

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 demure 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 adamant 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 distrustful 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 up front 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 an inappropriate and intrusive level of help, even for an individual receiving a high level of care.

see Services on page 12

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 Deadline: December 7, 2016

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

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“Improving Health and Wellness for Individuals with ASD”
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Autism Spectrum News is a Quarterly Print and Online Publication of Mental Health News Education, Inc, a 501(c)(3) Nonprofit Organization.

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460 Cascade Drive, Effort, PA 18330 • www.mhnews-autism.org

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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,



Elizabeth V. Roberts, PsyD

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

While modern psychologists have studied the self in myriad ways, relatively few studies have examined these ideas in ASD.

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

Mentalization 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 con-

ceptual 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

see *The Self* on page 20

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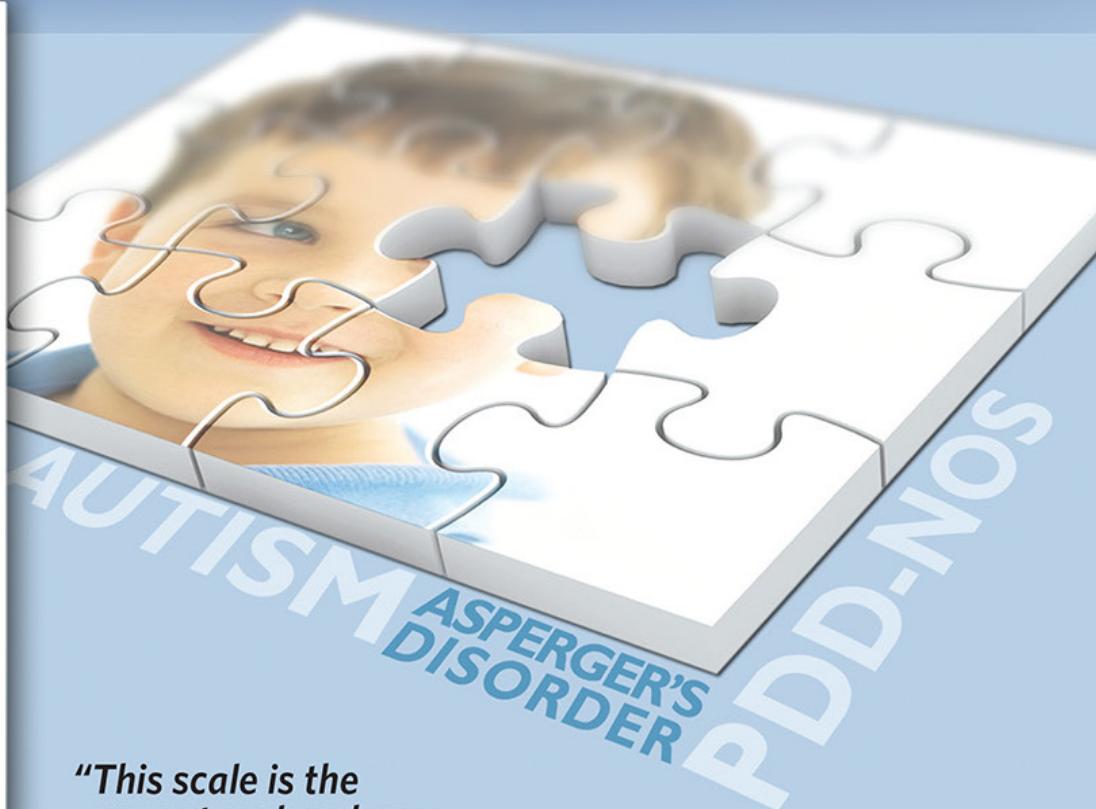
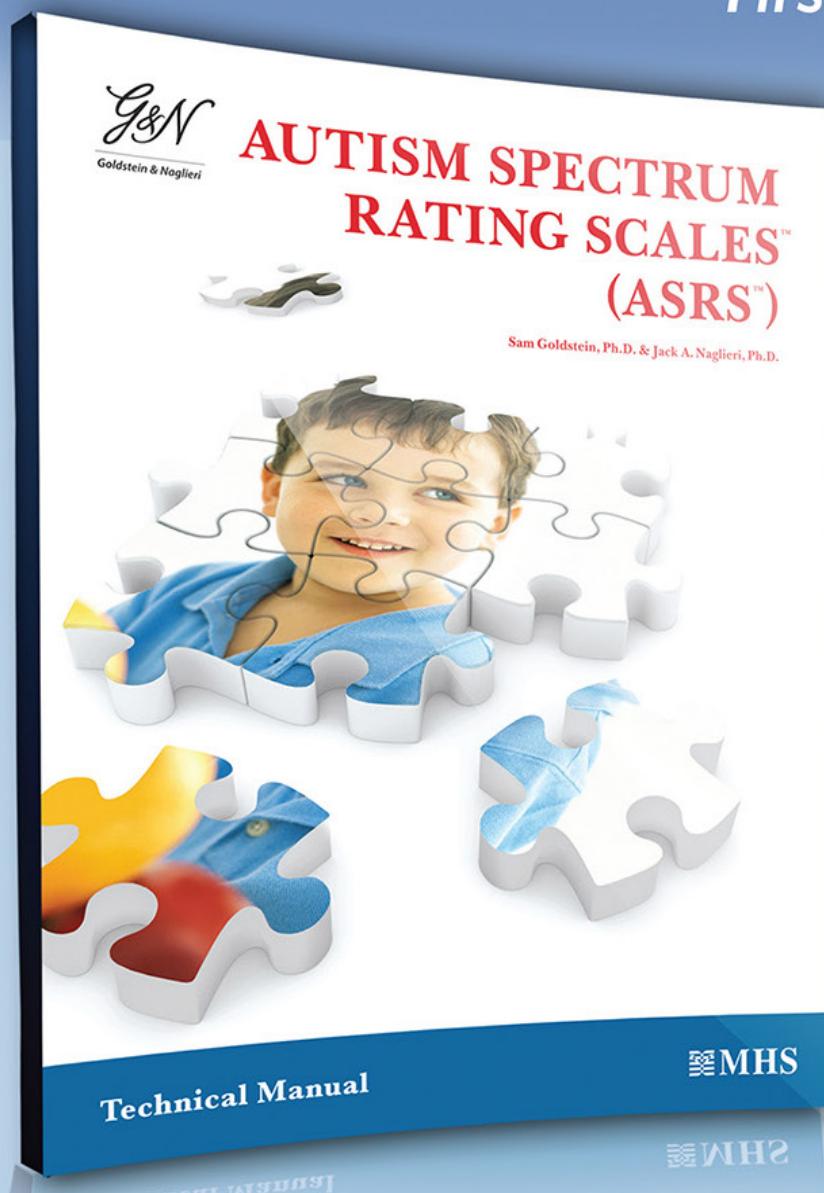
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Charting a New Course for the Future of its Publications, New Leaders Join the Board of Mental Health News Education, Inc.

