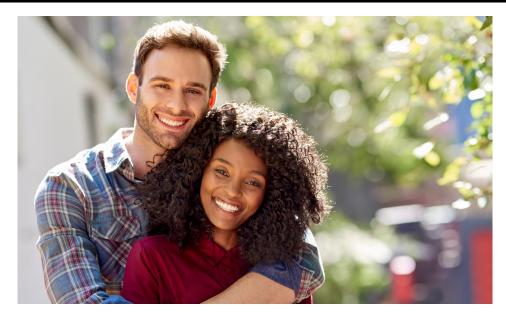
The mission of AANE's Peter M. Friedman Neurodiverse Couples Institute is to increase awareness, support, and resources for neurodiverse couples - in which one or both members are autistic - by providing specialized training for therapists to recognize, understand, and treat this unique population.

The Institute began with two courses for professionals: Training 101 and a follow-on course called Certification 201. Since 2017, over 176 couples therapists, and coaches have been trained and can be found on the AANE website's map. In 2021, the Institute's offerings expanded to include an online, self-paced course for neurodiverse couples: Couples 101.

TRAINING 101: Fundamentals of Working with Neurodiverse Couples in Therapy teaches therapists how to recognize, understand, and effectively treat neurodiverse couples in therapy. This is a 10-hour, selfpaced online training.

Developed by Grace Myhill, MSW, the course includes in-depth lectures from Grace and other experts in the field, including insights and observations from a panel of therapists who work with neurodiverse couples. In addition to hearing from professionals, participants will get an intimate peek into the lives of 10 neurodiverse couples as they share their experiences and the complexities of being in a neurodiverse relationship.

CERTIFICATION 201: Case Presentations and Advanced Topics in Neurodiverse Couples Therapy is for those who want to hone their skills and knowledge about working with neurodiverse couples in therapy. Classes meet 8 times for 90 minutes by video conference.



With a small group of 5 - 8 fellow clinicians, participants hear short lectures by Grace Myhill, MSW, on topics such as telling a couple they are neurodiverse, dealing with episodes of dysregulation, and discussing physical intimacy. Participants also present and discuss their own clients and have a Q&A session with a neurodiverse couple and a specialist in the field of neurodiverse couples therapy.

101 for Couples: Fundamentals of Recognizing and Understanding Neurodiversity

For neurodiverse couples, improving connection requires an awareness of each partner's neurological profile and an understanding of the role their neurological differences have on the relationship.

The three-hour online course is self-paced and includes four lectures by experts in the field of neurodiverse couples therapy and intimate interviews with nine neurodiverse couples on recognizing and understanding neurodiversity. There are also recommended resources and four downloadable PDFs, which describe common autistic characteristics and their impact on each partner and on their relationship dynamics, with strategies that worked for the couples.

The couples that you meet in the course love one another and work hard to understand and accept their differences. You will learn about the unique strengths and challenges these couples commonly face.

Experts in neurodiversity Grace Myhill, MSW, and Jamie Freed, MSW, cover areas of importance for couples to understand such as theory of mind, weak central coherence, and sensory sensitivity. Theory of mind is recognizing that others may view something very differently than you do and understanding their perspective. Weak central coherence is when an individual may be detail-oriented but has trouble seeing the overall picture. For example, those with weak central coherence visualize only what is shown on a partially rolled up map, such as a portion of a river or a road, but can't visualize the whole map in their mind until it is unfurled. Another area discussed in the course is sensory sensitivity. This refers to the impact of touch, sound, smell, body

awareness, and other senses that people might experience differently.

AANE also offers Couples Coaching. Intimate relationships can be hard, but they are especially challenging when partners have different perspectives, communication techniques, approaches, and skill sets. In Neurodiverse Couples Coaching sessions, which can occur individually or together with the spouse/partner, discussing their unique relationship is at the center. Neurodiverse Couples Coaching includes learning to problem solve, develop coping strategies, and build skills to improve their relationship. Topics that neurodiverse couples often seek help with include: communication, social or general anxiety, executive function challenges, rigidity, obsessions or hoarding, sensory issues, lack of emotional reciprocity, or physical intimacy.

AANE offers open groups for the neurotypical spouses in neurodiverse relationships. They will gain a sense of community and find others navigating similar situations, along with learning new words and phrases to explain some of what they are experiencing and a host of resources to assist them

AANE has much to offer couples and spouse/partners as well as families and individuals including free resource and referral calls with clinicians, online discussion forums, conferences, webinars,

Training 101

support groups, and coaching, not to mention the many first-person accounts on the website. Check out www.aane.org and subscribe to AANE's emails and newsletter to stay informed.

Pat Schissel, LMSW, is a social worker and New York Director of the Asperger / Autism Network, AANE. She taught at the graduate level at CW Post and Adelphi Universities and was given an honorary doctorate at Adelphi for her contributions to the field of autism. Pat facilitates a number of groups for AANE including a monthly Spouse/Partner Group. She is a certified coach through her work at the Peter M. Friedman Neurodiverse Couples Institute at AANE and is an Advisory Team member of the Institute. Pat is a founding member of the Editorial Board of Autism Spectrum News. Pat can be reached at AANE at pat. schissel@aane.org or at her private practice for couples or neurotypical spouse/ partners at patschissel.msw@gmail.com.

Grace Myhill, MSW, is a pioneer and leader in the field of neurodiverse couples therapy. Since 2004, she has worked with over one thousand neurodiverse couples together or separately. She has developed numerous skill-building tools and lessons to enhance communication and emotional connection. Grace offers a variety of online groups for the many facets of this unique population: for neurodiverse couples together, for partners with an Asperger's/autism profile, for neurotypical partners who are currently in a neurodiverse relationship, and for neurotypical partners who are separated or divorced from an ex-partner with an Asperger's/autism profile. She currently holds the titles of Director of Couples and Partner's Services and Director of the Peter M. Friedman Neurodiverse Couples Institute at AANE, where Grace trains professional clinicians to work effectively with neurodiverse couples through online courses she developed for AANE. She has written several articles and is a frequent guest on podcasts. For more information visit www.gracemyhill.com.

For therapists or partners in a neurodiverse couple who would like to learn more about AANE's online trainings and other resources, contact Grace Myhill at grace. myhill@aane.org.



Training and resources for neurodiverse couples and couples therapists.

Courses from AANE's Peter M. Friedman Neurodiverse Couples Institute

https://www.aane.org/neurodiverse-couples-institute/

101 Certification 201 101 f



101 for Couples

Sexual Consent and Communication

By Kate McNulty, LCSW and Morrigan Hunter MA, MSW

istorically, professionals have assumed autistic people are incapable of engaging in partnered sexual activities or are uninterested in intimate relationships. Most services for autistics continue to focus on affected family members with children. Until recently, research on autistic sexual relations was directed at controlling and regulating the behaviors of autistic and other disabled people. Instead, these marginalized groups are now seeking to explore and express their sexual identities.

We see increasing recognition among academics, caregivers, and clinicians that autistic adults have a right to advocate for themselves as sexual beings. While autistic self-advocates have made gains, services to specifically address the sexual needs of autistic adults do not exist yet. Television shows like Love on the Spectrum and Atypical acknowledge that autistic children do indeed grow into adults who experience romantic interest, so there has been progress. However, even this programming usually includes the participation of parents and their commentary on the adult subjects' personal lives. On a cultural level, including parental perspective in this type of media content serves to further diminish autistic autonomy.



At the same time, autistic people often require additional skills or supports to effectively communicate and navigate nuanced interactions. Autistic people have a range of abilities and strengths and should be seen as being capable of making their own decisions. Many have been through training or therapies that encourage compliance at the expense of recognizing their own needs. This becomes especially difficult for people who lack interoception, the awareness of one's internal bodily sensa-

> We love Students with

> > Special

needs!

tions; or who experience alexithymia, difficulty with knowing and naming emotions. We need to develop a sex education curriculum customized to the communication and decision-making needs of autistic people.

The sexuality of disabled adults has long been viewed as a social issue because of a wish to prevent unintended pregnancies. Fear of the disabled reproducing and potentially creating more disability or dependents for society to contend with has led to denial of the full adulthood and personal liberty of autistic people, particularly those with high support needs and those who remain in institutions.

With the advent of the #MeToo movement, interest heightened in the topic of consent during sexual interactions. For autistic people and their partners, it remains especially important to develop skills and awareness about consent. Here are some elements of autistic experience that contribute to difficulties, with suggested strategies.

Sensory Issues

Autistic people deal with unusual reactions to noise, fragrance, and lighting. One partner might experience irritation from background music intended to set a romantic mood. These sensory challenges often apply to tactile sensations as well. Someone may become distracted by a gentle caress or a surprise embrace. Autistics may feel pleasure from different sensations or levels of intensity than neurotypical people. For example, it is common that autistics request touch with deeper pressure; some experience sexual pleasure through stimulation that would be perceived as painful by a neurotypical person.

Processing Time

Needing extra time to think of what they

see Sexual Consent on page 23

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Demystifying Autistic Gender

By Bernard Grant, PhD Writer, Editor, and Neurodiversity Advocate

earch online to learn about Autistic gender and you'll find a range of allistic (nonautistic) articles stating that the link between autism and gender "diversity" and "dysphoria" are "not so clear." Researchers apparently "do not yet understand why" there's a strong correlation between autism and gender variance, or why some studies have found that Autists have higher rates of gender variance and "dysphoria" than the neuromajority.

Some of these articles incorrectly conflate gender variance and dysphoria and miss the reality that gender "dysphoria" is a result of parents and doctors making decisions about someone's identity before that person is old enough to determine who they are.

Part of the confusion stems from viewing gender as a biological fact. Gender is a neuromajority social construct, an everchanging collection of cultural beliefs related to biological sex; it's an unnatural concept created from neurotypical cultural norms. Gender identity refers to a person's perception of their gender. Gender is not binary: woman or man. Neither is biological sex.

The expectations society places on a person based on that person's perceived bio-



logical sex are cultural, not logical. Most parents and doctors give infants gender identities that "align" with their perceived sex, and many determine a baby's gender before that baby is born. Infants grow. Many learn that gender is merely a social construct that they have not internalized the way their parents and doctors intended. This is especially true of Autistic people.

Much of the confusion about Autistic gender also results from viewing autism as a medical condition, some kind of "disorder." Autism is a natural neurological variance: a neurotype - a cognitive style attuned to logical reasoning.² Autism, unlike gender, is a biological fact.

Logical thinking is a key difference between Autistic and neurotypical minds. That Autistic minds are logical spaces explains so much: why Autists think and speak literally and in details, why high intelligence is common in our population, why we follow routines, seek truth, justice, and turn many our interests into specializations. Logical thinking is why small talk and other aspects of neurotypicality don't make sense to us - why many of us don't identify with the gender doctors and parents assigned us as infants.

Autists often don't notice social constructs, and if we internalize them we tend to internalize them in "unexpected" ways that don't align with mainstream views. Many of us see ourselves as gender agnostic. Many more have no attachment to our physical bodies, due to alexithymia and interoception variances.

Neurotypical culture is, conversely, concerned with physical appearance, and most neuromajority people attach their identities to their physical appearances, constructing their "selves" to align with how their bodies (should) look in relation to mainstream views.

Presenting towards society's gender expectations (heteronormativity) rewards people and sometimes the reward is that you simply aren't mistreated. An Autist's adherence to gender binaries is often a form of masking or camouflaging their Autistic selves to "blend in," appearing neurotypical, to avoid persecution.

Autists are not as mysterious as society claims we are.³ Neurotypicals simply lack insight into our culture, like we lack intuitive insight into neurotypical culture, as stated by the double empathy problem

see Autistic Gender on page 22

The Neurodiverse Love Relationship GPS (Gaining Perspective for Success)

By Mona Kay, MSW, PhD Founder Neurodiverse Love

eing married for 30 years and not knowing we were a neurodiverse couple until our 29th year of our marriage created a lot of "unintentional" hurt and pain for both of us. Learning we had differently wired brains helped me see our challenges and differences through a new lens, which led to forgiveness, healing, and emotional growth.

My ex and I divorced in 2018. However, I still love and care about him, and probably always will. We have the most amazing adult daughter in the universe, and she is an awesome combination of the best of us. In addition to creating her own amazing tapestry, she also has threads of my ex and I woven into her DNA that make her my favorite person in the world!

I am also very grateful for the 32 years my ex and I shared together. He was one of my best friends and my life partner for most of my adult life. However, I also know that, because we both loved each other deeply and I wanted to help him succeed in every aspect of his life, our relationship became "co-dependent." In addition, I over-functioned individually and in our marriage and that prevented both of us from fully realizing and becoming our authentic selves.

Since 2017, I have taken the time to learn about the changes I could have made



in our marriage to be both a better partner and friend. In addition, I've learned how I could have shown up differently for myself and my ex as well as how I contributed to the end of our marriage.

None of us can go back and change the past, however we can learn, forgive, heal, and grow-and that is what creating the Neurodiverse Love community has helped me do. In addition, I created the Neurodiverse Love GPS to offer some guidance regarding lessons I've learned that have helped me and may help others as we navigate the various routes that can lead to success (or challenges) in our neurodiverse relationships.

The GPS we may use every day in our cars helps us navigate the traffic jams, accidents, and other inconvenient delays that can prevent us from getting to our destination on time. However, when we are patient and open to trying "alternative" routes, we eventually arrive at the final destination we programmed into our GPS.

That's how I now view Neurodiverse Love relationships. When our destination

is a successful, healthy relationship with ourselves and our partners, we can find different routes (perspectives) that will help us get to the place we want to be. Whether we stay with our partners and learn from each other's strengths and differences or we end our relationships, the suggestions below may help each of us find a "route" that will bring more peace, joy and understanding to our lives.

Don't take things personally. Assume positive intent. If you're confused about something that was said or done, get curious and ask for clarification in a calm, respectful tone. Asking questions with compassion and respect helps you gather information that can lead to increased understanding. Don't assume that your partner is being critical or condescending if they ask questions or if they respond with blunt, short responses. We all have different communication styles and when we understand and value the way we each communicate, it can be a game changer!

Communication is more than just exchanging information or one-word responses. It includes reflecting back what you heard, acknowledging, and validating your partner's thoughts and perspective, sharing feelings, thoughts, and ideas. "Say what you mean and mean what you say.' However, do it with respect, kindness, and grace. Reduce defensiveness, blame, contempt, and judgment by using "I" statements instead of "you" statements. Discuss "one" issue or topic at a time. Slow down. Listen to understand. Find ways to communicate and connect with kindness and appreciation throughout the day. Share jokes, memes, songs, quotes, and information you think will bring joy to your partner's day. Sharing is caring!

Each of you can have different perspectives and both be right. What your partner says and does may not always make sense to you. However, don't make assumptions based on what "you" would do, or what "you" believe to be true. Be curious, ask questions with kindness, respect, and compassion. Work to create an emotionally safe, "judgment free" relationship, where you both feel comfortable being your authentic selves. Seek to "understand" each other even though you may not always agree with each other. Find the humor in life and try not to take life, yourself, or your partner too seriously.

see Relationship GPS on page 35

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Neurodiverse Couples: Making Meaningful Moments of Every Day - Having a Good Morning

By Grace Myhill, MSW Director, Peter M. Friedman Neurodiverse Couples Institute AANE

any neurodiverse couples struggle with emotional connection and intimate communication. They yearn for a romantic touch, a knowing glance, a kind gesture to make them feel close. These little things make a big difference in an intimate relationship. And when these small connecting moments do not happen for a couple, it can feel lonely and isolating for one or both partners.

As a neurodiverse couples coach, I use tips, tools, and strategies to help couples build closeness and learn to express their love in a way that works for both partners. By consciously creating moments of emotional closeness, neurodiverse couples can develop their own unique language of intimacy that strengthens their intimate connection.

Each day there are countless opportunities to create small connecting moments for partners to enhance closeness in their relationship. Taking advantage of these little moments can make for big changes in your relationship dynamics.

Through this series, let's go through



the parts of a day - morning, afternoon, evening - and see how you can do simple things to make big enhancements to your intimacy and connection with your partner.

Having a Good Morning

Good Morning Greetings - If you want to make it a good morning, think about how you and your partner greet each other for the first time you see each other in the morning. After a long break from each other during the night, how you first respond to each other in the morning can set the tone for the day. You don't have to literally say the words "good morning," but acknowledging your partner at the start of the day with a kind greeting or gesture lets them know that you are happy they are a part of your life.

