The Unique Needs of Girls and Women with Autism

Advice from a Young Woman in College with ASD

By Michele Ramsay, EdD
Program Director, CIP Brevard Center

Why is it sometimes difficult to identify females on the autism spectrum? Have they taught themselves to behave differently in social situations? Have they mastered the act of a social fake? Or have they simply figured out how to seek refuge and escape?

In working with students on the autism spectrum, female students often present themselves differently than their male peers. To dig deeper into this topic, we interviewed Stephanie Smith, a 24-year-old student at CIP's Brevard Center in Florida. She also attends the University of Central Florida where she is majoring in political science.

The Challenges of Adolescence for Girls with Autism Spectrum Disorders

Q. At what age were you first diagnosed with autism?
A. It wasn’t until I was in middle school when a doctor diagnosed me with autism. Prior to that, I was diagnosed as bipolar with ADD.

Q. How did your diagnosis affect you?
A. I remember feeling horrible about my diagnosis in the beginning. I had to be placed on all new medications and meet new doctors. Now this label is not so scary, and I can better understand the WHY to some of my behaviors. That allowed me to cope better and use the techniques the doctors were showing me to fit in.

I have heard that when a female is depressed and not very talkative that she can be passed off as shy. If she gets really emotional and passionate about something, then someone says that’s her hormones, and not emotional dysregulation, which is what they would say with a male student showing those characteristics. I feel that society isn’t going to change anytime soon and it will always be easier to diagnose a guy over a girl because too many people say … it’s just a female thing.

Q. What are some general challenges (at least 3) that you have faced as a young woman with autism?
A. 1) Not being taken seriously as someone with ASD because most people on the

see Advice on page 10

Challenges and Solutions When Providing Services to Females with Autism

By Sandra A. Rogers, MS, BCBA and Mary Jane Weiss, PhD, BCBA-D
Melmark

The majority of individuals with autism are male, and females with autism are often overlooked in discussions of needs and program planning. Special challenges exist in serving individuals with autism who are female. In addition, females may be vulnerable in ways that are often not acknowledged or publicly discussed. We will review the special challenges associated with accommodating family requests for female-only staff, protecting individuals served from abuse, and ensuring that curricular resources are developed to achieve increased independence and self-protection.

Many homes serving those with developmental disabilities are co-ed. Due to the nature of the challenging behaviors that are experienced by the individuals served, there are often more male staff than female staff working in the home. It is generally an expectation that any staff member, regardless of gender, could be expected to work with any client male or female.

Male staff is expected to shower and dress and take care of all toileting needs (including menses) for female clients. There often are complaints from the male staff that it made them uncomfortable to care for a female client, especially during her menstrual cycle. Similarly, female staff members often experience severe discomfort when performing personal care on male participants.

Families also have concerns in these regards. In our experience, many parents are adamantly that their female child could not be toileted, bathed, or be assisted with any hygiene routines by male staff members. Furthermore, many of the male staff were scared and uncomfortable with being asked to assist a female client with hygiene needs. If we grant family wishes, we also send a trusting message to male staff members. We also may be guilty of a double standard. Do we impose the same restriction on female staff members with male clients? Parents of females expressed many times that they worried about their daughters being victims of sexual abuse if a man were to be providing the care in the bathroom. The male staff members similarly expressed fears about being accused of sexual improprieties if they were required to work with female clients.

We have tried to share with families and staff that sometimes it may not be possible to have a female staff to assist in the bathroom—and during those times we would have to have a male staff assist. Also, we try to explain that we screen all applicants prior to hiring them to work with anyone.

All of the individuals we serve are vulnerable, but because there is a higher rate of reported abuse for females than men, they may be at greater risk. We understand families’ concerns, and we always try to be as respectful as possible without promising something that we cannot always comply with.

Below is a summary of the guidelines we use in this context.

1) We have men work with men and women work with women as much as possible. This eases everyone’s anxiety at least a little. People tend to be more comfortable working with individuals of the same gender, at least when it comes to hygiene needs.

2) We are upfront about the fact that if we do not have a female staff working on a particular day, then we may have to assign a male staff for that time period.

3) We educate everyone about our standards for taking care of vulnerable individuals (both men and women), and that we would not tolerate any improprieties.

4) We emphasize the importance of teaching independence with hygiene skills as a top priority, since individuals that are more independent are less at risk to be violated. Also, female clients use sanitary pads as opposed to tampons—even though mainstream society typically prefers tampon usage—because tampon assistance would be inappropriate and intrusive level of help, even for an individual receiving a high level of care.

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Spring 2017 Issue:
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Summer 2017 Issue:
“Improving Health and Wellness for Individuals with ASD”
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The ‘Self’ in Girls and Women with Autism Spectrum Disorder

By Elizabeth V. Roberts, PsyD
Clinical Assistant Professor
NYU Child Study Center

“Know thyself.” Socrates

A central focus in autism spectrum disorder (ASD) research and clinical practice are core challenges in social reciprocity and social interaction - the interpersonal. The self in ASD - the intrapersonal - has been paid relatively little attention. This article presents preliminary thoughts about the self and why exploring the self may be important in understanding and helping girls and women with ASD.

The self is a composite of the ways a person defines him or herself. Nineteenth century philosopher William James described two aspects of the self: the “I Self” and “Me Self.” The I Self reflects what people see or perceive themselves doing in the physical world whereas the Me Self is a more subjective and psychological phenomenon, referring to an individual’s reflections about themselves. Researchers have continued to elaborate on this idea, for example, with theories concerning the evolution of the self across the life span, social and cognitive constructs affecting and affected by self, the roles various aspects of the self-play in life experience, the interplay of self with culture, others, and other influences, and ways that suffering results from discrepancies between the actual and idea self. New terms and ideas continue to evolve out of this body of work, namely self-awareness, self-reflection, self-as-agent, and others.

The Self and Autism Spectrum Disorders

Lind (2010) examined memory and the self in ASD, and argued for a bi-directional relationship between aspects of memory and self-concept. She found impairments in autobiographical episodic memory and episodic future thinking in ASD and concluded that these implied a diminished sense of self, or personal history, and of personality continuity through time. Others have investigated the sense of agency (SoA) embedded in the self: SoA is the experience of initiating and controlling one’s own actions and producing desired changes in the world with those actions and it is a component of the self. The few studies that have investigated SoA in ASD have reported contrasting results, as some have shown this ability to be spared (David et al., 2015) and others, to be impaired (Zalla & Sperduti, 2015). Much else needs to be understood about the many aspects of the self and ASD.

Knowing Oneself: Mentalizing

Mentalizing is a form of imaginative mental activity about others or oneself, namely, perceiving and interpreting human behavior in terms of intentional mental states (e.g. needs, desires, feelings, beliefs, goals, purposes, reasons). People mentalize for many purposes - to teach, learn, communicate, and collaborate. Intrapersonal mentalization is necessary to know that we are and who we are. There are conceptual overlaps between mentalization and other abilities - mindfulness, psychological mindedness, empathy, and affect consciousness (awareness of emotion) for both self and other. Mentalization lies at the intersection of these concepts and captures the mental state of being aware in the broadest sense - of one’s physical being in the moment, the motives, emotions and beliefs of self and other that drive behavior in the moment, and the ability, on either a cognitive/intellectual or affective (feeling state) level, to use one’s imagination of the mental states of the self and the other (Fonagy et al., 2002). Mentalization is an elaborated version of Theory of Mind (ToM), a central focus in ASD. Mentalization has been studied largely in the field of personality disorders. A recent study (David et al., 2015) found that mentalization (of the other) was impaired in ASD (David et al., 2015) but little attention has been focused on mentalizing or ToM as it applies to the self in ASD.

Link to Social Competence

The relationship between self-awareness and other-awareness and social competence has been investigated primarily in other conditions - personality disorders, alexithymia, and schizophrenia. Clinician-researchers concluded that fostering
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It began with, “Let me tell you a story about a man from New York suffering with mental illness.” The year was 1987 and he was 38 years old. He had always been a happy and productive person throughout his entire life. He had earned a Master’s Degree in Mental Health News Education, Inc., (MHNE), publisher of Behavioral Health News and Autism Spectrum News, has announced the appointment of four new board members. “We are delighted to welcome four outstanding and well-known leaders from the behavioral health and autism communities to our board. They are: Rachel Fernbach, Esq., Josh Rubin, MPP, Yvette Brissett-André, MPA, and Dr. Robert Ring, PhD,” stated Mrs. Brown-Bellamy. According to Ira Minot, LMSW, MHNE Executive Director, “MHNE is embarking on an exciting new chapter in its 16-year history, which will reshape how our publications are made available to our growing readership.” David Minot, BA, Associate Director of MHNE added, “Our vision for the future is to transform our publications into a more modern print and digital media presence which we believe will have an even greater impact on educating and supporting individuals and practitioners in the mental health, substance use and autism communities.”

Let’s introduce you to our new board members.

Rachel A. Fernbach, Esq.

Rachel A. Fernbach, Esq. is an attorney admitted to practice law in New York and New Jersey and is a graduate of Tufts University and The George Washington University Law School. Ms. Fernbach is currently the Deputy Director and Associate General Counsel of the New York State Psychiatric Association (NYSPA), the medical specialty association of psychiatrists practicing in New York State and a division of the American Psychiatric Association. She has held this position since 2013 and previously served as NYSPA Staff Attorney from 2001-2013. Ms. Fernbach’s work with NYSPA includes providing legal and policy guidance on statutory and regulatory issues affecting psychiatrists, advocacy on issues of importance to psychiatrists and their patients, and training and various lectures on legal and practice management issues. In addition, Ms. Fernbach is an attorney in private practice with the law firm Moritt Hock & Hamroff LLP, located in Garden City, New York. Ms. Fernbach concentrates on legal and practice management issues.

Rachel A. Fernbach, Esq.

From the Publisher’s Desk: “The Handshake of Hope”

By Ira H. Minot, LMSW
Founder and Executive Director
Mental Health News Education, Inc.

With the holidays only a month or so away, I recall a true story I wrote about several years ago in this publication. It began with, “Let me tell you a story about a simple handshake that saved the life of a man from New York suffering with mental illness.” The year was 1987 and he was 38 years old. He had always been a happy and productive person throughout his entire life. He had earned a Master’s Degree in Social Work and worked for many years in nonprofit organizations that were helping people in the community.

Suddenly, out of nowhere, he began to experience severe anxiety and depression. His mother had recently lost a heroic battle with cancer a few years before, and he had been separated from his 8-year-old son due to a recent divorce.

In a matter of weeks he was in the throes of a most severe form of depression that would last 10 years. His illness caused him to endure such despair and hopelessness that he tried to end his own life on several occasions.

He watched in horror as his life slipped away from him, and was further tormented that his young son—the love of his life—was growing up under the shadow of his illness. In the end, he was left homeless and destitute. During his last inpatient hospitalization before his health insurance ended, he was offered Electroconvulsive Therapy (ECT) as a last chance to save him from a most horrible end—being sent to a dark ward at a nearby state hospital. Miraculously, the ECT worked in his case, and over the coming months he felt the dark curtain of his depression lifting.

It was now 1997 and he was living in supportive housing and attending outpatient treatment. To fill the other lonely hours of his day he began attending a newly opened consumer-run drop-in center. He hoped that by keeping busy and sharing the comradery of others would help set him on the path to recovery.

One day at the drop-in center, Jim, the director, was giving a tour of the facility to a supporter who happened to be a well-known local banker. Seeing the two men dressed in business suits walking through the center reminded him of how he used to dress and collaborate with colleagues and community leaders before he became ill. He was a taken aback and a bit embarrassed when the director and banker came over to where he was sitting.

The banker extended his arm and our recovering man stood up and shook the outstretched hand. The banker smiled at him, patted him on the shoulder, and told him, “Keep up the good work.”

It was a simple gesture, but that handshake had a profound and lasting impact. For many years after that day, the man in recovery often referred to that kind banker and his reassuring handshake. “It made me feel like things were going to be OK and I would finally get well again.”

You see, that man was me. With the kind encouragement of that banker and the many other people I met along the path of my recovery, I was inspired to create this publication in 1999. Through the following years, in what has seemed like an instant, I was able to rebuild my life. I just celebrated my 65th birthday in July, and this publication has been in existence now for over 16 years!!