Staff Writer
Autism Spectrum News

Constance Brown-Bellamy, MPA, incoming Board Chair of 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 delight-

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

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 As-

sociation. 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



Rachel A. Fernbach, Esq.

ed 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,



Joshua Rubin, MPP

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.”



Yvette Brissett-André, MPA

sistant 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 As-



Robert H. Ring, PhD

private practice with the law firm Moritt Hock & Hamroff LLP, located in Garden City, New York. Ms. Fernbach concentrates

see Leaders on page 26

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



Ira and David Minot

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 out-

stretched 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

see Handshake on page 21

“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 sex-



Eva Mendes, MA, LMHC

ual 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),



Hillary Hurst Bush, PhD

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 includ-

ed 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

see *Gender Identity on page 25*

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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 ASDs end up feeling lonely and sad. This kind of social isolation results in a poor quality of life for these individuals, with concomitant risks to mental and physical health.

At the Yale Child Study Center, our mission is to improve the mental health



Kathy Koenig, MSN, APRN

of youth and families, to advance understanding of their psychological and developmental needs, and treat and 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 ques-

tions 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 2 ½ 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

see Initiative on page 30

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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 differenc-



Marisela Huerta, PhD

es 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.

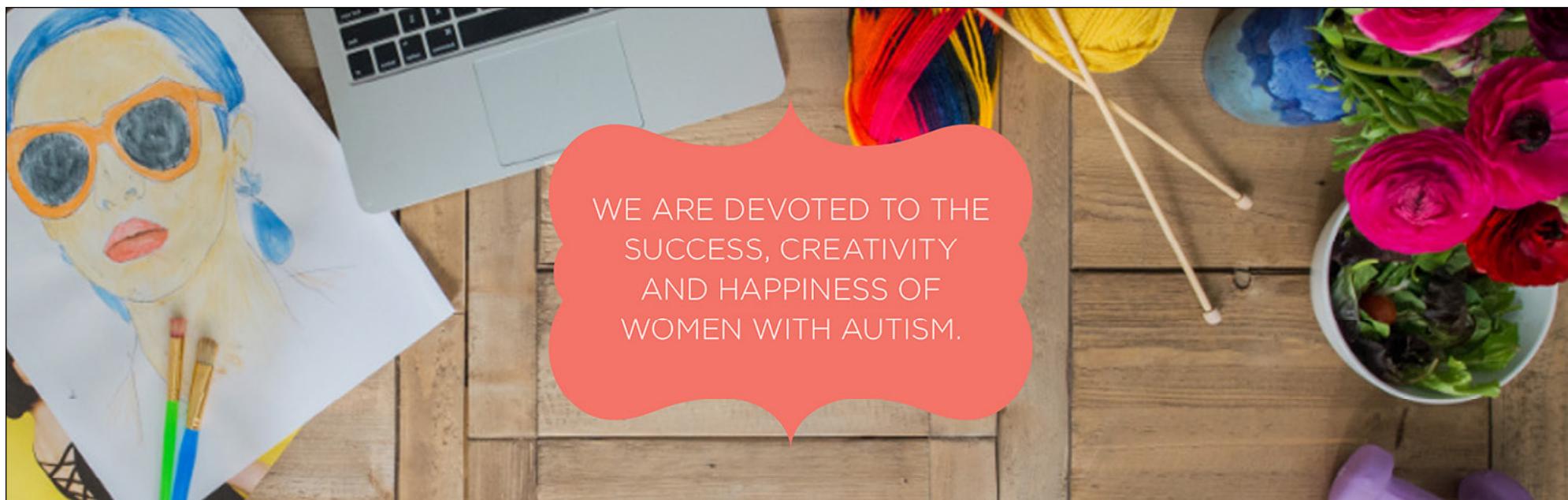
“At [college name], we had a group where we would play games...so just to have that again!”

“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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Advice from page 1

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 make-up 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 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 be 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



**CIP Brevard Student
Stephanie Smith shares insight
and advice as a young woman
on the autism spectrum**

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

see Advice on page 20

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.



Izzie and Julia preparing doll outfits for sale at Girl AGain

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 learn-

ing 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!

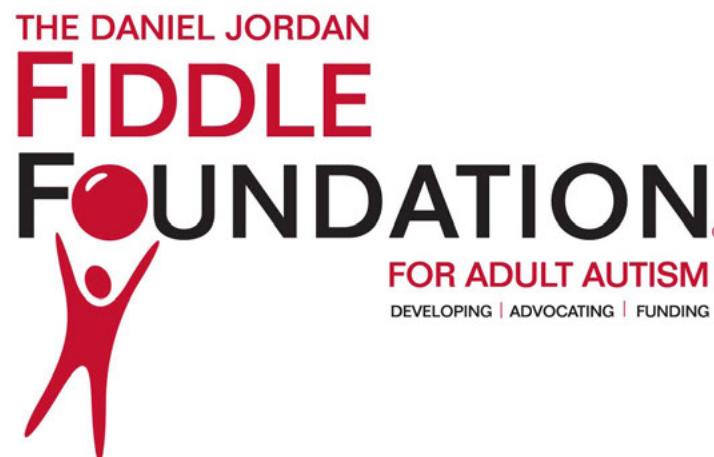
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Services from page 1

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 person-



Sandra A. Rogers, MS, BCBA

al 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



Mary Jane Weiss, PhD, BCBA-D

“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, is Director of Adult Behavioral Services at Melmark Pennsylvania, and Mary Jane Weiss, PhD, BCBA-D, is Senior Director of Research at Melmark. The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. With service divisions in Berwyn, Pennsylvania, and Andover, Massachusetts, Melmark provides evidence-based educational, vocational, clinical, residential, healthcare and rehabilitative services, personally designed for each individual in a safe environment of warmth, care and respect. For more information, please visit www.melmark.org and www.melmarkne.org.

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“Give a Spit” to Help Scientists Uncover the “Female Protective Effect” for Autism

By The Autism Science Foundation

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. Tak-



ing 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 Eevee 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 project is being overseen by a scientific advisory panel led by Joseph D. Buxbaum, PhD, Director of the Seaver Autism Center at the Icahn School of Medicine at Mount Sinai, along with experts in genetics, statistical genetics, epidemiology, and ASD clinicians.

“We’re learning more and more about how autism affects males and females differently, as well as the underlying factors behind these differences,” said Alycia Halladay, PhD, chief science officer of the Autism Science Foundation. “This is an exciting and promising opportunity to leverage that understanding for deeper research into potential factors that could have a significant impact on the lives of many people with autism. Right now, the limiting factor is a lack of genetic data. The Autism Sisters Project will help eliminate that barrier and rapidly move the science forward.”

