

AUTISM SPECTRUM NEWS

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Supporting Girls and Women with Autism

Girls and Autism: Overcoming the Gender Gap to Ensure Best Outcomes

By Jennifer Labowitz, MS, NCSP, BCBA
and Maggie Haag, MEd, BCBA, LSW
Melmark Pennsylvania

The Centers for Disease Control (CDC) estimates that 1 in 59 children has autism spectrum disorder (ASD), with boys being four times more likely to be diagnosed than girls (Mandy et al., 2012). Recently, through a meta-analysis of epidemiological studies, it was concluded that the true ratio may be closer to three times more likely in males (Loomes et al. 2017). We currently have no definitive reason as to why more boys are diagnosed with ASD than girls. This disparity in diagnosis between genders has an effect on how well we as professionals understand autism and how it may impact boys and girls differently. In recent years, the unique presentations of females with ASD has been noted, and the field is just beginning to address the ways in which gender might influence diagnosis, assessment, treatment planning, and the assess-



ment of success in intervention.

There are many different factors that need to be explored when looking at the differences between males and females

with ASD, including diagnosis and intervention. It has been posited that females who are considered high functioning may be diagnosed later or have their diagnosis

missed due to their communication skills, which can mask some other traits exhibited by boys diagnosed on the autism spectrum (Rynkiewicz et al. 2016). Regardless of gender, a delay in diagnosis is common, yet girls with ASD can be predominantly at risk (Giarelli et al. 2010). There is growing research to suggest that current diagnostic procedures may fail to capture female manifestation of ASD, which exaggerates the gender imbalance in prevalence rates (Halladay et al. 2015; Kirkovski et al. 2013; Loomes et al. 2017). For example, the Autism Diagnostic Observation Schedule, Second Edition (ADOS 2), in addition to other diagnostic tools, were developed based on the typical presentation of characteristics of ASD in boys, not in girls (Rynkiewicz et al. 2016).

As practitioners we must critically evaluate the research we use to guide intervention, including the population assessed, to best guide the appropriate application of the research findings. This becomes more

see *Gender Gap* on [page 22](#)

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Using Summer Programming to Prepare for Post-Secondary Education

By Ernst VanBergeijk, PhD, MSW
Professor and Director
The Threshold Program
at Lesley University

Each year 50,000 young adults on the autism spectrum turn 18 years of age (Roux et al., 2013). How can parents and educators ensure that these young people are ready for the transition to post-secondary life? A good number of these young people are academically ready and prepared for the intellectual rigors of college life. Post-secondary education requires more than academic skills. Post-secondary education should ultimately lead to employment and independent living. Young adults need to have skills in three core areas. These core areas are pre-employment and employment skills; independent living skills; and social skills with an eye on community engagement. Without a solid foundation in these core areas the ultimate goal of joining the world of work and independent living will be elusive. Summer programming can bolster these skills and can be used to help assess a young person's readiness to make the transition to post-secondary education.

While in elementary and secondary school some students on the autism spectrum will be eligible for extended year services as a part of their Individual Education Plan (IEP). The thought is that a student without summer programming or summer school, would regress or lose gains they had made through the course of the academic year. The focus, however, is in the maintenance of academic skills such as reading, writing, and arithmetic. Only a small portion of special education students receive such services. According to the U.S. Department of Education Fast Response Survey System (FSRS), only 29% of alternative schools and programs even offered extended day or extended year services. This was the least frequently required service (NCES, 2002). Parents and educators need to include pre-employment, independent living, and social skills goals in the IEP that can be assessed and worked upon during the summer.

Th pre-employment skills can be learned through community-based internships. Some of these skills include learning the importance of work; interviewing techniques; cover letter and resume writing; dressing appropriately for job interviews versus the work site; communicating with supervisors and co-workers; how and when to disclose a disability; asking for reasonable accommodations; and travel training that covers contingency management skills, i.e., what to do when your commute on public transportation goes awry. Job coaches may be necessary for on site supervision and an integrative seminar to discuss common workplace issues lead by the job coaches can help students develop pre-employment and entry level employment skills.

Independent living skills often are much more difficult for school districts to teach. Infrastructure and policy constraints hamper educators' efforts to teach these critical life skills. For example, a high school may teach laundry skills to the students en-



Ernst VanBergeijk, PhD, MSW

rolled in a summer program, but the skills may not generalize from the classroom to the home environment for a couple of reasons. First, the washing machines and dryers at school may not look same as they do at home or in the post-secondary environment. Washing facilities at colleges are either coin operated or have swipe card systems. This additional step can throw a student on the autism spectrum for a loop and prevent them from learning the task, and more importantly developing this skill into a habit. Second, doing laundry once in a while at high school is not the same as relying upon yourself to wash clothes weekly as would be necessary in post-secondary environments. The skill will not be ingrained as a habit if the parents do not insist upon the student doing their own laundry weekly. Teaching financial literacy can also be very difficult for school districts to teach effectively. Money is an abstract concept that many students on the autism spectrum struggle with. Aside from learning the dominations of coins and bills, and making change, learning the value of money can be allusive. Teachers will use mock checking accounts and use play money which makes the learning a dual abstraction. The student has no vested interest in learning the material. However, if the lessons around money are tied to earning a stipend for internship work, and the money is used by the student to pay for fun recreational and social activities, the lessons become more meaningful and real. If not going to work results in not having any spending money, then the natural and logical consequences reinforce the financial lessons the educators are trying to impart. Often school district policies prevent educators from using real money from teaching these essential independent living skills. Similarly, medication management is a vital life skill a student must master before transitioning to post-secondary life. No college or university will manage a student's medication, so it is imperative that students develop systems to help them remember to take their medication at appropriate times and remember to refill their prescriptions BEFORE they run out. Schools either rely on school nurses to administer medications or leave it up to the parents to give the medications before and after school. Students who learn to manage this own their own before leaving high school are in better shape to make the transition to post-secondary life.

Social skills are another pillar or core area necessary for student on the autism spectrum to master in order to ease the transition to post-secondary life. Basic skills include how to start, maintain, and end conversations appropriately; reciprocity in conversations; how to begin and grow friendships; the importance of friendships; effective communication in the workplace; getting along with roommates; and unwritten rules in social situations and on social media. More advanced topics include navigating romantic relationships and sexuality. Students on the autism spectrum need to be introduced to concepts concerning dating, informed consent, sexual assault, sexual harassment, and stalking. Individuals on the autism spectrum are at higher risk for sexual assault because many are unable to read the intentions of others making them extremely vulnerable. In colleges and universities, Title IX, which is a federal law that prevents discrimination on the basis of sex, governs the institutions regarding to their response to these issues including prevention programs. Not only are students on the autism spectrum at higher risk of being victims of sexual assault, but they are also more likely to be accused of stalking than their typically developing peers. School districts try to teach the basic social skills in a variety of formats. However, a typical IEP may prescribe a psychologist, social worker, or speech therapist to teach these skills on a 1:1 format one time a week for 45 minutes a session. The IEP might even include an additional 45 minutes of group to teach social skills. Given the importance of social skills are in the lives of students on the autism spectrum, 1.5 hours a week of instruction during a shorten summer session is inadequate. Furthermore, if the student simply goes home after a 6 hour or shorter school day, and simply goes home to play video games and does not have the opportunity to apply these skills in real life, it is unlikely these skills will become habits. Other summer programming, by the nature of their structure, may be better suited to teach the necessary social skills to ensure a smooth transition to post-secondary life.

Sleep away summer camps provide students on the autism spectrum the opportunity to separate from their families and live independently. Without this basic ability, the transition to post-secondary education is far more difficult. Not only do sleep away summer camps provide the student the opportunity to separate from their families, it also allows them to have autonomy in their decision making. Further, summer camps require students/campers to practice their social skills 24 hours a day, seven days a week. They are less likely to allow a student to retreat into a world of video games and withdraw from social interactions. Sleeping in cabins provides an opportunity to share a living space with others which is a necessary skill when one goes off to college and share a dorm room for the very first time. Sharing a living space also means having to manage their possessions and clean communal living spaces which are all good independent living skills. Sleep away camps also provide opportunities to practice daily hygiene skills, manage

laundry, and engage in physical activity. Having a child attend summer camp many years in a row will help prepare them for moving away from home and heading off to school.