I didn’t understand it at the time, but it turns out that it was my desire to help others that was the key to helping myself get better. I wanted to find a way to provide education, resources and hope to people who were lost and struggling (as I had
“Labels Do Not Describe Me”
Gender Identity Among Women on the Autism Spectrum

By Eva Mendes, MA, LMHC and Hillary Hurst Bush, PhD

A large number of women with Autism Spectrum Disorder (ASD) are currently undiagnosed or misdiagnosed. In the United States, for every four males diagnosed with ASD, only one female is diagnosed (Centers for Disease Control and Prevention, 2012). While there is likely to be a true sex difference in the prevalence of ASD, females are also more likely to be underdiagnosed with ASD. This may reflect, in part, to a lack of awareness among health professionals and the general public about what ASD in women looks like. In addition to women being underdiagnosed or misdiagnosed with ASD, little empirical research currently exists on how they experience their sexualities. This is an unfortunate oversight, seeing that sexuality is common to all human lives. However, some of the existing literature on ASD and sexuality suggests that individuals with ASD may be more likely than individuals without ASD to identify as a “tomboy” or have a non-traditional gender identity (Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007), and to identify as a sexual minority or experience same-gender sexual attraction (Byers, Nichols, & Voyer, 2013; Gilmour, Schalomon, & Smith, 2012). In this article, our goal is to shed light specifically on the gender identities of women with ASD, drawing from our research and clinical experiences with autistic women in the community.

The research findings reported in this article are drawn from the [Autistic] Women’s Sexuality Study (Bush, 2016), Dr. Bush’s survey-based dissertation study of multiple aspects of sexuality and well-being among young women (18-30 years old) with and without ASD. Gender non-conforming individuals, including transfeminine women, were invited to participate too. In total, 248 individuals with ASD and 179 individuals without ASD participated, for a total sample size of 427. The clinical case vignette included here is drawn from Ms. Mendes’ work with hundreds of women (14-74 years old) with ASD, for diagnosis, individual and couples’ counseling, and in support groups.

What is Gender Identity?

Gender identity is one’s internal, deeply held sense of one’s gender. In many societies, people are primed to have a gender identity either as a woman (if they are designated female at birth) or as male (if they are designated male at birth). When one’s gender identity aligns with the sex they were designated at birth, they are considered cisgender. However, for some people, their gender identity may not align with the sex they were designated at birth. Further, some people notice changes in their gender over time. Regardless of which sex they were designated at birth, people may identify as masculine, feminine, both, neither, or as other genders.

In the [Autistic] Women’s Sexuality Study, participants were asked to describe their gender identity in an open-ended format. Among the 248 participants with ASD, 50% reported having a non-binary gender identity, as compared to only 21% of participants without ASD. Aside from seeing Gender Identity on page 25

Eva Mendes, MA, LMHC

Hillary Hurst Bush, PhD

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The Initiative for Girls and Women with Autism Spectrum Disorders at Yale

By Kathy Koenig, MSN, APRN
Director, Initiative for Girls and Women with ASDs
Yale Child Study Center

In the summer of 2013, a program for building relationships and promoting community for teenage girls and women with autism spectrum disorders began at the Yale Child Study Center, supported by a gift from Jim and Marilyn Simons. The initiative was conceptualized as a means of bringing together teens and women, not for clinical intervention, but simply to offer an opportunity to experience the joy of sharing activities and conversation with friends. At Yale, we recognized that girls and women with an ASD diagnosis are often socially isolated. They find it challenging to meet like-minded friends in school or in their community. Social programs developed for those with ASDs often have many more males than females, so girls and women don't have the chance to develop the kind of close connections that neuro-typical girls and women tend to have. All this means that girls and women with an ASD diagnosis are often socially isolated. They find it challenging to meet like-minded friends in school or in their community. Social programs developed for those with ASDs.

At the Yale Child Study Center, our mission is to improve the mental health of youth and families, to advance understanding of their psychological and developmental needs, and treat prevent mental illness through the integration of research, clinical practice, and professional training. We care deeply about the lives of these teens and young adults and are focused very strongly on doing what we can to make their lives healthy and joyful.

Our program began with a series of focus groups for families, with targeted questions for parents about social challenges and other issues that impacted their daughter's health and happiness. Parents targeted a lack of friends, limited social opportunities, bullying and cyber-bullying, difficulty helping their daughter manage personal hygiene and self-care, and worries about their daughter's safety and vulnerability as they tried to make their way in the world. We also noted poor adaptive functioning - day-to-day living skills - in females with ASD as compared to their neuro-typical peers. In a sample of females with ASD culled from clinic settings at Yale and at Marcus Autism Center in Atlanta, we found that girls from ages 8 to 18 years of age showed adaptive functioning that was delayed relative to typical peers by 2½ standard deviations (Saulnier et al., 2016). Our focus group work and the results of this study have helped us to understand what kinds of programs could support teenage girls and young women with ASD as they develop.

Our offerings have varied over time based on the needs and interests of participants. We began with a weekly group for little girls, ages 8–11 years, which included art, jewelry making and yoga classes. Yoga was particularly successful; our girls enjoyed the focus on the body as well as the process of centering oneself. Our teens got involved in horseback riding, pizza parties, movies, and a twice monthly art class taught by an artist from Yale Center for British Art. In May of 2016, we presented Artworxx, an exhibition of art created by our teens at the Yale Center for British Art. Over 200 visitors attended the opening reception and viewed the exhibition. It was a tremendous success!

For young adults, the Initiative offered Lean Out: Networking and Working for Women with ASDs, a program addressing a significant problem for adult women with ASDs, finding and maintaining employment. We used the phrase “lean out” as a bit of a play on Sheryl Sandberg’s book, Lean In: Women, Work and the Will to Lead. Ms. Sandberg’s book described the tough working environment that women face in the contemporary era in America, and leaning in means: “being ambitious in any pursuit.” We thought about leaning out as an expression that captures the need to network and build relationships effectively in order to find and maintain satisfying employment. Lean Out was supported by a community service grant from Autism Speaks. A major focus was learning the “soft skills” needed to function in the workplace, including presenting oneself at the interview and in the workplace, socializing on the job, and collaborating with others on work projects. Eighteen women attended the program, which included presentation of important information using visual supports (Powerpoint, workbooks) as well as targeted discussion. A significant
The Social Needs of Women on the Autism Spectrum

By Marisela Huerta, PhD
Senior Advisor
Felicity House

Current research on adults with Autism Spectrum Disorder (ASD) without intellectual disability suggests that outcomes for adult women with ASD are especially poor relative to those of men (Taylor, Henninger, & Mailick, 2015). These findings stand in sharp contrast to recent findings that women and men with primary ASD are largely similar in symptom presentation (Van Wingjngarden-Cremers et al., 2014) and that in some affected women, the condition may be milder (Wilson et al., 2016). What then explains these differences in outcomes? Are there particular challenges for women on the autism spectrum that are currently being overlooked? What are the necessary supports for their success?

From the Perspective of Women with ASD

As part of the development of Felicity House, a new program for adult women with ASD, focus groups with key stakeholders were conducted to identify the specific needs of this population. Women on the autism spectrum were invited to discuss their perceptions of the sex differences in ASD, their experiences of being on the spectrum, and their sense of the current gaps in services. The resulting discussion highlighted the current gaps in community-based adult programs.

The focus group participants immediately commented on how “different” and “nice” it was to be in a room full of women on the spectrum. Many shared that this was a first for them. This then was the re-occurring theme of the meeting: that women with ASD often feel “alone” and like a minority within a minority group. The women explained that their efforts to socialize often lead to feeling “misunderstood” and “lonely” because they frequently are the only person with ASD or the only female with ASD in a given social scenario. A number of the focus group participants further noted that their social interaction “style” has been consistently at odds with those of their male peers, making their minority status particularly problematic. Additionally, as a result of being the token female in group activities designed for adults with ASD, the women often receive unwanted sexual attention.

“If autism is a form of the extreme male brain, where does that leave women with autism?”

“There’s...a disconnect between what society expects of women with ASD and what we can do.”

“In the support groups for ASD, it’s either get hit on or be seen as an alien!”

“I don’t know how to meet people.”

“I’ve had bad (social) experiences.”

Most striking was that the participants quickly zeroed in on the lack of social activity as their chief need. Rather than describe the limited availability of clinical services and employment opportunities for adults, the women made a point to describe all of the social opportunities they had as students and contrast this with their experiences as adults. Participants identified social programming specific to women with ASD as most needed, specifically a safe space to pursue leisure interests and build social experiences. Many of the women reflected on their own social and communication challenges, the difficulties involved in interacting with same-age women without ASD, and their interest in building their social experience in the context of a supportive system.

“At [college name], we had a group where we would play games...so just to have that again!”

“I have been looking for programs...with people who are serious about music, drawing, creative writing.”

“We need opportunities to build “real” social connections...”

“...led by someone without ASD, to be able to stop (us) from speaking too much, making sure everyone has a turn”

see Social Needs on page 30

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spectrum are males.

2) Wondering, “Were my struggles hormonal changes or the autism spectrum in me?” During puberty, I was actually put on meds that I didn’t need, and eventually realized it was more of an emotional regulation thing due to puberty than it was ASD. No one considered that it was a bit of both.

3) Doing girly stuff that has sensory consequences. I thought nail polish and makeup was pretty, but sensory wise I felt so uncomfortable wearing it. If my makeup did not look like a magazine model or one eye was darker than the other, I would have to wash my face and repeat the process over and over. I would usually get so frustrated that I would remove it because it caused anxiety to go out in public with it.

Q. What helped you to get to the point where you were comfortable with makeup?

A. I had to deal with my perfectionist issues and I really needed practice. Then I started to find makeup fun and I liked putting pretty colors on my face. My advice: Don’t wear makeup because you think boys will like you and you need to fit in with other girls. If it’s truly a sensory issue for you, don’t do it. Let makeup by your choice - makeup cannot make you beautiful on the inside.

Q. What in particular have you found challenging in transitioning to adulthood?

A. 1) My parents not trusting me. To this day, they still feel like they have to protect me. I have a neurotypical sister and I notice that they don’t protect her as much.

2) Figuring out what is appropriate to say in social situations. I still need help to figure out boundaries with different peer groups. Now that I’m in the workplace, I notice that there is a lot of different levels of social engagement and it’s difficult sometimes to figure out what information you can share with each person. I quickly noticed this the other day when I told my supervisor something that I thought was funny and her response was that was too much information, but if I told my co-worker the same story she probably would have laughed.

Q. How do you cope with or handle that particular challenge as a female?

A. Sometimes I will ask people, “Am I being inappropriate?” and if someone gives me feedback like that’s TMI, I will thank the person for their honest feedback and let them know it helps me. I don’t want people to gossip about me.

Q. What would you suggest as a coping mechanism for other young women who might experience that challenge?

A. Don’t do this during a job interview, but maybe on your 1st or 2nd day go to your coworkers or supervisor and don’t fully disclose your challenges, but say in a fun way, “I can sometimes be a little socially awkward” or “I have social anxiety, so please let me know and give me feedback - it is really helpful to me.” You also have to read their body language; is this someone you can have this conversation with? I’ll use a first impression or judge their character as to gauge how much personal information I will share with someone. I also suggest first observing how the co-workers are communicating; you can observe what coworker has what type of personality. You have to learn their interest.

Q. What does self-confidence mean to you?

A. To me, it is being aware of your strengths and weakness and being proud of your strengths and acknowledging your weaknesses because you have to know what they are. Acknowledge strength, acknowledge weakness and embrace both as a young woman.

Q. What does a self-confident woman look like to you?

A. I have a girlfriend named Lauren who knows where she is going and knows that she has a place to go. She’s happy in relationships and content with her life. Content is the big word because that gives them strength to help their friends.

Q. What does the term self-esteem mean to you?

A. Being proud of who you are, what you are, and the components that make up that whole self.

Q. How might you support to another young woman struggling with her self-esteem or self-image? What might you tell her?

A. It’s important to praise and emphasize good qualities in people because not everyone has the talents that you have but everyone does have a talent and the ability to be great, it just takes time to see it. Many ASD young adults are disgruntled because society has their idea of good, but our good may be something really special within the situations we deal with, such as finding housing and who is going to support us. This sometimes does not allow us time to explore our special traits.

People on the spectrum often have special interests and we need to highlight that there is a place in this world for them. These people have talents and abilities and passion that are lacking in neurotypical people, like Temple Grandin and her
Women at Work

By Marjorie Madfis
President, Yes She Can Inc.