You can connect verbally with "Hi," or 'Good morning," or "How did you sleep?" Or you can connect non-verbally with a smile, a touch, a hug, or a kiss. If you don't see each other in the morning, you can connect by leaving your partner a note with a heart or a smiley face, or send a text or email, even if it's just an emoji. A morning greeting may not seem like a big deal, but saying nothing may send the message that you are not happy to see your partner or that you don't care about them. There are many ways to communicate, to create a small meaningful connection, so pick a way that feels meaningful and comfortable for both you and your partner.

Coffee or Tea, and Quality Time with Me? After a sweet good morning, you can also make someone's day with a kind gesture. When someone knows that their partner is thinking of them and taking the time to do something nice for them, it makes them feel loved. If your partner is a coffee or tea drinker, or if they like almond milk, orange juice, eggs, and bacon, or whatever they like first thing in the morning, consider making it for them. When your partner sees that you are focused on doing something for them that they like, it will show them that you care and that you know

see Good Morning on page 32

Autism, Masking, and Sense of Self

By Sam Farmer Neurodiversity Community Self-Advocate, Writer/Author, and Public Speaker

n a rightly ordered world, the need to mask, or to hide one's true self in order to "fit in," would not exist. We all deserve to be who we are without being punished for doing so. But the world in which we live is anything but rightly ordered in this respect. A multitude of autistic individuals including me can relate. We have had to endure far more than our share of challenge and adversity, simply for being who we are: social isolation, sexual violence, bullying, torture, workplace discrimination and disproportionately high unemployment/underemployment rates, to name but a few examples. After all, we have no choice but to contend with rules around socialization and behavior which were not written with us in mind.

I listen to the stories being told by my fellow autistics on social media and during support group meetings and I often find myself heartbroken. I react this way in part because of the injustices that are leveled upon good, well-intentioned people and partly because some of them feel they must hide their true selves in trying to avert such injustices. Masking comes at a cost, particularly when practiced continually over long stretches of time, in which case some of the autistics I've heard from actually



lose track of who they are. Furthermore, there is a risk of burnout because of the sizeable expenditure of energy and emotional hardship which masking frequently entails. As for unmasking, the prospect of doing so is often extremely anxiety-provoking, if not frightening, largely because of the stigma surrounding autism.

Some of the autistic individuals I have met admit that they don't know how to mask while others mask but to little or no avail. Trying to be somebody you are not, but which the greater society expects you to be, is a tall order to say the least. That kind

of expectation is both unfair and unrealistic.

Stimming is a form of behavior commonly exhibited by autistics which involves repetitive body movements or noises. It is a self-regulatory strategy on which we often rely when dealing with sensory overload or when experiencing intense emotions such as joy, excitement, boredom, fear, stress, and anxiety. Arm or hand-flapping, finger-flicking, nail-biting, rocking back and forth while sitting or standing, jumping, spinning, and twirling are typical examples.

Stimming is one reason why autistics mask. In this case, fear can be a motivat-

ing factor, the fear of what could happen should others bear witness. When stimming is suppressed, the risk of a meltdown escalates in that autistics are denied an important means of coping with challenging situations. The sensory sensitivities which tend to accompany autism lead to challenging situations becoming commonplace, resulting in a heightened need to stim and the greater likelihood of a meltdown. A no-win scenario, regardless of whether stimming is exposed or masked.

My own lived experiences as an autistic illustrate how the stigma around autism and the act of masking adversely impact self-esteem. During my formative years, I wore the mask of a people pleaser. Doing so unfortunately made perfect sense, granted my pronounced sensitivity to confrontational situations as well as the fact that I knew I was different but did not want to be.

Masking was my way of turning away from myself by trying to cover up my differences so that I could be more like my peers. I believed that doing so would lead to a greater sense of belonging. My need for conflict avoidance was the driving force behind my eagerness to be on good terms with everybody with whom I associated. And yet, I was publicly ridiculed, bullied and cut down to size more often than I should have been, and frequently felt socially isolated. It didn't occur to me at the time, though looking back in hindsight,

see Masking on page 26

An Exploration of Why Autistic Adults Are Practicing Consensual Non-Monogamy

By Janet Walsh, BPsychSc(Hons) and Mark A. Stokes, PhD Healthy Autistic Life Lab Deakin University School of Psychology

utistic people are more likely to report difficulty making and sustaining relationships, ¹⁻³ leading to assumptions that they aren't drawn to socializing, but we now know that autistic people desire and benefit from platonic, romantic, and physical relationships to a similar degree as non-autistic people. ⁴ In a recent study of general sexuality, autistic respondents were more likely to report engaging in polyamorous and/or non-monogamous relationships. ⁵ This is notable given that the existence and complexity of autistic relationships is often still underestimated.

Polyamory is a subset of a practice referred to as ethical or consensual non-monogamy, or CNM. CNM encapsulates relationships where all parties are aware of, and consent to, potentially engaging in multiple simultaneous relationships, be they solely romantic, only physical, or both.⁶ CNM is estimated to be practiced by about 4-5% of adults in Western populations,⁷ however this is noted as unreliable, as polyamory, polygamy, infidelity and CNM are often conflated, stigma may sup-



press reporting, and convenience sampling can result in unrepresentative cohorts.8

CNM relationships take many forms,^{9,} with all members dating each other or seeing different people. Some make agreements not to date outside the established group, to only date people of a specified gender, or that additional partners are only to be seen on a non-romantic basis. Some groups live and raise children together, and

some CNM relationships are conducted entirely by long-distance, with little to no physical contact.

In a society where monogamy is the more common relationship choice, these various structures can lead to complicated social dynamics and difficult emotions, with little societal modelling for how to navigate them. ¹¹ This may lead to expectations that autistic people would be less interested

in such relationships, given characteristic challenges with socialising and emotional regulation. ¹² However, some facets of the lifestyle may actually lend themselves to autistic tendencies.

Why Does Consensual Non-Monogamy Appeal to Many Autistic People?

Just as we know that all autistic people are individuals in their personal preferences, there could be many and varied reasons that some may find themselves interested or involved in CNM relationship dynamics.

As it can lead to less time spent with each partner, CNM can suit those who prefer autonomy and control over their living space and schedule.¹³ CNM can also allow them to delve into their special interests without distraction.¹⁴

Long-distance relationships are often maintained through written exchanges. These allow emotional connection without feeling obligated to engage in physical interactions. Such remote and careful responding suits autistic people with challenges in verbal communication, auditory processing, or sensory sensitivities.¹⁵

The tendency for most autistic people to be compelled towards overt honesty¹⁶ may, at times, cause more frequent disclosure of

see Non-Monogamy on page 31

Intimate Relationship Failures From an Autistic Perspective

By Zosia Zaks, MEd, CRC Zaks Autism Consulting

he standard narrative positions autism as the cause of relationship trouble when a non-autistic person dates or falls in love with an autistic person. The autistic partner is assumed to be the disruptive or difficult one. Self-help books offer non-autistic partners tips on how to cope with their autistic partner's neurodivergent traits and behaviors. This paradigm is rarely questioned. Even many autistic people assume their autism-related features are a serious barrier to relationship success. This is simply not true. My three serious, long-term relationships of many years all ended in total failure - but ultimately, discrimination and ableism is to blame - not autism.

My first relationship was a long time ago before my autism diagnosis, and while worthy of exploration, I am going to focus on my second and third relationships in this essay. My second partner became extremely abusive. Often, her abuse was related to my autism. If I had a sensory issue, she would accuse me of "faking it" to get out of an activity. If I needed time alone, she viewed this as a personal attack. She abused me mentally, physically, sexually, and financially. Our partnership, which included marriage and children, ended in a horrible divorce. She then dragged me through the court system for years, try-



ing to take the children away from me by claiming my autism and my transgender identity made me unfit to parent. Eventually, the children and I got the protection we needed. I have had sole legal and physical custody since they were four years old.

My third relationship, of nine years, seemed to be a dream come true. After a life filled with traumatic events and mistakes, I thought I had won the love lottery. She was kind. She was funny and fun. She was smart. She had disabilities, too. She claimed that she accepted my neurodivergence and that she loved my unique traits

and perspectives. I followed all of the usual relationship "how to" advice, proceeded slowly, and made tremendous effort to communicate and compromise. I was sure we would be partners for the rest of our lives. We looked forward to growing old together, sipping tea on the porch, and making sarcastic remarks about everyone and everything, just like Walter and Slater in the Muppet Show.

I was in shock, then, when after nine years of what seemed to be a dream, I discovered she had been cheating on me for the better part of a year. She had begun to

go away on weekends because she said she was under tremendous pressure at work and needed time alone to destress. I always believe that what people are telling me is true. Many autistic people do. I took her on her word that she was going away to get some respite. Self-care is good, right?

I walked over to her house for dinner one night - we chose to live nearby but in separate houses for several reasons - and she was wearing someone else's ring! My heart actually hurt physically. I called my doctor because I thought I was having a heart attack.

We went to therapy, ostensibly to salvage our relationship. She secretly took this person on vacation and lied about the trip while attending therapy virtually! Anyway, she stated that it was my fault that she cheated. According to her, my autism traits and limitations were so irritating that she just had to turn to someone else. I could not believe what I was hearing!

She said, for example, that she was sick and tired of "walking on eggshells" because of my sensory issues. I have a really difficult time with the sound of silverware scraping plates and bowls. This makes eating with others a little challenging, but not impossible. Options for reducing my sensory distress include scrape-free plates, plastic forks, picnics, finger foods... When I was very young, my mother tenderly let me eat alone in my room and then as a com

see Relationship Failures on page 34

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Autism and Adolescence: For Many, the Most Challenging Time of Life

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

t is a well-known conventional wisdom that adolescence, or the teenage years, are a difficult time of life for everybody and that this has probably been the case since time immemorial. It is equally well known in the autism community that middle school (or, as it was known in my day, junior high school, or intermediate school) is by far the most difficult and painful school experience for nearly every autistic. It is no coincidence, then, that the onset and early part of adolescence occurs during the middle school years. This is the time when, due to puberty, sexuality first manifests and the transition from childhood to adulthood begins. Many issues that had not been very significant, or even conspicuous, and which were little more than personal peculiarities (perhaps even considered "cute"), suddenly present substantial challenges. While these may be daunting even for typical adolescents, they can be formidable and possibly insurmountable for most autistics. They can also be especially difficult for those on the spectrum who do not have severe impairments and are not intellectually disabled, particularly if they have splinter skills or unusual talents, or are "twice exceptional" students (as I



would no doubt have been classified had the diagnosis of ASD existed at the time), because there is a presumption that they should be able (or learn) to cope with such challenges on their own.

The Emergence of Sexuality

The most significant (and obvious) aspect of adolescence is the appearance of sexuality, which to a great extent was not present prior to this time. This is accom-

panied by changes in the body, along with powerful new drives that are completely unfamiliar. These in turn result in many psychological and socialization changes to the individual. Personally, I have always believed that these are essentially the same for autistics as they are for the general population and am not aware of any biological or medical reason why such should not be the case. The way that autistics react and respond to these changes, however, is usually very different. This is to be expected,

because the nature of social interactions, particularly between the sexes, changes dramatically around this time and social skills become far more important than they had heretofore been. An autistic with deficient social skills, who may not have experienced serious disadvantages up to that point, may suddenly find themselves at the "bottom of the social food chain" and not understand why this is happening.

One aspect of forming relationships that is especially challenging for autistics is the substantial "hidden curriculum" of requisite behaviors, which are implicitly understood by participants but never explicitly articulated, that is involved. Also, since most forms of romantic and particularly sexual involvement among adolescents are strongly discouraged and sanctioned by society, such activities among this age group are necessarily of a clandestine nature. This begins with the making of initial contacts and the formation of early relationships and continues as they progress. Clearly autistics, who are generally oblivious to both hidden curricula and clandestine activities, are at a tremendous disadvantage here. Also, they may never have experienced or even been exposed to such situations prior to adolescence, but now find themselves in an environment where they are commonplace. Once again, they are at a significant disadvantage.

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Intimacy and Sex from page 14

(Myhill & Jekel, 2015). Without a firm understanding of how neurodevelopmental differences are coming up in a partnership, couples can sometimes believe their partners do not have the best intentions for them or the relationship. In neurodiverse couples therapy, this requires psychoeducation about autism and helping couples re-contextualize their relationship through this valuable lens. Once a couple is able to see how the differences in brain wiring are impacting their relationship, they can begin to re-establish trust. Trust is a vital component of a healthy relationship, especially when discussing intimacy and sex. This allows couples to recognize the good intentions that exist from their partner and work on building communication that is clear and concrete so as to have better success in talking about ways to intimately connect. This is particularly important if one partner is feeling more vulnerable about sex or is less interested in this being a primary relationship goal.

Common Challenges

While building communication and reestablishing trust are vital steps, there are additional unique challenges that exist in neurodiverse partnerships related to sex and intimacy. Due to different neurodevelopmental wiring, partners often come into relationships with vastly different experiences and ideas which can present



Leslie A. Sickels, LCSW

barriers to connecting intimately and sexually. Some areas to be further explored in couples therapy, by either a therapist or a couple, include: past experiences with intimacy and sex, expectations of what relationships "should be," sensory experiences, social and sexual quota/desire, sexual preferences, executive functioning skills including initiation of intimacy and sex, rigidity about intimacy and sex being a particular way, and other co-occurring conditions such as depression and anxiety. It is crucial to explore these areas within couples therapy to identify if any of them are having an impact on the misses in com-

munication and each partner's experience of, and satisfaction in, intimacy and sex.

"How To"

One of the most important aspects of neurodiverse couples therapy is for a therapist to translate for each partner and work to build more effective, clear, and concrete communication. This means addressing neurodiversity, working on core relationship challenges, and setting specific goals related to intimacy and sex. In order to effective work on these challenges and differing needs, they have to be brought up within couples work. A neurodiverse couples therapist should facilitate conversations about each partners' needs, desires, and quota for both sex and intimacy. It requires giving context, or more information than you otherwise may think necessary, to clarify why something is experienced as unfulfilling and the specifics of what is needed for it to improve. Without clear goals around addressing deficits, strategies cannot be identified. This does not mean one partner identifying a need and the other one complying. Rather, it is an exploration of why someone needs a particular thing to feel fulfilled and satisfied based on neurological differences. Then, how their experiences of intimacy and sexual contact may improve with different understanding, tools, and strategies. Mitran (2022) noted that "an individual's ability to consider others' perspectives increases the likelihood of relational success." This further

reinforces that once couples can see the others' perspectives by clearly and openly communicating about their needs and desires related to intimacy and sex, they can begin to effectively strengthen this area of their relationship in couples therapy.

Leslie Sickels, LCSW, works with neurodiverse couples and individuals on the autism spectrum in New York. For more information about Leslie's therapeutic work and neurodiverse couples therapy visit LeslieSickelsLCSW.com.

If you are a therapist and want to learn more about supporting neurodiverse couples, Neurology Matters offers a training and certification program available at aane.thinkific.com.

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What My Autism Has Taught Me About Dating and Relationships

By Claire Jack, PhD Autistic Therapist and Training Provider

was diagnosed as autistic in my late forties, after a counsellor first suggested I might be autistic. Discovering I am autistic has helped me make sense of almost every aspect of my life, including my long-running unsatisfactory history of dating and relationships, up until the point I met my husband.

My entry onto the relationship scene started when I was seventeen when I met Gary, a 24-year-old man who was the object of my affections. My obsession with Gary transcended all my previous obsessions (namely dogs and U2). I had no interest in anything or anyone else and skipped any classes he wasn't in so that I could spend time with him. Never great at regulating my emotions, I felt sick in his company and would blush so deeply my skin would develop unpleasant welts which looked like someone had taken a blunt instrument and scored it all over my neck and chest. Despite this, and despite the fact I had no inkling of his feelings, Gary liked me too.

After he manufactured a situation where we were both sitting side by side on his bed, he put his arm around me. I felt shockwaves go through my entire body, and not in a good way. My head felt like it was going to burst and I thought I was going to vomit. "I'm not comfortable," I



told him, whilst remaining stock still and looking straight ahead. He apologised and muttered something about picking up the wrong signals. I didn't try and correct him. There were no words to describe the depth of longing, and overwhelm, and feelings which were so huge they were unmanageable. There was no way to tell him how much I wanted to be touched, but that it had come as a shock I wasn't prepared for and it felt too strange for me to process. Instead, we sat in an awkward silence for an hour before I found an excuse to leave.