There are thousands of camps in North America. Camps can be generalized in terms of the activities they offer and populations they serve. Others will be specific to a sport, hobby or activity like basketball, soccer or baseball camps, or music or band camps, scuba camps, or creative writing and art camps. The populations also vary from serving the general population to certain religious affiliations or special needs camps that can be by specific type of disability or medical condition. "Web sites like the American Camping Association (acacamps.org) can help you find accredited camps of all kinds. IncludeNYC sponsors New York City's largest fair for young people with disabilities and their families where over 100 different recreation program gather. The representatives are from all over the U.S. and Canada, and offer both summer and year-round programs (includenyc.org/resources/events). This event provides families the opportunity to conduct side by side comparisons of various programs" (VanBergeijk, 2020; P.33).

As the student on the autism spectrum reaches his or her later teens, the options become less frequent. Sleep away camps often cap the age at which they accept campers. Some will extend the age range they serve by offering multiple week travel camps. The benefits of these programs are that they allow participants to practice traveling on a wide variety of modes of transportation, practice their social skills, management of their possession and medication, and can help with flexibility and coping with transitions.

Another option for older teens on the autism spectrum are college-based summer programs. Some are operated by private companies that rent out the empty dorm space during the summer months. For example, "Musiker Summer Discovery Programs offer pre-college experience for middle and high school students in Universities such as University of Michigan, UC Santa Barbara, Georgetown, Cambridge University & London; Yale NUS-Singapore to name a few locations. These programs are not specifically designed for students with disabilities; however, it is incumbent upon the parent to ask if sufficient supports are in place for his or her son or daughter (summerdiscovery.com)" (VanBergeijk, 2020; p.34).

Many colleges and universities offer their own summer programming. These may be organized around a particular theme or discipline. Some will even offer college credit to the students who participate in courses. This may be an excellent way for families to gauge whether or not their son or daughter is ready for not only the academic rigors of a university or college, but also the independent living and social skills necessary to navigate post-secondary life.

"Postsecondary transition programs and colleges dedicated to teaching individuals with disabilities is another way to find

see Programming on page 17



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at least once per week

With Thunberg in Time's Spotlight, Those on the Spectrum Seeing “A Profound Moment”

By Stephen M. Shore
Professor of Special Education
Adelphi University

In just several months, Greta Thunberg, 16, has played international leaders, electrified climate advocates and served notice that her generation will bring new urgency to saving the planet. Her voice is forceful, her intensity unapologetic and her expressions candid.

She's also on the autism spectrum, diagnosed with Asperger syndrome, as Time magazine noted in naming her Person of the Year.

For those on the spectrum, this is a profound moment—not only acknowledgment but a full-throated declaration that neurological differences can be assets, not just hurdles.

It's a crucial and empowering message as autism diagnosis rates rise. The Centers for Disease Control and Prevention now estimates prevalence at one in 59 children. By peeling away the disability label, society can better see many autistic traits as abilities, a dramatic shift that helps foster productive and fulfilling lives.

Time painted a clear portrait of Thunberg: She “doesn't operate on the same emotional register as many of the people she meets,” the magazine wrote. “She



Stephen M. Shore

dislikes crowds; ignores small talk; and speaks in direct, uncomplicated sentences. She cannot be flattered or distracted. She is not impressed by other people's celebrity.... But these very qualities have helped make her a global sensation.”

To be sure, traits associated with autism are different for everyone on the spectrum, and many bring undeniable, even lifelong challenges. The key is to identify, understand and work with the promise in each of those characteristics instead of fighting them.

Another era might have left Thunberg isolated over her unconventional approach. The same goes for a young man we'll call “Robert,” who helps travelers find their way in New York's Penn Station. And for “José,” who folds and stacks clean laundry in St. Petersburg, Florida.

Robert guides lost tourists with instructions that are detailed, data-driven and helpfully repetitive. According to his supervisor, Robert's boyhood fascination with the metropolitan public transportation system probably explains why he is faster and more accurate than his coworkers.

Down in Florida, José revels in pulling hot clothes from a dryer and folding them with precise creases. He's done this so many times that his movements dazzle as he folds and stacks whatever is in front of him. José doesn't talk but communicates by pointing at pictures on an iPad.

Early on, I wasn't so fortunate. School would have been much better if teachers had wrangled my fascination with astronomy to navigate my difficulties in math instead of telling me I'd never learn numbers.

More educators these days would notice such a highly focused interest and use it to teach needed curricula. I've since learned enough math to teach college-level statistics.

Long before my arrival in academia, my first formal job was cleaning tables in a

busy restaurant. The noise and fast-paced hustle and bustle overwhelmed my senses. I realized I needed work somewhere I would be competent, regulate my sensory input and find enjoyment.

At the time, I could disassemble a bicycle down to the ball bearings and spokes, then have it back together working better than before. After several tries, I landed a job as a bike mechanic and looked forward to work every day, just as I do now as a professor of special education at Adelphi University.

Today I'm proud to share fundamental truths with Thunberg, Robert and José: We're all productive, making useful contributions and living full lives on the spectrum. But such fulfillment remains a relative rarity among people with autism.

Our traits aren't necessarily a burden but often a gift. It's time that society reframe the spectrum as something to work *with* instead of *against*. The sooner that happens, the sooner we'll be striving for fruitful, meaningful lives as the rule rather than the exception.

Just like everyone else.

Stephen M. Shore is a clinical assistant professor in the College of Education and Health Sciences at Adelphi University. An author, researcher and educator in the autism field, he was diagnosed with regressive autism at the age of 18 months.

Meeting the Unique Needs of Women on the Autism Spectrum

By Marisela Huerta, PhD
Program Director
Felicity House

The research on adults with Autism Spectrum Disorder (ASD) 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 research reports that find women and men with primary ASD are largely similar in symptom presentation (e.g.; 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 social program in New York City for adult women with ASD, focus groups with key stakeholders were conducted to identify the specific needs of this population. Women on the autism spectrum were invited to discuss their perceptions of the sex differences in ASD, their ex-



Marisela Huerta, PhD

periences 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.

At the start of 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. Focus group participants already involved in coed social programs further noted that their communication “style” is consistently at odds with their male peers, limiting their social participation. Additionally, unwanted sexual attention was a common experience for the token female in group activities designed for adults with autism.

“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.”

“I don't know how to meet people.”

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

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

Most striking was that the participants quickly zeroed in on their desire for social connections and 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 designed for 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 Unique Needs on page 31

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Coronavirus (COVID-19): Preparation Tips for Families Affected by Autism

**By Assemblyman Angelo Santabarbara
Chair of the New York State
Assembly's Sub-Committee
on Autism Spectrum Disorders**

As Chair of the New York State Assembly's Committee on Autism Spectrum Disorders, with the help of fellow board members of the International Board of Credentialing and Continuing Education Standards (IBCCES), we have gathered some tips and suggestions to keep in mind with the rise of COVID-19 disease cases. These tips are tailored for individuals and families with a loved one on the autism spectrum but can be helpful for many individuals.

Tip #1 Stay Informed

The most important thing you can do is make sure you have a conversation with your children providing statistics and facts as soon as possible making them fully aware of what is happening. The goal is not to scare them with information but help them feel informed and prepared. Be mindful of media influence contributing to anxiety, and potential misinformation being shared by peers and other sources. Make sure you are gathering information and updates from reputable sources.



Tip #2 Practice Good Hygiene

- Wash your hands often with soap and water or use an alcohol-based hand sanitizer.
- Create visual cues and reminder cards to demonstrate hand washing practices. Consider posting the CDC hand washing poster by the sink along with practice, modeling, and supervision.
- Cover your mouth and nose with your elbow or a tissue when you cough or sneeze.
- Avoid touching your eyes, nose and mouth if your hands aren't clean.
- Avoid close contact with anyone who is sick.
- Avoid sharing dishes, glasses, bedding and other household items if you're sick.
- Clean and disinfect surfaces you often touch.
- Stay home from work, school and public areas if you're sick.

Tip #3 Remain Calm

It is important for parents and caregivers to portray a calm demeanor during an emergency such as a quarantine, travel delays, or other significant changes in routine or mobility. We understand it is difficult to keep emotions at bay during stressful situations such as this, but your other family members may sense your emotional state and mimic it.

Tip #4 Be Prepared for Immediate Needs Before a Possible Emergency

Create a network of relatives, friends or co-workers to assist in an emergency. Don't be afraid to ask for help in making a plan ahead of time. Also, make sure to wear any needed medical alert tags or bracelets to identify you or your family member's needs. This may alleviate some of the stress for both you and any staff assisting in the case of an emergency.