When I founded Yes She Can in November 2013 I created the motto: Women with Autism. We work. With you. It was my vision that with proper training and support, women with autism could and should join the competitive workforce and work side by side with neuro-typical peers, whether it were shelving books, creating software code, or selling dolls. Back in the spring of 2014 I introduced the readers of Autism Spectrum News to our job skills development program run at Girl AGAIN boutique. We had only been open for two months so I had little actual experience in achieving my vision.

Now two and a half years later, Yes She Can has worked with 22 women with autism spectrum disorders and related social and learning disabilities; many also have intellectual disabilities. Like their neuro-typical peers, our trainees truly desire to be independent. They want to work for money, and can - even if it is for just 15 hours a week. Women transitioning from school to adulthood need to stretch, take risks, try and possibly stumble, and learn how to recover. They need to transform from dependent students and social service “consumers” to confident problem-solving women.

Given their social and emotional challenges, the women we serve need a safe and supportive environment to begin their exploration of their capabilities. They also need an environment where they can connect with other women who share their challenges - where they can “be themselves,” as one trainee put it, while learning to stretch.

Typically at school, girls are the minority in co-ed special education classes, where the boys’ agenda can overwhelm the girls’ needs and interests. At our training program at Girl AGAIN, not only do we focus on women’s issues but also our store caters to girls, so our trainees can relate to our customers. This gives them the opportunity to talk about the product with the little girls and their moms and grandmothers, and to assist the girls at the craft workshops where trainees can be leaders. Being the expert is a rare experience for our women.

Our trainees say they can be more relaxed without the concern of young men around them and focus on the skills. The job coaches can also be more direct in coaching on behaviors. So while our all-female training place may not reflect all workplaces, we do think it is a good learning environment.

The Women’s Card

As we know, neuro-typical women’s behavior and presentation is judged more harshly than men. This seems no different for women with autism: clothing, hair style and accessories, weight, table manners, topics of conversation, and posture and presence are held to a higher standard than men. A “quirky” even rude man with a stained shirt is acceptable to his work peers while an “odd” women with sloppy table manners who stumbles at chit-chat is rejected by her work peers. I have heard several women with ASD report that they believed they were fired because of a social faux pas that would be tolerated of men.

see Work on page 28

This is what success looks like...

This is what an adult living with autism looks like!
5) We emphasize the importance of teaching an individual to be a good advocate for himself or herself. When someone can report a violation, he or she is less likely to be victimized. We teach this skill even to our non-vocal program participants, and we believe it is an essential focus for all learners.

6) We train EVERYONE in our settings to stay alert and to be aware of odd interactions between any client and any care giver. There are some behavioral indicators that an individual (even those that are not able to verbalize) has been victimized in some way—whether it be physical or verbal. It is important to create and foster a culture where staff members are advocates for the clients, so that if something odd is observed, it will be reported immediately.

7) All staff members are Mandated Reporters and are thoroughly trained about these obligations.

8) If a client expresses that he or she prefers female/male staff members, then we try to make every attempt to honor that.

In addition, we try to focus on safety and risk in our curricular programming. However, there are real challenges to this goal. First, it can be difficult to convey an accurate concept of privacy, when the individual served is assisted with personal care many times a day from multiple staff members. It is also difficult to teach stranger danger, because turnover rates in most facilities are pretty high and there is a constant cycle of new staff or over time staff that primarily work in other environments. Often, a client may only have been introduced to a new person briefly before that person is assisting them with toileting/showering/etc. In addition, there are a number of additional factors associated with adolescence that make these challenges even more significant. Young adolescent clients may experience “crushes” or attraction to care givers, may call them “boyfriend/girlfriend,” and do not have the mental capacity to understand why that is not appropriate.

Finally, we teach individuals with disabilities to be compliant with directions, which may inadvertently make it difficult to identify situations in which inappropriate conduct is taking place or in which discomfort is being experienced by the client. It is imperative that we do more to teach these learners when it is ok not to comply with a request.

Learners with autism are a vulnerable population of individuals, and females with autism may be the most vulnerable. It is important to acknowledge this worry in families. It is imperative that staff members be trained in ways that reduce this likelihood and that enhance independence and self-advocacy in females with autism. We have shared some of the policies that have assisted us in meeting the needs of females with autism, respecting the families’ wishes, and preparing staff members for the challenges and sources of discomfort associated with providing personal care. It is important for all of us to share our struggles and our solutions, so that more organizations can thrive and provide clear information to families, and so that more individuals with autism are protected from abusive and inappropriate conduct by staff member, and so that all individuals with autism are provided with safe, humane, and effective treatment.

Sandra A. Rogers, MS, BCBA

Mary Jane Weiss, PhD, BCBA-D
For years, we’ve known that four times as many boys as girls are diagnosed with autism. More recently, genetic research has surprisingly shown that the various genes that cause autism are equally distributed in boys and girls. So what explains this difference - why do some girls who have the exact same autism genes as their brothers never develop autism? What protects them?

To find the answers to these critical questions, the Autism Science Foundation - a not-for-profit organization dedicated to supporting and funding autism research - has launched the Autism Sisters Project, a search for what is referred to as autism’s “female protective effect.”

The Autism Sisters Project will give unaffected sisters of individuals with autism the chance to play an active part in accelerating research into the “female protective effect.” The goal is to build a large genetic database that researchers can use to explore this phenomenon and discover how the protective factor can be harnessed to help people with autism of both genders. Once scientists know what causes that protection or resilience, they may be able to develop new drugs or therapies.

Here’s how it works: the Autism Sisters Project is seeking families that have a child with autism and an unaffected sibling. Taking part is easy and painless. All the siblings need to do is visit the Seaver Center at Mount Sinai Hospital in Manhattan, play some simple thinking and language computer games, take part in a basic assessment and then spit into a test tube. There’s no blood test - all the DNA is collected through that saliva sample. The researchers will take care of the rest!

“I don’t want to change my brother, but if there was something that I could do to help him, I know I definitely would,” said Evee Lopes, who participated in the study and whose brother Tommy has autism. “By participating in the Autism Sisters Project, I’m getting one step closer.”

The important genetic information that will be gathered from these new genetic samples will be added to information from earlier studies that included a non-diagnosed sibling. By pooling all this information, scientists will be able to study the “female protective effect” much more quickly and efficiently. The more information researchers have to work with, the better.

“The female protective effect is a very important area of investigation in the autism research community and the Autism Sisters Project is going to jumpstart the process of developing a necessary cohort of unaffected female siblings,” said Dr. Buxbaum. “I, and all my colleagues at Mount Sinai, are thrilled to be partnering with the Autism Science Foundation on this initiative. This is an enormously exciting opportunity for sisters of individuals...
On Being a “Unicorn”

By Becca Lory, CAS
Director of Development
GRASP

“Tell me and I forget. Teach me and I remember. Involve me and I learn.”
Benjamin Franklin

Usually writing comes easily to me. It’s one of the unexplainable gifts that comes with my autistic brain. I fully expected that I would sit down in front of the screen, access my encyclopedia-esque brain, and bang out this article in an afternoon. After all, the topic of females on the spectrum is not just something I do for work every day but it IS my every day. My every single waking moment is being a living, breathing woman on the autism spectrum.

Day one passed without a word written and I just thought, “Oh I must be tired. Maybe it was a bit of a sensory overload day yesterday,” so I waited. Day two, I kind of knew what I should say but it didn’t feel right. So, I left my background program running and decided to try again tomorrow. On and on for a week straight, I tried to write with no success. The blank page in front of me never filling with words. My default setting was corrupted but why?

Why with this topic that I live and breathe daily was I struggling to get my thoughts on paper? And then it finally occurred to me. I was tired.

Tired of repeating the same things over and over again. Tired of advocating to deaf ears about the challenges women on the autism spectrum face. Tired of reminding people how many women are diagnosed late in life because their sons get diagnosed first. Tired of describing the clear difference between the male and female phenotypes we see repeatedly in the ASD community. And mostly, I was tired of being reminded how little this part of our community has changed regardless of how many mountain tops the female autism advocates scream from.

When I was first diagnosed at age thirty-six with what was then called Asperger Syndrome, I remember the relief. The sense of belonging. The very fresh eyes as I began to understand myself for the first time. I also remember a clinician who was so excited to meet me because meeting an adult female diagnosed late in life was such a treat. I remember the words that were used. “You are the unicorn of unicorns,” she said. As a female diagnosed after age thirty, having nothing to do with a spouse or a son, to her, I was a mythical beast that is rarely sighted and even more rarely captured alive.

At the time, I was honored to be considered so unique. Unicorns are magical, mythical creatures known for their gentle, intelligent and, YES, empathic nature. Not to mention their ability to heal. They have made their way through time from the Ancient Greeks to modern science fiction. There is even a well-known legend that when Noah gathered two of every kind of animal, he neglected to gather the unicorn, which is why they do not exist today. I rather enjoyed thinking of myself as a rare mystical creature, for a while.

Years later, the idea of being so very distinctive has lost its shine. Because the truth is, I am not a unicorn, let alone a unicorn of unicorns. In fact, there are more and more females on the autism spectrum getting diagnosed, speaking up, demanding that our voices be heard and that our needs be met each year. We live in the shadow of what once was believed to be a childhood male disorder. The idea that autistics would grow up, grow old and not just be capable of but desire a successful and happy life is just now being addressed. Within the autism community, the very notion that someone would want to cure autism, a very important core piece of your personhood, is barely ever mentioned anymore. We talk about inclusion, diversity, supports, challenges, and life planning. Still, the mountain that is the female autism phenotype has barely begun to be traversed.

We have long conversations about how women on the spectrum present differently than men and why. We talk about how the evaluation and testing materials are skewed toward young males. Yet we are stuck in the 4:1 male to female ratio the CDC published years ago though it likely is not representative of the actual population as many women live their entire lives without ever receiving a formal diagnosis.

Improving and enriching the lives of Adults and Teens on the Autism Spectrum and their families through community advocacy & outreach, education, peer supports, programming and services, at no cost to its members.

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Sex Differences in Autism: A Treatment Perspective

By Tom Cariveau, PhD, BCBA-D, M. Alice Shillingsburg, PhD, BCBA-D, Caitlin Delfs, PhD, BCBA-D, and Lawrence Scanhill, MSN, PhD, Marcus Autism Center and Emory School of Medicine

Sex differences in prevalence have been reported in several mental disorders. For example, the prevalence of trichotillomania, anorexia nervosa, and bulimia nervosa are reported to be as much as 10 times more common in girls than boys (American Psychiatric Association, 2013). By contrast, autism spectrum disorder (ASD) is reportedly four to five times more common in boys compared to girls (Baird et al., 2006; Centers for Disease Control and Prevention [CDC], 2016). The accuracy of this ratio has been questioned with some authors citing the potential gender bias in diagnostic instruments as many of the measures were developed and standardized in predominantly male samples (Kreiser & White, 2014). In addition, behavioral characteristics such as stereotypic and disruptive behavior may be more pronounced in boys, which may increase the likelihood that boys will come to clinical attention (Mandy, Chilvers, Chowdhury, Salter, Seigal, & Skuse, 2011). On the other hand, others contend that male gender increases the risk for ASD (Baron-Cohen, Lombardo, Auyeung, Ashwin, Chakrabarti, & Knickmeyer, 2011).

In the 2007 report by the CDC, the prevalence of ASD was 1 in 150 children (CDC, 2007). The current prevalence estimate is 1 in 68 children (CDC, 2016). Despite the rise in the estimated prevalence, the male-to-female ratio has remained remarkably consistent (see CDC, 2007, 2016). Current prevalence estimates are 1 in 42 for boys and 1 in 189 for girls – nearly 5:1 (CDC, 2016). If these prevalence estimates of ASD in boys and girls are accurate, then the male:female ratio in several large-scale clinical trials is indeed representative. For example, we tallied the male:female ratio in five federally-funded multisite trials in children with ASD (Aman et al., 2009; Bearss et al., 2015; King et al., 2009; Research Units on Pediatric Psychopharmacology Autism Network 2002; Research Units on Pediatric Psychopharmacology Autism Network, 2005; Scanhill et al., 2015). Across these trials, there were 682 participants (age 4 to 17 years); 585 were boys and 97 were girls. Given the relatively small number of girls in each study, it was not possible to evaluate sex as a moderating variable in any of these studies. A similar conclusion was reported in a review of 5 meta-analyses on the effectiveness of Early Intensive Behavioral Interventions for children with ASD (Reichow, 2011). In the absence of larger samples of girls with ASD in treatment studies, it is unclear how girls respond to the currently available evidence-based interventions.