Gary persisted, and after a few weeks of handholding and lying side by side on top of his bed, we got together properly.

I never got any better at reading, or responding to, signals from would-be partners and my crushes never got less intense.

I didn't understand how my friends could fancy several people at a time; I only ever had one romantic obsession at a time which was so all-encompassing there was no room to like anyone else. It was rare that whoever I had a crush on had the faintest idea I fancied them.

What impact did all this have? Well, firstly it prevented some potential relationships from ever coming to fruition. In some cases, men I'd been secretly in love with told me, years after, that I'd come across as abrasive and a bit scary, which had put them off. In other cases, it meant I settled for being with people for whom my feelings *were* manageable; those who I wasn't obsessed with. In one case, I ended up in a relationship for five years with someone, mainly because it was easy and I

wasn't desperately in love with him.

In addition to the overwhelm and obsession I felt for people I liked, I had to deal with an inability to cope with anything approaching a pressured social environment. More formal "dates," arranged through dating apps, were a disaster. It must have been impossible for the person on the other side to marry up the shy and awkward person in front of them with the witty and articulate written version of me. To get through the dates, I generally ended up drinking very heavily, which never ended well.

At the age of 35, as the single mother of an 8-year-old boy (fathered by the man I'd "settled for"), I'd given up the dating scene. With the exception of a few one- or two-night stands, I'd been single for eight years. In addition to being unable to cope with dating, or picking up on signals, my self-esteem was shot. I'd recently left the academic job of my dreams due to the fact I couldn't cope with departmental politics. My social life consisted of seeing mums at the school gates; and having no idea how to communicate within the mums' world of kiddie conversations which was alien to me.

So, when Bryan – who was temporarily staying at my next-door neighbours' (his parents') house – turned up at my door at half-two in the morning and told me he fancied me, I was more than happy to invite him in. I can see why a lot of people

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Why Autistic Children Struggle with Developing Friendships

By Corinne Isaacs Certified Applied Behavior Analyst Therapist

hat makes it difficult for children with autism to develop friendships? Children with autism often struggle with social skills and attendant social cues. This includes both conveying and interpreting social cues. Social cues are the form of communication individuals develop and utilize to assess and interpret another's social behavior(s). By way of example, simple eye contact with another in and of itself is a basic form of communication. When we make eye contact typically it cues us the other person is listening to us. This leaves us with a sense of validation. Eye contact is a form of an emotional communication which tends to "bond" our relationships as well. While often we may take eye contact with another for granted, mere eye contact can often be difficult for the child with autism. The inability to read body language is often a barrier for children with autism as well, which includes a struggle to read facial expressions and appropriately detect the tone and cadence of a voice which can lead to misperceptions in interpreting the behaviors of others.

Social settings and basic task transitions are highly anxiety-producing for autistic children. They often struggle with a "stead-fastness" in their thinking and the child



may inadvertently come across as uncooperative, stubborn, and downright defiant. Often, too, when children with autism become extremely frustrated they may physically lash out which may be shocking to other children. Emotionally, children with autism struggle with processing jealousy which can create wedges in friendships and/or make it difficult for another individual or child to be and remain compassionate and understanding about the origin of the jealousy. Not knowing it is a barrier

affiliated with autism, the Autistic child may then be inappropriately shunned and/ or dubbed too needy.

Should you be able to put yourself in the shoes of a child with autism facing these significant communication barriers, I think you can surely agree there are a number of potential barriers and/or hurdles a child with autism must master, thereby making the ability to develop friendships difficult. Not only can the emotion of jealousy be burdensome to the child with autism; in a

fast-paced world where instant gratification is commonplace, neurotypical children often become impatient and lose interest in trying to develop stable and longstanding friendships with Autistic children.

Through a solution-based mindset, I would like to address the ways in which you can help a child with autism make and maintain friendships. A Washington Post article titled "How to Help Children With Autism Make, and Keep, Friends" has some great suggestions about how to accomplish this goal: "To be successful, they need to begin exercising their social and emotional muscles early, and in different settings, with children who have similar issues, and with those who do not. There are plenty of opportunities to gain experience in special programs designed for them, such as autism group meetups where they may engage with people their age who have similar needs." The article further validates this practice and informs us: "Children who do well get a lot of practice in generalizing skills in different scenarios, which they can then apply to other situations." The article finally establishes: "Programs that include typically developing kids alongside those with special needs can have benefits. For instance, they can help children with disabilities learn to interact with people in situations outside a closed community.

After learning of the broad barriers' children with autism face it would only be

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Inside Dell Technologies' Neurodiversity Hiring Program: An Autistic Cybersecurity Analyst's Success Story

By Sam Farmer Neurodiversity Community Self-Advocate, Writer/Author, and Public Speaker

ow can a company's neurodiversity hiring program be evaluated? In part, by listening to its participants' stories. Alex Sobil, Cybersecurity Analyst at Dell Technologies, is a case in point. His is a success story as inspirational as it is indicative of a truly inclusive workplace.

Sobil works on the Identity Governance and Administration corporate solutions team in Dell's Security & Resiliency Organization. He leads the quality control testing process for new computer applications, ensuring that team members have proper access to these applications while helping to keep Dell secure. He thrives in this role, in part because it aligns with his ambition to equip his colleagues at Dell with everything they need to be successful.

Sobil found out about the Dell Technologies Neurodiversity Hiring Program from a college career resource while searching for meaningful work after graduation. The program provides career readiness training, internships, and full-time career opportunities for autistic and other neurodiverse



individuals. He was invited to participate in a two-week session during which he learned about career opportunities at Dell, met with hiring managers and worked on real-world projects. This format enabled him to meaningfully showcase his unique skills, both as an individual and within a group dynamic, and under considerably less pressure than is often felt during a traditional job interview.

As an autistic, Sobil admits that it is difficult for him to express his value to a potential employer. While in Dell's Neuro-diversity Hiring Program, he worked with managers and mentors who understand the learning and thinking differences of neurodivergent individuals and received on-the-job training with a dedicated career coach. He describes the work environment as one that not only meets his

needs but champions his passion, knowledge, and unique perspective, motivates him to expand his skillset, and builds his confidence.

"Outside the box" thinking is a common attribute among neurodivergent individuals and Sobil is no exception. He regards finding and solving security defects through unconventional, creative methods as being among his finest accomplishments. Sometimes the issue at hand cannot be solved by classic techniques, in which case a proactive approach becomes necessary. He is able to anticipate the potential challenges he may need to address and places himself in the application users' shoes by considering the unique situations in which they may find themselves. This approach results in the discovery of security defects significantly sooner than would otherwise be the case.

A neurodiversity hiring program is only going to be as successful as the degree to which the people who are responsible for making it tick are committed to its success, and the extent to which the workplace culture is accepting of it. Put another way, those with whom neurodivergent participants in these programs associate will either make or break them. For Sobil, those

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Autistic Gender from page 17

(Milton, 2012). We do understand a lot more about neurotypical norms than neurotypicals understand about us - we've done this necessary work to try to understand those we share a world with. Yet we're pathologized, stigmatized, spoken over and for, mistreated, murdered. Marginalized. Even, or especially, when we ask people to include and accept us.

We accept that mainstream society has accepted man/woman identities for so long, yet allistics pathologize us for living within our own culture. Autism means experiencing life in your own space at your own time. We own ourselves. We also own our culture. People internalize their culture. Society pathologizes ours.

One aspect of Autistic culture that is public is autigender. Autigender means a person's gender identity is influenced by their Autistic mind. Though not every Autist identifies as autigender, the term illustrates why Autists are more likely than their neurotypical peers to identify with atypical gender variances - Autistic minds do not accept illogical concepts and thus make sense of them in unique ways, unless they reject these concepts altogether

I'm an Autist who lives true to my neurotype. Living this way promotes joy and self-acceptance and helps me avoid Autistic burnout. A common route to Autistic burnout is attempting to embody neuromajority culture. I've found that I can avoid burnout by seeing myself through as logical lens: as a raceless, genderless, asexual

human who lives and thinks Autistically, kinetically (ADHD), and through images and language - I think through words in part because my mind is dyscalulic: without numbers.

The prevalence of Autistic people who accept atypical sexual and gender identities is not pathological or "abnormal;" it simply represents the increasing prevalence of Autistic people who have rejected the labels society imposes on them. Likely because they accept themselves or are in the process of doing so.

Gender exploration usually means a person is seeking self-acceptance. If you want to support the Autists in your life through their gender exploration, a neuro-diversity-affirming approach will validate them and help you maintain a trusting relationship.

People like to discuss what Autists supposedly can and cannot do. Not enough people ask Autists what we want or do not want to do. Neurodiversity-affirming allies respect bodily autonomy, allow us to do what we wish with our minds and bodies. Instead of judging someone's choice to identify authentically, honor their choice, and believe them when they tell you who they are.

You can support gender variances by validating names, pronouns, and other language choices. Resist any urges to use a person's deadname, misgender them, or otherwise change someone into someone they are not. Release expectations if you want to connect with someone, and assume each person is an expert in their experience. Instead of trying to make someone fit your idea of what a human should be, find

out who each individual is and how that person identifies, no matter their neurotype or gender identity.

A neurodiversity-affirming approach to gender means that neurominorities determine their own individual definitions of gender. I believe that were over seven billion genders as everyone has their own gender - I see this when people who are comfortable with their gender identities express their gender uniquely. Authentically. Authenticity can't be wrong.

What's wrong is to pathologize someone because they fall outside cultural norms. Authenticity deserves celebration, for learning to accept yourself as neuro- and gender-variant is an accomplishment in this neuronormative, heteronormative society. Neurodiversity, the diversity of human minds, is about all of us, all humans. Diversity promotes stability. Stable environments help us all.

Bernard Grant is a writer, editor, and neurodiversity advocate (www.linkedin. com/company/writerly-nourishment). Learn more at their website BernardGrant. com, LinkedIn, or send an email to BernardGrant@gmail.com.

Footnotes

1. In a Neurodiversity Studies essay titled Language games used to construct autism as pathology, Nick Chown (2020) argues that the "failure of neurotypical society to appreciate that societal language games are, by definition, neurotypical language games has adverse consequences for Autistic people because of the inevitability

of cultural biases favoring neurotypicality" (p. 27). For similar reasons, it's helpful to label aspects of neurotypical culture as such and aspects of Autistic culture as such. Otherwise, we'll never understand the infinite variety of differences between neurotypes. And when we label neurotypical thoughts, beliefs, and behaviors as "human," we encourage society to see neurodivergent people who don't practice neurotypicality as pathologies, rather than humans.

- 2. If you don't believe Autistic minds are logical, keep in mind that Autists who try to embody neurotypical culture appear not to have logical minds when they enter Autistic burnout; they lose skills, and miss out on the opportunity to trust and improve their logical reasoning skills. Also honestly ask yourself if you understand logic or Autistic minds.
- 3. Our sensemaking "social" lives have been public and online for decades.

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AUTISM SPECTRUM NEWS ~ FALL 2022

Making Meaningful Connections: Amy Kelly Discusses Value of Devereux's Internal Family Support Group

By Amy Kelly, MBA, MNM National Director of Family Engagement Devereux Advanced Behavioral Health

t Devereux Advanced Behavioral Health, we are always looking for ways to better support our talented and hard-working team members. Devereux National Director of Family Engagement Amy Kelly, MBA, MNM, leads a family support group for Devereux employees and their significant others who are parents, caregivers or siblings of a child or adult with autism spectrum disorder and/ or intellectual and developmental disabilities. The support group offers a safe space for staff to discuss issues and explore solutions; offer strategies and resources; and manage stress and feelings of isolation.

Recently, Kelly, whose 20-year-old daughter, Annie, has autism and intellectual and developmental disabilities, shared how members of the support group, and their families, celebrated the end of summer and the beginning of the new school year.

"Summer always seems to go by so fast – days of heat and humidity, fun in the sun, staycations or, maybe, vacations to someplace new. Then, one morning you wake up with dew on the grass, a chill in the air



Devereux National Director of Family Engagement Amy Kelly, MBA, MNM, leads a family support group for Devereux employees and their significant others who are parents, caregivers or siblings of a child or adult with autism spectrum disorder and/or intellectual and developmental disabilities.

and leaves on the ground. Hello, fall.

Before the start of the new school year, members of Devereux's internal support group decided to get together in person (after meeting virtually once a month for more than a year) with our families to say, 'so long to summer.'

A colleague generously hosted the group

in her 'autism-friendly' house, meaning it was a safe space for our children to play and there were sensory activities built in. There was a relatively small group of us: two dads, four moms and five neurodiverse children, ranging in age from 5 to 20. Four out of five kids use speech-generating devices, and a few carried their favorite stuffed animal, or 'lovey,' for comfort.

One might think a 15-year age gap could dissuade our kids from 'playing together.' Nope, not one bit.

It was remarkable to see how the children (and us parents) easily assimilated to each other and the new environment. Sure, some kids flew around the space like tornadoes until they got their bearings, checking out every little thing in the house, while others hung back and stayed on their iPad or speech-generating device until they were ready to interact. After the first half-hour, this was a group of people who you never would have known had just met for the first time. The children had an innate acceptance of each other, not seeing differences, but rather similarities. After all, who doesn't like pizza, water games, tie-dye and pinatas filled with candy?! For us parents, it was wonderful to have a welcoming place to go with our 'unique'

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Sexual Consent from page 16

want to say, as well as finding the right words, autistic partners may struggle to adjust to changing circumstances as a sexual encounter develops. A non-autistic partner can associate spontaneity with romance and excitement while the autistic partner finds unplanned intimacy overwhelming. The autistic person may agree to a position or activity, only to find what they thought would be enjoyable is not as anticipated. This can lead to meltdowns or shutdown episodes that result in misunderstanding, hurt feelings, or worse.

Uneven Social Development

Autistic people are nine times as likely to be intellectually gifted as the general population. This can create a misleading impression of a mature social presentation in someone who is sexually naïve. Confusion comes up when the experienced partner realizes the bright person with a broad vocabulary or intellectual prowess doesn't know how to navigate an intimate interaction. Preventing abuse of autistic people involves teaching them how to differentiate what types of contact feel wholeheartedly good and what is unwelcome. This means focusing on identifying sensations of pleasure and enthusiasm.

Sexual Minorities

Autistics are six times more likely to be LGBTQIA than the general population. This factor increases vulnerability to harassment and abuse. Until recently



Kate McNulty, LCSW

sexual minorities encountered difficulty finding suitable partners in adolescence and deferred dating until college or later. With greater social acceptance this is finally changing, but in general Autistic young adults tend to be "late bloomers" and thus have less opportunity for learning experiences.

Helpful Tactics

Autistics are every bit as diverse in their sexual interests and practices as non-autistics; some value a robust interest in sex and imaginative intimate lives while others could take it or leave it. Adapting to the above challenges involves cooperation and

modifying expectations about how to express oneself. Partners can strive for flexibility in accommodating one another. For example, partners can problem-solve tactful ways for the sensory-sensitive person to express discomfort without rejecting the other person.

Autistic people can benefit from guidance about relationships and dating in general. The tendency to communicate directly and avoid small talk can make it difficult to connect with prospective partners. In terms of sexual interactions and consent, specific behavioral guidance can increase confidence and reduce misunderstandings and awkwardness.

Clinicians and educators can equip autistic adults with language and non-verbal communication so they can interact effectively in dating and sexual encounters. Examples of this include talking about a yes/ no/maybe list prior to sexual activity; using gestures and signals to indicate overwhelm or need for a break or typing out text communication on a phone. Someone who craves spur of the moment liaisons can work with their partner to identify what conditions or circumstances may make this possible. Meanwhile they can also broaden their repertoire to welcome excitement through planning and preparing for sex, sharing suggestive daytime text messages or flirtatious exchanges that cultivate anticipation for both people.

Partners can vary the communication medium they use as needed, so that a shoulder tap or shaking one's head serves to convey discomfort when talking isn't accessible. People who demonstrate caring and affection by accepting a range of behaviors, not just conventional or preferred styles, are much more likely to enjoy and sustain the intimate aspect of their relationship.

Future Directions

Services for autistic adults are progressing in terms of independent living opportunities, supported communication and recognition of autistic strengths. Along with these promising trends, the focus in sex education for disabled people on preventing problems like unintended pregnancy or STIs needs to shift to teaching about consent, pleasure and fulfilling relationships. This sex-positive, affirming framework will lead to increased sense of pride in autistic identity and seeing oneself belonging to a community of full-fledged adults.