Also, be sure to pack a "safety & calm" kit, which could include:

- Weighted blanket
- Sensory toys, therapeutic comfort aid or other comforting distractions
- Personal hygiene items

see Coronavirus on page 25

Assembling an Emergency Toolkit for Children with Disabilities

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

In the journey of parenthood, one of the most challenging things caregivers of children can encounter are the inevitable injuries and emergencies. Last year, I had to take my daughter, Annie – who has autism and intellectual and developmental disabilities – to the emergency room (ER). Going to the ER is scary enough, but for children living with disabilities, and their families, it can make these types of situations even more frightening.

With few minutes to spare, and as my own panic started to set in, I remembered that I had created an "Emergency Toolkit" list for an assignment I was working on several years ago. Luckily, I quickly found the toolkit on my computer and printed it out. I then grabbed a bag and filled it with the toolkit essentials, not anticipating I would need them, but preparing for the worst.

Thank goodness I remembered! After spending nine hours in the ER, my daughter was admitted to the hospital for three days. I don't know that those first 24 hours would have been manageable, let alone successful, without my toolkit.

Emergency Toolkit Essentials

- Favorite book



Amy Kelly, MBA, MNM

- Favorite toy
- Favorite "snuggly" item, including blankets, binkies, dolls and stuffed animals
- Communication devices, including a PECS book, iPad, Dynavox, iTouch, paper and pencils
- Activities to keep a child busy independently, including playdough, crayons and paper, word finds, Sudoku,
- Nintendo DS, iPods and music and portable DVD player with favorite videos
- Sensory objects, including squishy balls, teething and biting toys, scratch and sniff books, rain-maker toy and sound-minimizing headphones
- Extra change of clothes
- Diapers or extra underpants (including an extra pair for the caregiver!)
- Tissues
- Drink and special cup or bottle, including water bottles, boxed drinks and other drinks that last
- Desired food and snacks the child might like that might not be accessible in a hospital or emergency situation
- A few top reinforcements, such as food, toys or electronics, that can be used for very difficult demands or tasks
- Visual schedule – a list, using pictures and words, of an upcoming day's events or activities
- First/Then card – a strategy that explains the order of events for a particular activity, like going to the doctor. For example: First blood draw. Then snack.

- Token card – a way to reward desired behaviors by giving a child "tokens" (stickers, stars, etc.) to work toward a final goal
- Social Story – a written story customized for the person (includes his/her name and pictures if available) to assist in preparing him or her for upcoming events or activities
- List of medications, including the name of the medicine and dosage, pharmacy and prescribing doctor
- List of current doctors caring for your child in any capacity
- Insurance card(s)

By the way, Annie did fantastic at the hospital and, fortunately, her health continues to be fine.

I wanted to share my family's toolkit with you and your family, hoping to provide you the same preparedness, and peace of mind, should you ever need it.

Amy Kelly, MBA, MNM, is the mother to Danny, Annie and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities and general anxiety disorder. Amy is the National Director of

see Toolkit on page 32



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Mentors Over White Knights - How to Support Autistic Women for Success

By Kate Trammell, MA
Arts Administrator and Educator

Like many neurotypical girls, I spent a lot of time growing up either reading or watching fairy tales in books or television. What's peculiar about women on the Autism Spectrum is that our advocates sometimes mimic those white knights in shining armor; Meaning that someone on our care team will want to rush to our side and offer their help when we're having a moment of sensory overload. In retrospect, I truly appreciate their concern. Now that I am 20+ years into my diagnosis, I am now asking you to listen instead of help.

Over the last 2 years, I have been actively mentoring young people who are also on the Autism Spectrum. Their abilities and interests are a spectrum in and of itself. As I work with them to figure out plans for their careers, I primarily take that and what accommodations are needed into account. These interests and accommodations require every mentee - especially female ones - to self-advocate in professional settings. In order to help us achieve our dream careers and live independent lives, I'm imploring everyone who advocates on behalf of a woman on the Autism Spectrum to take two major things into account.



Kate Trammell

Talking It Out When You Meet Us Halfway

First of all, it helps to understand that this condition should not be treated like a disease that should be pitied. In my humble opinion, having Autism Spectrum Disorder (ASD) only becomes a problem if encouragement and services aren't provided after diagnosis. Women with ASD aren't helpless. Not fitting the mold of what it means to be a typical girl or woman shouldn't negate what we are capable of. Just because we have trouble picking up non-verbal cues and social norms doesn't mean that we cannot achieve the same

amount of personal and professional success as neurotypicals. When you interact with us, give us the benefit of the doubt if we struggle with interpersonal communications at first. For example: If we don't understand when it's appropriate to leave a tip for a server at a restaurant, take the time to explain these social norms to us in practical words. Use concrete directions so that we know what to do on our own. As you are teaching us the skills that we need for meeting social expectations, stop assuming that we learn social cues by observing what other people do.

Train Us to Be Our Own Heroes

If you really want to support a girl or woman with Autism, then train us to be our own advocates. In other words, encourage us to grow into women who can support or rescue ourselves. There's still so many of us who don't get diagnosed until later in life, if at all. In a 2018 report, the Autism and Developmental Disabilities Monitoring (ADDM) Network reported that "males were four times more likely than females to be identified with ASD (Baio et al, 2018, 2). In female-only support groups for women on the Spectrum, I am considered one of the unique Aspies that received a diagnosis as a child. Even now, most people are surprised when I disclose. More than one person has said "but you're

so eloquent." I took this response to mean that since I appear to enjoy socializing and can maintain eye contact with whomever I am speaking with at parties, I don't fit into the stereotypical "Rain Man" mold for a person on the Spectrum.

As you might tell with this sociable Aspie, some stereotypes don't apply. In order to find out what being on the Spectrum means to us, might I suggest that you listen to us before automatically assuming that we are in need of whatever help that you can provide as a neurotypical? When I'm feeling anxious and stressed, I prefer going somewhere completely quiet by myself or going for a run alone. When I mention how I am feeling to someone that I've disclosed my condition with, sometimes their reaction is to automatically offer something that helps them. What you need to understand is that we're not like you.

So, if you want to support us, understand that what helps you won't always help us. Ask us questions about what being on the spectrum means to us. Start by asking if there's anything specific that makes us feel overstimulated or unregulated. Asking us about what we do to cope in these overwhelming moments can also bridge the divide of what to do in those tense, over stimulating situations. Knowing the person leads to knowing what you can do to help

see Mentors on page 27

Different is My Identifier

By Becca Lory Hector, CAS, BCCS
**Autism & Neurodiversity Consultant/
 Speaker/Author/Advocate**
Evolving Skye, LLC

Iwas eight years old the first time I remember being aware of my difference. It didn't have a name yet, that was still decades away, but nonetheless, suddenly at the ripe old age of eight, I was cognizant of that I was indeed different. For the seven years of life prior to that, I happily lived in my imagination, playing alone for hours, and only vaguely conscious of my peers. Satisfied with the social of parallel play, what other people thought of me and whether I was playing right mattered not to my young self, that is until it began to matter to others.

Because my difference had no label yet, the adults in my life gave me some of their own. As teachers, doctors, therapists, and family members alike each experienced their version of my difference, they would attach descriptors to me in an effort to explain my difference to each other. Complicated, difficult, different, stubborn, and manipulative were used so often to "discuss me" that they would become synonymous to 'Becca' in my head. Decades later, as I began to unpack the trauma of being undiagnosed through therapy, I realized that all the descriptors I had been given to use about myself were not only not accu-



Becca Lory Hector, CAS, BCCS

rate, but their frequent use had obliterated my ability, and opportunity, to develop a healthy, accurate sense of self.

Almost eight years after receiving my autism diagnosis, I can finally say that I have developed a much more accurate sense of self. A correct diagnosis, years of therapy, and a dedication to personal growth later, and I have managed to reprogram my internal monologue to reflect reality. I have painstakingly rebuilt my confidence in myself, relearned how to trust my-

self, and amassed just enough self-esteem to begin to value my own needs as much as the needs of others. None of it was easy and all of it should have been unnecessary.