Given the current state of knowledge, we can either assume that there is no difference in treatment response in girls or begin a line of research to test this assumption. If we assume no difference based on sex, we simply accept that the results of empirically supported treatments apply to boys and girls. However, if there is reason to believe that girls may respond differentially to specific interventions, it may be informative to enroll female-exclusive samples into treatment programs with demonstrated efficacy in boys. With support from the Autism Science Foundation, we are about to launch an evidenced-based social engagement intervention in girls with ASD (Shillingsburg, Bowen, & Shapiro, 2014). We hope that other treatment programs will pursue this line of research in order to promote our understanding of girls with ASD.

Tom Cariveau, PhD, BCBA-D, is Post-doctoral Psychology Fellow, M. Alice Shillingsburg, PhD, BCBA-D, is Assistant Professor of Pediatrics, Caitlin Delfs, PhD, see Perspective on page 29
What Happened to All the Females with Autism Spectrum Disorders?

By David H. Skuse, MD, FRCP
Head of Behavioral and Brain Sciences
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The concept of an autistic disorder is generally accepted to have emerged with Leo Kanner and his classic 1943 account of ‘Autistic Disorders of Affective Contact’ (Kanner, 1943). He described 11 children with what would now be regarded as severe autism. Three of these 11 were girls, and as children their symptomatic profiles were very similar to those of the boys. It is less well-known that he conducted a follow-up study in 1971, and discovered that all those girls were in State Hospitals, vir- tually uncommunicative to both staff and their families (Kanner, 1971). As diagnostic criteria developed, and standardized instruments were devised to measure autistic traits, Kanner’s male-typical template – associated with severe to profound learning disability – was used for validation. For many years, diagnosticians regarded the typical child with autism as male with generalized learning difficulties. A high proportion have associated neurological complications such as early developmental regression and/or epilepsy. The male:female ratio is widely found to be 4:1 in ascertained cases, a figure that disguises the remarkable fact that among those with very low IQ the ratio is only 2:1. Leading clinical centres in the USA have almost never diagnosed ‘high functioning females’, so in North America there is a dearth of research on girls and women with autistic traits whose verbal IQ is above average.

Recent epidemiological evidence from the National Center for Health Statistics reports changes in the apparent prevalence of autism spectrum disorders in school age over the period from 2007 to 2014 (Blumberg et al, 2013; Zablotsky et al, 2015). This survey reflected diagnoses that were provided to families by paediatricians from around the United States. The figures show the expected rapid increase. They also show that by far the greatest change has been among children in mid to late adolescence, the great majority of whom do not have severe to profound learning disabilities. This increase in ascertainment has been predominantly of boys. By 2012 about 1 in 30 boys in the USA had been given a diagnosis of an ASD, compared with just 1 in 140 girls. In 2014, there was a change in the way the telephone survey was conducted. That change led many children who had previously been categorized as having primary generalized developmental delay to be reassigned to an ASD category. Reassignment impacted primarily on girls, where prevalence jumped over 60% from the 2011-2012 figure (compared with a mere 2% increase in boys), and the findings have two significant implications. First, ASD is still disproportionately recognised in boys; girls in the USA have almost never been diagnosed (at least, in the USA). Second, there is a persisting tendency to recognise autism in girls only if it is associated with generalized developmental delay.

The DSM-5 defines two dimensions of impairment associated with an ASD, comprising social communication defi- cits, and repetitive/stereotyped interests and behaviors, with sensory sensitivities. If there are girls out there in the general population with these characteristics, who have not been diagnosed, how would we recognise them? If there really is an ascertainment bias, one possibility is that those females with higher IQ, especially verbal IQ, are able to disguise their symptoms – a process that is known as ‘compensa- tion’ (Lai et al, 2011). The motivation for compensation comes both from influences that are common to all females. These include, first, a biologically engendered greater awareness of other females’ social behaviour, plausibly related to the possession of a second X-chromosome (Skuse, 2000) and, second, the influence of socialization pressures that have evolved in concert with those biological differences (Adler et al, 1992). Clinical experience of interviewing many ‘high-functioning’ females with ASD in the UK confirms a widespread wish to act normal which is not so prevalent among affected males at any age.

As we lack a biomarker for ASD, the opportunity to validate the hypothesis that there is a large number of undiagnosed females with ASD seems limited. One approach we have taken is to evaluate ASD traits by screening a general population for parents of girls group had to be delayed. Male or female children filled quickly, the parents of girls group had to be delayed.

A Support Group for Parents of Tween Girls with Autism Spectrum Disorder

By Erika Drezner, LCSW
Director of Programs for Child and Teen Services
Asperger/Autism Network (AANE)

The gender imbalance among those diagnosed with autism spectrum disorder (ASD) is 4 to 1 boys to girls. When considering those diagnosed with ASD without intellectual disability, the imbalance is even greater - 7:1 (Skuse & Mandy 2015). One consequence of this gender imbalance is that parents of girls with ASD often find themselves without a supportive community. Girls with ASD not only present differently from boys with the diagnosis, they also face unique challenges as females (Faherty 2002). Parents of girls find that, within the ASD parent community, they are in a distinct minority. Turning toward the parents of neurotypical girls for support may not create a service that they did not need a curriculum. Even though their daughters were close in age, the variation in physical development was quite significant. For example, while there were parents in the group who were very worried about how to address their daughter’s first menstrual cycle, there were many parents for whom this milestone was in the past. The variety of experiences meant that these parents could advise one another based on their own experiences.

As the leader, I felt it was important to be flexible, so I discarded my curriculum and addressed the issues that surfaced naturally. The parents’ concerns were very much in keeping with the growing literature about females diagnosed with autism without intellectual disability; mental health issues came to the forefront rather quickly (Mandelli 2015). Most parents expressed concern about their daughter’s emotional regulation and anxiety. Related issues raised by the group included school refusal, self-injury in the form of cutting, and depression. As with any support group, members were able to normalize experiences that they received as shameful by sharing them with others and learning that they were not the only families with these issues.

The sense of parental isolation was quite striking. While some parents had daughters who were diagnosed young, many had been diagnosed quite recently. Because we do not require that participants in any of our programs or services have a formal diagnosis, there were participants who were in
It's August now. The days are still long and hot and humid, but there is a tinge of autumn in the air, especially at night. Most of you are starting to think about school again. You are reading over your supply list for seventh grade and wondering if your new teacher is nice or strict. I wonder if you remember a boy named Jack from last year. He's tall, and he wears glasses, and sometimes he jumps around a lot. He bought his lunch from the cafeteria every single day. For the annual science project he made an experiment with cotton candy to see if it would dissolve in water. A lot of times he got mad. He got mad about the computer, about recess, and about the complicated tangle of friendships his spectrum brain could not unravel. He screamed swear words. He threw books. He banged his head on the wall and flapped his hands around his ears. Sometimes when he got mad, the teachers had to take all of you out of the classroom so he could try to calm down by himself. Maybe this made you nervous. Maybe you exchanged looks with each other as you filed out into the hallway. Maybe you worried about him, or you were scared of him. Maybe you knew about his autism so you felt a little sad for him.

He hates himself for that. He hates himself for the room-clearing and the book-throwing and head-banging. Have you ever hated yourself? Have you ever been so embarrassed and ashamed of the way you acted that you felt dark and empty and all alone inside? This boy Jack, he feels that way a lot of the time.

In a few short weeks, you will go to the middle school that was built in 2007 and is attached to the high school and meet your new teachers. You will eat your lunch in the cafeteria and check books out of the library, and in this middle school, you will start to dream of your future, grown-up selves. Maybe you will dream of becoming astronauts, or ballerinas, or teachers or gardeners or lawyers. Or of moving to Florida, or flying a plane, or backpacking across Europe. This boy Jack, well, he just dreams of being normal.

He dreams about being like each one of you, with your easy smiles and your calm, still bodies. He dreams of shedding his autism the way a caterpillar sheds his cocoon and turns into a bright, incandescent butterfly.

Jack is not coming back to public school this year. Over the summer, his mom and his dad spent a lot of time researching academic options and meeting with people for an out-of-district-referral. This was very hard for them. They never imagined their son would not make it in public school. Their son is not making it in public school. And the mom, well, she has tried to avoid this solution for as long as she could. See, she has five kids and she always pictured them like five little ducklings walking a similar path. Now she has to pluck one of her ducklings out of line, and send him off to a school ten miles in the other direction all by himself.

This school, it only has thirty-five kids. It is mostly boys with just a couple of girls. There is no cafeteria. There is no big bus. On the first day of his school, this boy Jack will climb into a minivan that has a sign attached to the top of it. The sign says School Bus, but it isn’t really a bus. This is what hurts the mom’s heart the most. It hurts her the most because she remembers when Jack started first grade and he insisted on riding the big bus like his older brother, Joey. He didn’t talk as well then but still, they knew what he meant. “Big bus like Joey. Ride big bus.”

But it’s time. This mom, she knows this. She knows that if she continues to clutch her dreams too tightly in her fingers, they will disintegrate like the luminous wings on her fragile butterfly. They will lose their color, and their softness, and turn to dust. She has to let her dreams breathe, and move, and change. It is time to accept what is before her and look at what’s ahead of her and be willing to consider a different boy and a different school and a different life.

Carrie Cariello

What Color is Monday? 
Someone I’m with Has Autism

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How Autism Manifests Differently in Girls: What Families Need to Know

By Lauren Agoratus, MA
Family Voices, NJ
and Myriam Alizo, BS
Statewide Parent Advocacy Network

According to the Centers for Disease Control and Prevention (CDC), in 2010 The Autism and Developmental Disabilities Monitoring (ADDM) Network released data that showed “ASD prevalence…was 4-5 times higher among boys than girls” (http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm). Questions remain as to whether there is a bias towards males, how autism is seen differently by gender, and why girls are diagnosed later.

Are There Really More Boys Than Girls with Autism?

It does seem that autism affects boys more often; however there are several variables that need to be considered. Health disparities and poorer outcomes occur for both boys and girls in underserved populations. Specifically, “black and Hispanic children were less likely to have a first evaluation by age 36 months” (http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm). This means that children are diagnosed later, or misdiagnosed, and miss out on early intervention from birth to age three. Early intervention results in better health outcomes. Differences in autism symptoms by gender are another determining factor. Lastly, research shows that girls in general are diagnosed with autism spectrum disorders later than boys.

Aging Symptomology in Girls

Studies have shown that there is a “male bias” in diagnosing autism due to differences in symptomology “including fewer restricted and repetitive behaviors and externalizing behavioral problems in females” (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4164392/). Social factors make it harder to diagnose autism in girls and they may need to have more behavioral issues or cognitive disability than boys in order to be diagnosed. Girls with autism may score the same on indicators of friendship or empathy as boys, but not the same as typically-developing girls. They want to socialize more than boys with autism, and have higher rates of depression and suicidal thoughts as teens. Preliminary research shows that the hallmark “brain differences” in autism vs. typical peers seems to hold true for boys, but not girls. A new forthcoming study by Kevin Pelphrey, PhD, director of the Autism and Neurodevelopmental Disorders Institute at George Washington University, will discuss “Listening to our Daughters (and their Sisters): Insights from the Study of Girls and Women Living with Autism,” and is available in as archived webinar at www.IANcommunity.org.

Diagnosis of Autism in Girls

It is noted that “Girls with autism may be harder to diagnose for several reasons, including criteria developed specifically around males” (http://www.scientificamerican.com/article/autism-it-s-different-in-girls/). Furthermore, “criteria for diagnosing autism spectrum disorder (ASD)—are based on data derived almost entirely from studies of boys” (Ibid.). Sometimes girls are missdiagnosed with other conditions such as ADHD, OCD, or even anorexia. Girls are often diagnosed with autism 2 years later than boys (http://www.theatlantic.com/notes/2015/10/autism-women/412270/).

How Gender Differences Influence the Needs of Girls on the Autism Spectrum

By Daniel Crofts, MA
Day Habilitation Assistant
Genesee County Chapter NYSARC

I have often argued – and will never tire of arguing – that people on the autism spectrum are human first, rather than primarily autistic. Being human means many things, but we shouldn’t forget one of its most fundamental aspects: Relating to the surrounding world through our bodies, wherein lie the senses and perception.