Kate McNulty, LCSW, had a long career as a therapist when she began to realize she was autistic and came from a thoroughly autistic family. She has since incorporated this awareness into her practice and now sees many autistic adults. Her latest book is "Parenting Adult Children." Her previous book, Love and Asperger's, was published in 2020. For more information, please visit www.AutisticTherapist.com.

Morrigan Hunter MA, MSW, is passionate about leading conversations on disability, sexuality, consent, and pleasure. Some of their recent work includes guidelines for providing trauma-informed care to Autistic adults and to survivors of abuse who experience disability. They are Autistic and agender.

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Sex Education from page 6

But who determines which topics are most important, and what the priorities should be in a sex education curriculum for autistic people? For too long, the services and supports accessed by autistic individuals have been developed without input from our community. What sets the AASK apart, however, is that it is a sex education curriculum that will be designed by and for autistic people. As Principal Investigator, I am grateful and excited to bring my personal experiences as an autistic adult to this project, as well as other autistic stakeholders who will act as consultants on the project and help us to identify priority areas.

Through this collaboration, the AASK curriculum will be a living document that

is directly informed by the population it is meant to serve. Our knowledge of sexuality is ever-changing, as is our knowledge of autism, and rather than have the AASK sit on a shelf, immutable and fixed like the encyclopedias of old, our aim is to update this curriculum in tandem with our growing knowledge and the invaluable input of our stakeholders. Once the curriculum has been pilot tested and revised, our final goal is to broadly disseminate the AASK, both to professionals working in the field and the wider public.

Adolescence and young adulthood is a difficult and unpredictable time, even more so when autism is part of the equation. When I think of that 12-year-old girl having her first period, I remember how hard it was to survive that time. I remember that girl's confusion, her loneliness, and her despair at believing that she was the only one who felt that way. A sex education curriculum made by and for autistic people could have served as an incredible guide for navigating my trickiest teenage trials and would have shown me that it was okay to ask questions and to be who I was.

It is my hope that, when our work is done, the AASK will make a meaningful difference in the lives of autistic people and their loved ones and will show every autistic teen and young adult that it is okay to be exactly who they are.

Learn more about Amy Gravino at www. AmyGravino.com and about the RCAAS at rcaas.rutgers.edu. Amy can be reached via e-mail at amy.gravino@rutgers.edu.



Amy Gravino, MA, CAS

Struggle from page 21

natural to wonder if there is a specific age group of children with autism that struggles the most with making and maintaining friendships? While a significant percentage of children with autism struggle with making friends you can well imagine as young children we tend not to notice so much the differences in people or tend not to be so quick to judge and stereotype. It is society, social environments, social pressure, and the totality of our negative experiences, generally, that tend to develop and formulate our biases leading to the over scrutiny and premature judgment of others as we age. Adolescence is a developmental stage in which children are largely influenced by peers and peer pressure. Adolescents and teenagers with autism may need additional support to traverse this developmental stage as social cues become advanced in

innuendo and ultimately more complicated in nature.

As a parent, role model or caregiver to a child with autism what measures and/ or steps can you, personally, take to assist a child with autism to develop friendships? An article titled "Autism Can Be Your Child's Ally, Not Enemy, in Making Friends: 5 Tips on Turning Peers to Pals" on the Psychology Today website shares some didactic tips.

Now that we have addressed how to help our children with autism make friends let us also look at your parental or caregiver ability to make new friends and your own level of anxiety in social settings and how that may affect a child. Children whose parents are transitioning through divorce and given the uncertainty and imminent fear of the parents' divorce often constantly "scan" a parent's emotions, thoughts, and behaviors during the

transition of the divorce. These children are often looking to a parent for reassurance that the transition will be okay and are extremely tuned into a parent's anxiety level. It is therefore important for the divorcing parent to remain calm and communicative and attempt to maintain self-confidence throughout the divorce process. These attributes, role modelled for many children dealing with any psychosocial stressor, are key to the development and growth of the child and can make the world of difference, naturally, on how well and rapidly a child adjusts to a psychosocial stressor. In other words, children will often react to psychosocial stressors based upon how you, the parent or adult, reacts to the psychosocial stressor. If you are very nervous in social settings, your child and particularly children with autism easily sense your discomfort which may put your child on edge as well.

Though children with autism struggle with making friends they are generally very keen to make friends and there can often be a sense of joy and exuberance for the child with autism once a friendship is developed. Observation, supervision, inclusion, consistency in parenting and educating the social circle of a child with autism are all keystones to success in helping a child with autism make and maintain solid friendships.

"Most people see what is, and never see what can be." – Albert Einstein

Corinne Isaacs is a Freelance Writer. She has been writing for 14 years under the name Corinne Frontiero in the United States, as Corinne Isaacs in Canada and as Corinne Isaacs-Frontiero, globally. Corinne may be contacted, directly, through her website at https://corinneisaacsfrontiero.weebly.com/.

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with whom he associates at Dell align quite nicely with the former outcome.

Sobil meets with his manager on a weekly basis to discuss his trainings, workload, and projects and is given ample opportunity to discuss any additional supports he feels he may need. His manager was trained as to how to properly support neurodivergent employees, always listens to what he has to say and proposes solutions when necessary. Sobil did not have to disclose his diagnosis or justify his capabilities. Instead, he was able to immediately apply his strengths and provide immediate value.

Sobil also has a job coach who helps

him develop interpersonal skills and deal with new challenges of which there have been many as a result of the pandemic. In addition, he is paired with a mentor who teaches him, among other things, how to network with his colleagues.

As for Sobil's peers and team members, he feels empowered to reach out to them whenever he requires guidance as to how to best approach and execute his projects. They are always respectful and kind such that he does not feel pressured to do work for which he feels unprepared. His colleagues have helped him expand his understanding of cybersecurity and of new technologies in this space.

Sobil benefits from accommodations

which enable him to be at his best. Regrettably, accommodations granted to neurodivergent individuals for this reason can lead to jealousy and resentment if the workplace culture is less than accepting of neurodiversity. Not the case for Sobil and the IGA corporate solutions team. In his view, the accommodations he receives are not even noticed, primarily because they contribute to his productivity and to his ability to support his fellow teammates. In a climate of acceptance, understanding and commitment to excellence, accommodations benefit not only their intended recipients but also those with whom they collaborate.

A truly diverse, equitable and inclusive

workplace, and a success story that proves it!

Sam Farmer is a neurodiversity community self-advocate, writer/author, and public speaker. Diagnosed later in life as autistic, Sam shares stories of lived experiences, ideas, and insights as to how one can achieve greater happiness and success in the face of challenge and adversity. A Long Walk Down a Winding Road - Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. Visit samfarmerauthor.com to learn more.

Family Support from page 23

children, and not feel judged if they did something unusual.

The comfort of a family support group is priceless. There is knowledge shared. It doesn't matter if you are just starting your journey or have been on this road for a while, you can always learn something new. There is mutual compassion, and someone who understands what it means

when you say you are having a 'bad day.' Also, there is a sense of trust and hope. We are each other's cheerleaders.

With their permission to use their names, I would like to give a special shoutout to Devereux internal family support group members Kristin Schloendorn, Anita Smith, and Rachel Cervin Kubel for sharing their families and a very special day with me and my daughter, Annie. As summer comes to a close, we wish

you and your family a successful school year ahead!"

Amy Kelly, MBA, MNM, is the mother to Danny, Annie and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities and general anxiety disorder. Amy is the National Director of Family Engagement for Devereux Advanced Behavioral Health, one of the nation's oldest and

largest nonprofit providers of behavioral healthcare, and serves as a family representative on several special needs boards in the community, locally and nationally. In addition, she participates with other patients and families in efforts supported by the Autism Care Network and serves on an executive committee for the American Academy of Pediatrics to assist children and adolescents with special needs and the importance of quality care.

Circles of Sexuality from page 1

Sexual Health and Reproduction - This category includes attitudes and behaviors related to producing children, the care and maintenance of the sex and reproductive organs, and the health consequences of sexual behavior (such as sexually transmitted infections). It includes the "factual" information we typically think of when it comes to sexual health, including puberty, menstruation, intercourse, pregnancy, and birth control. Often, our sex education programs start and end here, but there's much more that should be included to be truly comprehensive.

Sexual Identity - This category includes the development of a sense of who one is sexually, including gender identity, gender expression, and sexual orientation. This is an especially pertinent topic for students with autism, as research shows that many autistic individuals identify as "not heterosexual" and often identify as trans or non-binary. While some may balk at the idea of including discussions of gender identity or sexual orientation in schools, the benefits of providing queer-affirming sex education have proven to be crucial for the wellbeing of students.

Intimacy - Intimacy includes the ability and need to experience emotional closeness to another human being and have it returned. Caring for others, liking or loving others, emotional risk-taking, and vulnerability are elements of intimacy. It also includes topics like social skills and communication - common themes for autistic individuals in other educational settings. The topic of intimacy is especially important for students with autism. There is a common misconception that autistic individuals are emotionless, or cannot feel love and intimacy in the same manner as neurotypical individuals. The reality is that people with autism need intimacy and connection just as much as anyone else, but sensory differences experienced by autistic individuals means that their expression of love may not mirror what our society views as "typical." This myth of emotionlessness can result in exclusion from these discussions, leaving them more vulnerable to abuse.

Sensuality - This topic includes an awareness, acceptance, and comfort with one's own body and the bodies of others. Sensuality covers a range of concepts, including body image, skin hunger (the need for physical touch), masturbation, and pleasure. This is often an area where the taboo of sexual pleasure can prevent educators from including these discussions in sex education programs. Namely, many educators and caregivers worry



Nellie Galindo, MSW, MSPH

that providing information on sensuality or pleasure will encourage students with autism to "just do it," or initiate sexual activity. The research on this tends to point toward the opposite, where students who received comprehensive sexual health education were more likely to delay the onset of sexual activity. Pleasure-based sex education programs help to normalize the idea of sexuality as a positive experience, rather than something to be feared. It also emphasizes the importance of giving and receiving consent, not just in sexual relationships, but any relationship.

Sexualization - Sexualization refers to the use of sexuality to influence, control, or manipulate others. It involves a range of behaviors from flirting and seduction to rape and sexual harassment. For individuals with autism, it's especially important to include these discussions in a sexual health education program as difficulty reading social cues or understanding boundaries can create scenarios where they could both be at risk of victimization or at risk of victimizing others. It is also beneficial to frame sexualization around the concepts of power and control. Recognizing when there could be a power imbalance within relationships (such as between a boss and an employee) can help autistic individuals more easily identify potentially unsafe or abusive situations.

Values - The final, and perhaps most important circle, are values. Values are central to our sexuality because they serve as a guidepost for how we conduct ourselves within sexual relationships. Values are also heavily influenced by family and cultural, spiritual, legal, and political systems. Helping autistic students determine their own values helps bolster their self-efficacy when it comes to choosing (or not choosing) sexual relationships. It also allows the individual the opportunity to be able to understand and name their values so that when they find themselves

in a situation where their values may be compromised, they feel better prepared to address it. It is imperative that sex education programs do not attempt to force or influence one particular value system onto the individual, but rather help the individual determine what their own values are and how to communicate these values to others.

The Circles of Sexuality framework is excellent at describing a comprehensive sex education program, but it can also appear overwhelming at first glance - especially when many of us have never received such a robust sex education. It can be difficult to find curricula that not only include these topics but are also adapted to meet the needs of students with autism.

It is also a topic that one educator or program cannot tackle alone. Do not be afraid to seek out those who recognize the importance of true comprehensive sexual health education and lean on the expertise of those who can adapt or create curriculum to meet the unique needs of autistic individuals.

Nellie Galindo, MSW, MSPH, is Founder & CEO of Accessible Sexual Health LLC.

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Masking from page 18

I was, to too great an extent, living my life according to what others wanted from me, and my self-esteem suffered for it.

I was unaware of the harm that my people pleaser mask was inflicting until my parents and a talk therapist I'll never forget managed to get through to me and wake me up to this reality. I am extraordinarily fortunate to have had them on my side. Prior to that point in my life, refraining from masking would have been unthinkable too scary for the younger version of me to consider. In this regard, the mask had been a survival strategy, albeit a deeply flawed one, until I began to break away from my old methods and bring forward more of the real me, slowly, and in small steps.

It wasn't until sometime in my mid 40's

that I emerged from the pit of doom into which masking and self-doubt had forced me, achieved self-acceptance, and finally felt comfortable in my own skin. Self-love would have eluded me had it not been for lots of hard work on myself, learning many lessons the hard way, help from clinicians, talents at which I was able to become proficient, and my parents and the aforementioned talk therapist repeatedly reminding me that I had plenty to be proud of and that I deserved to think highly of myself for this reason. Today, I am happy, emotionally stronger, self-confident, and not afraid to open up about my experiences with autism.

I want autistic individuals who contend with masking and compromised self-esteem to have what I had as I embarked on my journey toward becoming whole. Less stigma and greater understanding and acceptance of autism are needed, all of which would result in less pressure to mask. It would then become easier for us to live according to our genuine, authentic selves without fear of adverse consequence. We have much to contribute to the world and we are able to bring out the best in ourselves when we feel safe to be who we are.

Sam Farmer is a neurodiversity community self-advocate, writer/author, and public speaker. Diagnosed later in life as autistic, Sam shares stories of lived experiences, ideas, and insights as to how one can achieve greater happiness and success in the face of challenge and adversity. A Long Walk Down a Winding Road - Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. Visit samfarmerauthor.com to learn more.



Sam Farmer

Suicide Prevention from page 9

for developmental pediatrics, autism, neurology, and other medical specialties. They found the highest positive rate for suicidal thoughts, 12 percent, in youth at the autism clinic.⁴

Some of those youth were already seeing therapists, psychologists, or psychiatrists. Depression, anxiety, and other mental health conditions are more common in people with autism. But in other cases, no one had suspected a mental health problem in some children before they screened positive, Lipkin says.

Doctors referred children who screened positive to mental health providers, day programs, or a hospital emergency department, or they prescribed a new psychiatric medicine, depending on the level of suicide risk.⁴

Other studies have also found higher rates of suicidal thoughts or behaviors in autistic young adults and children. Among autistic people who were 25 years old or younger, 25 percent had thoughts about suicide, and 8 percent had made a suicide attempt, according to an analysis of 29 studies by researchers in Ireland. Less than 1 percent had died by suicide.⁵

As part of its suicide prevention plan, the American Academy of Pediatrics recommends that doctors screen all patients starting at age 12 for suicide risk and depression.

Screening Autistic Youth for Suicidal Thoughts and Plans

For researchers, one challenging part of screening children and teens for suicidal thoughts is getting patients and their parents to agree to it.

In the 2017 study of the ASQ tool, about 30 percent of the parents of autistic youth at Kennedy Krieger declined the suicide risk screening. Most of those parents did not believe their children would understand the questions or did not think they were at risk for suicide.⁴

A few worried that asking about suicide might be harmful. "Some families were afraid to introduce those types of questions for fear that they might make their children think about something they hadn't thought about before," Lipkin says. "And other parents said they believed that children with autism and intellectual disability were not capable of suicidal thinking or actions."

There is less research on suicidal thoughts and behavior in people with both autism and intellectual disability. "Assessing suicidality in people with severe autism is very challenging, as intellectual disability and, more importantly, communication impairment, are significant barriers," says child psychiatrist Matthew Siegel, MD, who researches severe autism for a sister study to SPARK.

One large study found that autistic people with intellectual disability are more likely to attempt suicide than other people. That same study found an even higher risk among autistic people who do not have intellectual disability. That study involved more than 2 million people in Sweden from 1987 to 2013.6

Autism and Repetitive Thinking

Could youth possibly start thinking about suicide, just because they were asked about it? "This is the biggest myth about screening, debunked by at least four research studies that say screening does not cause typically developing people to think about suicide," says Horowitz of the NIMH. But autistic people are more likely to focus intensely on a topic, a kind of repetitive behavior.

Lipkin says his study is examining that question. "Our current study is looking at the whole notion of rigidity of thinking in autism, with a short follow-up to see if there's been some persistent repetitive thoughts about death," he says. "So far, it seems that those on the autism spectrum are not suggestible of suicidal thoughts as a result of the [screening] questions."

Safety Planning for Someone with Suicidal Thoughts

Researchers at Kennedy Krieger and at hospitals in Pennsylvania, Ohio, and North Carolina will be studying an intervention for decreasing the short-term risk to autistic people ages 15 to 24 who have suicidal thoughts.