While I would love to believe that I am one of a few autistic females diagnosed in adulthood who suffered from a disrupted sense of self identity, it is quite simply not true. I would venture to say that most, if not all, autistic women struggle with a distorted sense of self. How could we not? For most of our lives we have been told both explicitly and implicitly, that what we are naturally inclined to do is wrong or bad. You stop trusting yourself, you stop liking yourself, and you stop wanting to be yourself. You begin masking, scripting, and mimicking in a last-ditch attempt to at the very least cover up that damn difference. Not surprisingly, if you spend enough years like that, trust me, you can no longer muster even a spark of self-confidence by just being yourself because you no longer have any idea who that even is anymore.

The good news is that this doesn't have to remain the narrative. We don't have to have thousands of autistic women and girls who are miserable and barely surviving because they are spending so much of their precious energy just pretending as hard as they can to be "normal," a nonexistent, unattainable ideal. We can do better, much better.

To begin, the girls and women of the spectrum need validation. They need to have their symptomology recognized,

their experience validated, and their needs understood. While for years, autism was thought to be a boys' club, we now know that it is not, and it's time that our testing, supports, and services start to reflect that. After all, a large part of having self-confidence and a strong identity is knowing that your needs are important enough to be recognized.

Next, autistic girls and women need role models. Not just as mentors but as goal posts and archetypes to aspire to. As a young girl, I needed real women in my life that I could relate to and look up to, but I could never find one who was 'different' like me. We need our autistic girls, to have strong, successful, autistic women to look up to. We need their parents to have these same women to look toward as examples of what their daughters can be. We need an infusion of loud and proud autistic femaleness to break this cycle of invisibility. Otherwise, I will continue to meet autistic girls and women who don't have anyone to look up to, parents who have never seen an autistic adult so they cannot imagine their child as a grown up, and teachers who continue to underestimate the abilities, and the struggles, of their autistic female students.

Lastly, listen and observe. Though we aren't loud enough yet, there are autistic women and girls shouting from their

see Different on page 28

Hormonal Fluctuations and Women with Autism: A Call for Increased Awareness and Assessment

By Jan Schlaier, EdD (c); FNP-BC
and Jacqueline Berko, RN BSN
Bergen’s Promise

The topic of hormonal influences on women with autism has received scant attention from health care researchers. The responses to hormonal fluctuations and/or depletion of estrogen are varied and present challenges in health care prevention and promotion for some women with autism. Treatment decisions for Premenstrual Syndrome (PMS), Premenstrual Dysphoric Disorder (PMDD), Perimenopause, and Menopause can be controversial and complex. Women with autism are at risk for being excluded from this decision-making process.

Behavioral disturbances before or during menses are a frequent presenting problem in gynecological referrals for women with autism. Several reports/case studies identify marked changes related to menarche (the onset of menses) and menstruation in girls and women with autism (the majority having additional intellectual disabilities): These studies describe cyclical self-injurious behaviors (Lee 2004); an amplification of symptoms associated with autism such as sensory issues, repetitive behaviors, (Hamilton et al. 2011; Lee 2004); and mood symptoms/emotional dysregulation



(Hamilton et al 2011; Obaydi & Puri 2008; Lee 2004). Oftentimes, psychotropic medications are prescribed without an adequate investigation of the cyclical nature of these behavioral patterns.

The condition known as PMS and its more severe form PMDD are often not addressed. PMS and PMDD are characterized by two key elements: symptoms (which can differ among women), and their timing in relation to the menstrual cycle.

The cyclical nature and the timing of symptoms are the central distinguishing features of these menstrual-related disorders.

In the most typical pattern, symptoms begin one to ten days before menstruation and continue until after the onset of menses. In other cases, symptoms begin just after ovulation and continue until near the end of the period.

PMDD is a classification of mental disorders described in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5). PMS has been associated with dozens of different symptoms, though some are seen more frequently than others.

see *Hormones* on page 34

TABLE 1 - COMMON PMS SYMPTOMS

- 1) Weight Gain/Bloating
 - 2) Trouble Sleeping
 - 3) Crying
 - 4) Lowered School/Work Performance
 - 5) Muscle Stiffness
 - 6) Forgetfulness
 - 7) Confusion
 - 8) Takes Naps or Stays in Bed
 - 9) Headaches
 - 10) Skin Disorders
 - 11) Loneliness
 - 15) Stay Home from Work/School
 - 16) Cramps
 - 17) Dizziness or Faintness
 - 20) Avoid Social Activities
 - 21) Anxiety
 - 22) Backache
 - 23) Cold Sweats
 - 24) Lowered Judgment
 - 25) Tiredness
 - 26) Throwing Up
 - 27) Restlessness
 - 28) Hot Flashes
 - 29) Difficulty in Concentration
 - 30) Painful or Tender Breasts
 - 33) Trouble Listening or Paying Attention
 - 34) Accidents
 - 36) Irritability
 - 37) General Aches and Pains
 - 38) Feeling Good then Feeling Bad
 - 40) Depression
 - 41) Slower in Doing Jobs
 - 42) Difficulty in Operating a Machine
 - 44) Change in Eating Habits
 - 45) Tension
- * Number of Symptom corresponds to MOOS Menstrual Distress Questionnaire

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A Shift Towards Better Understanding and Improving the Lives of Girls and Women With ASD

By Cortney Janicki-Menzie
and Kristin V. Christodulu, PhD
Center for Autism and Related Disabilities

It has been widely established that females are less frequently diagnosed with autism spectrum disorder (ASD) than males. On average, prevalence of ASD is four times higher in males than in females (Baio et al., 2018). This ratio appears to be an inaccurate representation of prevalence by sex/gender. When comparing males and females who are severely impacted by their ASD symptoms, the ratio is closer to 1.33-2 males for every one female (Baio et al., 2018). Determining the ratio of males to females with less severely impactful ASD symptoms has been more complicated. The prevalence ratio has been found to be anywhere between 6-8:1 (Baio et al., 2018) to as high as 16:1 (Fombonne, 2003). Perhaps for this reason, females with ASD had largely been under-represented in ASD literature. However, a growing body of research has worked to include more females with ASD in studies and specifically look at the female presentation of ASD.

Thus far, the most consistently reported finding on the difference between males and females with ASD is that females have lower IQ scores (i.e., <70) than males (Giar-



Cortney Janicki-Menzie

relli et al., 2010). Research on IQ and ASD has looked at discrepancies in Verbal and Nonverbal IQ performance, finding some evidence for better performance in Nonverbal/Performance IQ compared to Verbal IQ (Charman et al., 2011). As is consistent with most of ASD literature, samples are disproportionately male and studies have not devoted time to parsing out gender differences in IQ discrepancies.

A recent study conducted at the Center for Autism and Related Disabilities exam-



Kristin V. Christodulu, PhD

ined IQ performance of females with ASD, comparing them both to males with ASD and females who were not diagnosed with ASD. The study sample included $n = 178$ children and adults ranging in age from 2 to 28 years old ($M = 10.03$, $SD = 5.24$). There were $n = 125$ males and $n = 53$ females in the sample, of which, $n = 76$ males and $n = 20$ females received an ASD diagnosis. ASD diagnosis was determined through the use of the *Autism Diagnostic Observation Schedule, Second Edition* (Lord et

al., 2012), and IQ was determined through administration of the *Stanford-Binet Intelligence Scales, Fifth Edition* (Roid, 2003).

Females with ASD had a mean Full-Scale IQ score of $M = 89.25$ ($SD = 17.11$), Nonverbal IQ score of $M = 91.45$ ($SD = 17.54$), and Verbal IQ score of $M = 88.25$ ($SD = 19.30$). The mean standard score difference between Nonverbal IQ scores and Verbal IQ scores for females with ASD was $M = 14.40$ ($SD = 8.74$).

Comparisons between females with ASD and males with ASD showed no significant difference in cognitive ability between groups. Multiple independent samples t-tests revealed no significant differences between ASD-males and ASD-females in regard to Full-Scale IQ score $t(94) = .47$, $p = .64$; Nonverbal IQ scores $t(94) = .63$, $p = .53$; and Verbal IQ scores $t(94) = .26$, $p = .79$. There was no significant difference between ASD-males and ASD-females in mean standard score difference between Nonverbal and Verbal IQ scores $t(94) = -1.45$, $p = .158$.