To have a body is, in turn, to have a gender. Recent years have seen some intriguing research on differences between boys and girls in terms of how they learn, think, perceive the world, etc. Before proceeding, I need to be crystal clear about something. The “differences” of which I speak are not value differences that justify gender stereotypes. They do not make either gender superior or inferior to the other. Rather, the differences between the sexes complement one another to make a complete and rich human tapestry.

If we do not take these differences into account, this can paradoxically lead to stereotyping and to the shortchanging of boys, girls, or both.

As an example, consider the fact that girls tend to have sharper hearing than boys (Sax, 2005, p. 17). A teacher who speaks in an above-average tone of voice that no boy ever finds troubling may disconcert his female students, thus interfering with their learning.

Let’s say the girls voice their concerns in this matter. Imagine the danger inherent in the teacher’s unawareness of this important perceptual difference in girls. With such awareness comes an understanding that they are responding to a very real, and understandably upsetting, phenomenon.

But without it, the teacher might be tempted toward a common stereotype – namely, that girls make much ado over nothing and are emotional to the point of irrationality.

The Importance of Gender Considerations in Autism Spectrum Disorders

All this said, how is the gender question relevant when it comes to dealing with autism spectrum disorders (ASDs)? Consider Mandavalli’s (2015) insights on this matter: “Even after a girl [on the autism spectrum] gets the right diagnosis, she may be offered (…) essentially the same services offered to a boy in the same situation. Scientists and service providers rarely acknowledge the additional challenges being female may bring, whether physical, psychological or societal. (…) Advocates and scientists in other disciplines have run up against and resolved many of these same problems, but in autism, the fact that boys and girls are different is sometimes treated as if it’s a startling new discovery (para. 10, bold added).”

To be sure, the unique needs of ASD females are many. But given limited space, I want to focus on a need that stands out most powerfully: Social life.

Face vs. Motion: Perception and Social Skills

In order to lay a foundation from which to consider the social issue, I want to focus on one major difference between neurotypical boys and girls cited by Sax (2005):

“Researchers at Cambridge University wondered whether female superiority in understanding facial expressions was innate or whether it developed as a result of social factors. (I did) [They] decided to study newborn babies on the day they were born. (…) The results of this experiment suggest that girls are born preferred to be interested in faces while boys are preferred to be more interested in moving objects. The reason for that difference has to do with sex differences in the anatomy of the eye (p. 18-19, italics included).”

This may explain why social interaction is, on average, more important to girls than to boys. All human beings are social creatures (however widely sociability may vary from person to person); but the friendships of boys and men tend to center around shared activity (hearkening back to the fascination with motion), whereas girls and women tend toward more person-centered relationships (facial focus).

From what I have been able to gather, girls on the autism spectrum are no different from their neurotypical counterparts in this respect. Center for Autism and the Developing Brain at Weill Cornell Medical...
The Challenges of Adolescence for Females with ASDs

By Elena Zaklis MA, BCBA
and Rory Panter, PsyD
Behavior Therapy Associates

Approaching adolescence can be a challenging time for many individuals. The challenges are certainly different for each gender and females with Autism Spectrum Disorder (ASD) may experience these challenges in a unique way compared to their neurotypical peers. The uncertainty of the physical changes that are happening to their bodies and how to cope with those changes can cause stress and anxiety for many teens. While families are often well prepared for helping their daughters transition to various developmental stages, from kindergarten to elementary school, many females find themselves unprepared when transitioning to adolescence and approaching puberty. Parents may find themselves “caught off guard” when their daughter experiences her first menstrual cycle or when they find out their daughter is being teased in the locker room because she is not yet wearing a bra (Nichols, Moravcik and Tetenbaum 2009). Adolescence and transitioning to puberty can be a stressful time for many parents and especially for parents of girls with ASD (Zamora et al 2014). Professionals who work with families and individual females can help them become better prepared for the transition to puberty and guide their daughters to cope with some of the challenges that they may encounter during this time.

Understanding your daughter’s individual abilities may help you to set up a plan that will ease the transition to puberty. Consider your daughter’s overall intellectual ability, how she copes with change, her abilities in communicating her feelings, her organizational skills, and any sensory challenges. The physical changes that occur in females during puberty may be a time of mixed emotions for many teens. Individuals with ASD may experience sensitivities to sound, touch, taste, light intensities, and some fluctuate between hypo-sensitive and hyper-sensitive (Mandy et al 2011). For example, the experience of having to wear a bra for the first time may be met with stress and/or sensory discomfort for some females with ASD. To help your daughter plan for this transition take into consideration if she tends to have sensory challenges. If you know she has a particular preference begin to discuss the different choices that are available. Plan in advance to try out the several different types so that she can chose a style that she is most comfortable with wearing. Chose an environment in which she is most comfortable and will allow her to experience success when practicing wearing the item. Keep in mind information and skills may not be learned the first time, therefore multiple repetitions may be needed to ensure skill acquisition (Nichols et al 2009). Consider your environment in advance: do you need to practice in the comfort of your home or in a fitting room at the store? Prepare by using visual supports such as picture cues or written words to help teach the steps. Think about the teaching techniques that are most effective with your daughter and use those strategies. Some strategies to consider may include behavior chaining techniques (e.g., backward chaining, forward chaining) which can be used to build up and improve an individual’s independent living skills. (Cooper et al 2007). Break down steps into small components and practice the steps by modeling the appropriate actions, role play, review and provide behavior specific feedback. Take the time to teach this new skill, practice often and provide positive reinforcement (Miles et al 2009). These tasks may be unpleasant to your daughter and it is important

see Adolescence on
improvement in self-reflection needs to precede efforts to support or teach “mind-reading” or theory of mind in the treatment of narcissistic personality disorder (DiMaggio et al., 2008). Alexithymia is a condition in which a person has difficulty recognizing his own thoughts and emotions. A functional magnetic resonance imaging (fMRI) study compared neurotypical individuals with above-average self-reflective abilities to individuals with alexithymia (non-ASD) and found that those with superior self-reflective ability were more capable of understanding others’ emotions and less prone to painful emotions than those with alexithymia (Moriguchi et al., 2006). In a study of schizophrenia, Corcoran and Frith (2003, 2005) found strong correlations between autobiographical memory retrieval (a component of self-awareness) capacity and performance on ToM tasks. Corcoran (2001) proposed that people rely on autobiographical memory to infer another’s mental state. That is, retrieved memories of one’s own life form the basis for making inferences about another person’s mental state. The notion that self- and other-awareness is also supported by neuroimaging and behavioral research. Neuroimaging research suggests that mentalizing about self and about others activates shared, overlapping although region activation depends on the degree to which mentalizing about self and about other activates shared, overlapping although that mentalizing about self and about others activates shared, overlapping although research. Neuroimaging research suggests that mentalizing about self and about others activates shared, overlapping although self-awareness (Corcoran R. (2001). Theory of mind in autism: A review and theoretical frame- reference to the present study). The tasks of girls with ASD is to establish a healthy lifestyle, navigate social and intellectual demands at school and in the workplace, find a career path, and attain a level of independence. Girls need support in establishing gender and sexual identity and negotiating passages through adolescence, young adulthood, adulthood, adult relationships, and, for many, through mother- and grandmotherhood. All along the way, parents, educators, clinicians, and researchers aim to support the maintenance of relationships with family members and peers and to encourage girls’ self-repre- representation, and cope with limitations in motor competence, attention, and executive functions. Clinical practice with girls and women has addressed the need to support the development of identity in both group and individual treatment. For example, in Girls Growing Up on the Autism Spectrum, Dr. Shana Nichols describes activities such as the “All about me” book, “What would you rather do?”, journal exercises, and creative activities to encourage girls to understand them- selves. Can we develop broader and deep- er methods to increase self-awareness and the development of a realistic self-repre- sentation? Would this lead to measurable improvements in social competence emotional regulation, and ultimately, quality and richness of life? We know that self-es- teem is crucial for girls, regardless of their sex. Does “building self-esteem,” but can authentic self-esteem be established without foun- dation skills in self-awareness and self-un- derstanding? What is the Meaning of Self for Girls and Women? Two, somewhat contradictory reasons why this is particularly important for girls and women come to mind. Historically, girls and women have derived key com- ponents of their identity from their rela- tionships with men - husbands, brothers, and in the workplace, find a career path, and attain a level of independence. Girls need support in establishing gender and sexual identity and negotiating passages through adolescence, young adulthood, adulthood, adult relationships, and, for many, through mother- and grandmotherhood. All along the way, parents, educators, clinicians, and researchers aim to support the maintenance of relationships with family members and peers and to encourage girls’ self-repre- representation, and cope with limitations in motor competence, attention, and executive functions. Clinical practice with girls and women has addressed the need to support the development of identity in both group and individual treatment. For example, in Girls Growing Up on the Autism Spectrum, Dr. Shana Nichols describes activities such as the “All about me” book, “What would you rather do?”, journal exercises, and creative activities to encourage girls to understand them- selves. 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I want them to take off the ASD label and treat me as an adult. As their daughter, I also have to realize that they are my par- ents. I guess that is their job to protect me and I really do appreciate it all they do for me. So I’ll live with the protection things, but I need them to trust me in that I will get things done without prompts. Q. What advice would you give to parents that may be having difficulty supporting their daughter as she transitions into adulthood? A. Let them make mistakes and don’t rush to too fast to give them the answer to their question. Coach them to come to you for the answer. Also don’t say, “You always make mistakes.” Repetition isn’t bad in a day and habits are not changed with correcting one mistake. Taking risks can cause anxiety but it has to be done to grow up.

Advice from page 10

Dr. Michele Ramsay has over 20 years of experience working with students with learning differences at various age levels and supports (teacher, director of special services, and program director). She is the Director of the CIP Brevard Center in Melbourne, Florida and presents at conferences around the nation on Advocacy, College Readiness, and Executive Functioning Skills. For more information about the CIP Brevard Center, please visit http://www.cipworldwide.org/.
The Unique Needs of Women and Girls with Autism

By Sarah Hendrickx
Consultant and Trainer

My own experience perhaps gives an insight into the repeatedly similar tales I hear from other autistic women and parents of girls. I came to the field of autism via employment in education and then as Training Manager of a specialist Asperger mentoring project for young people. By this point, there had already been personal family realisation – it became obvious through my professional learning that my partner, Keith, is autistic and other members of my family were one by one being diagnosed as well. I embarked on an extensive self-instigated learning mission for both professional and person insight, eventually writing a number of books on autism and studying for a Master’s degree in Autism.

I made myself an expert in the people I worked and lived with but despite this, I failed to see it in myself. The reason I missed it was because my learning hadn’t taught me about autistic people who looked like me: autistic people who had big, chaotic lives rather than small, isolated ones. Autistic people who knew they didn’t fit but tried their hardest to do so, often at great cost. Autistic people who were impulsive, dangerous and who loved (self-initiated) change. I knew that I was odd and that every relationship I’d had was with someone who probably fitted the autistic mold. I knew I was highly logical and struggled to interact in non-structured social situations. I knew I had “phases,” 35 failed jobs and self-harmed. I knew all of that, but it didn’t look like the autism that I had studied. Keith was the epitome of the autism I had studied and I knew that I understood him, and he me, but we were so different. Weren’t we? The autism that I had studied had only given me a partial picture, because that was all we knew about it at the time. In the past few years, things have changed and changed fast, and this has meant that we now know that autism can look a whole load of different ways – for females, males and others. It is important to note that what is often called the “female autistic profile” doesn’t just apply to women – it can apply to anyone – it’s just that it appears to partly explain why so many females got missed along the way. The other part of the explanation can be put down to a self-fulfilling historical bias towards males receiving autism diagnoses, but we don’t have time for that here. It should be stated that the females that have largely been missed are those without accompanying intellectual disabilities – the Asperger profile – and that’s predominantly who this article will focus on.

So, who are these females and what do they look like, if they don’t all fit the nerd/loner stereotype? Well, from the extremely small and sparse gender focused autism research that has taken place along with an increasingly vocal female autistic population, especially through social media and blogging, we are starting to see some patterns and shared experiences that at first glance appear to entirely contradict the traditional triad of autistic cognitive processes, but on closer examination, actually reveal them, in my opinion, to be reasonably accurate but simply presented in a different way.