During a "Safety Planning Intervention," doctors typically work with patients to make a plan to keep them safe while they receive therapy, medication, or other care. They discuss when to put the plan in action, things they can do to distract themselves, and emergency services they can use. "When someone is in a suicidal state, you

want to distract them," explains Horowitz, the clinical psychologist at NIMH.

Researchers want to see if modifications to the Safety Planning Intervention, which has been used with typically developing people, will help teens and young adults on the spectrum.

Modifications could include helping youth to identify their feelings and warning signs of a crisis, as well as finding autism-friendly activities to distract them from suicidal thoughts, says clinical psychologist Jessica Schwartzman, PhD, a researcher at Vanderbilt University Medical Center who is not involved in that study.

A safety plan may include activities such as time alone in a quiet, sensory-friendly room and doing something the youth enjoys, such as drawing or music, says Schwartzman, who researches depression and suicidal thoughts in autism. Some autistic teens may want to socialize with others in person, while others may prefer to distract themselves by chatting online, she says.

If their suicidal thoughts persist, youth can ask for help from relatives or other trusted adults, doctors, therapists, school counselors, or the 24/7 suicide prevention and crisis line at 988, Schwartzman says.

"Every child should have that [988] number in their phone so they can have someone to talk to at any hour," Horowitz says.

Making the home safer for someone with suicidal thoughts is another important step in safety planning, Horowitz says. That may mean storing over-the-counter and prescription medicine, weapons, and ammunition safely away from children and teens with suicidal thoughts. "You want to make sure there are no lethal means available," she says.

"When people are struggling with intense suicidal thoughts, they are not always thinking clearly. There are fundamental safety measures that people can take," Horowitz says.

Screening for suicidal thoughts in children and teens, and seeking mental health treatment, can relieve their current suffering, Horowitz says. And it may possibly prevent future problems.

"Suicidal thoughts are a gateway to having psychiatric disorders as an adult. If you can have early intervention in this process, maybe you are preventing this gateway from opening, where you have a child growing up to be an adult with a lot of psy-

chiatric problems. You have a chance to intervene on a developing person and spare them from a lot of suffering as an adult," Horowitz says.

Lipkin, who has diagnosed and treated children on the spectrum for decades, encourages his fellow pediatricians and pediatric specialists to think about suicide screening and prevention now. "We all know the dramatic numbers now around mental health and suicide. It is a huge public health issue that is, little by little, getting the attention it deserves."

Resources

- For help 24/7, please call or text the Suicide and Crisis Lifeline at 988 or call 1-800-273-8255. Online chat available.
- Text TALK to 741741 to reach the Crisis Text Line.
- Read the American Academy of Pediatrics' Blueprint for Youth Suicide Prevention.

Read part one of this series, "Autism and the Troubling Risk of Suicide."

Interested in joining SPARK? Here's what you should know.

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individually structured framework of the curriculum. Critical to success was that the instructors were comfortable discussing sexual content and able to offer accurate and fact-based information and participants felt that they were part of a supportive and non-judgmental group.

In an environment where uncensored social media content and the internet are so easily accessible, sexuality education is essential for all children and adolescents. Parents, caregivers, and educators are important partners in providing factual, age-appropriate, and accurate sexuality education to autistic individuals who have a demonstrated need for sexual awareness and safety, as well as a right to express themselves sexually and engage in romantic relationships.

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For more information about Devereux Advanced Behavioral Health, please visit devereux.org.



Kate Langston-Rooney, MEd, BCBA

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Grief Support from page 7

grieving experience (Barbato & Irwin, 1992). Raskin and Rogers (2000) explain that the person-centered approach must be maintained on the principles of empathy, unconditional positive regard and congruence."²

Empathy, empathic attunement, compassion, and a range of symptoms of grief were shared with the group to support them, to normalize their experiences, and promote self-understanding with the intention of decreasing any self-judgment. When one meets the bereaved with empathy, a compassionate presence and harmony, one can help the bereaved person give expression to their mourning and facilitate healing. Writer Lily Pinkus in her book Death and the Family: The Importance of Mourning shares, "From the moment life begins, human growth depends on accepting and mastering loss. The alternative to feeling loss in our gut is to risk irreversible damage to the life that remains."3 Creating a safe space to share feelings helps in promoting an acceptance of loss. The importance of grief support cannot be underestimated and the support can take many forms - through talking, sharing stories or photographs and memories; creating art by drawing, painting, a group collage or mural, and music; sharing food, favorite recipes or cooking along with many other activities and rituals.4

The grief support session was provided to 17 people including all participants who attend this S:US day habilitation program plus management staff, Direct Support Professionals (DSPs), and the bus matron from the bus transportation company. Compassion was emphasized, along with patience and self-care practices to help them process their grief and begin to express their mourning. Shaida, a participant in the day hab, shared that the grief support session "...was really good for me, it helped me to be open to what I feel and how I may change (with grief). It



Lori Lerner, LMSW, RYT-200 hr.

got me through missing Octavia and made me a stronger person. The session made me think of all the good times I had with her - sharing lunches, going out with her, swimming and visiting the water park. I feel angry that it happened. It's taking a long time but I'm getting there...she was like a sister to me. I really appreciated it (the session). It got me through some tough times. It helped me think of what Octavia would want us to do - be happy, continue living my life, and think of the good times I had with her. I just keep going forward."

Daymont, another participant from the same program shared, "I felt shock... the session was helpful. I am still missing her. It's okay to feel your feelings, make space for them."

For Stephanie, a DSP, the session was beneficial for her and for her work with the people that she supports. Stephanie views her mourning through the lens of "...acceptance and connecting with others. I learned to be patient with myself and others in the healing process. I continue to reminisce

about Octavia, to talk about our good memories and experiences that we had with her, and encourage the people we support to share them along with their feelings when they come up." Making space for memories and feelings are essential in encouraging healing when a loved one dies.

In the book <u>Healing Your Grieving Heart: 100 Practical Ideas</u>, Alan D. Wolfelt, Ph.D. writes: "The journey through grief is a long and difficult one. It is also a journey for which there is no preparation. Be compassionate with yourself as you encounter painful thoughts and feelings of loss and grief. Don't judge yourself or try to set a particular course for healing. Let your journey be what it is. And let yourself - your new, grieving self - be who you are." 5

Dr. Wolfelt encourages pausing, slowing down, making space for whatever feelings arise and honoring one's needs when one is in mourning. Justin, another friend of Octavia and program participant concurred when he shared, "Yes, the session was helpful, it was good that you made space for our feelings." Mary, a close friend of Octavia and another program participant, shared that the support was "...very helpful because I was a little heartbroken because we lost Octavia and I was close with her... I still can't get over it. I expect her to come running to me when I come to the day hab. I really miss her, I will never forget her and I have good memories of her. The support helped us gather around together, grieve together as friends and as a family to support each other. Holidays will be totally different without her.'

In The New York Times, writer and psychotherapist Patrick O'Malley wrote, "The truth is that grief is as unique as a fingerprint, conforms to no timetable or societal expectation." There is no reward for speed when one grieves. It is essential to make space for whatever feelings come up, seek out compassionate, kind people, and be kind and gentle to oneself in one's journey of mourning. It is a journey to be honored

and respected, along with one's unique experience in mourning, and reflective of the relationship that one had with the loved one who passed away.

The grief support session was valuable as it informed people that they can be compassionate and respectful towards their mourning. And as it pertains to their needs, they can share their feelings about Octavia as they come up, reminisce about the good experiences they had with her, and help each other during the difficult times as they continue to remember her and heal.

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Friendships from page 1

Tips for Parents and Caregivers

1. Introduce your child to social stories and use them as often as possible.

Many children with autism benefit from visual guides, particularly when learning something new. Social stories are a good way to teach a child how to respond appropriately in a specific situation. Writing scripts and drawing out the flow of a conversation can help your child understand the basics of how to talk to a friend.

Suggested resource: The New Social Story Book: Over 150 Social Stories that Teach Everyday Social Skills to Children and Adults with Autism and their Peers.

2. Create opportunities for your child to meet peers, such as scheduling playdates.

Help your child get together with other children who share his or her interests and strengths. This could be through a playgroup, a special interest club at school, or an after-school class. If your child goes to school, you could ask your child if there is someone in their class who they would like to be friends with. You could talk to your child's teacher to determine if there are children showing interest in your child, or which children have similar interests. It will likely take more effort on your part as the parent for the playdates to succeed, but the time and investment will be worthwhile for your child's social development.

3. Focus on the quality of your child's friendships.

Even if your child has one friend, this is a huge deal. Encourage that relationship in any way you can because that one friendship will likely be the foundation for your child to develop future friendships. It is not about the number of friends your child has, but it is more about the depth of the connection they have with their small peer group. So, do your best not to compare your social experiences or another child's social experiences to what you have observed with your child.

4. Educate your child on the meaning of friendships.

This may seem like common sense, but it is important that your child understands the role of a friend, the purpose of a friendship, and the role they play in a friendship. It will be much more difficult to make friends if your child does not know what it means to be a friend. These conversations can involve asking their perceptions of a friendship, how they know someone is their friend, and what traits they have that



April L. Coleman, PsyD

make a good friend. These conversations should include language understood by your child that is brief, clear, and concrete. Stay away from abstract concepts and use plain language.

Tips for Teachers

1. Educate yourself.

This means researching and learning what characteristics contribute to social acceptance and making friends. Trainings, consultation with qualified mental health professionals, reading books and other materials, and collaborating with other teachers are ways educators can learn and expand their knowledge base of Autism Spectrum Disorder and social skills.

2. Set up lunchtime social groups.

These friendship groups can give children the opportunity to have fun and connect with peers in a smaller setting, but within the school environment. They can be taught specific skills to determine common interests and engage in meaningful conversations and being involved can create a sense of social acceptance and belonging to a peer group. Teachers and/or school counselors can coordinate these groups within the school setting with a specific goal of promoting various social skills that can be generalized to different social environments.

3. Encourage group activities.

Make every effort to involve students in play groups and shared learning activities. Pairing students with one other person or putting them in small groups of three within the classroom can also promote social connection.

4. Create a positive buddy system.

When children with autism are paired with a confident classmate, they will learn to make friends, play well together, and adhere to social rules in an unstructured setting. These pairings can help in encouraging prosocial behaviors and can occur while walking down the hall, during recess, and when there is other unstructured time.

Most importantly, parents, caregivers, and teachers should have fun when supporting their children and students in social settings. If making friends feels like work, children will likely avoid the interaction. Support your child and students and make the process as fun and playful as possible because making friends is not always easy and can be especially overwhelming for autistic children and adolescents.

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Dr. Coleman enjoys working with families from diverse backgrounds and circumstances. She has worked in a variety of settings including schools, community mental health clinics, community service boards, child advocacy centers, specialized treatment centers, social service agencies, and private practice. She has also collaborated with institutions to conduct assessments within residential treatment facilities, within juvenile detention centers, within foster homes and group homes, and for the Georgia Division of Family and Children Services. With her years of experience, Dr. Coleman's clinical work extends beyond the assessment process and also involves providing support, guidance, and consultation to parents and caregivers post-diagnosis to ensure that the families' needs are met as best as possible.

Dr. Coleman is a former clinical psychology graduate level professor of five years in which she taught child and adolescent psychopathology and life span development, and she led a diagnostic assessment seminar for students within the child and family curriculum. She also is the current practicum site supervisor for graduate level students at Mercer University and the University of Georgia. Dr. Coleman is a graduate of Georgia State University and The Georgia School of Professional Psychology. She holds a Bachelor of Science degree in Psychology and a Master of Arts and Doctor of Psychology in Clinical Psychology. Dr. Coleman resides in Metro Atlanta with her husband and their 16-month-old daughter.

More information about Dr. Coleman and how to connect with her can be found at https://linktr.ee/psychdrapril and www.georgiaautismcenter.com.

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Reframing from page 10

Actually, there *is* a reason why we do this. The answer carries more explanation than justification, but whether you live in a more sex-negative or less sex-negative place on earth, what we are always fighting with our cultures is biology. The frenulum, clitoris, and anus want what they want. We don't have to give it to them all the time, but the degree to which we deny our bodies' needs is often far more developmentally debilitating than we'll ever know. Our cultures are always in conflict with our biology because we try to control said biology.

Look, autistic or not, I'm herein not that interesting either. I knowingly give in to cultural conceits because of my desire to be the best father I can be as well as to happily remain with the love of my life for as long as I can. For culturally-enforced reasons, few of us proposition fellow parents sitting next to their spouses at PTA meetings, and we don't have sex with a co-worker, at work, on a desk, in front of everyone, even if there's (semi) informed, mutual consent.

But my difference is that I've had educational opportunities to learn about certain culturally-enforced lies about sex. I know that no one needs to be "in the mood" to have sex. If the genitals are rubbed the right way, gosh dang it, almost all of us will get into that mood quite easily (Why does this come up? Why would you want to be in a relationship where you didn't want to take care of your partner's needs?) I also know that monogamy is not our natural way of living as a species. Uncertain paternity made life safer for children back in our hunter-gatherer days...

And again, many of us who think ourselves sex-positive are anything but. Think about it...

• You're straight parents. You'd be fine if your child was LGBTQ? Well how many LGBTQ events do you take them to, and what does that show (as about to tell)



Michael John Carley

your child about your comfort level with all things LGBTQ?

- Do you see people whose bodies show more pounds than usual and regard them as having less sexual potential than supermodels? Culturally-enforced depression and shaming may be a factor, but their genitals work the same.
- Are you a vagina-owner who has used hygiene products even though you have no discernible medical problem down there? Well, there's nothing wrong with the smell (anthropologically, it has also played a very integral role in our species' advancement). Many books even refer to the vagina as having "its own ecosystem - such fluids, as well as the semen from penises, actually contain far fewer germs than the saliva in our mouths.
- Are you a penis-owner who thinks of another penis-owner's values as reflecting their religious or political beliefs, but think of "How many men has she slept with?" when the same word ("values") is posed to you regarding women or non-binary folk?

I could go ON and on...but you get the

Autistics Get "Sex is wonderful, BUT!..."

As autistics, many of us may not have the great marriage. We may not have the great career or straight "A" students as kids (and that's should we have kids at all). Sex may be the best thing we have in our lives, and that includes those of us for whom elaborate and self-loving masturbation rituals might be the ceiling.

But often because of the horrors of law enforcement encounters, the dangers are driven into us at the expense of the benefits. Many of us charged with educating the spectrum young prefer to discourage, rather than encourage. This drives many of our folks away from even *wanting* a great sex life (and when this decision occurs, I have seen the relieved faces of many parents. This is sick).

Unwanted pregnancies, STDs, sexual assault, sexual assault charges...we teach these imperative lessons. Good. But we teach them under the wrong umbrella. The first two are *caused* mostly by sex, but they are not "sex." They should be under the umbrella of "Health."

So teach them as "Health" lessons.

The latter two are even more heinous. They revolve around either "the law" or "violence," not "sex." And I'm sorry, but what kind of a society confuses violence and sex?

So teach them as lessons about "the law."

My objection to teaching sex alongside relationships? Easy. Sex is not complicated, but relationships are. We can easily teach sex because of the biology. We can teach techniques for how to please another person using a penis, vagina, anus, hand, mouth, foot, or a toy...on a frenulum, clitoris, or anus... And usually? This is the only kind of sex education we actually want! What we *all* want is confidence!

But relationships are *really* complicated (another article, perhaps). So teaching the two together then makes sex feel much more complicated than it is. Also..."Friends first"? Baloney. No one gets aroused because someone looks friendly.

During my ten years of running the largest membership organization for adults

on the spectrum in the world (at the time, GRASP), I can't tell you how many spectrumites I talked to who physically shook as they conveyed that "Michael I don't want to have sex because it's too scary!"

And they usually didn't. We did that to them. It was mean. It was an awful thing to do, perhaps to several generations.

So: Let's teach sex as sex. It's exciting and fun. No one suffers from low self-esteem when they're having an orgasm.

Let's inform our kids what their options *really* are. The probability of a non-speaking individual requesting to go to a "Donald Duck rules" sex club (i.e., no pants) may elicit laughter. But it is possible (and happens!). So let's help them find that sex club - Oh, and if you're not comfortable with that (admittedly, few are), find someone who is - Uncle Ralph, or exotic cousin Edna - otherwise you deny them as sexual beings.

Give us permission to *give ourselves permission* to seek physical pleasure.