“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

see *Give a Spit* on page 25

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SIBLINGS HAVE A HUGE ROLE TO PLAY IN UNCOVERING THE CAUSES OF AUTISM

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For years, more males have been diagnosed with autism than females, but little is known about why. Science suggests that females may be protected in some way. The Autism Sisters Project aims to build a large genetic database of unaffected female siblings to explore this female protective factor. Autism researchers need DNA and information from the entire family, especially from sisters who don't have autism.

I GAVE A SPIT FOR AUTISM. YOU CAN TOO.

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Autism Sisters PROJECT
An Initiative of the **AUTISM SCIENCE FOUNDATION** and **THE HILIBRAND FOUNDATION**

EVEE AND TOMMY

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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?



Becca Lory, CAS

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.

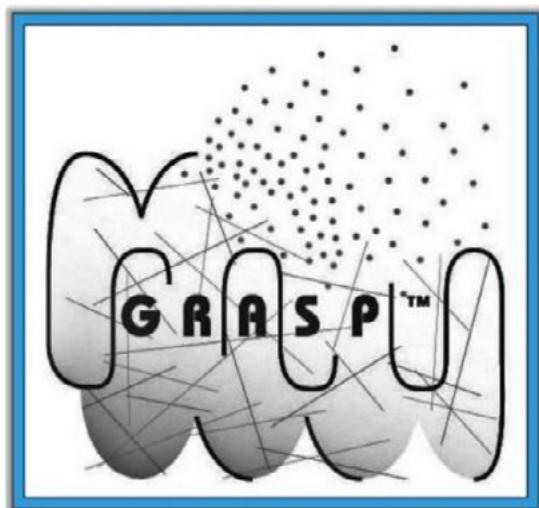
At the time, I was honored to be considered so unique. Unicorns are magical, mythical creatures known for their gentle, intelligent and, YES, empathic nature. Not to mention their ability to heal. They have made their way through time from the Ancient Greeks to modern science fiction. There is even a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

day. 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.

see Unicorn on page 23



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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 Scahill, 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; Scahill 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

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What Happened to All the Females with Autism Spectrum Disorders?

By David H. Skuse, MD, FRCP
Head of Behavioral and Brain Sciences
Institute of Child Health, London

The concept of an autistic disorder is generally accepted to have originated 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, virtually 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 were reported to 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



David H. Skuse, MD, FRCP

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 reveal 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 adolescence are rarely newly 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 deficits, 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 'compensation' (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 opportunities to validate the hypothesis that there is a large number of undiagnosed females with ASD seem limited. One approach we have taken is to evaluate ASD traits by screening a general population

see *Females on page 28*

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 great fit, as parents find that their daughters may need a different kind of help to support their daughters as they face the challenges of growing into young womanhood.

A recognition of this led to the creation of a support group for parents of tween (ages 9-13) girls with ASD. The group has run successfully for two years and has now been expanded to include parents of teen girls as well. Prior to the group launch, we attempted to gain a sense of whether there was a need for this kind of support



Erika Drezner, LCSW

for parents of girls. We held an informal discussion night in which staff members who had daughters with ASD lead a discussion specifically for parents of girls ages 18 and below. That event was followed by a book talk by Eileen Riley-Hall, author of *Parenting Girls on the Autism Spectrum*. The turnout and enthusiasm for these events led us to believe that parents of girls needed more services geared specifically for them.

In spite of the enthusiasm the parents had indicated, the group was slow to start.

In the fall of 2014 we launched three parent support groups, including the group for parents of girls. While the other two groups which were open to parents with male or female children filled quickly, the parents of girls group had to be delayed by a month to give it time to meet the minimum number of participants to run. We generally advertise our programs by email. In this case, I made personal calls to those who attended the previous events and were eligible for the group based on their daughter's age. I also made the decision to run the group on the weekend, rather than an evening during the week, so that parents from outside the surrounding area could attend. While the majority of attendees were local, we did have parents who traveled over an hour to attend the group. Even within a major metropolitan area – we are located just outside of Boston – it took some flexibility to initially fill the group.

I began the group thinking that it would be psychoeducational and planned for each meeting, with topics and resources ahead of time. I imagined that parents of females who were on the cusp of adolescence would want information on puberty, hygiene, and social skills. While it was the case that most group members were struggling with some of these issues at home, it was clear 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 forefront rather quickly (Mandavilli 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 they perceived 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

see *Support Group on page 26*



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

By Carrie Cariello

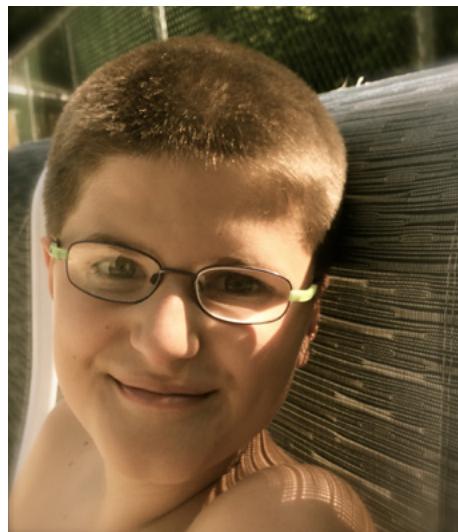
This Boy Jack

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



Jack Enjoying Summer Vacation

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.

see This Boy on page 22



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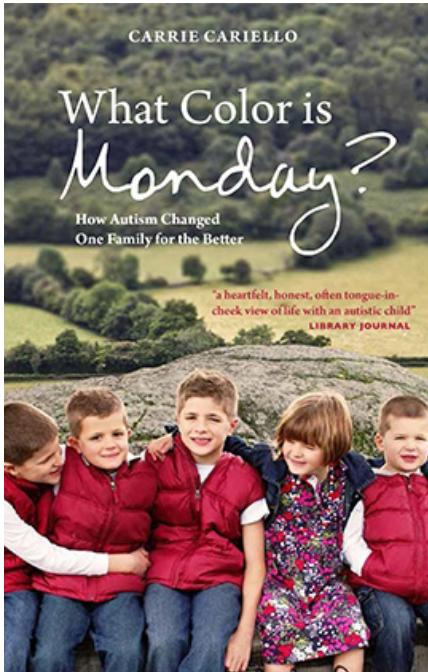
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How Autism Manifests Differently in Girls: What Families Need to Know

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/preview/mmwrhtml/ss6302a1.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



Lauren Agoratus, MA

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.