The females often love to talk from a young age and may have precocious vocabularies, which makes them appear very social and hence no tick in the autism box. What can be apparent on closer listening is that the conversation is not reciprocal, or is fairly surface level with little depth of understanding or nuance and hidden agenda. It is considered that in early years autistic girls perform better than their male counterparts but that things change once teenage years are reached. It’s not that the girls regress, it’s that their female peers shift gear into a more nuanced, non-verbal personality based friendship league which our autistic girls struggle to keep pace with, and often don’t want to. Autistic people are known to love the topics of fascination and interest and this certainly equally applies to females. However, an expectation of the trains, dinosaurs and space type object based interests of the stereotypical profile may not always quite fit for females. In my experience, autistic females often have an interest in people, but almost from an outsider perspective. They study people as an object, an alien species, in a bid for understanding and perhaps acceptance. I have met many women who have studied psychology, anthropology, religion, genetics and many other wide and varied loose ‘people’ topics to try and see where they fit in the world in its broadest sense. Fashions with celebrities, serial killers and historical figures feature frequently along with the devouring of self-help books and endless efforts to improve, change and belong have led to the individual themselves being their own special interest. I have met nurses, psychologists, counsellors – all professions that would not be associated with an autistic profile, but all roles require the ‘working out’ of human and social rules. When talking to these women it is clear to see that the social skills that they feel that they require to be accepted in the world are ones that they have had to learn from whatever instruction manual they could find.

Despite, her best efforts at learning mechanically what non-autistics know intuitively, she is likely to still to struggle with reading people and interpreting hidden messages and agendas. This leads her to be direct and straightforward in her manner and communication, offering less social smiling and social padding than is expected for females. This can lead her to being judged more harshly because of her gender. A blundering male can sometimes be forgiven for awkwardness or limited understanding of others: ‘it’s just how men are’ is a term of our times. But a woman behaving in the same manner can be considered ‘cold’, ‘nasty’, ‘a bitch’, and thus the female autistic faces the additional challenge of not only contravening typical social norms, but gender norms too. Added to this is the fact that for many autistic females, their efforts to mask, hide and mimic learned social responses means that their autism can be incredibly invisible, only leaking out in times of stress or when the script/template cannot keep up with the current situation. This means that faux pas look deliberate, out of context with the usual persona – and often it is just that, a series of personas for different settings – and the resulting negative feedback from recipients is crushing.

The difficulties in reading people can also lead to a vulnerability and naivety in some females which can be dangerous. Wanting to belong can make a person grateful for any attention from others and unable to determine whether it is genuine and safe. I know from my own experience that despite having an IQ of 150+, I am unable to tell if someone is lying or has an alternative motive, which has led me into situations of harm. Being clever doesn’t protect you if you are socially gullible, as I am.

It’s not all doom and gloom, of course. The greatest surprise in my journey has been the discovery of my ‘tribe’, which I didn’t even know I needed. Connecting with other autistic women has enabled me to feel a sense of belonging that I didn’t know existed. Sometimes these are strangers on social media, but it doesn’t matter: we ‘get’ each other. When we share a tale of woe, stupidity or joy, there is no frown or confusion, no roll of the eyes of judgement, only solidarity: empathy. Yes, empathy: empathy for our own kind, for shared experiences and a shared world view. It’s just everyone else that we don’t understand.

We can learn lessons from those undiagnosed until later life that can be passed on to our girls now finding their way with diagnosis, support and knowledge.

We need to encourage their individuality, give the tools to navigate the world without losing who they are along the way, which so many have done in the past. Autistic girls and women are glorious, unique creatures, defying social and gender norms, and if supported well, should be able to embrace their eccentric selves as a first rate autistic person rather than feeling like a second class version of neurotypical.

For conference bookings and other enquiries, please see www.asperger-training.com or email: info@asperger-training.com. Please note that Sarah lives in the UK.
See, when it comes to autism, there are no do-overs. There are no second chances. This mom has just one opportunity to be his mom and she has to make the very best right decision for him, even when the best right decision is so terribly hard that it makes her heart fold over on top of itself.

“I will go. Like Joey.”

She told him last Wednesday about his new school. They were driving home after the last day of his summer program, and he was talking on and on about his teacher for seventh grade and whether or not they should look for blue pencils. She pulled the car into the garage and turned off the engine and turned to face him in the seat next to her.

“Jack, buddy. Listen to me. You aren’t going back to public school.”

They didn’t plan to tell him this way, the mom and the dad. They planned to sit him down at the long kitchen table and have a discussion so they could explain the reasons and outline the plan. But if she had to hear him talk about seventh grade one more minute she was afraid she might go crazy. It felt too much like a big, ugly, sneaky lie.

Sitting in the cool, dark garage, it was as if everything around them—the dad’s old work boots and the broom on the hook and the soccer ball in the corner—took a collective breath together and waited.

This boy Jack, well, he simply dissolved. There is no other way to describe it.

She held him across the console of their red minivan and even though she could feel the hate and rage and shame radiate off of his body like the sun, she let him hold her. He doesn’t always let her hold him.

“Just let me be normal please let me go I will be good please please please I have to go I need a new start I will do it right I will be good like Joey I have to go like Joey.”

While he sobbed and screamed, she thought about all the things she wanted him to know.

She wanted him to know this is not because he was bad or because he did something wrong. She knows how hard everyone around him worked—his teachers and his aide and his case manager. She knows how hard he worked.

But at some point, autism made his corners sharper and more rigid, and it became harder and harder to wedge him into the round, smooth games at recess.

She wanted to tell him how many nights she and his dad spent talking in the darkness—each playing something called devil’s advocate and tossing around options and trying to figure out a way to keep their precious son marching in his duckling line.

“What if we paid for...?”

“The school said we can’t do that.”

“How about if we try one more year?”

“I don’t think I can take one more year, and neither can he.”

“He’s going to be devastated.”

“I know.”

She held him while he cried big, wet tears. She stroked his soft hair and for a second he laid his head in her lap and she rested her head on top of his, and then all at once he lifted up and slammed into her chin and she bit her tongue very hard. Tears sprang into her eyes.

“Why? For you. Are CRYING.”

Oh, my Jack-a-hoo, she thought in her head.

She wanted to tell him she was crying for all the things he wouldn’t have; a tuxedo for the prom and hot lunch in a noisy cafeteria and the chance to stand at the bus stop with his three brothers and one sister on the first day of school.

But she knows it is time—it is time to make his world small and cozy and warm. It’s time for him to relax in his cocoon, and just be the most perfect-est caterpillar ever.

In his new school, he can blossom into a butterfly whenever he’s ready.

It’s August now. In just a few short weeks, you will make the climb up the hill to the middle school that was built in 2007. As you sit in your new classrooms and listen to your new teachers, I only hope one thing.

Don’t forget him.

Please, don’t forget this boy who tried so hard and who will never give up and who wants to be just like you.


See, when it comes to autism, there are See, when it comes to autism, there are

### Differences from page 18

College Director Catherine Lord observes that “[o]n average, girls [on the spectrum] are more chatty, less disruptive and less likely to be entrained by trains or moving vehicles than boys are” (as cited in Mandavalli, 2015, Girl power section, para. 7).

As ASD girls progress through developmental stages in which socialization becomes increasingly important, they are likely to require more specialized attention and services. Mandavalli (2015) puts it this way:

“In early childhood, boys and girls with autism are about the same. If anything, girls appear to be more social — whether because they actually are or are just perceived to be. As they edge closer to adolescence, however, girls with autism lose this early social advantage, becoming less and less likely to have friends, and more likely to be isolated (Social networks section, para. 2).”

No one on the autism spectrum, whether male or female, wants to be alone. People with ASDs are as desirous of human connection as anyone else, but lack the natural capacity to navigate the complexities of the social world.

But whereas boys are more apt to accept this as a given and forgo the effort, girls on the spectrum appear more likely to behave as “social butterflies” in spite of their deficits, which can open them up to embarrassment and/or abuse.

The Other Girls

It is also helpful to consider the neurotypical girls surrounding girls on the spectrum. They, too, possess the female “facial-focus,” which can mean one of two things.

As Mandavalli (2015) suggests, neurotypical girls can come to see themselves as “protectors” of their ASD peers (Growing up section, para. 6). But in adolescence, the “facial-focus” can also translate into a fixation on self-image, which in turn becomes an obsession with cliques and the “mean girl” attitude. Here you have a potentially volatile arena in which the social hurdles ASD girls face could get them into trouble.

A Possible Aid

Without trying to discourage friendships with female peers, I would like to suggest that appropriate friendships with boys of the same age group may be helpful to girls on the spectrum. According to Mandavalli (2015):

“Imagining studies have reported that the social brain is underactive in people with autism, but [Yale professor Kevin] Pelphrey’s lab has found that if typical girls have the most active social brains and boys with autism the least active, typical boys would tie with girls who have autism somewhere in the middle.”

That kind of blew us away,” he says. (Different worlds section, para. 6, italics added.)

To be sure, gravitating towards too large a number of male friends carries its own risks. In adolescence, the social vulnerability of ASD girls could make them prey to sexual abuse. As in all things, prudence is of the essence.

But perhaps if parents and teachers are able to come together and identify trust-worthy boys - and girls, for that matter - with whom ASD girls attend school, they could get the proverbial ball rolling on positive change.

Conclusion: Personal Reflections

As a Male on the Spectrum

Autism is a broad condition that involves social and conceptual difficulties resulting from uneven sensory experience, which in turn involves a combination of hypertrophied and atrophied senses. Which senses are hyper-alert and which are under-alert varies from person to person.

But as much as this and other variations within the spectrum may be recognized, autism has traditionally been viewed as a male disorder.

Looking back on my own experience with Asperger Syndrome, I must acknowledge the irony in the fact that my condition has, in a certain sense, led to greater sympathy with the female sex than with the male sex (especially during my school days).

I think this may stem from the fact that one of my hypersensory senses is the sense of hearing — which, as mentioned, tends to be stronger in females than in males. While I cannot prove this in anything approaching a scientific manner, the theory makes sense in my mind. Like girls, I was always very sensitive and had strong emotions – a fact that may have roots in the sensitivity of the ears.

So as much as people may associate autism with males, we may recognize that the overall “picture” is more complex than we might suppose.

### References


How Supported Decision-Making Can Help Family Caregivers

By Lauren Agoratus, MA
Parent
Family Voices NJ

I

dividuals with autism should have a choice in what happens to them throughout their lives. Too often, parents of children and adults with autism, intellectual, or developmental disabilities are advised – and often when their child is very young, long before it is possible to predict their future decision-making and independent living capacity – that their only option is guardianship. However, there’s a new way to help people with autism and other developmental disabilities make choices about their lives, and it is called Supported Decision-Making.

What is Supported Decision-Making?

The National Center Resource Center for Supported Decision-Making (http://supporteddecisionmaking.org) has the motto “Everyone has the right to make choices.” Too often, people with autism, intellectual, or developmental disabilities are thought of as incapable of making their own decisions. With supports, individuals with disabilities can make their own life decisions. Even when their disabilities significantly impact their independent decision-making capacity, they can still have meaningful input into the choices that are made about their lives. They should have a say about where they live, go to school, work, etc. This is the “next generation” of self-determination.

How Does it Work?

Supported Decision-Making occurs when an individual with a disability has a “supporter” or support team to help them decide on important issues. Some states are starting to have Supported Decision-Making options with actual sample forms. This can be done informally and the supporter can be a family member, friend, etc. The Autistic Self-Advocacy Network has a toolkit “The Right to Make Choices” which discusses current laws and options including samples of forms (see http://autisticsavc.org/2016/02/the-right-to-make-choices-new-resource-on-support-decision-making/). Schools can also play a major role in building the capacity of students with disabilities to be able to make decisions through a focus on independence and self-advocacy starting from a very young age. The DC Public Schools have excellent resources including an overview of goals that build toward independence and decision-making capacity at every grade beginning with preschool (see http://supporteddecisionmaking.org/events/support-ed-decision-making-and-youth-transition) and a Supported Decision-Making Consent form (see http://cps.dc.gov/page/support-ed-decision-making).

Why is Supported Decision Making a Good Choice?

Research has shown that self-determination effects health outcomes, inclusion in the community, overall independence, and recognition and resistance to abuse. Conversely, research has also indicated that guardianship has a “significant negative impact on physical and mental health, longevity, ability to function, and reports of subjective well-being.” In addition, as a person with a disability becomes more independent there is less family caregiver burden, but most importantly, better life-long results for the individual.

What Do Individuals with Disabilities Want?