Sex is wonderful. (No "BUT!...")
That's it

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wouldn't see that as a great move, but his approach was perfect for me. We carried on what I guess many people would call a "booty call" type of relationship for a couple of years, despite the fact that I was completely obsessed with him and pined for him when he moved to a different part of the country. I kept my feelings deeply hidden. And I liked the fact that I had someone I liked, who I could have sex with, without the hassle of getting ready for, or going to the pub or having to thinking of witty conversation.

Bryan and I have now been together properly for thirteen years, in addition to the early casual days. I panicked to the point of nearly not turning up during our first coffee date. Despite the fact we'd been sleeping together for years, I struggled with the conversation as much as I had on any blind date of the past. Luckily, we

knew enough about each other to make it a little more bearable.

I know that my less-than-auspicious start to my relationship with Bryan wouldn't be appealing to a lot of women, and many of my friends thought I was "missing out" or "being used." In fact, for me (and I can only describe this from a personal perspective), our slow-burning relationship, without the pressure of dating, meeting the families, buying Christmas presents, and all the other stuff which overwhelms me, was the ideal foundation for a marriage and building a family.

What have I learned over the years? Firstly, sometimes autistic people thrive in unconventional situations and relationships; it might look odd to other people, but if it works you then it's fine. Secondly, I'm never going to come across well in a formal social dating situation; I need to meet people in different social contexts. Thirdly, I experience things very intensely; trying

to ignore those feelings means I miss out. Finally, I know myself better than anyone else does, including my limitations when it comes to relationships. I know that, if anything were, God forbid, to happen to Bryan I would stay single; it's been so tough meeting the right person and creating a life which accommodates both our needs that I wouldn't go through that again!

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Claire Jack, PhD

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seek to learn more about ASD and how it effects your partner and your relationship, you will likely be grieving the loss of prior expectations.

As you learn more and work on acknowledging the role an autism spectrum disorder plays in your relationship, it will be helpful to seek out knowledgeable professionals and/or join a support group for women partnered with men on the autism spectrum. These resources are available but may be hard to find. It can also be helpful to make a list of the positive and desirable qualities which attracted you to your partner. It is important to keep these in mind, especially when going through a challenging time in the relationship.

It will also be helpful to keep a list of your positive qualities. It can be hard to remember these positive traits about yourself when you are in the middle of very difficult and confusing times. Remembering the positive characteristics of both you and your partner will enhance your self-esteem and help motivate you as you work through your relationship challenges. Over the years, I have appreciated the determination I have seen from both the ASD and non-spectrum partners in pursuing solutions to build a stronger and loving bond.

2. Recognize and Address Sensory Needs (and issues with your partner)

Sensory issues very often affect individuals on the autism spectrum. As mentioned before, one or more of the senses may be affected. Senses may be overly sensitive (hypersensitive) and/or under sensitive (hyposensitive). Some people with ASD are hypersensitive to various lighting. For example, they see the blinking and/or hear the buzzing of fluorescent lighting. For some, headaches are triggered. A person on the autism spectrum may be overly sensitive to various smells and/or sounds in the environment. Light touch may feel like pins yet actual pinpricks may not be felt at all.

In some situations, a person on the autism spectrum may appear not to process sensory information from one or more of the familiar five senses of sight, smell, sound, taste, and touch. They may seem unaware of what is in plain sight and/or process words as "noise." These situations can seem very curious. Three other less known sensory systems are also often affected for many on the autism spectrum. These are the vestibular system (balance), the proprioceptive system (muscle/joint movement, coordination, motor planning and sense of your body in space), and the interoceptive system (state of internal body functions). Interoception is often referred to as the eighth sense.

There is some evidence that individuals on the autism spectrum can have both an impaired and an enhanced time perceiving their own bodily functions. This is called atypical interoception or interceptive dysfunction (Shah et. al., 2016). There are accounts of little awareness of needing to use the bathroom, get a drink (due to thirst), and/or eat (due to hunger). Some women report that they need to remind their partner to eat or drink something especially when they are deeply engaged in an activity that takes all their focus.

Sensory issues can impact just about all aspects of life from the selection of

clothes, foods, bedding, and furnishings that are comfortable for both partners to what environments and activities may be enjoyable for both partners. There are situations where heightened sensory processing can be an asset, such as an ability to process visual information quickly and/or in unique ways. Designing, carpentry, and engineering are skills that persons on the autism spectrum, including your partner, may possess as a result of excellent visual processing skills.

Sensory needs/issues can change over time and even vary from day to day. As an adult, your partner has likely learned to either cope with and/or avoid various sensory stimulation in the environment. Some common strategies used to effectively limit environmental sensory overload include tinted glasses, earplugs, and hats or specific clothing choices. Some individuals enjoy keeping small "fidgets" which can be calming and help counter the sensory overload.

At home, sleeping in total darkness and using a weighted blanket can be helpful for some. At home, hopefully, it is easier to adjust lighting and control or mask sounds and smells in the environment. Sometimes working with an occupational therapist who is trained in sensory integration can be beneficial.

Sensory issues can also affect intimacy. If there are sensory issues in the bedroom, they can be addressed with better understanding, patience, and developing strategies to accommodate the needs of both partners. You and your partner can discuss various sensory differences and consider specific adjustments that will be successful.

In situations where a person on the autism spectrum is stressed, s/he can more easily experience sensory overload and, as a result, shut down or possibly experience a "meltdown." A self-aware adult on the autism spectrum can usually recognize early warning signs and develop strategies to exit and calm down. Both partners who are aware of this can work together, so that both are accommodated. Many couples develop signals to communicate if the ASD partner is becoming overstimulated and needs a break. A break can take various forms that can be discussed in advance. If need be, this might mean taking two cars to an event so the ASD partner can exit the event and the non-ASD partner does not

3. Learn and Use Communication Strategies (that work best for you and your partner)

Optimum communication is important in all relationships. Social communication, by definition in the DSM-5 (APA, 2013), is a deficit for a person with ASD. Non-verbal communication, such as interpreting facial expressions, gestures, and vocal intonation is often extremely difficult. Verbal communication can be difficult for people with autism to initiate. These difficulties are due to a difference in neurology and not a lack of motivation.

It is helpful to your partner if your communication is clear, calm, and predictable. The person with ASD will usually want to meet their partner's needs once s/he understands how to meet those needs. Explicitly communicating your social, emotional, mental, physical, including sexual needs, is important. Together, partners should discuss information about behavioral expectations. Think in terms of explanation in-

stead of correction. Tell your partner your expectations and have them tell you their expectations.

Often you will need to provide very explicit and concrete instructions that your partner can follow. For example, if you need your partner to help with a chore such as doing laundry, give step-by-step directions on what, when, and how the clothes need to be washed. If your partner cannot figure out what to wash, perhaps having a system of preparing laundry baskets is needed. For example, circular baskets can be used for dirty laundry and square baskets for clean laundry.

You may need to give your partner with autism explicit information and practice on how to give hugs. This may seem as though your partner does not want to be affectionate with you, but remember not to judge their actions and needs through your non-spectrum lens. Any areas of need are important to address in detail. Communicating very literally and concretely will be important for many aspects of life. Some couples find that texting, emails, and/or information written out on paper, sticky notes, calendars, or wipe-off boards is very advantageous.

Consider scheduling a time each day to both sit and communicate. Sitting side by side might work best for communication. People with ASD almost universally say it is difficult to process verbal information while maintaining eye contact. This would be especially true when discussing each other's needs. This time together can go a long way to making life more satisfying and keeping your bond as a couple strong.

Again, consider using visual information (notes, email, a white board, even examples from books or other visual media) to convey or supplement verbal messages. Be creative. Visual information is much easier for most individuals on the autism spectrum to process, and it can be used as a permanent resource when anxiety, sensory overload, or executive functioning skills are causing challenges for our partners on the autism spectrum.

Realize that you might not understand your partner's perspective. Seek to clarify. Recognize that your partner may have a hard time asking (initiating) for clarification and/or even knowing that clarification is needed. Non-spectrum partners cannot interpret ASD behavior through their non-spectrum filter and assume that they understand the meaning of a particular behavior of their ASD partner. Likewise, the partner on the autism spectrum may have a hard time understanding their own needs. Each partner should identify their needs and tell their partner. It may not seem genuine if you have to tell your partner every step to meet your needs. Though it can be hard at first, do not think of it as meaning your partner does not care. Think of it as an important step to better appreciate, trust, and respect each other.

4. Find Outlets to Unwind (together and individually)

You and your partner likely have different ways of alleviating stress. Everyone is different and has different ways to relax. Being a neurodiverse couple, there may be more differences you will experience that will, at first, challenge you both. It is important that you both learn your personal ways of de-stressing and express these needs to each other. Partners must also respect each

other's needs and means to get rid of tension and anxiety. At times, this will mean separate and/or "parallel" activities. The partner, on the autism spectrum, may need much time to themselves and/or "extra" time to pursue their special interests.

Transitioning from work to home may be stressful for your partner on the autism spectrum. An "alone break" immediately upon arriving home is often described as "critical" by men on the autism spectrum. Without understanding and then planning for this important transition break, a road-block in the relationship can take place.

Your need to communicate and connect with your partner may have to wait and that can be very frustrating. Couples might use a visual system such as a wipe off board to communicate their stress level at this time of day. Plan for your partner's initial time alone when s/he gets home. Set a designated 30 minutes or whatever is reasonable and possible in your situation. Afterwards, time together or with the children can be scheduled. If needed, more alone time can be scheduled for later in the evening. Chores and other tasks and activities can also be scheduled. Predictable evenings can help alleviate stress and go a long way to ensure more relaxing and enjoyable times together as a couple.

Leisure time together can be an important bonding opportunity. Encourage humor in your life together. This will help enhance the relationship and help relieve some of the "extra" stress. It can be wonderful if you can find the right activities to enjoy together. This can include each of you exploring special interests together. This might take extra patience at first especially if some boundaries are important to establish. Parallel activities can also be explored; you are both in the same room or space but may be engaging in different activities for a period of time. It can be helpful to decide on the designated period of time in advance. A timer or other concrete reminder can be set. Be creative!

Social events are often difficult for a person with ASD and you will likely be the one arranging the social events. You may be the one with the most interest in these events and have the better "neurological" abilities (i.e., executive function capabilities) to make the arrangements. Your partner may be going along with your ideas because s/ he wants to please you and/or will enjoy most things if you are there. They will also usually enjoy themselves once they know what to expect. It can be beneficial if a "role" can be established for your partner at various social functions. This role could be any task(s) that would contribute to the event, such as helping with setting up or checking drinks or food. Discuss and plan what this would involve. Also, discuss options for a quiet space or place to retreat to take a break during social activities.

Your partner may need an actual "escape" plan when socializing gets too overwhelming or over stimulating. As mentioned before, one plan couples often use is to drive two cars so that the ASD partner can leave before their stress level gets too high as to result in a shutdown or meltdown.

You may have found your partner is very content to spend a lot of time pursuing a special interest. This can be an important calming technique. It is important that this time is balanced with other life activities and couple time together. If possible, this

Non-Monogamy from page 19

desires for additional partners. In turn, this may lead to negotiation for CNM instead of pursuing an affair, to maintain a sense of integrity.

Delays in social development can cause autistic people, particularly males, to start dating much later in life after acquiring the necessary social skills and confidence.17 Conversely, autistic women more often report staying in relationships formed in their teenage years, despite developing self-awareness that their needs are diverging from their partners. Whether they hope to engage in the kind of dating they missed out on in early adulthood or find partners who suit their newly developed self-identity, there could be reluctance to lose attachments formed with those who appreciate their unique tastes and mannerisms. This may be driven by fear of ending up alone or causing harm to those they care about.

Sometimes these personal revelations include increased awareness of sexuality and gender identity, and long into a treasured relationship, one might realise they're attracted to genders other than their partner's, or they might desire a transition to a gender which doesn't match their partner's orientation¹⁸ - CNM enables these needs to be explored whilst retaining these important connections and the lives built together.

Evidence suggests autistic people report LGBTQIA+ identities significantly more often than their non-autistic counterparts¹⁹ and the LGBTQIA+ community have historically been more likely to pursue CNM than cisgender or heterosexual individuals.²⁰ As well as those exploring gender and sexuality, CNM can appeal to those who don't feel comfortable in relationships that include both sex and romance. This can include asexual and aromantic people, who have also reported a higher tendency to be interested in CNM relationships.²¹

A newer term coined by the LGBTQIA+ community is "platoniromanticism." Yet to be attributed or formally defined in research circles, this refers to difficulty differentiating romantic and platonic attraction. When this occurs specifically due to neurodivergence, it is referred to as "nebularomanticism." Some research has indicated that polyamorous and asexual people are more likely to report this kind of "blurred" relationship status.²² Possibly relating to the difficulty many autistic people express in identifying emotions and sensing social boundaries. In turn, this could lead to more friends being elevated to partner status.

Difficulties Associated with Practicing Consensual Non-Monogamy

Although CNM may suit the needs of many, some may be compromising their ideal relationship structure to seek approval and secure or maintain intimate relationships, as autistic people demonstrate a higher likelihood of being victims of abuse and coercion.^{23, 24}

Research conducted by Pecora et al. (currently in submission),²⁵ suggests autistic people may feel obligated to engage in "transactional" relationship behaviours, where they agree to do things for their partner that they'd rather decline if they felt empowered to do so. In some situations, CNM may be one such compromise.



Janet Walsh, BPsychSc(Hons)

Autistic people can also be more likely to acquire STDs, especially where safe-sex curricula in schools is lacking, as they may find it harder to gain communal wisdom through friendships in adolescence.^{3, 24, 26, 27} Even when one receives standard sexual education, the safe-sex practices which apply in a committed monogamous relationship may not carry over when one has multiple partners.

Interest Within the Community and Caring Professions

Programs focusing on providing guidance in intimate relationships for autistic adolescents and adults are proliferating. ^{28,29} One such program has reported receiving feedback from the autistic consultative group requesting that polyamory be included in the curriculum. ³⁰ Books written to encourage and guide autistic people in enjoying satisfying intimate relationships have also touted the potential benefits of exploring CNM. ³¹

As well as increasing recognition of the needs of the diverse adult autistic population,³² more psychologists and counsellors are also specialising in CNM,³³ and professional training programs are emerging which guide them in tailoring their practice to meet the needs of these groups.

Studies in Development

To date, scientific insights on autistic CNM have been incidental, predominantly provided in open text fields by autistic respondents in more general studies investigating sexuality and relationships.34, 35 However, the number of online blogs and public discussion boards discussing the topic suggests that autistic and other neurodivergent CNM practitioners would welcome a deeper understanding of whether they are more likely to have interest or experience in CNM, and if so, what might be driving this phenomenon. As such, the Healthy Autistic Life Lab is currently preparing a study to gather information from the autistic and CNM communities, with the hope that knowledge of the underlying factors may contribute to autistic adults enjoying personally meaningful, healthy relationships.

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Good Morning from page 18

something about them that they like. You don't have to do it every day, but this small gesture makes a big impact on your partner.

For an extra connecting morning, sit with them while they have their beverage or meal. You don't even have to speak. Just spending that time with them will show them they are a priority to you, and it will mean a lot to them.

What's on the Calendar for the Day? Knowing what is happening later in the day and being in sync with schedules and plans is important to a lot of couples. The morning is a good time to make sure that both partners are aware of what's on the calendar for that day. Take a few minutes to check that you both understand what your responsibilities are for the day. It feels like a team when you are both aware of and working together on that day's activities. What your partner needs to know is that you will follow through on what you took responsibility for - a dinner date, picking up a child from school, getting milk, etc. Knowing that your partner will be there makes a relationship stronger.

This communication might be short and concrete or there may be some problem-solving around who must do what. Whether chatting over coffee, in a text, email, or note, sharing what is on the cal-



Grace Myhill, MSW

endar provides the opportunity to get your team on the same page for the day, and for each partner to feel supported.

See You Later, Alligator... Many couples leave each other in the morning, so when you do, it's important to separate with a connecting feeling. Acknowledging the transition away from your partner with a simple "see ya later" feels very connecting. You're leaving them physically, but your sweet goodbye stays with them throughout the day. It sets a nice tone as you each move into your separate daily activities. This act acknowledges that you are phys-

ically separating from each other, but that you are also looking forward to seeing your partner later.

To create an even more connecting communication exchange as a couple, try a reciprocal conversation, where one partner says, "See you later, (alligator or your own nickname)" and the other responds, "In a while, (crocodile or your own nickname)." Use your own nicknames for each other if you have them.