Autism Symptomology in Girls

Studies have shown that there is a “male bias” in diagnosing autism due to differ-



Myriam Alizo, BS

ing symptoms “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 em-

pathy 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 an 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 misdiagnosed 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/>).

see *Manifests on page 27*

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

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

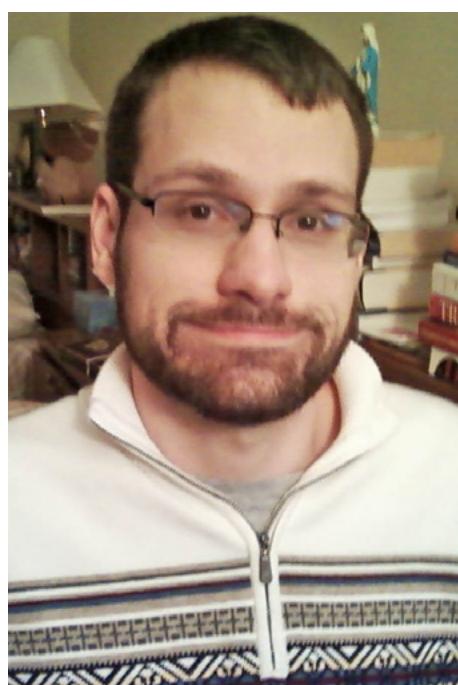
I have often argued – and will never tire of arguing – that people on the autism spectrum are human first, rather than primarily autistic. Being human means many things, but we shouldn’t forget one of its most fundamental aspects: Relating to the surrounding world through our *bodies*, wherein lie the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



Daniel Crofts, MA

turb 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 Mandavilli’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[.] (. . .) [They] decided to study newborn babies *on the day they were born*. (. . .) The results of this experiment suggest that girls are born prewired to be interested in faces while boys are prewired 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

see *Differences on page 22*

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



Elena Zaklis MA, BCBA

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



Rory Panter, PsyD

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 choose a style that she is most comfortable with wearing. Choose 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 upon 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

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The Self from page 4

improvement in self-reflection needs to precede efforts to support or teach “mindreading” 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 different brain regions. The degree or nature of the difference or overlap in brain region activation depends on the degree to which the individual perceives the other as similar or different from the self (Uddin, 2011). All of these lines of investigation support a rationale for investigating the relationship between self-awareness and social competence.

Mood and Behavior Regulation

The more we are able to distinguish our perspective from other’s, the more we are likely to manage emotions and meet our own needs (Lane & Schwartz 1987). The relationship between self-representation and self-awareness has not been studied in ASD. Emotional and behavior dysregulation are sometimes crippling challenges for talented, otherwise competent girls with ASD that impede their academic and vocational progress.

Implications for Research and Treatment
Girls and women with ASD need sensi-

tive, individualized, evidence-based support across the lifespan in so many areas. Staying safe in the physical and cyber communities, at school, and in the workplace is of pressing, primary importance. The tasks of girls with ASD are to establish a healthy lifestyle, navigate social and intellectual demand 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, manage mood, behavior, and anxiety regulation, 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 developing the “All about me” book, “What would you rather do?”, journal exercises, and creative activities to encourage girls to understand themselves. Can we develop broader and deeper methods to increase self-awareness and the development of a realistic self-representation? Would this lead to measurable improvements in social competence, emotional regulation, and ultimately, quality and richness of life? We know that self-esteem in ASD is important, and we work on “building self-esteem,” but can authentic self-esteem be established without foundation skills in self-awareness and self-understanding?

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 components of their identity from their relationships with men - fathers, husbands, brothers, and male workplace supervisors. While for some women, in some societies, in some respects, this has gradually changed, it remains a reality. It is particularly important for girls with and without

any mental health condition to consciously prioritize the development of a deep, rich self-representation that incorporates the interpersonal universe that includes boys and men, but also stands on its own.

Second, sex difference research has found that, neurotypical females are generally more competent than neurotypical males at empathy, theory of mind, and other aspects of social competence. Societal expectations and the media are certainly in line with these scientific findings. That society expects greater social competence in females than males is something of an irony for girls and women with ASD. This does not imply that we need to develop social competence in girls in order to meet an unfair or unrealistic standard. Rather, we need to support girls and women in developing their social competence to its fullest capacity for its own satisfying sake and to be safe and comfortable in our social world.

In Conclusion

ASD research has historically focused on the interpersonal world of social competence. Concepts of self-representation, self-awareness, and self-reflection have been studied in typically developing people and individuals with other types of mental health challenges but have received little attention in the field of ASD. While girls with ASD have many urgent needs for loving, thoughtful care and attention across the life span, it is important to delve into concepts of self-representation, self-awareness, and self-reflection in ASD in order to understand similarities and differences with typical development and other mental health conditions, and develop effective treatment approaches.

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Advice from page 10

passion for cows, they become scholars in their area of interest. Not everyone with ASD reaches that level, but their unique special abilities make them awe inspiring and they can be used for a better purpose. Like Dr. McManmon says, “We are made for good purpose; we just need to have access to that purpose.”

Support for Parents with Daughters on the Spectrum

Q. What level of support do you feel you receive from your parents?

A. Now, definitely more than the typical age 24-year-old women. They are helicopter parents. I think it was important for me at times, but not so much today. They have also supported me unconditionally in

many areas of my life that I did not even ask for but needed. Although, I think their constant support inhibited me as an adolescent because I needed to fall and make mistakes.

That is why they found CIP, so I can fail as an adult, but the staff now provide me support with a non-emotional way that lets me learn from my struggles. I sometimes fall into a pit and the staff shouts advice from the top of the pit, sometimes I don’t listen and fall lower. Sometimes I listen and as I gradually climb up they shout down but as I get to the top they stop talking, although they are still standing there as my safety net. It’s scary as I climb higher because I fear falling down, but on each level I climb I gain more confidence in myself. Growing up, my parents didn’t shout advice, they gave me a ladder, and I couldn’t learn anything from that to apply in daily situations without

their support or the ladder. I needed to do it on my own.

Q. In what ways would you like to be supported by your parents moving forward?

A. Ideally, I would like to be treated as an equal. 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 parents. 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 in me 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

in too fast to give them the answer to their mistake. Coach them to come to you for the answer. Also don’t say, “You always make mistakes.” Rome wasn’t built 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.

About the Author

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 realization – 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 personal 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 love (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 explana-



Sarah Hendrickx

tion 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 have 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. Fascinations 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 that 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 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 re-

sponses 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 any 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.

Handshake from page 6

been) with mental illness.

My son David, who was inspired by my recovery and vision to help others, joined me as my Associate Director in 2008 to publish *Autism Spectrum News* - now a leading publication helping thousands of families and individuals cope with the challenges of autism spectrum disorders. To-

day, *Behavioral Health News and Autism Spectrum News* reach over 160,000 hard-copy readers across New York State and beyond. Our plans to enhance our online delivery and presence has the potential to expand our educational mission to numbers even beyond our greatest expectations.

This Holiday Season, we need your support more than ever before. We are a small organization with a vital mission.