Females with ASD were also compared to $n = 33$ females who were not diagnosed with ASD. Results from multiple independent samples t-tests showed no significant differences between females with ASD and non-ASD females in regard to Full-Scale

see Understanding on page 33

Supporting Young Women with ASD Through Transition Services, Employment and Volunteer Opportunities

By Tibi Guzmán
Executive Director and CEO
The Arc Westchester

Over the next decade, approximately half a million young people on the autism spectrum will transition to adulthood (Demer, 2018). When they turn 21, they must leave behind the programming and funding that has supported them throughout their lives, with many families not knowing what to do next. For some it could mean day habilitation programs or volunteering, but for others it could mean employment in the community.

Employment is a socially normative activity that often occupies the majority of adult lives and is a key component of passage into adulthood (Fussell, 2005). Unfortunately, the majority of people with developmental disabilities remain either unemployed or underemployed despite their ability, desire, and willingness to work; according to Autism Speaks, nearly half of 25-year-olds with autism have never held a paying job.

People with developmental disabilities such as autism should have access to the supports necessary from individuals and systems to assist them with finding and keeping community jobs based on their preferences, interests and strengths. They



Tibi Guzmán

have the right to receive comparable wages and be free from workplace discrimination. With the right transition services and supports, individuals with autism can be set up for success in a job that they are qualified for and enjoy doing.

The goals of transition planning and services—that is, preparing for the transition from adolescence to adulthood—include promoting career exploration and development, extending education or training opportunities, supporting independent life

skills, and enhancing health and well-being (U.S. Department of Health and Human Services, 2017). At The Arc Westchester, transition services are provided in a myriad of ways: through volunteer programs and groups, our supported employment program and through our Project SEARCH Autism Enhancement* (PSAE) internship program.

Since boys are four times more likely to be diagnosed with autism than girls (Baio J, Wiggins L, Christensen DL, et al, 2014), it's important not to lose sight of meeting the latter's needs. While all our programs and services are person-centered and tailored to each individual, we have picked up on the unique needs of the young women in our programs and try to meet those needs where we can. Over the years, the Project SEARCH staff has noticed that young women in the program are craving appropriate social interactions with their peers. Sometimes they can feel isolated and our staff has helped them create social circles within themselves. We present opportunities for them to interact with each other outside of the classroom, inviting them to an event on the weekends or helping schedule a meal for all of them together, in the hopes that when they graduate these connections and relationships can hopefully continue.

Here are just a few stories of young women with autism supported by The Arc

Westchester and how they have successfully transitioned into contributing members of their community through employment and volunteering.

Carlie – Project SEARCH

Finding and keeping a job is hard for many people with ASD; navigating the social dynamics of the workplace, coping with sensory overload, organizing and completing tasks and communicating with coworkers may be challenging (Roux, Rast, Anderson and Shattuck, 2017). Our PSAE is a one-year internship program targeted for young adults ages 18 to 25 with ASD whose goal is competitive employment. PSAE uses the proven curriculum from the original Project SEARCH program at Cincinnati Children's Hospital Medical Center and was enhanced by NEXT for AUTISM in partnership with The Arc Westchester, New York-Presbyterian Hospital, and New York-Presbyterian's Center for Autism and the Developing Brain.

Carlie was a member of the 2018-2019 Project SEARCH class, and went through the intense, pre-vocational training using UNC TEACCH® Autism Program strategies. After graduation, we knew very well what a good job for her would be: Carlie needed a job with limited distractions.

see Supporting on page 34

The Daniel Jordan Fiddle Foundation for Adult Autism Shares Its Pioneering Mission On the Global Stage in Beijing, China

By Ryan Shindler
The Daniel Jordan Fiddle Foundation

On August 22-23, 2019, The Daniel Jordan Fiddle Foundation attended the International Symposium on Rehabilitation and Advocacy for Autism sponsored by the Ai You Foundation at the Crowne Plaza in Beijing, China as an invited KEYNOTE addressee.

Over the course of two days, this international conference featured lectures on psychosocial support for families with Autism, organizational management of Chinese rehabilitation centers, and - led by renowned behavioral analyst Vicci Tucci - how the Competent Learning model fosters inclusion for Autistic children. Two of our founding Board of Trustees members, Howard and Frederick Fiddle, proudly represented The Daniel Jordan Fiddle Foundation as the only international organization invited to share its trailblazing mission, representing the US Charitable Sector at the Conference.

Howard Fiddle participated on an international panel that discussed capacity building and vital support from the charitable sector. Frederick Fiddle presented a KEYNOTE address on the work of The Daniel Jordan Fiddle Foundation since its



Linda Walder, Co-Founder and Executive Director of the Daniel Jordan Fiddle Foundation, shares her vision of neurodiversity acceptance, valuing all with ASD with a global audience.

inception. This includes the establishment of hundreds of adult Autism programs throughout the United States, educational and public service publications relating to topics focused on adult Autism and most

recently the historic establishment of five endowed funds at America's leading universities, each focused on unique areas that vitally impact adults diagnosed with Autism Spectrum Disorder. Tugging at the

heartstrings of the audience, Frederick Fiddle led a moving story of Danny Fiddle, his late son for whom the foundation is named.

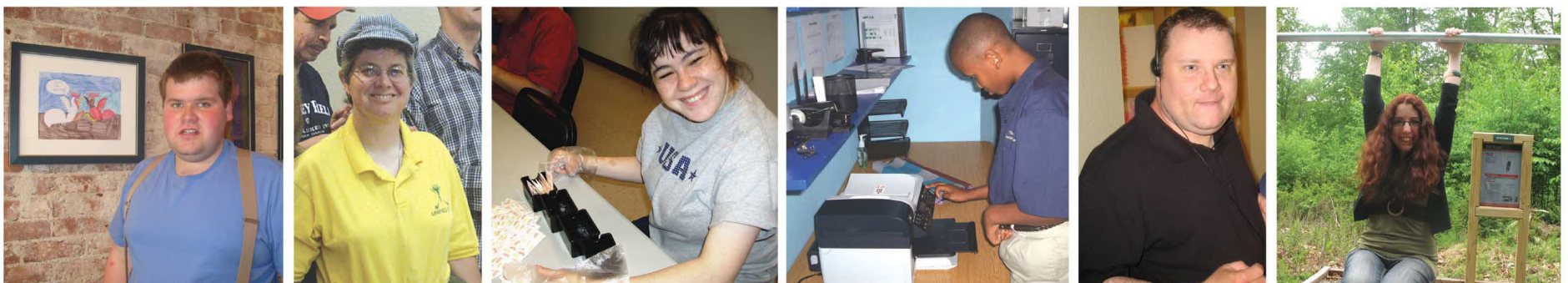
Sponsoring the event, the Ai You (AY) Foundation spawned with the then new foundation laws in China in 2004, uses its entrepreneurial staff to push Chinese non-profits into the 21st century. AY dedicates its efforts to the medical needs of children who need it most, including the Ai You HeKang Rehab Center for children with Autism.

The Daniel Jordan Fiddle Foundation shared its visionary mission of worldwide acceptance of neurodiversity and the need to value all individuals. Starting out in New Jersey, Executive Director Linda Walder expanded the foundation's outreach to all forms of media worldwide, including *USA Today*, the *New York Times*, *Traditional Home* and *Redbook* magazines, to name a few. Today she writes in the blog she established entitled, *Autism for a Lifetime: Finding Joy in the Journey*. The Daniel Jordan Fiddle Foundation shared its innovative and collaborative model that focuses on joint-ventures and partnerships aimed to achieve specific societal change.

The Daniel Jordan Fiddle Foundation assures a global focus on cutting edge research, program development, and public policy in the world of Autism through the

see Fiddle on page 21

This is what success looks like...



This is what an adult living with autism looks like!

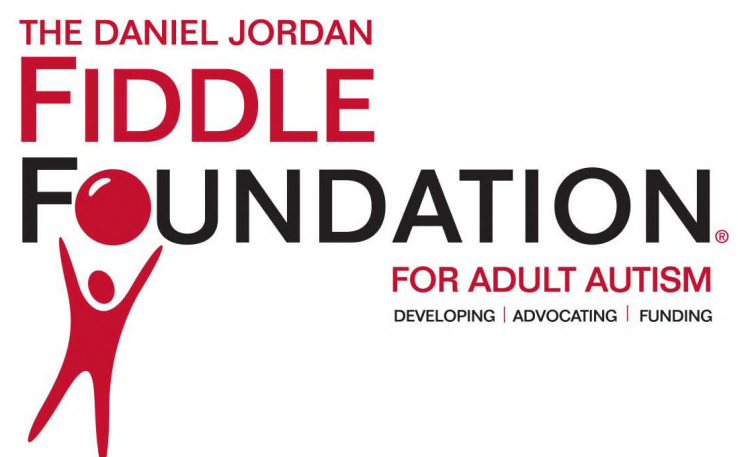
Building successful futures for adults living with autism takes innovative program development, advocacy, funding – and a belief in their strengths, talents and promise.