This reciprocal back and forth between partners can feel like an intimate language of your own. Or if you prefer, you can give each other a hug, a kiss, a touch, or some combination, with the goal of creating a connecting feeling as you leave each other to begin your separate days.

Additional Resources

- Decoding Dating: A Guide to the Unwritten Social Rules of Dating for Men With Asperger Syndrome
- PFA Tips: Dating He Said/She Said

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This article is part 1 of a 3-part series. Coming soon will be part 2: Having a Good Day and part 3: Having a Good Night.

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article at www.pathfindersforautism.org/ articles/social/pfa-tips-neurodiverse-couples-morning.

Grace Myhill, MSW, is a pioneer and leader in the field of neurodiverse couples therapy. Since 2004, she has worked with over one thousand neurodiverse couples together or separately. She has developed numerous skill-building tools and lessons to enhance communication and emotional connection. Grace offers a variety of online groups for the many facets of this unique population: for neurodiverse couples together, for partners with an Asperger's/autism profile, for neurotypical partners who are currently in a neurodiverse relationship, and for neurotypical partners who are separated or divorced from an ex-partner with an Asperger's/autism profile. She currently holds the titles of Director of Couples and Partner's Services and Director of the Peter M. Friedman Neurodiverse Couples Institute at AANE, where Grace trains professional clinicians to work effectively with neurodiverse couples through online courses she developed for AANE. She has written several articles and is a frequent guest on podcasts. For more information visit www.gracemyhill.com.

For therapists or partners in a neurodiverse couple who would like to learn more about AANE's online trainings and other resources, contact Grace Myhill at grace. myhill@aane.org.

Tips for Women from page 30

time can be scheduled but flexible. In times of greater stress for your ASD partner, s/he may need more time pursuing their interests and/or time alone.

At the same time, you may need to schedule time for your individual interests. If this includes additional socializing, you may need to look for scheduling time with friends, joining clubs, volunteering and/or pursuing other interests that involve other people. You may find you will need these outside activities and social opportunities to connect with others in addition to your emotional fulfillment with your partner.

5. Find Professional Support (for ASD and any secondary mental health needs)

It may be important and necessary to find professional support for the communication and sensory issues you encounter as a couple. It might also be helpful to address executive function issues with a professional. As mentioned before, executive function skills can be very weak for someone on the autism spectrum. A professional who can address executive function issues may be hard to find but worth the effort. The book by Dawson and Guare (2016) listed under resources at the end of this article may also be helpful in understanding and addressing executive function deficits.

Be aware that individuals with an autism spectrum disorder are at greater risk for depression, anxiety, obsessive-compulsive disorder, and/or other mental health disorders (Roy et. al., 2015; Croen et. al., 2015). Low self-esteem due to negative social interactions and experiences can also affect your partner's mental health.

You can also experience your own mental health issues. Approximately 40% of the general population meets the criteria for a mental health diagnosis at least once in their life. For people on the autism spectrum, the rate of co-occurring mental health symptoms is thought to be at least 69% (Lever & Geurts, 2016). You may also be at greater risk to experience anxiety and/or depression as an effect of your relationship with your partner, especially if s/he was undiagnosed and/or untreated until recently.

The person with ASD may need dependable periods of social isolation. This may be difficult to understand and not take personally. Your partner may also have developed a pattern of retreating to their special interests, in part as a coping mechanism and not knowing what to do to make you happy. This can be due to communication differences and difficulties such that s/he does not have the information needed to carry out your wishes. S/he then decides it is better to do nothing then to do the wrong thing.

Over time and when sharing a home, misunderstandings and problems will occur. Because of the nature of ASD, you may feel a lack of communication and emotional contact with your partner. As you try to work on your relationship, it is likely that contact with others will become more limited causing further loneliness. This can lead to depression, and maybe even feelings of despair. For various reasons, it could be important for you and your partner to be assessed and treated for any mental health conditions.

It is very important to work with a professional who has knowledge and experience working with adults on the autism spectrum. If a therapist with knowledge and experience about ASD is not available, you will want to find someone who has an interest in supporting neurodiverse relationships and who has qualities that are a good fit for someone with autism.

Cognitive Behavioral Therapy (CBT) is an evidence-based practice used with typically developing adults as well as those on the autism spectrum. Research has shown that adaptations of CBT such as a more structured, concrete, and visual approach and possibly shortening or lengthening sessions can be important to meet the needs of someone on the autism spectrum (Cooper, et.al., 2018; Spain et.al., (2015). Dania Jekel, the previous Executive Director of AANE (Asperger/Autism Network), wrote a blog post describing what to look for in a therapist.

You are most likely reading this article because you are frustrated, unhappy, and/ or confused about the behavior of your partner on the autism spectrum. It may be a new diagnosis for your partner. You are seeking information and support. It may be very hard, at this time, to think of things your partner does well and appreciate their gifts. There were gifts you saw that led you to make a lifelong commitment to your partner. Remind yourself to remember, observe, and acknowledge your strengths and the strengths of your partner at every opportunity.

This article is meant to offer you basic information, tips, and tools for strengthening your relationship with your partner on the autism spectrum. Everyone's journey is unique. Some issues such as parenting, family vacations, and employment related issues have not been addressed within this article. Included below are some resources you may wish to pursue for further information. With the right tools, commitment,

and support, you and your partner can experience a lasting, positive, rewarding, and loving relationship.

Marci Wheeler, MSW, is Social Work Specialist at the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community at Indiana University, Indiana's Center for Excellence on Disabilities. For more information, visit https://www.iidc.indiana.edu/irca/.

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Suicide Risk from page 9

Researchers found the highest rate of suicide attempts and death by suicide among autistic people who do not have intellectual disability. Within that group, the autistic people with attention deficit hyperactivity disorder, or ADHD, had the highest rate of all. About 1 in 10 of them had attempted suicide, a rate that is seven times higher than the comparison group.

Autistic people who have intellectual disability also had a higher risk of suicide attempts, about double the risk of the comparison group.

The study findings were startling for girls and women. One in five females who had both autism and ADHD (but not intellectual disability) had attempted suicide at least once. Other studies have not found a higher risk in girls and women, although they were not as large as the Swedish study.

When researchers took into account psychiatric conditions that increase suicide risk, such as depression, anxiety, and substance abuse disorders, autistic people still had a higher risk than the comparison group.

The researchers also found a higher risk of suicidal behavior in the close relatives of people on the spectrum - parents, siblings, and children - than in the comparison group. That suggests that family risk factors, along with mental health conditions, may contribute to the risk of suicidal behavior in autistic people, the study says.

What Puts Autistic People at Risk?

What else might help explain the risk of suicidal thoughts and behaviors in autistic people?

Some of the risk factors for suicide in the general population occur more frequently in people with autism, although researchers do not know for sure if these factors have the same influence on autistic people. For example:

• Children with autism are bullied more

- than their peers.⁷ Research shows that both bullies and their victims have a higher risk of suicidal thoughts and behaviors.⁸
- Autistic people have higher rates of underemployment or unemployment than the general population.⁹
- Youth and adults on the autism spectrum have higher rates of mental health conditions, such as depression, bipolar disorder, schizophrenia, anxiety, and ADHD, than other people.^{2, 10, 11}

Learning Who Might Be at Risk

How do you know if someone is thinking about suicide? According to Lisa Horowitz of NIMH, "The best way to identify someone at risk for suicide is to ask them directly."

Some families worry that youth on the spectrum might start thinking about suicide if a healthcare provider asks about it. Studies of people who do not have autism show that it is safe for a trusted adult to ask about thoughts of suicide, Horowitz says. Research that might shed more light on this issue with autistic youth is underway.

In the meantime, providers balance a family's concerns and the higher risks for suicidal thoughts and behaviors in these youth, says clinical psychologist Jessica Schwartzman, PhD, who researches depression and suicidal thoughts in autistic people at Vanderbilt University Medical Center. Research shows that autistic teens and adults "are much more likely to have thoughts about dying," she says. "So I think it's important to screen and ask about these thoughts directly with patients."

What if an Autistic Youth Mentions Suicide?

Listen to a child who brings up the subject, Horowitz says. "We need to take all talk of suicide seriously, and pay attention to it," she says. "While suicide is a very rare event, if a child is talking about

thoughts of suicide or wanting to kill themselves, it's important to say things that make them feel less alone." For example, the adult could say, "'I'm glad you are telling me. I take this very seriously. My first priority is keeping you safe, and I want to be able to help you. We will get through this together," she says.

Parents can seek help from their children's doctor or therapist, and by calling or texting the U.S. Suicide and Crisis Lifeline at 988. If they believe their children may try to harm themselves in the near future, parents can take them to the emergency room, she says.

Families are not the only ones who can be alert for suicidal thoughts in people with autism

Doctors can play an important role in suicide prevention, says Paul Lipkin, the doctor at Kennedy Krieger. The American Academy of Pediatrics, a professional association of pediatricians, recommends that doctors screen all youth ages 12 and older for suicide risk.

Lipkin, Horowitz, and others want to make it easier for those doctors and clinics to find out if youth with autism and developmental disorders have suicidal thoughts. They are working on a study of the effectiveness of a suicide risk screening tool specifically for these youth. Another study, led by researchers at University of North Carolina and University of Pennsylvania, is looking at ways to adapt a suicide prevention intervention for autistic teens and young adults.

Resources

- For help 24/7, please call or text the Suicide and Crisis Lifeline at 988 or call 1-800-273-8255. Online chat available.
- Text TALK to 741741 to reach the Crisis Text Line.
- People in the SPARK autism study have participated in studies of mental health and suicidal thoughts through Research Match.

• Read the American Academy of Pediatrics' Blueprint for Youth Suicide Prevention.

To learn more, see the next article in this series, "Working to Prevent Suicide in Youth with Autism." Interested in joining SPARK? Here's what you should know.

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Footnotes

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Autism Spectrum News Editorial Calendar

Winter 2023 Issue

Understanding and Promoting Autism Advocacy

Deadline: December 1, 2022

Spring 2023 Issue

Supporting Newly Identified or Diagnosed Children and Adults

Deadline: March 2, 2023

Summer 2023 Issue

Legal Issues and the Law

Deadline: June 1, 2023

Fall 2022 Issue

Supporting Families and Caregivers

Deadline: August 30, 2023

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Relationship Failures from page 19

promise I would join the family later for dessert. I thought my ex and I were finding compromises and solutions that worked for both of us and that we had broken through ableist notions about what people should and should not be able to do. Not everyone can sit at a table. Not everyone can handle the noise of a restaurant. What happened?

Ironically, I accommodated her disabilities all the time. She was part deaf, had mobility issues, and had ADHD and mental health issues. We frequently cut short activities if her legs started to hurt or if she became too hot. For example, once we took her son and my two children to the state fair. The kids went on several rides. We also got lemonade and watched farm animal competitions. The kids and I went on a few more rides and we were having a great time, but my ex was sweltering and her ankles were swollen. I told the kids we needed to cut the day short. I explained to them that human beings and their feelings and needs are higher priority than a few hours of fun. We found a pizzeria with good air conditioning and still had a good time that evening. I never once felt like I was making a bitter sacrifice. I loved her way more than a Ferris wheel!

As I heard her blame my autism for ruining our relationship, I hated myself all over again. Me - a well-known autism advocate! I sank into a deep shame. I cursed being autistic. On top of feeling as though my autism ruined yet another relationship, I also could not fathom how a person could seem loving and dedicated to disability justice, only for that to evaporate seemingly overnight.

Slowly, with the help of my incredible autism colleagues, my mother, and the small circle of good friends I have, I came to see that I had internalized her ableism. It is just not true that autistic traits are the problem in a relationship. This is the perspective I want to share with other autistic people so that they, too, can set fire to that shame. What I came to realize as a result of the breakup of my third long-term relationship is that our autistic needs, our autistic traits, and our neurodivergent characteristics have been pilloried. Non-autistic people accommodate one another's needs and habits as a matter of course, but autistic needs and habits are stigmatized.

Once, I went to visit an old friend from college I hadn't seen in a decade. She was newly married. Just a few minutes into the visit, she gave me a tour of her house. I noticed through the glass-covered kitchen cabinets that her plates and bowls were arranged diligently by color: blue, green, orange; blue, green, orange; blue, green, orange.

"Why are your plates and bowls stacked by color?" I asked.

"Oh, my wife has a thing about it. She really needs it to go by color, so I just do it," my friend explained.

And neither of them is neurodivergent. No one knows why her wife needs the plates arranged by color. My friend simply accepted her wife's need which was easy enough to meet whenever it was time to unload the dishwasher.

Recently, my acupuncturist told me how when she was pregnant with her third child, she and her husband took the older two kids to see Star Wars and she found the movie theater just too loud. "Maybe I was more sensitive because I was pregnant - I'm not sure," she relayed, "so I said to



Zosia Zaks, MEd, CRC

my husband, 'Honey, I can't sit in here! I'm going to drive around and do a few errands. I'll pick you and the boys up when the movie is over!'" And he was totally supportive. Neither of them is neurodivergent. Her husband simply accepted that the theater was too loud for her that day. He did not question her self-assessment and did not accuse her of ruining the afternoon, abandoning him, or refusing to spend quality time with the family.

Non-autistic people are allowed to have rituals, routines, and sensory issues. They are allowed to get tired and need to go home early. They are allowed to be shy at a party. Whether sports or crafting or the stock market, non-autistic special interests are called "hobbies." They view one another's intense interests as a normal part of having a healthy and constructive life. They even accommodate communication differences. Some speak directly; others are more subtle - partners adjust to one another's communication styles. If you are autistic, you are not afforded these same graces.

Our traits and our needs are framed as "special" or a "burden" and non-autistic partners are positioned as "heroes" for their willingness to love us anyway. Simi Linton, an amazing disability rights activist and artist, once famously said, "If I hear the term 'special needs' one more time, I am going to throw up" (Linton & von Tippelskirch, 2013). Special needs do not exist. Our neurodivergent traits are human traits. Our needs are human needs. Our hearts are human hearts. Stigma is the problem: Not you!

Out of my failures. I have learned that autistic people should never feel ashamed in relationships of all sorts, not just romantic ones. You have a right to leave a loud party early. You have a right to get takeout instead of remaining in a crowded diner. You have a right to spend a few hours watching cargo shipping charts online. You have a right to always use your Star Wars Rey spoon for breakfast - the one that came in the Cheerio's box and that changes color when you add the milk. You have a right to only wear socks if they match your underwear, and you have a right to have a crisis if you cannot find the right ones. These are traits that make you who you are - a precious human being.

Of course, all relationships require negotiation and compromise. Out of love, both partners compromise and sacrifice, an inherently imperfect and sometimes messy

process. For example, one time my partner won a prestigious award. The ceremony took place over dinner at a loud venue. I went because this was a very important life event for her and I wanted to support her. I wore ear plugs - that helped with the noise a little bit. I also took a break or two to walk around outside. If one partner always catered to the needs of the other and never got any of their own needs met, the relationship would be lopsided.

The problem for autistic people is that when it comes time to negotiate and compromise with a partner, the things we ask for are viewed with skepticism. We are never given the benefit of the doubt. When we are simply being our neurodivergent selves, enjoying our special interests or setting boundaries, our partners tend to view our behaviors through an ableist lens: They make negative assumptions about whatever we are doing. We are never honored for the sacrifices we make out of our love for our non-autistic partners, either. We are never seen as giving.

For example, once my girlfriend came over to my place unexpectedly. Many people, especially non-autistic people, enjoy spontaneous socializing. But spontaneous socializing can be difficult for me. I need time to transition from whatever I am doing to the new situation. That day, I was writing. I was smack in the middle of a tough paragraph. I acknowledged that she had needs, too! She needed time to interact that day. This is where compromise and negotiation in good faith comes in.

I could have just ignored her. Again, it is extremely taxing for me to shift between activities. But I am not a selfish person. Despite the massive amount of energy it took to halt my writing, move my body to face her, and then to form words, I politely said, "I'm so glad you came over. I really want to hang out with you! Can I please have five minutes to finish writing this sentence and transition to a social state of mind?" At the time, she said that would be fine. She played with my cat while I quickly wrapped up my writing project, closed my eyes for a moment, switched my mental gears, opened my eyes, and struck up a conversation with her. We had a lovely spontaneous afternoon from then on - or so I thought.