Please look for our Annual Fall Appeal letter that will be arriving in the coming weeks - take a moment and consider us in your annual giving plans. You can also make a donation directly on our website at: www.mhnews.org/donate.htm.

Please help us to continue providing hope to people with mental illness, substance use, and autism spectrum disorders. Your tax-deductible contribution to *Behavioral Health*

News and Autism Spectrum News this holiday season will be a meaningful and heartfelt "Handshake of Hope" to someone out there who is lost and alone right now. We need to reach more people like that, shake their hand, and give them the encouragement they need to move forward and improve their lives. As simple as a Handshake may seem, it has been proven to save a life and start something wonderful.

This Boy from page 17

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, snakey 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, he let her hold him. 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-boo, 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.

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

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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 entranced by trains or moving vehicles than boys are” (as cited in Mandavilli, 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. Mandavilli (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 Mandavilli (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 Mandavilli (2015):

“Imaging 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 *trustworthy* 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 hypertrophied 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.

Daniel Crofts is a 31-year-old man with Asperger Syndrome. He has an MA in English/Literature from the State University of New York College at Brockport and experience in the fields of freelance journalism, substance abuse prevention, online higher education, and service to people with developmental disabilities. He runs a blog called [Forming Horizons \(forminghorizons.com\)](#), which is dedicated to the mission of dialogue and information among and for the various parties impacted by autism spectrum disorders.

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A Clarification From the ASN Summer 2016 Issue

By Lawrence Scahill, MSN, PhD
Professor of Pediatrics,
Emory School of Medicine
Director of Clinical Trials,
Marcus Autism Center

We were delighted to see the mention of our study on parent training in children with ASD and disruptive behavior in the article “Employers Supporting Parents Through ABA-Based Technology” by Angela Nelson, MS, BCBA, Rethink, in the summer 2016 issue of *Autism Spectrum News*. The multisite study included 180 children with ASD (ages 3 to 7 years) who were randomly assigned to a structured Parent Training (PT) program or Parent Education for 24 weeks. The paper was published in the April 21, 2015 issue of the *Journal of the American Medical Association* (a major feat for a behavioral intervention in children with ASD). We showed that PT was more effective in reducing disruptive and aggres-

sive behavior than Parent Education. The PT program provided parents with specific strategies on how to manage serious behavioral problems such as tantrums, aggression, self-injury and noncompliance in children with autism spectrum disorder. Parent Education offered useful information about ASD – but did not provide guidance on how to manage serious behavioral problems.

The front page article incorrectly stated that “48% of parents who underwent 24 weeks of behavioral training reported improvement in their child’s behavior as compared to 32% of parents who received 24 weeks of just basic education on ASD.” The sentence that follows (starting with “Additionally...” is not incorrect - but is potentially misleading.

This would be more accurate: “After 24 weeks of treatment, children in the parent training group showed a 48% improvement on parent ratings of disruptive behavior compared to a 32% decline for parent education. Overall progress was rated by a clinician who was blind to treat-

ment assignment. At Week 24, the treatment-blind clinicians rated 70% of the children in the parent training group with a positive response, compared to 40% for parent education.”

Note: The 48% decline in PT vs 32% decline in Parent Education reflects the mean change from baseline on the measure - not the percentage of children rated as “improved” by the parent. The next sentence (beginning with “Additionally...” missed the very important point that the rater who made the judgement about improvement was blind to treatment assignment. Taken together, these findings indicate that both treatments resulted in improvement - but PT was superior.

Other facts: this was the largest randomized trial of a behavioral intervention in children with ASD. The Parent Education program was equal in the number of visits and duration of treatment. We also showed that children in the PT group showed greater gains in everyday living skills. The study was funded by the NIMH.

Resources

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How Supported Decision-Making Can Help Family Caregivers

By Lauren Agoratus, MA
Parent
Family Voices NJ

Individuals 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 to 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 (see <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://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>).

[ed-decision-making/](http://supporteddecisionmaking.org/).)

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://dcps.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.¹ 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.”² 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 now 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*

Unicorn from page 14

We have only just begun to discuss the unique needs and supports of women on the spectrum. We become wives, mothers, scholars, and so much more but still the supports are not our supports. Most recently, the topic of the lack of research studying adult females on the autism spectrum has come to the forefront of conversation. An important topic, as without quality research the supports will not get funded. All in all, we do A LOT of talking. But what we really need and what we really want is some doing. We need supports to help girls going through puberty with

sensory issues to be able to find and wear a bra should they desire. We need systems in place to support us as professionals. We need education for the women on the spectrum that choose to be wives and mothers. We need the researchers and clinicians to include us in the work they do because we want to be involved as much as they will allow us. We want the inclusion, the diversity, the testing, and the supports; to be equal to that of our brothers on the spectrum as they are our community as much as we are theirs.

This unicorn of unicorns no longer wants to be a unicorn at all. I just want to be me. To be supported, respected, challenged,

and involved not as a mythical beast but as an adult woman living a happy successful life on the autism spectrum. To know that I only have to traverse a mountain if I want to, not because I have to. I want to stand side by side with my fellow spectrumites, knowing that we share a neurology, that our needs are being met equally and easily, that we are included in our futures, and that our voices are being heard.

I want to hang up my horn and just breathe knowing that my time as unicorn was not wasted.

Becca Lory, CAS, was diagnosed with Asperger Syndrome as an adult and has since

become an active advocate for individuals on the autism spectrum. She is currently the Director of Development of GRASP (Global and Regional Asperger Syndrome Partnership) as well as sitting Chair of the GRASP Board of Directors. Ms. Lory has published multiple articles, speaks publicly about being on the autism spectrum with the goal of spreading awareness, understanding, and encouraging self-advocacy. Ms. Lory is developing and teaching improvisational workshops in order to assist adults with the practice of independent living skills. For more information about GRASP, please visit www.grasp.org. To contact Ms. Lory, email blory@grasp.org.

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Caregivers from page 23

abilities. Supported Decision-Making is recognized as "autonomy with support."

Options for Family Caregivers Besides Guardianship

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

Administration for Community Living Supported Decision-making Blog: http://www.acl.gov/NewsRoom/blog/2015/2015_01_28.aspx

Getting the Community Life You Want: A Guide to Home and Community Based Services Advocacy – Boggs Center: http://rwjms.umdnj.edu/departments_institutes/boggscenter/products/GettingtheCommunityLifeYouWant.html

Person-Centered Planning Tool - NJ Department of Human Services: <http://www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/PCPT%203-13-13.pdf>

Supported Decision-Making and Alternatives to Guardianship factsheet – Statewide

Parent Advocacy Network: <http://www.spanadvocacy.org/sites/g/files/g524681/f/files/Alternatives%20to%20Guardianship%20Fact%20Sheet.pdf>

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

Supported Decision-Making Brainstorming Guide: <http://supporteddecisionmaking.org/node/388>

Supported Decision-Making: What, Why and How: <http://supporteddecisionmaking.org/node/399>

Winning the Case for Supported Decision-Making: <http://supporteddecisionmaking.org/events/representing-clients-guardianship-actions-winning-case-supported-decision-making>

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.