The Daniel Jordan Fiddle Foundation Signature Programs provide the blueprints that create opportunities for the diverse population of adults living with autism to build rewarding futures.

To learn more about
The Daniel Jordan Fiddle Foundation
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Guiding Your Child with Autism Through Puberty

By May Ng, MBBS, MSc, LLM, PhD
Consultant Paediatrician
United Kingdom

The early changes of puberty usually occur between the ages of 9 to 13 years (Odel, 1989). They are noticeable in girls by the budding of breasts and then pubic hair, with menstrual periods starting between 11 to 14 years of age. Boys usually develop testicular enlargement and then pubic hair between the ages of 9 to 14 years. Underarm hair, facial hair and deepening of the voice in boys occur typically between 13 to 16 years. If there are concerns about delayed puberty, or signs of puberty that occur at an earlier age than usual, it may be necessary to refer to a specialist paediatric endocrinologist for an assessment.

Some schools may address puberty and sex education at an age appropriate level, but others may not. Preparation for this discussion is advisable as children with autism need a longer period of time to understand and adjust to changes in their bodies. Even in children who do not have autism, puberty can be a difficult transition due to hormonal changes and mood swings are commonly reported. For a child with autism who cannot understand what is going on, it can be so much harder and behaviours such as emotional swings, aggression, self-harming and masturbation



May Ng, MBBS, MSc, LLM, PhD

can sometimes be escalated (Paul, 2008). In children with Autism Spectrum Disorders (ASD) or special needs, communication issues are common and many children may not be able to express their emotions (Osterlin et al, 1994).

Help your child understand and cope with visual aids and be explicit in your language and communication with a child with autism (Charlop-Christy MH, 2002). Explain and use labelled pictures to explain about when puberty happens and how each part of the body will change including what fluids will come out- such as sweat,

tears, semen, menstrual blood, and vaginal discharge. The use of visual aids will often help with developing a routine for hygiene in a step-by-step manner such as which parts of the body are needed to pay special attention to in the bath or shower, how to shave and how use a menstrual pad. Do not “assume knowledge” in your child (Light et al, 1998).

During pubertal years, it is not uncommon to have sexual urges and your child may masturbate. This is a healthy and normal part of pubertal development. It is important to explain and discuss and reassure and some of these new sensations can cause anxieties. Teach your child the difference between being in public and in private, and that some activities could only happen in private such as undressing or masturbation. Teach your child safety; how to say “no,” that he/she should not let anyone touch his/her private parts, that he/she should never touch anyone else’s, and that he/she should tell you if anything like this ever happened. Note that child sexual abuse and exploitation is higher in children with special needs (Tharinger et al, 1990).

Many adolescents can begin to develop a romantic interest in the opposite sex, or same sex. Help your child to understand these feelings and what sexual relationships are. This can be supported by using social stories and visual drawings using stick figures or photographs. It is likely that your child may already have devel-

oped a curiosity about the topic. If he/she shows an awareness, be prepared to discuss this and let them ask you questions. Topics can progress through from what is sexual intercourse, to gaining sexual consent and the importance of protected sex as they develop further understanding.

Puberty is an important developmental stage with changes that occur physically, emotionally and socially. As parents and caregivers, puberty can be challenging and being prepared and informed on how to approach any issue as they arise is advisable.

Quick Tips

- Puberty brings a raft of new challenges that can be behavioural, so make sure you are fully prepared
- Do not “assume knowledge” in your child. Explain and use pictures to explain about when puberty happens and how each part of the body will change
- Use visual aids to teach your child to how to be hygienic and, be explicit with naming private parts of the body
- Teach them to say ‘no’ and difference between private and public behaviours such as masturbation and undressing only in the private room

see *Puberty* on [page 28](#)

Dating and Relationships: A Perennial Challenge for Many Autistics

By Karl Wittig, P.E.
Advisory Board Chair
Aspies For Social Success (AFSS)

This is one area about which, like so many on the autism spectrum, I can hardly be considered an expert. Nevertheless, because of its importance to so many in the autistic community, I feel the need to share what little I have learned on the basis of meeting and talking to others who have faced these challenges, as well as my own personal life experience; these constitute the only basis of whatever knowledge I can claim.

Having attended and facilitated numerous Aspie support groups in New York City over the past 20 years, I distinctly recall that some of our best-attended meetings were those that dealt with this issue. In fact, it became the traditional topic for February meetings, which always fell near Valentine’s Day.

Sex and Sexuality

Above all, I need to emphasize that the all-too-common belief about autistics not being interested in romantic or sexual relationships is both entirely false and highly detrimental to the autistic community. From my own experience, I can ascertain that the vast majority of autistics are very interested in such but face a variety of



Karl Wittig, P.E.

challenges when it comes to pursuing them (this was certainly the case for me). Consequently, this myth needs to be immediately and completely discredited once and for all.

Although I have no actual data to support this, I am strongly of the impression that most autistics face the same issues concerning sex and sexuality as does the general population. Many difficulties that are identified as sexuality-related are, in

my opinion, really manifestations of the many interpersonal and social challenges faced by virtually all autistics. Such skills, in our society, are essential to forming any kind of romantic or sexual relationship, and deficits here can create considerable difficulties for autistics (as they do in so many other aspects of life). I have come to this conclusion from hearing the stories told by many autistics, male and female, straight and gay, as well as from my own life experiences. There needs to be serious reconsideration of these issues; in particular, autistics need to be regarded as no different from anyone else where these areas are concerned, and simply have their very real challenges addressed in whatever manner is appropriate and effective.

What Are the Real Issues?

The fundamental skills needed to find and form relationships involve, among other things, socialization, nonverbal communications, and an understanding of the other person’s perspective (theory of mind). Autistics are generally deficient, sometimes severely, in any or all of these things. Is it any wonder that they have such well-known difficulties in the area of relationships as they do? Whatever methods are used to help them with these challenges in other aspects of their lives most emphatically need to be applied here as well. These methods can range from therapeutic

techniques, when indicated, to basic counseling and coaching (which can go a long way when done by someone who really understands the challenges).

One major concern here involves the means of finding suitable prospects for potential relationships. Venues that do not require a high level of social ability are especially desirable; these need to be identified and promoted to the ASD community. Also, any activities or groups that involves special interests or abilities, for the many autistics who have such, should be investigated. Many successful relationships where one partner is on the autism spectrum involve another who has some personal eccentricities or peculiarities, comes from a foreign or otherwise different culture, or has had very unusual life experiences (I was actually married to someone considerably older than myself who had spent many years in a convent). In such cases, the differences of the autistic person are often seen as little more than personal peculiarities rather than something objectionable.

Another significant problem is that, regardless of the underdiagnosis of ASD in females and what the true ratio between males and females might be, the numbers of diagnosed or even identified ASD males are much larger than those for females. The result is that socializing within the autism

see *Dating* on [page 26](#)

Providing Menstrual Care Instruction to Adolescents with ASD

By Mary Donahue, PhD, BCBA-D, LBA
and Lisa Barzotto, MS, BCBA, LBA
AHRC New York City

Adolescence is a developmental period that brings challenges to all children and parents. More extensive challenges can be experienced by children with Autism Spectrum Disorder (ASD) and their families. Understanding and coping with the physical, social, and emotional changes of adolescence is difficult for young teens. The socialization, communication, and learning challenges associated with ASD contribute to the greater challenges faced by these teens. Individuals with ASD often take longer to adjust to and understand changes in their lives than typically developing teens. High quality sexuality education is essential in preparing adolescents for the physical and social changes they'll be experiencing. For students with ASD, sexuality education material generally needs to be adapted to effectively provide for acquisition of essential knowledge and skills. Important areas of sexuality education focus include personal boundaries and space, understanding the difference between public and private, prevention of sexual abuse, and personal hygiene skills.


One area that has not received sufficient attention in the literature is skill instruction for menstrual care. The ability to independently manage menstrual care provides women with disabilities greater privacy and more extensive life options. At AHRC New York City schools, a multifaceted approach to menstrual care instruction, addressing both knowledge and skill acquisition, has been found to be most effective.