This generation of self-advocates prefer as much control and decision-making power over their lives as possible. There is a movement towards “person-centered planning” in both the educational and national medical arenas. In healthcare, it is known as “shared decision-making” and “shared responsibility.” But shared decision making should apply not only to health decisions but to all areas of a person’s life. Person-centered planning builds on the person’s strengths and preferences. Children with autism and other developmental disabilities need to learn from an early age how to speak up for themselves and self-advocate. These children should have as much input as possible based on their

see Caregivers on page 24
Options for Family Caregivers

There are many ways that parents can assist their family member with a disability to make important life choices. These include:

1. Supported Decision-Making Agreements - These can be drawn up by families, though as mentioned above some states have templates.
2. Health Care Proxy - This form addresses medical decisions.
3. Advanced Directives - Decisions on end-of-life care can be made using this document.
4. Power of Attorney - This gives another individual control over legal decisions. Please note that there is also an option for “durable power of attorney” for temporary situations such as mental illness that can be revoked once the person regains decision-making capacity.

In summary, although this is a personal decision for every individual with a significant disability and their family, there are new options for parents of children and adults with autism, intellectual, or developmental disabilities. Even if an individual will not live completely on their own, Supported Decision-Making allows them choices throughout their lives. It is essential to remember, regardless of disability, “Everyone has the right to make choices.”

Additional Resources


REACH for Transition: Supported Decision-Making & Alternatives to Guardianship - Statewide Parent Advocacy Network: http://www.spanadvocacy.org/content/supported-decision-making-and-alternatives-guardianship


Lauren Agoratus is the parent of a child with autism/kidney disease. She is the NJ Coordinator of Family Voices, the national network that works to keep families at the center of children’s health care for children with special healthcare needs; in NJ, Family Voices is housed at the Statewide Parent Advocacy Network (SPAN), www.spanadvocacy.org. SPAN is also the home of the state’s Family-to-Family Health Information Center. Lauren can be reached at (800) 654-SPAN or by email at familyvoices@spannj.org. Families can find free help in their state at www.familyvoices.org/states.php.

Footnotes

1. Ishita Khemka, Linda Hickson, Gillian Reynolds Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse Am J Ment Retard. 2005 May;110(3):193-204.

Michelle Wehmeyer, Michelle Schwartz Exceptional Children 1998; Vol.63, No.2, pp.245-255.


cisgender, which was reported by 50% of the ASD sample, the following genders were endorsed by participants with ASD: agender (having no gender; not identifying as masculine, feminine, or another gender; 17%); gender non-conforming/ non-binary/genderqueer (not identifying exclusively as masculine or feminine, and not ascribing to the traditional gender roles and societal expectations of the gender associated with one’s sex assigned at birth; 15%); demigirl (identifying primarily, but not completely as a woman, girl, or as feminine; 7%); genderfluid (moving across genders or having a fluctuating gender identity; 4%); transgender (having a gender identity that the sex one was assigned at birth; 3%); bigender (having two gender identities, which may be masculine, feminine, and/or other genders; 1%); and pangender (not identifying exclusively as masculine and/or feminine and instead experiencing all genders, possibly genders that they cannot describe, or that society does not recognize; 1%).

What Do People with ASD Say About Gender Identity?

In the study, participants were asked: “If you identify as being on the autism spectrum, how if at all has being on the spectrum influenced your sexuality and/or gender identity?” Some participants discussed their gender identity when responding to this question:

“I’ve always kind of been the ‘weird kid’ and have never really considered to gender, so I don’t think I grew up with anything that I cared about really expecting me to be straight or genderconforming. If you’re different from the start, it doesn’t really surprise anyone all that much when you keep being different...” (Genderfluid, 27, Asian American)

“I just accepted that I was vastly different than a lot of my peers and moved on with life. I have noticed that I am a lot more likely to completely discount gender identity as important than most of my peers, which is part of the reason I identify as genderqueer and pansexual (because as far as I’m concerned everyone else is sort of genderqueer too; the gender doesn’t matter to me).” (Genderqueer, 29, European American)

These insights are consistent with the experiences of many gender non-conforming individuals. Ms. Mendes has encountered in her counseling work. Below is a fictitious, composite narrative, intended to further illustrate the experiences of gender identity of some women with ASD. This is not based on any specific individual or client.

Meet Anik

Meet Anik, who is White, European American, and 22 years old. Anik entered counseling at their parents’ recommendation due to concerns about their gender identity when responding to others’ assumptions about other people’s identities based on the way they look or seem. For some people, their outward appearance is very much linked with how they identify on the inside, but for others, important aspects of their appearance may be different from their inner identity. Further, some individuals have fluid gender identities that fluctuate over time. These changes may happen very quickly or very slowly, and people may choose to use different terminology to reflect these changes (e.g., a person who previously identified as heterosexual may now identify as asexual). Overall, there are no fixed rates of identity expression. Ms. Mendes encourages individuals with ASD to be encouraged to educate themselves on how this population – particularly young women – may experience gender differently. Eva Mendes, LMHC, is an Asperger/autism specialist, psychotherapist, and couples’ counselor in private practice in Arling- town, MA. She has met and worked with hundreds of individuals, couples, and families with Asperger’s/Autism with diverse profiles, circumstances, and backgrounds. She also facilitates workshops and trainings at various universities, mental health, and medical centers. Her book Marriage and Losing Relationships with Asperger’s Syndrome was published last year. She can be reached at her website www.evemendes.com or email at evemendes2911@gmail.com.

Hilibrand Foundation is a major financial support for this research initiative. The Hilibrand Foundation is established in 1991 by Debbie and Larry Hilibrand. A key mission of the Foundation is to support scientific funding of autism research.

The Autism Sisters Project is initially seeking participants in New Jersey, New York and Connecticut, with additional sites to be added in the US and data included from studies from outside of the U.S.

To participate in the Autism Sisters Project, interested participants should contact the Seaver Autism Center by phone at 212-241-0961 or by email at theseasecenter@mssn.edu.
Support Group from page 16

the process of getting the diagnosis for their daughters. This is not terribly surprising, as the literature tells us that girls with these kinds of profiles are diagnosed on average two years later than boys (Mandavilli 2015). The period before diagnosis can be difficult for parents, who are struggling with children who don’t completely understand. Parents report receiving advice from friends and family members that is unhelpful at best and at times insulting. In fact, an early group meeting focused primarily on the issue of feeling judged by members of the extended family, friends and neighbors.

Group members also developed relationships with one another and between their daughters outside of the support group setting. We encourage this, as one of the goals in our mission is to facilitate the creation of community for those with ASD and their families. Additionally, many of the parents were interested in expanding their daughters’ social circles. Their daughters had experienced a great deal of social rejection and the parents were very concerned about their isolation and loneliness. Nearly every parent expressed pain at the social rejection each girl had experienced.

This fall the group will enter its third year. The continuing interest in this program demonstrates the need parents of girls have for supportive communities. Hopefully, the increased understanding of the different presentations of ASDs will lead to earlier diagnosis of girls, so they and their families can access the support they need. Parent support groups can be an effective part of that support.

To learn more about AANE programs and services as well as find information on ASD in girls and women, please visit our website, www.aane.org.

References


More research is needed regarding gender differences in autism. If recent trajectories hold, autism expert Simon Baron-Cohen predicts that “once we’re very good at recognizing autism in females, there will still be a male bias,” Baron-Cohen says “It just won’t be as marked as four to one. It might be more like two to one” (http://www.sciencemag.org/article/autism-it’s-been-more-like-two-to-one/).

Families need to be aware that there are differences in symptoms of autism in girls. If they have concerns, they should contact their pediatrician for a screening, then possible diagnosis (see Resources at the end of this article).

Another factor that might delay diagnosis in girls is the use of more than one language at home. In these cases, autism could be masked as a speech delay due to the bilingualism. Many times the pediatrician tells the parent that their daughter needs more time to catch up because she is exposed to two languages at the same time.

Support for Parents with Daughters on the Spectrum

Adolescent girls with autism benefit from engaging in social skills groups specifically designed for them. These groups follow modules that address the needs of this age group, such as: hygiene, grooming and the importance of physical appearance regarding perception, sexuality, dating, friendship and peer pressure, bullying, anxiety, anger management, living skills, social media management, and transition to adult life.

Families that have girls in the autism spectrum disorder benefit from connecting with other parents. Usually the social skills group facilitator meets with the parents, as a group, at the end of each session. When parents connect with each other, they share experiences and resources they have found in the community. In this sense, it also works as a support group for the parents. This connection also fosters friendship among the girls.

In the long run, girls with autism might need ongoing counseling sessions with a professional. Individual counseling is recommended when girls have trouble communicating their feelings and managing stressors in their daily lives, particularly as they approach adulthood and new responsibilities.

For families that do not speak English at home, the problem becomes more complicated when families have trouble finding resources. Parent Centers play a great role assisting families that have difficulties navigating the systems.

Adolescence

to pair this experience with a positive interaction.

Consultation with a psychologist or a board certified behavior analyst (BCBA) can also provide guidance on the teaching methods or types of materials that would be appropriate to use with your daughter. Preparing your daughter for the changes that come with adolescence, especially during her first menstrual cycle, can cause some fear and anxiety. Talking with her medical physician will help you understand the developmental signs that may be associated with this upcoming change. Her medical doctor may be able to guide you to websites that are approved by the American Academy of Family Physicians (AAFP). Parents may want to review various teaching techniques and decide on a method that would work successfully with their daughter. Planning ahead of time and being proactive as much as possible will help her know what to expect. Teach your daughter some of the steps of personal hygiene by using detailed visual supports, using a task analysis and breaking tasks into smaller steps, and use positive reinforcement when your daughter is successful. The use of a wall calendar can also provide a monthly reminder and serve as a guide to review the steps of how to prepare. Remember the goal is for your daughter to be independent and apply strategies to reach her goals. If her goal is deal with her menstrual cycle each month independently, initially parents may help their daughter set up an action plan on how to achieve that goal. Include methods on how to self-evaluate, make adjustments, monitor progress and review the plan to see if it was a success (Agran et al 2000). Remember to keep instructions simple, use visual cues, model instruction, practice, repeat, and reinforce (Nichols 2009).

While adolescence can be a stressful time for all individuals and their families, females with ASD are faced with a unique set of challenges. Females with ASD are likely to require more direction and guidance than their neurotypical peers in order to navigate puberty and sexual development. By using evidenced based strategies, as one would to help their child acquire any new skill set, and obtaining guidance from a professional with experience in working with females with ASD, parents can more effectively support their daughter in successfully navigating through adolescence.

Elena Zaklis MA, BCBA and Rory Panter PsyD, are from Behavior Therapy Associates in Somerset, New Jersey and can be reached at ezaklis@behaviortherapyassociates.com or rpanter@behaviortherapyassociates.com and at www.BehaviorTherapyAssociates.com.

References


Autism Spectrum News 2017 Editorial Calendar


Spring 2017 Issue: “Supporting Adolescents with Autism” Deadline: March 2, 2017

Summer 2017 Issue: “Improving Health and Wellness for Individuals with ASD” Deadline: June 1, 2017

Fall 2017 Issue: “The Latest Advances in Autism Science” Deadline: September 7, 2017
Work from page 11

There is significant pressure for women to “fit in” and that is not something most women with ASD can do and many don’t want to.

While my mission is not to fix this gender bias, we do work on these social skills in our program. That is where typical female peers so are important and helpful to our trainees so we would like to have more typical peer mentors volunteer with program.

AAgain range in capabilities but they have some common character-

istics: anxiety and fear of making a mistake. They wait to be told what to do and they expect help before exerting much effort. They lack resilience. On the other hand, they want to please their job coach and they desire to do a good job. They know they have challenges and they want to overcome them. They want to be included without having to conform. We do not know if these are uniquely women’s traits but would be delighted to participate in research that studies the differences between men and women with autism in the workplace.

Some of the work behaviors we focus on with our trainees include:

- Collaborating with peers and knowing when and how to seek input from colleagues — this is especially hard given the lack of theory of mind.
- When and how to take initiative — doing work without having to be told to do so, suggesting a solution to a problem, or offering help to someone else.
- Accepting critical feedback — and without falling apart, and then being able to take the corrective actions.

Some of the social behaviors we address include:

- Manager-staff conversations
- Appropriate “watercooler” topics
- Summer attire at work

The women in our training program are very interested in social relationships and are motivated to develop work skills in a collaborative setting. We have seen significant development in many of our participants since joining Yes She Can and our goal is to continue to help more young women with Autism Spectrum Disorders.

Note: Yes She Can is seeking volunteer job coaches as well as participants in an advisory council.