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

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behaviors of adults with mental retardation and developmental disabilities. American Journal on Mental Retardation, 100, 632-642.

2. Jennifer L. Wright, Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA, 33 Int'l J.L. & Psychiatry 350 (2010)

Gender Identity from page 7

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 partially, 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 does not match 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%)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 conformed to gender, so I don't think I grew up with anyone 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 their questions about ASD and gender identity. Anik prefers the pronouns *they*, *them*, and *theirs*. They dress in business casual attire – oversized silk blouses neatly tucked into their tailored trousers, and keep their messy, curly hair in a ponytail. They have a bachelor's degree in history, but they are currently unemployed and looking for a job. Anik was designated female at birth and was given a traditionally female name. Over the last two years, however, they have not identified as female or as a woman – they are questioning whether they have a gender identity at all ("agender"). They have assumed a new name, Anik.

Anik has a somewhat complicated psychiatric history. Anik first received a diagnosis of anxiety disorder and ADHD at 12 years old, when they first began to worry about their parents getting a divorce, despite the fact that their parents remained married. At 15 years old, Anik was diagnosed with depression and anorexia, and was briefly hospitalized. Recently, Anik was reading online and came across a blog about women with autism. Upon learning more about ASD and its symptoms and features, they began to wonder whether they might have ASD. Their parents thought that it would be useful for Anik to see a specialist to find out more about ASD.

In counseling, Anik was found to meet diagnostic criteria for ASD. Being formally diagnosed with ASD was a relief to both Anik and their parents. Finally, Anik was able to understand why they struggled with social anxiety, had emotional meltdowns, was very sensitive to certain clothing textures, and had difficulty initiating conversations and picking up on others' body language and other social cues. After several sessions focused on increasing Anik's knowledge of ASD and awareness of ASD traits and experiences, Anik felt comfortable discussing their gender identity. They shared, "I have been wondering about whether I am agender. I first learned about this concept a couple of years, when a friend posted something about it on Facebook. I feel like 'agender' describes who I am because I do not intrinsically feel either male or female. I really do not identify with either."

Conclusions

Some autistic women identify as cisgender, or female: they are designated female at birth, and grow up to have a feminine gender identity that is consistent with their sex. However, this is not the case for many individuals with ASD – including about half of the participants in the [Autistic] Women's Sexuality Study. These findings

were consistent with the few other studies in which autistic adults self-reported on their own sexuality identities and experiences (e.g., Byers et al., 2013, Gilmour et al., 2012). Autistic individuals who are designated female at birth but have a gender non-conforming identity may be relieved to know that their experience is common. It may be the case that aspects of their neurology, while currently unidentified, may account for differences in their gender identity. Self-knowledge can be empowering to live authentically and to pursue meaningful relationships.

A theme that emerged from participants in the [Autistic] Women's Sexuality Study was the being less tuned into social communication subtleties – a feature associated with ASD – may protect someone from being oppressed or held back by social norms around gender. For some individuals, these norms can feel very restrictive. As a result of feeling less bound by social norms, people with ASD may feel freer to explore their gender identity and to identify as neither female nor male, but as something different or somewhere in between. However, given the focus on women and young adults in the [Autistic] Women's Sexuality Study, we do not know whether males or older adults with ASD may be more, less, or equally likely to endorse non-binary gender identities as the participants in the [Autistic] Women's Sexuality Study.

Raising the awareness of families, friends, and professionals about the diverse continuum present in gender identities of people on the autism spectrum is important so that they can demonstrate sensitivity, understanding, and acceptance. For health professionals, it is important not assume that anyone is cisgender. Instead, people in these roles are encouraged to ask their clients/patients about which pronouns they prefer (e.g., "she," "he," "they") and use these respectfully. Also, asking questions of this nature also demonstrates comfort and willingness to discuss gender and sexuality. Further, it is important not to make 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, their outward 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, people involved in the lives of individuals with ASD are encouraged to educate themselves on how this population – particularly young women – may experience gender differently.

Eva Mendes, LMHC, is an Asperger/au-

*tism specialist, psychotherapist, and couples' counselor in private practice in Arlington, 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 Lasting Relationships with Asperger's Syndrome* was published last year. She can be reached at her website www.evmendes.com or email at evamendes2911@gmail.com.*

Hillary Hurst Bush, PhD, recently received her doctorate in Clinical Psychology at the University of Massachusetts Boston. She is now a Clinical Fellow at Massachusetts General Hospital. She can be contacted at umbwomensstudy@gmail.com.

Footnotes

1. Please note that these definitions are adapted from those provided by Nonbinary.org, the GLAAD Media Reference Guide, and recent scientific research on gender identity.

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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 theseaevercenter@mssm.edu.

Give a Spit from page 13

with autism to take a proactive role in advancing important research."

The Hilibrand Foundation is partnering with the Autism Science Foundation on the Autism Sisters Project, providing major financial support for this research initiative. The Hilibrand Foundation is a

private family foundation that was established in 1991 by Debbie and Larry Hilibrand. A key mission of the Foundation is to support scientific funding of autism research.

"The Hilibrand Foundation is proud to be a collaborative partner of the Autism Science Foundation," said Debbie Hilibrand, co-Founder of the Hilibrand

Foundation. "The Autism Sisters Project is a very promising research initiative that should provide significant insight into the causes and potential treatments for autism by conducting a thorough investigation into the reasons behind the gender discrepancy of diagnoses."

The Autism Sisters Project is initially seeking participants in New Jersey, New

Leaders from page 6

her practice in the area of not-for-profit, health care and corporate law, representing health care providers that provide programs and services for individuals with mental illness, intellectual disabilities and developmental disabilities. Ms. Fernbach was previously an associate at the law firm Stein & Schonfeld LLP and a staff attorney at the Greater New York Hospital Association.

Joshua Rubin, MPP

Joshua Rubin, MPP is a Principal in Health Management Associates' (HMA) New York City office. His specialty over his nearly two decades of service to New York City's mental hygiene service system has been service funding conversions, strategic planning, agency mergers, internet-based treatment, disaster preparedness and response, housing and homelessness, day and vocational services, and crisis services, including suicide hotlines.

During his time with HMA he has been deeply involved in New York State's Care Management for All initiative—especially the behavioral health and care management for all carve-ins, DSRIP, CCBHCs, and Value Based Payments. Prior to joining HMA,

Josh was a government official, service provider and advocate. During his government service he was the Assistant Commissioner for Mental Hygiene Policy for the City of New York Department of Health and Mental Hygiene. During his years of City service he also served as the Assistant Commissioner for Chemical Dependency Services, and the Division of Mental Hygiene's Chief Policy Officer and Chief Administrative Officer.