Social Stories

Knowledge of menstrual care should include an understanding of what menstrual flow will look like, that the flow is normal for girls, that it will happen for five or six days each month, and that special hygiene skills must be performed. We have found the use of Social Stories to be very effective for students unable to understand this information through traditional instruction.


Social Stories is an instructional approach using easily understood information to provide students with ASD an understanding of events, behaviors, and social rules for a wide range of situations. Ballen and Freyer (2017) describe Social Stories as explaining "a situation, concept, or social skill from the perspective and comprehension level of a child with ASD" (p266). Through the use of short text and relevant cues, the expected behaviors for a given situation are provided. Social Stories typically consist of five to ten sentences, utilizing certain sentence types. They generally consist of two to five descriptive sentences related to the situation, one directive sentence explaining appropriate behavioral response to the situation, one perspective sentence depicting the feelings and response of others, and one control sentence depicting how and when one would use the learned strategies and skills. Social Stories effectively answer the relevant "wh" questions for the situation, such as when, where, and why the skill will

My Story About Menstruation

Once, I was a baby. 

Then, I was a little girl. 

Now, I am a big girl and later, I will be a woman. 

Women have a menstrual cycle that comes once a month. Blood comes from your vagina. This is so a grown up woman will be able to have a baby, if she wants. 

The blood flow lasts about 5 days.

You need to wear a sanitary pad inside your panties so that blood does not get on your clothing.



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be needed. In addition to text, pictures are often included in the Social Story to add additional cues or clarification.

Social stories have been demonstrated to be an effective strategy for menstrual care instruction for girls with ASD. Klett & Turan (2012) effectively taught girls to independently complete an 11-step bathroom routine for changing a sanitary pad through the use of Social Stories and an instructional task analysis. They used three Social Stories with the girls, "Growing Up," "My Period," and "How to Take Care of My Period" along with skill instruction using the task analysis.


AHRC NYC schools have used Social Stories to address a variety of issues related to emerging sexuality, including boundaries, privacy, relationships, and menstrual care. Specific to menstrual care, Social Stories have been implemented that address general information about menstruation, and specific behaviors related to changing a menstrual pad and related personal hygiene tasks. Social Stories are individually developed for each learner. In addition to considering the receptive language level and reading ability of the student, it's important to consider any variations in language used by the family for specific terms, such as "period" or "time of month," etc. Consideration also needs to be given to various skill expectations for the home setting, such as where soiled underwear should be placed, or how to dispose of the pad. Based upon the learner's ability, there will need to be variation in the type and extent of visual material included in the Social Story. Incorporating pictures is often helpful in facilitating understanding of concepts and related feelings. When more extensive information is needed, it is often best to write separate Social Stories for different aspects of the situation, rather than making one long story. For example, a separate Social Story might address coping with PMS. Teens with ASD will experience the same symptoms of premenstrual syndrome (PMS) as typically developing teens; however, teens with ASD may find it more difficult to communicate or regulate the emotions that might accompany PMS. A Social Story might describe how she might be feeling (e.g., irritable, trouble concentrating, sore stomach, sleepy, etc.).

A significant advantage of Social Stories

When you go to the toilet, wrap the used pad in toilet paper and put it in the trash. Put a new pad in your underpants.



When you have your period, or menstruate, it is important that you wash between your legs every day. Wash to feel fresh and clean.

Sometimes, when you have your period, you can feel a pain in your tummy. This pain is called cramps. If the cramps hurt, you can ask your Mom for Tylenol or Midol. 

Sometimes, just resting or putting a heating pad on your tummy helps you feel better.



Having your period means you are growing up.

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is that they allow for repeated review of the same information without variation. A copy can be sent home so parents can also review the Social Story, especially in context of personal hygiene care.

ABA-Based Instructional Strategies

Applied Behavior Analysis (ABA) uses evidence-based strategies to systematically teach new behaviors. Task Analysis and Chaining are common ABA instructional approaches. Task Analysis involves break-

ing a task down into sequential component steps that can be targeted for instruction. Chaining involves sequentially teaching these steps through use of prompts and differential reinforcement. Menstrual care skills have been effectively taught using these approaches in a number of studies (Ersoy, Tekin-Iftar, Kircaali-Iftar, 2009 and; Veazey, Valentino, Low, McElory, LeBlanc, 2016).

At AHRC NYC schools, instruction using task analysis and chaining has been provided both using dolls and in vivo training with the student. Instruction using dolls can include a simulation of a soiled pad with food coloring. Task analysis steps include removing and properly disposing of the soiled pad, replacing it with a clean one, and following proper hand washing procedures. Similar strategies can be provided during in vivo training depending upon the support needs of the student. Repeated instruction on specific task analysis steps is provided using modeling, a prompt hierarchy, and response feedback, including error correction or reinforcement. Video modeling can also be considered as a potential option for instruction. Consideration needs to be given as to whether instruction will only take place during menstruation, or also will be provided at other times. Providing more frequent instruction facilitates faster learning, but may cause

see Menstrual Care on page 30



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Presentation of Autism Spectrum Disorder in Females: Diagnostic Complexities and Implications for Clinicians

By Jessica Scher Lisa, PsyD
and Harry Voulgarakis, PhD, BCBA
St. Joseph's College

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by pervasive deficits in social communication and patterns of restricted, repetitive, stereotyped behaviors and interests (American Psychiatric Association, 2013). Beyond the main diagnostic criteria, however, there is considerable heterogeneity in the symptom presentations that is demonstrated by people with ASD, including severity, language, cognitive skills, and related deficits (Evans et al, 2018). Regarding sex differences, it has been well established that ASD is diagnosed more often in males than in females, with recent estimates suggesting a 3:1 ratio (Hull & Mandy, 2017). Despite the fact that this is well known, there is considerable uncertainty about the nature of this sex discrepancy and how it relates to the ASD diagnostic assessment practice (Evans et al, 2018). Additionally, it has been widely accepted that males and females with ASD present differently, which has implications for the sex discrepancy in diagnostic practices, thus females are generally under-identified (Evans et al, 2018).



Jessica Scher Lisa, PsyD

The fact that females with ASD are under-identified and often overlooked can be due to a number of factors. First, they often don't fit the "classic" presentation that is most often associated with the ASD diagnosis; specifically, there is a distinct ASD female phenotype that looks dissimilar to the typical ASD male presentation. Females with ASD tend to present with less



Harry Voulgarakis, PhD, BCBA

restricted interests and repetitive behaviors (RRBs) (Supekar and Menon, 2015), thus standing out less both in society, as well as on screening and diagnostic measures. Fewer RRBs makes ASD appear in a different way, often more subtle, than what is considered to be the norm. It is also important to note that evidence suggests that even when females with ASD are identi-

fied, they receive their diagnosis (and related support) later than equivalent males with ASD (Giarelli et al, 2010). The implications for under- or late-identification are enormous and deserve empirical attention in an effort to improve diagnostic methods for ASD in females.

While no consistent, reliable differences have been found between sex and core ASD symptoms (e.g. Bolte et al, 2011; Holzmann et al, 2007; Mandy et al, 2012), it has been well documented that compared to males, females with ASD that are undiagnosed or are diagnosed at a later age generally present with less severe ASD symptoms and more intact language and cognitive skills (Begeer et al, 2013; Giarelli et al, 2010; Rutherford et al, 2016). Research has also noted that females with ASD may be better able to compensate for symptoms despite having core deficits associated with ASD (Livingston & Happe, 2017; Hull et al, 2017). There has been some suggestion that females must exhibit more severe symptoms, impairment, or co-occurring problems in order to receive diagnoses of ASD (Evans et al, 2018). This finding is due to an analysis of previous research that demonstrates the following: females with ASD perform better on measures of nonverbal communication (which

see Presentation on page 24

Considerations in Diagnostic Assessment of Females for Autism Spectrum Disorder

By Caroline I. Magyar, PhD, BCBA
Magyar Psychological Services, LLC

The literature suggests that autism spectrum disorder (ASD) may go undiagnosed in females who do not have intellectual and/or language impairment (e.g., Mandy et al, 2012). Research on differences in ASD symptom presentation in females versus males is not yet well-developed and findings across studies are equivocal. The Diagnostic and Statistical Manual-5th Edition (DSM-5; American Psychiatric Association (APA), 2013) indicates that females may present with less impairment in social communication skills than their male counterparts (p. 57) and that for some individuals with ASD, impairments that do exist may not become an area of concern for self or others until contextual demands exceed compensatory strategies (e.g., camouflage; see Head, et al, 2014; APA, 2013). Clinical practice indicates that adolescent females may experience an increase in anxiety and/or develop depression in response to an increasing self-awareness that they are "different" than their peers. This can lead parents/self to pursue research on-line about symptoms and to discuss concerns with others. In some cases, this leads to the pursuit of a diagnostic assessment.