About Marjorie

I am the mother of a 20 year old young woman with ASD. After a 30 year career in corporate marketing, I founded Yes She Can motivated by my experience that the best way to teach an individual with autism is through immersive learning and leveraging their passion. My daughter’s passions are Disney and American Girl dolls. Her career goal is to work at the American Girl store in the doll hair salon. During high school she had a job in a career program where she had several internships in addition to being a trainee at Girl AAgain. She is currently enrolled in College Steps at Westchester Community College.

For more information, contact Marjorie at mardescanin@verizon.net or visit www.YesSheCanInc.org. Yes She Can Inc.

- Women with Autism. We work. With you.

Females from page 16

sample of typical children, ascertained in the course of a UK birth cohort study (ALSAPC study team, 2001). Unlike most trait measures, our screening questionnaire of social communication competence was not developed from a male ASD prototype, but from a female prototype (Skuse et al, 2005). The provisional sex ratio of those boys and girls at very high risk of ASD was found to be 2:1. This is exactly the same sex ratio as has been reported for children with ASD who have severe to profound learning disabilities (Fombonne, 2003). We draw the inference that females who are not learning disabled are often motivated and capable of ‘compensation’. Even if they have significant autistic traits, their autistic vulnerabilities are not being recognised clinically; the higher their IQ, the greater the ascertainment bias.

We concluded that females with ASD traits and normal/high IQ are less likely to be identified clinically, and we have found evidence from this general population study (ALSAPC) that high verbal IQ is protective for females (Skuse et al, 2006). Genetic risk in the 47,XXY condition was nevertheless shared with clinically identified samples of ASD, implying that the same neural substrates were likely to be responsible both for clinically significant manifestations and for more subtle traits (Robinson et al, 2010). In other words, there is a continuum of genetic risk between clinically identified autism and autistic traits in the general population – the term neurotypical is only relatively true for either sex.

If females at high ASD risk are really able to compensate at least in part for their difficulties, then this should mean they have learned how to interpret social cues by a conscious rather than by an intuitive process. Using a novel test of emotion recognition (Boraston et al, 2007) that they would not have seen before (and for which they could not have learned the appropriate response), we found that high-risk girls in our general population sample had great difficulty answering correctly. Their performance was no better than that of high-risk boys (Kothari et al, 2016). Yet on a compar-

ison task of face-recognition emotion (a skill that could have been learned), they performed perfectly well (unlike the boys). Does it matter if girls with ASD traits are not diagnosed, if they are able to compensate for their difficulties? Yes, it does. They cannot cover up those deficits forever, and in any event the process of doing so is highly stressful. There is a developmental pattern, by which reasonably successful adjustment to the social environment is often achieved early in childhood and the prepubertal period. Once puberty and ado-

lescence supervenes, the social world becomes so complex for girls with ASD that they find it hard to cope any longer. They typically respond with internalizing problems, including depression and perhaps with self-harm and school-refusal, with psychosomatic features. One striking characteristic, rarely recognised by clinicians, is that there can be major difference-

es in their behavior at home and at school (Mandy et al, 2012). Intense efforts are put into compensating for social difficulties at school, the typical high functioning female with ASD being the ‘perfect child’, quiet and well behaved. In contrast, the child who is lauded at school for her diligence and excellent deportment is, at home, sul-

len, aggressive and even violent. Failure to recognise that this home-related behavior is not due to natural or inappropriate parenting, but rather a reaction to the stress and daily exhaustion of disguising her social-communication difficulties in the school environment, can lead to months of inappropriate family therapy. Parent-blam-

ing does not help anyone to deal with the underlying issues.

In summary, there is emerging evidence that the true sex-ratio in ASD is 2:1 across the entire range of verbal intelligence. A certain bias has bedeviled the inter-

pretation of research studies into genetic risk, because there has been an over-representation of girls with developmental learning difficulties in such samples – general-ized learning disorders can have their own genetic etiology and confounded stud-

ies into ASD-risk genes (Skuse, 2007). Research into female-typical ASD has been hampered by the fact that the diagn-

otic template for the condition has, for 70 years, been male. Most standardized instruments that are widely used in ASD research in North America reflect this bias, thus studies that use those instruments are destined to perpetuate the myth that autism is extraordinarily rare among ‘high functioning females’ — what used to be called Asperger syndrome. We are failing those
References


Manifolds from page 27
If You’re Concerned: http://www.cdc.gov/ncbddd/actearly/concerned.html
(in Spanish) http://www.cdc.gov/ncbddd/Spanish/actearly/concerned.html

Books on Autism and Girls
“Asperger’s and Girls: World-Renowned Experts Join Those with Asperger’s Syndrome to Resolve Issues That Girls and Women Face Every Day!” by Tony Attwood

“Pretending to Be Normal: Living With Asperger’s Syndrome” by Liane Holliday-Willey

“Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-teen and Teenage Years” by Shana Nichols

Lauren Agoratos is the parent of a child with autism/kidney disease. She is the NJ Coordinator of Family Voices, the national network that works to keep families at the center of children’s health care for children with special healthcare needs. She coordinator of a statewide Advocacy Network (SPAN). www.spandw.org. SPAN is also the home of the state’s Family-to-Family Health Information Center. Lauren can be reached at (800) 654-SPAN or by email at familyvoices@spannj.org. Parents can find free help in their state at www.familyvoices.org/states.php. Myriam Alizo is the mother of two daughters and works at NJ’s Parent Training and Information Center, SPAN, where she helps parents, especially in Spanish-speaking communities, start and run local special education support and advocacy groups. She also works with SPAN’s national Center for Parent Information Resources and Assistance, tools and materials for the more than 90 Parent Centers funded by the U.S. Department of Education to serve families of children with disabilities across the U.S. and territories. Myriam is a member of the NJ Special Education Advisory Council, which was part of the National Center for Learning Disabilities (NCLD) Parent Leader Team since 2010.

Free Support Group For Families of Adults with Asperger’s Syndrome and High Functioning Autism
The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger’s Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

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

Socialization and Life Skills Group For Asperger’s Syndrome and High Functioning Autistic Adults
Focused on: Employment and Vocational Issues, College Coaching and Supports, Socialization, Self-Advocacy, Dating, and Relationships

For more information, visit www.ASDGroupsWestchester.com or contact the facilitators:
Robin Kaufman, PhD, and Lauren Greiner, PhD | ASDGroupsWestchester@gmail.com 914 497-1590


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265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532
factor that emerged through the classroom discussions was that anxiety played a large role in impeding these women from pursu- ing the work they would like. Thus, our re- vised curriculum addresses this issue. The Lean Out Curriculum, participant work- book and slides are available for download at no charge is available on our website (http://childstudycenter.yale.edu/autism/clinical_services/initiative/young_adults/).

We are hopeful that this program will be used and modified to fit the needs of young women anywhere who need help with this important life task.

A weekly support group for young wom- en began this past winter. Our group tack- led the fact that caregivers and participants talk about how they cope with parents, siblings, the demands of college and the workplace. We learn about each woman’s experience as they try to navigate through the academic and social world. A significant piece of this process is helping young women feel self-confident about who they are so they can advocate for what they want and need.

In the program, discussion surrounds an atmosphere that promotes relationships build- ing through sharing ideas and experienc- es. A lot of conversation about music, movies and media, school work, parents and friendships happens. Positive energy flows throughout the room as our partici- pants get to know one another, sharing stories, videos and jokes. Participants often exchange numbers and some get together outside of the group. For many of our teens and young women, our ac- tivities are the only social opportunities they have.

We hope to expand the program in scope, so that new activities address unique char- acteristics. For example, we are developing a healthy mind and body, developing posi- tive relationships and an optimistic out- look for the future. Our Advisory Board, which includes parents of girls on the spectrum, professionals, and individu- als on the spectrum, as well as additional (anonymous) donors have helped in this regard. Parents, young women and teens have been very enthusiastic about the pro- gram, and with requests for more activities. Our plan is to increase the opportunities for participation for girls of all ages and all levels of functioning and we hope to incorporate clinical training and research into the program over time. The Initiative for Girls with ASD provides an extraordinarily rich social experience for all who participate.

“Activities with structure, like using Rob- erts Rules or something…to help us know when to talk”

“For young women with ASD to not feel alone or different and to have space (a place) to belong to, for once!”

The Literature on Women’s Experiences

The experiences reported by the women in the focus group are consistent with the research on typical social development and gender-based risks to mental health. First, the level of functional social participa- tion is significantly higher for females than for males. Starting in the early adoles- cent years, girls are expected to be adept in relationship building skills not required of boys (Hannah and Murachter, 1999). So- ciety also places greater social demands on women that go beyond specific skills. As noted by a recent article in the Spring 2016 issue of Autism Spectrum News by Dr. Mi- lot (2016), patterns of socialization create added chal- lenges for the female gender. As a re- sult, the social gaps between non-affected females and females with ASD are greater than they are for their male counterparts.

Beyond gender-based differences in so- cialization, a not-so insignificant challenge for women with ASD is that they are more likely to have been diagnosed later in life than their male peers (Begeer et al., 2013). Such differential access to formal diag- nostics means that women risk losing access to services and intervention, which in turn, increases the risk for mental health problems that are already heightened for the female gender (Kessler et al., 1994). In- deed, as compared to typically developing girls, those diagnosed with ASD exhibit significantly more internalizing symptoms such as anxiety and depression (Jamison & Schuttler, 2015).

Supporting Adult Women with ASD

As expressed by our focus group partici- pants, adult women with ASD are lacking social opportunities that are inclusive of their needs and interests. As opposed to didactic activities, the women described a need for a community of their own where they can share and build experiences. To provide this, it is not sufficient to simply gather women with ASD together. Pro- gram structures that take into account the effects of social information processing difficulties are required. In this respect, ideal supports are those based on principles of Universal Design, such as incorporat- ing a design for activities that make them adaptable with respect to pace and com- plexity. Social supports include visual supports; the goal is to supplement verbal information when necessary, with- out overwhelming visual cues that can con- fuse or distract the participant. All in all, this approach requires much pre-planning, opportunities for ongoing revisions of pro- grammatic practices, and consultation with professionals who have expertise working with adults with ASD.

Due to the heterogeneity of ASD, an- other important program element involves anticipating the variety of social communica- tion needs that can occur with this condi- tion. At the group level, this can be accom- plished via a menu of programs that caters to a wide range of participant interests that are in rich opportunities for discussion as well as those designed for participants who are more interested in doing than talking. Programming content should also be examined by the experiences and inter- ests of the women. Differences in social motivation are also important factors that affect participation. Thus, identifying spe- cial interests, as well as previous negative experiences, is essential at the individual level. Additionally, programs will require participation and staffing models that can account for changing mental health needs. As best practice, this involves highly indi- vidualized and flexible planning and prac- tices for fostering thoughtful discussions with each participant around their social goals and mental health needs.

How Does Felicity House Meet These Unique Needs?

Established in 2015, Felicity House is a non-clinical program designed to support the social development of women with a diagnosis of ASD. We strove to provide a dedi- cated space with a design that accommo- dates large and small group activities, as well as rooms designed to provide restora- tive, quiet activities. Participation plans are flexible and individualized; they are uniquely informed by a new member pro- cess which includes a series of meetings and interviews between a woman and staff member, along with ongoing follow-up as needed. Programming is varied and cons-ists of structured events such as lectures, workshops, and special interest groups, as well as unstructured activities like movie nights and openings. Each event is supported by at least one staff member and all activities include modifications with an eye towards facilitating participation.

The latter responsibilities include careful use of visual supports; the goal is to supplement verbal information when necessary, with- out overwhelming visual cues that can con- fuse or distract the participant. All in all, this approach requires much pre-planning, opportunities for ongoing revisions of pro- grammatic practices, and consultation with professionals who have expertise working with adults with ASD.

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What Have We Learned?

The needs of women with ASD are made complex by gender-specific expectations of social participation, minority status within the ASD population, later access to a formal diagnosis, and increased rates of anx- iety and depression (Milot, 2016). This may lead to poorer outcomes than their male peers. Increased availability of social programs designed specifically for women with ASD is needed and they may be an im- portant mechanism to improving outcomes. However, such programs must take into ac- count the complex needs and heterogeneity of the population, and there is still a great deal to be learned about how to best support women to meet their social needs.

In addition to her role as Senior Advisor at Felicity House, Marisela Huerta, PhD, is an Assistant Professor of Psychology in Psychiatry at Weill Cornell Medical College and an Attending Psychologist at NewYork-Presbyterian/Center for Autism and the Developing Brain. For more inform-
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