Josh was also the Vice President and Chief Operating Officer of the Mental Health Association of New York City (MHA-NYC), a leader in services, advocacy and education for people with mental illness and their families. MHA-NYC and its subsidiary, Link2Health Solutions, Inc. operate a wide range of behavioral health services, including residential, rehabilitation, child and adolescent and family support services as well as the National Suicide Prevention Lifeline, Veterans Crisis Line and NFL Lifeline.

Prior to joining MHA-NYC, Mr. Rubin was the Director of Policy and Planning for YAI Network, and was on the staff of

the Coalition of Voluntary Mental Health Agencies. Josh has a Master of Public Policy degree from the John F. Kennedy School of Government at Harvard University and a bachelor's degree in religion and the humanities from the University of Chicago.

Yvette Brissett-André, MPA

Yvette Brissett-André, MPA, joined Unique People Services (UPS) in 2008. She oversees the organization's budget of \$20.6 million and a staff of over 230 employees. She is responsible for executive planning, contract management and real estate negotiations. Her expertise includes over 20 years of experience in the areas of finance and budgeting, program development, contract negotiation, low-income housing development and proposal writing. Yvette ensures that the agency's programs are well funded and operate at effective levels of service.

Yvette Brissett-André brings to Unique People Services a wealth of knowledge regarding federal and state funding regulations through her work with the New York State Office of Mental Health, New York City Department of Homeless Services, Office for Persons with Developmental Disabilities, and the New York City Department of Health and Mental Hygiene, among many other government funding sources.

Her quest and success in acquiring awards of new contracts for the agency has proven to be one of her hallmarks, thus establishing a position of creating opportunities with a continuum of care for the benefit of individuals with special needs. Under her leadership, UPS has grown from a \$16 million company to the present \$22 million and has received several contract awards as a result of winning grant proposals. These include funding from New York City Department of Health and Mental Hygiene under the Ryan White HIV/AIDS Program, additional funding through Human Resources Administration HASA Scatter Site.

Over the years Yvette has worked with community officials and boards in the agency's program service areas throughout the Bronx, Manhattan and Queens. She is one of the founding members of Advanced for Greater New York; a member agency formed to mobilize the Developmental Disabilities programs towards managed care, currently is a member of the executive team of Fortune Society, sits on the Interagency Council of

NY Board and was the past Board Treasurer of Adolescent and Family Comprehensive Services in the Bronx.

Yvette is instrumental in initiating the agency's first major fundraising strategy and public relations campaign. With full support and leadership from the Board of Directors, she is at the forefront of the development and implementation of these two ambitious achievements. Under the fearless leadership of Yvette, in 2017, UPS endeavors to open a 69-unit housing development for low-income New Yorkers.

Yvette holds a Master's degree in Public Administration from CUNY/Baruch and a Bachelor's of Science from SUNY/Plattsburgh. She is a National Urban Fellow and was one of the first participants in their America's Leaders of Change program.

Robert H. Ring, PhD

Dr. Robert Ring is a seasoned Research and Development (R&D) leader, with 16 years of diverse experience in executive, strategic and technical leadership roles in the pharmaceutical industry, non-profit sector and venture philanthropy space. Throughout his career, Ring has distinguished himself as an innovator, with a track record of accomplishment and collaboration across all stages of the translational research value chain. With his unique background, broad scientific expertise, and diverse management experience, Dr. Ring offers a portable skillset applicable to a range of different leadership opportunities.

Dr. Ring most recently served as the Chief Science Officer (CSO) of Autism Speaks (AS), the world's largest science and advocacy non-profit operating in the rapidly expanding autism/neurodevelopmental disorder space.

Among his accomplishments at AS, Dr. Ring spearheaded a collaborative partnership with Google to establish MSSNG, an unprecedented cloud genomics database featuring open-access, whole-genome sequence data from 10,000 multiplex families (www.mss.ng) with autism. He also helped establish and lead DELSIA, a venture arm of AS working to facilitate the commercialization of scientific innovations by entrepreneurs, academic institutions and small companies across the autism space.

Before joining AS, Dr. Ring served on the executive leadership team of Pfizer's Neuroscience Unit, and headed the glob-

al pharma giant's groundbreaking Autism Research Department. From basic target identification to phase 2 proof-of-concept studies, Pfizer's autism program pioneered efforts to develop first-in-disease medicines for autism and closely related neurodevelopmental disorders, with an emphasis on rare genetic syndromes such as Fragile X, Rett, Tuberous Sclerosis and Phelan McDermid. At the helm of the program, Dr. Ring was centrally involved in developing the company's research, regulatory and commercial strategies for this new therapeutic area.

Prior to Pfizer, Dr. Ring distinguished himself during decade-long tenure in CNS drug discovery and development at Wyeth Pharmaceuticals. Scientist, lab head, team leader, group leader and therapeutic area head – at Wyeth Ring earned his way to senior leadership through the traditional ranks of discovery roles. Through it Dr. Ring earned a deep, fundamental understanding of the drug discovery and development process. In addition to a strong track record of developing and leading cross-functional teams, Robert has extensive experience developing talent, strategic planning and managing externalized research programs and collaborations.

A neuroscientist by training, Dr. Ring earned his PhD in molecular neurobiology from the City of Hope National Medical Center in his native Southern California. Today, he remains engaged academically, with faculty appointments (adjunct) at Mount Sinai School of Medicine (Dept. of Psychiatry), as well as Drexel University College of Medicine (Dept. of Pharmacology & Physiology) where he serves as an instructor in Drexel's high-profile Drug Development Program.

Dr. Ring is a member of numerous professional boards and societies, and serves as a public member on the Interagency Autism Coordinating Committee (IACC), an appointment he received from HHS Secretary Burwell in 2015.

After stepping down as CSO earlier this year, Robert left AS to found the private consultancy practice (Autós). Autós has effectively leveraged Ring's diverse professional experience and expertise to provide strategic planning, technical diligence, and expert advisory solutions to clients operating across the life sciences, including biotechnology companies, non-profit foundations, and philanthropists.

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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 they 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.

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Manifests from page 18

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.scientificamerican.com/article/autism-it-s-different-in-girls/>).

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.

There is at least one Parent Center in every state. A list of the Parent Centers is available at www.parentcenterhub.org/find-your-center.

Parent Centers provide information and support about special education topics, trainings and local resources. Parent Centers empower families who have daughters with autism by helping them understand their rights and the services to which their children are entitled under the law, including social skills training and counseling.