During the breakup process, she highlighted this specific incident as evidence that my autism made me incapable of a "normal" relationship - and proof of the saintly burden she bore. Deconstructing this incident and many others helped me climb out of my quagmire of shame. I am completely capable of intimacy and completely able to socialize. I need time to transition from solitary pursuits to social ones. Another human being may not have this need - but then they will have other needs. I am not an insufficient or incapable human being because this is one of the needs on my list. The problem is that the needs on my list are seen as abnormal.

Autistic people may need to compromise and negotiate about things that non-autistic partners find surprising. An autistic partner may suggest non-traditional solutions when solving an issue. And autistic partners may like reading schedules for public transit in Romania instead of the Sunday New York Times. But isn't love all about the joy of discovering another person? If autism was not stigmatized as it currently is, then our partners would see our needs and traits - and theirs - as opportunities to grow closer through compromise and mu-

tual support. As well, they would honor the effort we put into accommodating to their non-autistic needs. Lastly, by seeing no particular need or special interest or trait as abnormal, non-autistic people would also be liberated to be their true selves. A gift autistic partners bring to their relationships is a reduction in the pressure to conform to society's expectations which are not that realistic for anyone.

Furthermore, non-autistic people can take responsibility for their role in miscommunications. The autistic trait that most irritated my partner was my autistic way of communicating. On top of being autistic I am also alexithymic and my interoception is very low. I am usually the last person to notice I am upset, sad, tired, or excited. It can take me days, weeks, months, or even years to fully know how I feel about a situation. I also tend to express my emotions by action: If I love someone, I do something for them. During the breakup, she accused me of never understanding her subtle hints and thus missing so many messages. But my autistic neurology was not new to her. If someone drops hints knowing I am autistic, why am I blamed when I miss the hidden meaning of a sigh or a glance of the eyes?

In summary, what I hope autistics walk away with after reading this is that - when it comes to romantic love - the problem is not you or your autism but discrimination. Non-autistics are not doing enough as allies if they still subscribe to the false narrative that relationships with autistic individuals are fraught. We are no more or less difficult to relate to than any human being. Two people considering a relationship need to ensure they are aligned, regardless of any diagnoses. If one person needs monastic silence at home to be at peace, and the other loves to blast music in the morning to get going before work, living together is going to be rough. The presence of autism has nothing to do with it.

An autistic friend of mine schedules out her days in increments of 15 minutes and even schedules bathroom breaks. She dated someone with an organic approach to life who balked at having to follow the day's list of activities and bristled at my friend's "autistic rigidity.," They broke up. Then my friend began dating someone with serious time management issues who just loves my autistic friend's scheduling powers. At last, he found a way out of the chaos of his life. They are now happily married and still follow the schedule each day. My friend's autistic trait is not an issue. Finding someone you are compatible with is what matters. This shift in thinking begins when non-autistic people stop stigmatizing us.

The best way to cope with relationship failure is to radically embrace who you are. You were not passed over on a dating app because vou are flawed - vou were passed over because many non-autistic people continue to discriminate, implicitly if not explicitly. You were not cheated on because your sensory issues made dinner complicated. You are not driving your non-autistic spouse to the brink because you communicate differently, because you operate differently socially, or because you enjoy special interests outside of the bandwidth of what society considers "the norm" - you and your partner are just very incompatible. Unless you yourself are abusive or wholly unwilling to compromise, your autism is not, and never should be, the problem.

Relationship GPS from page 17

Appreciate and value your partner. Take time every day to say something kind to your partner. Ask your partner what their "love language" is and how you can show them love and appreciation in a way they will hear and value. Respect and seek to understand each other's different "love languages."

Socializing can include sitting in the same room, not talking, and being engaged in "parallel play;" visiting with friends or family (in real life or online); going out together to run errands or to go out on a date. Understand and clearly communicate your social needs and limits. Understand each other's social quotas and find creative ways to both get your needs met. If your partner struggles with social anxiety or doesn't understand social cues, ask how you can help them feel more comfortable in social situations.

Sharing and understanding emotions can be challenging for anyone. Emotions may not be logical or rational, however they are real and are often connected to an "unmet need." When sharing something emotional, learn how to regulate yourself and co-regulate together before talking. It is very difficult to communicate respectfully or to hear effectively when either partner is dysregulated. Take time-outs when needed and reconvene when you are both calm. Use breathing techniques to calm yourself. Learn about your triggers. Understand what you need to do by yourself and with your partner to get and stay calm and centered. Take time to practice that on a regular basis. If the things that calm you change, make sure to share that information with your partner so they can help recognize signs of dysregulation and you can work together to calm your nervous sys-



Mona Kay, MSW, PhD

tems. Always remember that you're both on the same team.

Schedule time to get together with your partner on a regular basis. Schedule or make time for "check-ins," date nights, special interests, decision making, vacations, family time, self-care, physical intimacy, and anything else that is important to each of you. Make sure you have time together as a couple, and that you both get your individual needs met. This can increase connection, fun, and peace, while also reducing anxiety and resentment.

Understand and respect any sensory sensitivities you each may have. These could be related to: food, scents, fluids, sounds, lights, touch, clothes, shoes, hygiene, physical intimacy, and many other things in life. Be non-judgmental, respectful, and compassionate so that you both feel comfortable sharing and processing this information.

Make decisions together that will impact

you and your partner and agree on a timeline that works for both of you. Give each other space and time to process the information needed to make an informed decision. Whenever you need to make decisions together, confirm with each other that you are both relaxed and in the mood to talk.

Share and schedule household responsibilities (including childcare) based on each other's strengths. However, at times each partner may have to go out of their comfort zone to meet the needs of the household. Be patient with each other as you learn new tasks or take on new responsibilities.

Understand each other's physical and sexual intimacy needs and desires. Take time to learn what your partner likes and doesn't like. Be respectful of sensory sensitivities, performance anxiety, health, or mental health issues, limited past experience, and sexual history. Be patient, compassionate, and respect your partner's "no's" or "I'm not ready for that yet" and have fun exploring and learning together.

Follow through and be consistent. When you agree to do something, please do it. If you can't follow through, provide the reason and reschedule as soon as possible. Be reliable and impeccable with your word. This builds trust, which is critical in any healthy relationship. Don't be afraid to say, "I'm sorry, I didn't mean to hurt you, but I think I did. Please help me understand what I could have done differently." Then work to change your mindset and your behavior.

Twenty-nine years into a 30-year marriage, Mona Kay, MSW, PhD, discovered that she'd been in a neurodiverse relationship and didn't know it. Mona and her husband had visited many therapists, but unfortunately none of them understood neurodiversity. A trained social worker

with three degrees in the field, Mona had seen the ins and outs of many a relationship during her career, but never had she taken this kind of a look at her own. On top of that, Autism Spectrum Disorder (ASD) hadn't been part of the picture when she'd earned her BSW and MSW in the 1980's, or her PhD in 2001. In 2017, Mona turned to books, articles, and videos to find any information she could get her hands on related to neurodiverse marriages. After quite a bit of pushback, Mona's ex agreed to begin the process to get professionally assessed for ASD. The conclusion? "Probably, but so what." Assessing adults is tough - it comes after a lifetime of social and emotional experiences that can impact anyone's personality. So, what difference did it make? Well, in Mona's marriage, not much. An official divorce was finalized in May of 2018, but that didn't mean that Mona's years of research had been for naught. With her 30+ years of social work experience as a foundation, Mona shifted gears in 2020 to create "Neurodiverse Love." She hopes that through the power and connectivity of social media and the "Neurodiverse Love" podcast that she, her co-hosts, and guests will be able to bring lived experiences, information, and tools to neurodiverse couples throughout the world to increase understanding of the strengths and differences that can help each partner thrive individually and as a couple.

Mona Kay, MSW, PhD, is the host of the Neurodiverse Love podcast. Order the Neurodiverse Love Conversation Cards. Dr. Kay can be found on Instagram @ neurodiverse_love. Please visit www. neurodiverselove.com and email neurodiverselove4u@gmail.com.

If you are interested in joining one of my "Neurodiverse Love" support groups for neurodiverse couples, or neurotypical/ non-autistic partners, please send Dr. Kay an email, or a DM on Instagram.

Relationship Failures from page 34

Dating and relationships are hard for all humans. I do hope that autistic people can take my insights and go into dating and relationship situations knowing just how wonderful they are. The best way to cope with dating and relationship failure is to know that your autism is not the cause of the trouble. I don't know if I will ever find a woman who wants to love me for who I am. But one thing I know for sure: When dating implodes and relationships fail, I am confident that there is nothing wrong with me. That secret is how we can survive the

lonely times, the trials and mostly errors, the times non-autistic people again and again fail to see our humanity. There is nothing wrong with me, and there is nothing wrong with you.

Zosia Zaks, MEd, CRC (Certified Rehabilitation Counselor) (he/him/his) has more than 20 years of experience supporting hundreds of teenagers and adults on the autism spectrum and with related conditions to live and work in their communities. From 2013 - 2022, he was manager of the Hussman Center for Autistic Adults at Towson University, where he

taught a disability social justice course that had students and autistic adults participating in activities designed to break down barriers, challenge stereotypes, and promote building a more inclusive society. While at Towson University, he also built a strengths-based support program for autistic college students and an on-campus work readiness program. He has extensive experience facilitating integration of neurodiverse individuals at worksites and in schools; speaks nationally on autism and neurodiversity related issues; continues to teach courses on disability social justice; and serves on the boards of several

regional and national organizations. Now consulting independently, Mr. Zaks brings unique perspectives to professional projects and trainings as a disability counselor, a transgender autistic self-advocate, and a parent of two neurodivergent children. Follow him on Twitter @ZaksZosia or email him at zaks.autism.consulting@gmail.com for more information.

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Adolescence from page 20

Autistics are affected by all this not only in the pursuit of romantic relationships, but also in the differing nature of simply finding and keeping friends. The changes in socialization among adolescents that result from the onset of sexuality are often not even perceived, let alone understood, by autistics who also have considerable difficulty adapting to them even after they become aware of such. This is yet another sudden change that places them at considerable disadvantage.

What Makes Adolescence So Difficult for Autistics?

There are numerous reasons for the dramatic increase in social difficulties faced by autistics entering adolescence. First, they encounter far greater social competition than they had ever experienced, or at least been aware of. This in turn requires a higher level of social skills than were previously needed. What can be difficult even for a typical person becomes, for an autistic who already had substantial deficits in this area, nothing less than a formidable challenge. All of this is further complicated, at least for less-impaired autistics (not to mention the undiagnosed!), by the fact that these issues are seen as universal and can be dealt with by such individuals in the same manner as the typical population. After all, everyone goes through these changes and manages to successfully adapt, so an autistic person who is not intellectually disabled, has no obvious major or severe challenges, and may even be exceptional in their areas of special interest or ability, should not have any more difficulty or require further support or assistance than a typical person.

I experienced all of this myself around that time. Up until that point, I had always identified primarily in terms of my specialized interests as opposed to more conventional group identities (e.g., ethnic,



Karl Wittig, PE

religious, etc.). These had included (of course) anything mechanical, electrical, or electronic; coin collecting (as well as other collections), the New York City subway system, atomic physics, astronomy, and some other things that today are regarded as "nerd" or "geek" culture. Back then, however, these were less fashionable than they subsequently became (and even then, only to a small degree). One of the rudest awakenings that I ever had happened around this time when I realized, for the first time, that not only did most people not share my interests, but often ridiculed and even had contempt for such. Coincidentally, this happened around the time of the Apollo moon landings, with which I was totally fascinated. As it happened, most people my age were much more interested in such things as popular entertainment, sports, and the political issues of those turbulent times. My unusual interests were not understood, and even led to social marginalization. In short, I was not at all "in sync" with my social environment, which resulted in numerous difficult and painful experiences.

Another experience that is common among autistics at that time in their life involves having tricks played on them or being used and taken advantage of. While many neurotypicals also have similar experiences, they usually learn, after one or at most a few incidents, how to recognize these and avoid them in the future. For autistics, who have difficulty interpreting nonverbal communications as well as theory-of-mind deficits (i.e., they cannot discern the intentions and motives of another person), this is much harder to do and, as such, they are far more susceptible to these devious manipulations. This is complicated by the fact that the perpetrators of such (even if they are unaware that the prospective victim is on the spectrum or perhaps never heard of autism) somehow know that their victim can be enticed with the prospects of gaining friendships, finding romantic partners, or simply being accepted into social circles where they want to belong. In my own experience, prior to adolescence, most tricks that were played on people were little more than minor mischief, such as the classic prank of putting a thumbtack on my seat when I was not looking. Subsequently, however, they became far crueler and usually involved inducement to doing something that led to embarrassment, humiliation, getting into trouble with authorities, or was otherwise against my own best interest. The copying of homework assignments and even answers on tests were another form of exploitation that I encountered. In many of these cases, an autistic person not only is unaware of what is really happening, but does not understand the underlying motive, even when there is a motive - sometimes these things are purely gratuitous.

What Can and Must Be Done

The principal consequence of all of this is that adolescence, for the overwhelm-

ing majority (perhaps nearly universal) of autistics, is by far the most difficult and painful time of their lives. A tremendous amount of human misery and pain during this period has been recounted in presentations by autistics (I once participated in an adult panel on this subject some years ago), not to mention support groups (I have attended and facilitated them for decades) and (this goes without saying) countless individual therapy and counseling sessions. Although I am not aware of any actual statistics, there have probably been significant numbers of suicides among autistic adolescents because of these difficulties. Something needs to be done.

The one certain conclusion that can be drawn here is that adolescence must be regarded and treated differently in autistics than it is for the typical population. Simply assuming that they will get through it in the same way that everyone else does is no longer a viable option. Those who care for, work with, or otherwise provide support of any kind to autistic adolescents need to be made aware of the issues involved and be prepared to provide adequate counseling and supports in areas where they have deficits and disadvantages that typical adolescents simply do not have. As with many other issues affecting the autism community, a reconsideration of beliefs and attitudes that have existed for a long time and never really been questioned needs to take place. This in turn must be followed by changes in policies and practices that, once again, are unquestioningly accepted as traditional wisdom. Although, as with a variety of other issues, changes may be indicated that could benefit neurotypicals as well as autistics, the needs of autistics at this especially difficult transitional period in their lives must be completely recognized and thoroughly addressed.

Karl Wittig, PE, is Advisory Board Chair for Aspies for Social Success (AFSS). Karl may be contacted at kwittig@earthlink.net.



Greater Hudson Valley, NY, Support Groups

One Sunday a month from 10:30 am - 12:30 pm YAI Tarrytown - 677 White Plains Road, Tarrytown, NY 10591

Free Support Group for the Family Members of Adults with an Asperger/Autism Spectrum Profile

This support group, formerly known as Families of Adults with Asperger's Syndrome/High Functioning Autism (FAAHFA) is now a part of the Asperger/Autism Network (AANE). This group is for parents, family members and friends of adult individuals who have an Asperger or similar autism spectrum profile. We will be hosting guest speakers at many of our meetings to address various topics of importance related to our loved ones.

Our mission is to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

For more information, visit the website www.aane.org or contact the facilitators: Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group for Adults with an Asperger/Autism Spectrum Profile

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences. Focused on: Socialization, Mindfulness, Creativity, Self-Advocacy, Health and Well Being, Career Counseling, Relationships and Fun!

For more information, contact the facilitators:

Anna L. Nasci, OTR/L, MS, NCC, LMHC | Masako Hashimoto, MS, NCC, LMHC - OpeningDoorsWestchester@gmail.com

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Autism Spectrum News (ASN), published by the 501(c)(3) nonprofit organization Mental Health News Education, began as a quarterly print publication in 2008. In response to readership feedback, ASN became an online-only publication in 2021. ASN was developed to provide the autism community with a trusted source of evidence-based information and education, the latest in scientific research, clinical treatment best practices, family issues, advocacy, and vital community resources.

ASN raises the level of the autism field by serving as a central repository of quality, practical information written by leading professionals in autism service delivery and research. The publication's content guides individuals, parents, and service providers in the right direction from the very beginning while taking efforts to avoid the promotion of unsafe and unproven interventions and treatment methods.

In keeping with the publication's evidence-based mission, the esteemed ASN Editorial Board will only accept articles and advertising offering science-based information and/or treatments proven safe and effective for autistic individuals.

ASN provides hope through education by collaborating with leading autism organizations and educational institutions that are improving lives every day. The publication serves to unite and improve our evolving systems of care and advocate on behalf of autistic individuals and their families to reduce the harmful effects of stigma in the community.

For information about advertising and article submissions contact David Minot, Publisher, at dminot@mhnews.org.