Resources for Families

[CDC Learn the Signs-Act Early](#)

Developmental Milestones: <http://www.cdc.gov/ncbddd/actearly/milestones/>

see Manifests on page 29

Autism Spectrum News 2017 Editorial Calendar

Winter 2017 Issue:

“Sexuality: Development, Risks, and Education”

Deadline: December 7, 2016

Spring 2017 Issue:

“Supporting Adolescents with Autism”

Deadline: March 2, 2017

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“Improving Health and Wellness for Individuals with ASD”

Deadline: June 1, 2017

Fall 2017 Issue:

“The Latest Advances in Autism Science”

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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 ease 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 daughters 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.

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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.

Trainees at Girl AGain range in capabilities but they have some common characteristics: 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 the manager and 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 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 been in a career readiness program where she had several internships in addition to being a trainee at Girl AGain. She is currently enrolled in College Steps at Westchester Community College.

For more information, contact Marjorie Madfis, President of Yes She Can Inc. at Marjorie@YesSheCanInc.org or visit www.YesSheCanInc.org. Yes She Can Inc. - Women with Autism. We work. With you.

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sample of typical children, ascertained in the course of a UK birth cohort study (ALSPAC 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 (ALSPAC) that high verbal IQ is protective for females (Skuse et al, 2009). Genetic risk in the ALSPAC cohort 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 ASD traits (Robinson et al, 2016). 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 comparison 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 during the preschool and the prepubertal period. Once puberty and adolescence 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 anxiety, perhaps with self-harm and school-refusal, with psychosomatic features. One striking characteristic, rarely recognised by clinicians, is that there can be major differences 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, sullen, aggressive and even violent. Failure to recognise that this home-related behavior is not due to inadequate 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-blaming 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. Ascertainment bias has bedeviled the interpretation of research studies into genetic risk, because there has been an over-representation of girls with developmental learning difficulties in such samples – generalized learning disorders can have their own genetic etiology and confound studies into ASD-risk genes (Skuse, 2007). Research into female-typical ASD has been hampered by the fact that the diagnostic 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

female children and women if we do not recognise and treat their social communication problems; it is a matter of urgency to do so.

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Manifests from page 27

(in Spanish) <http://www.cdc.gov/ncbddd/Spanish/actearly/milestones/index.html>

If You're Concerned: <http://www.cdc.gov/ncbddd/actearly/concerned.html>

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Books on Autism and Girls

"Asperger's and Girls: World-Renowned Experts Join Those with Asperger's Syn-

drome to Resolve Issues That Girls and Women Face Every Day!" by Tony Attwood

"Pretending to Be Normal: Living With Asperger's Syndrome" by Liane Holli-day-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 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 family-voices@spannj.org. Families 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 advisory groups. She also works with SPAN's national Center for Parent Information and Resources which provides technical 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 and has been a part of the National Center for Learning Disabilities (NCLD) Parent Leader Team since 2010.

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Initiative from page 8

factor that emerged through the classroom discussions was that anxiety played a large role in impeding these women from pursuing the work they would like. Thus, our revised curriculum addresses this issue. The *Lean Out Curriculum*, participant workbook 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 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 women began this past winter. Our group tackles any subject that comes up, as participants talk over what it means to cope with parents, siblings, the demands of college

and the workplace. We learn about each woman's experience as they try to navigate through and understand their place in the 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 this program, we strive for an atmosphere that promotes relationship building through sharing ideas and experiences. A lot of conversation about music, movies and media, school work, parents and friendships happens. Positive energy flows through the room as our participants 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 activities are the only social opportunities they have.

We hope to expand the program in scope, so that new activities address unique challenges for these girls such as developing a healthy mind and body, developing positive relationships and an optimistic outlook for the future. Our Advisory Board, which includes parents of girls on the spectrum, professionals, and individuals 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 program, 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 and Women with ASD* provides an extraordinarily rich social experience for all who participate.

Kathy Koenig, MSN, APRN, is Associate Research Scientist, Clinical Nurse Specialist in Psychiatry, and Director, Initiative for Girls and Women with Autism Spectrum Disorders, Child Study Center at Yale School of Medicine. For more information about the Initiative for Girls and Women with Autism Spectrum Disorders at the Yale Child Study Center, please visit http://childstudycenter.yale.edu/autism/clinical_services/initiative/.

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Social Needs from page 9

"Activities with structure, like using Roberts 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 skill required for social participation is significantly higher for females than for males. Starting in the early adolescent years, girls are expected to be adept in relationship building skills not required of boys (Hannah and Murachver, 1999). Society 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. Milot, the current social culture exerts unique pressures on adult women to take on caretaking roles and conform to particular expressions of femininity (Milot, 2016). Such patterns of socialization create added challenges for women on the spectrum. As a result, 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 socialization, 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 diagnosis is concerning because it means less 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). Indeed, 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 participants, 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. Program 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 incorporating a design for activities that make them adaptable with respect to pace and complexity. The latter requires a careful use of visual supports; the goal is to supplement verbal information when necessary, without overusing visual cues that can confuse or distract the participant. All in all, this approach requires much pre-planning, opportunities for ongoing revisions of programmatic practices, and consultation with professionals who have expertise working with adults with ASD.

Due to the heterogeneity of ASD, another important program element involves anticipating the variety of social communication needs that can occur with this condition. At the group level, this can be accomplished via a menu of programs that caters to diverse needs, including experiences that are rich in opportunities for discussion as well as those designed for participants who are more interested in doing than talking. Programming content should also be informed by the experiences and interests of the women. Differences in social motivation are also important factors that affect participation. Thus, identifying special 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 individualized participation plans and mechanisms 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. The program has dedicated space with a design that accommodates large and small group activities, as well as rooms designed to provide restorative, quiet activities. Participation plans are flexible and individualized; they are uniquely informed by a new member process 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 consists of structured events such as lectures, workshops, and special interest groups, as well as social routines like movie nights and open hours. Each event is supported by at least one staff member and all activities include modifications with an eye towards facilitating participation.

Special consideration is given to the fact that Felicity House exclusively serves adults, and programming reflects the maturity and sophistication of adult women. Activities are chosen based on participant interest and the feedback collected at each event. Staff meet regularly to review and revise the content and design of the program activities and participants are included in this process through a monthly program-wide leadership meeting where Felicity House participants share ideas, offer feedback and troubleshoot issues that may affect participation.

To make the program accessible, participation is at no cost to the women. There is no requirement of functional limitations for inclusion. On the contrary, the goal at Felicity House is to provide support for women who are able and ready to increase their social participation, including those that may not be able to access state-funded resources due to eligibility thresholds.

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 anxiety and depression; all of which ultimately 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 important mechanism to improving outcomes. However, such programs must take into account 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 infor-

mation about Felicity House, please visit www.felicity-house.org.

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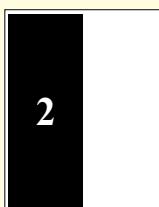
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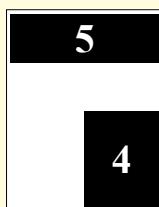
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