Assessing females for ASD should follow best-practice guidelines, the same as is



Caroline I. Magyar, PhD, BCBA

the case for males. Best practice in ASD diagnostic assessment recommends using multiple methods and informants (e.g., Magyar & Pandolfi, 2012; Ozonoff et al., 2005). Practice considerations include:

- **Record Review** (for history of developmental levels: cognition, language, motor (previous testing information; psychiatric history; medical history; context: home, school/work, community))
- **Interview** (with parent: history of de-

velopment, play and social behavior, emotions and behavior (temperament), psychiatric and medical; with teen: self-report of symptoms and experiences)

- **ASD Questionnaires/Rating Scales:** parent completed
- **ASD Questionnaires/Rating Scales:** individual completed
- **Direct Assessment:** Autism Specific Measure (e.g., Autism Diagnostic Observation Schedule-2, Childhood Autism Rating Scale-2)

Data obtained from the assessment should be analyzed for evidence of ASD core impairments using the DSM-5 symptom criteria as a guide. Differential diagnostic practice should be applied for ASD diagnosis with/without co-occurring behavioral health conditions. For females without a developmental history of delays or impairment, particular attention should be paid to:

- the individual's social communication and interaction history (i.e., quality and nature of play, friendships, and co-worker relationships),
- the qualitative nature of speech forms used during interview (i.e., formal language, idiosyncratic),

- age-expected understanding of social relationships and social interactions
- if anxiety and/or depression is present, the areas related to the individual's distress should be analyzed (e.g., social, performance, routines, rituals), and
- age-and-developmental appropriateness of the social communication and reciprocal social interaction during interview and upon direct assessment.

In addition to following the considerations in best-practice diagnostic assessment, there are a couple of other considerations that, if applied, may increase the likelihood of earlier identification of females at risk for ASD. One, increased **awareness** and **knowledge** of the risk factors associated with ASD and the myriad of ways these may present. ASD is a neurodevelopmental condition and early signs may be related to age-inappropriate behavioral reactions such shut-downs/meltdowns, avoidance of social situations (including school refusal); age-inappropriate and excessive/indiscriminate social approaches (e.g., poor peer choice, internet safety issues); developmental factors such as cognitive and language impairment(s); and the onset of behavioral health conditions (e.g., anxiety disorder, depression).

see Assessment on page 23

Addressing the Female-Specific Challenges of Autism at Yes She Can

By Lesli Cattan
Director of Training
Yes She Can Inc.

Empowerment is the theme that is woven into the training model at Yes She Can, Inc. Training young women with autism to be successful employees starts with a shared belief that women with autism can develop powerful voices in their own lives and in supporting the lives of others.

We integrate training around the specific challenges to women; as well as focusing on learning basic employment and business skills while also teaching and supporting emotional regulation skills and building social competencies. Behavioral skills (often referred to as soft skills), generally the most challenging for our trainees, is our focus area. Developing strategies to manage one's own anxiety and behavior, to feel confident in interacting with a boss or co-worker, shifting tasks or responsibilities, and taking someone else's perspective are just a few of the skills we address.

We want our trainees to develop employment readiness skills to be prepared to move onto more challenging and independent settings. Participants gain competencies at their own pace, with direct feedback from both coaches and managers, which builds confidence not only at work but in all aspects of their lives.



Baneesha discussing her blog post ideas with her coach, Laura

Societal expectations of women in general differ from the expectations of men. The most common expectations of women are that of a nurturing, intuitive and socially connected person – yet, these are the most common challenges of both women and men on the spectrum.

Women with autism are often more adept at observing and learning social norms, enough to present as perhaps a bit quirky but able to “pass” as neurotypical. We see the impact of the often-herculean efforts to

“pass” leading to heightened levels of hypervigilance, high levels of anxiety, often retreating into their own world and physical and emotional exhaustion. Feeling confident in their ability to interact with the world is a challenge, particularly when young women are cognitively aware that they have “committed” all sorts of faux pas, even if they don't understand the social rules they have broken.

Some women with autism, who have less ability to observe and learn simple social

norms, are described as cold or blunt. Understanding another's point of view, the concept of theory of mind, challenges both men and women with ASD. Yet, it is more socially acceptable in the work world for men to be blunt and direct. Women with ASD who present as “unfeeling” and more direct are often viewed as inappropriately aggressive.

Training at Yes She Can includes non-judgmental discussions about expected social norms vis a vis interacting with co-workers, bosses, coaches and customers. Discussions not only include the “what” but also the “why” of social norms. Understanding the purpose of the business where the training takes place is a part of these discussions and explains the “why” of business processes, even if trainees disagree with the process. Whenever possible, social rules are spelled out and practiced. Comparing one situation to another similar situation is necessary since generalized learning is so challenging.

Trainees at the Yes She Can program are frequently apologizing for the things that they say, or behavior they are unsure of or for missing cues. We encourage and support making mistakes: trying out or practicing new skills means making mistakes without apology and leads to more integrated learning and confidence.

Building confidence also comes from experiencing the expectation of success.

see Yes She Can on page 32

Programming from page 4

summer programs. Often their web sites will list a description of their offerings. Comprehensive listings of these programs are often hard to find. Thinkcollege.net is an excellent starting point in identifying colleges that support people with disabilities including in college-based transition programs. George Washington University's Heath Resource at the National Youth Transitions Center is a clearinghouse on postsecondary education for individuals with disabilities (www.heath.gwu.edu). Lesley University Threshold Program published an e-Book entitled *Comprehensive Guide to Transition Programs* (<https://www.lesley.edu/six-qualities>)” (VanBergeijk, 2020; p.34).

Post-secondary transition summer programs are geared toward helping individuals with disabilities acquire pre-employment, independent living and social skills. They are also designed ease the transition into the institution. Participating in a summer program is a great litmus test both for the student and the program. Usually the summer curriculum is a sample of the more extensive curriculum offered during the academic year. By participating in a summer program at the same university, the adjustment to academic year program is smoother. Frequently students live in the same residence halls in the summer as they do during the academic year. They also use the same dining halls, sports facilities, libraries, etc. They become familiar with not only the facilities and staff, but the other students in the program as well. This helps reduce the anxiety of the selection of

roommates for the fall semester.

Ernst VanBergeijk, PhD, MSW is a professor at Lesley University in Cambridge, MA and is the Director of the Threshold Program (www.lesley.edu/threshold) which is a post-secondary transition program for students with a variety of disabilities. He also oversees the Lesley University Threshold Alumni Center which provides life-long support for graduates of the Threshold Program. Beginning Summer 2020 the Threshold Program will be offering a 6-week summer program focusing upon the acquisition of preemployment, independent living and social skills.

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Individual with Autism Succeeds from Classroom to Career

By Susan Bardack, Buzz Media
and Jennifer Lawrence, NYSID

When you ask those who know Christopher Payne about his work performance, comments like “incredibly hard worker,” “enthusiastic” and “positive” resonate. Chris landed a staff position at NYSID (New York State Industries for the Disabled, Inc.) as a commodities administration specialist assistant where he supports the business operations and communications departments. Although Chris has autism, he works through challenges that are presented to him and completely embraces employment.

“I enjoy everything about my job. I enjoy the people that I work with, as well as the work that I am doing every day. I like NYSID so much because I am doing many different tasks. I do not even consider this amazing job ‘work’ because I enjoy it so much,” said Chris.

NYSID president and CEO Maureen O’Brien said Chris is a fantastic addition to the team and work culture. “I can’t even begin to tell you how often Chris has thanked us for hiring him, and even better than that, he expresses gratitude that we provide him with lots of work. He is doing a great job and is a pleasure to be around. He is all about ability and making important things happen. At NYSID we work hard to create



Chris Payne enjoys working in his first career job at NYSID, where his keen attention to detail is appreciated.

meaningful opportunities for people with disabilities in the area of employment. More than 60 percent of New Yorkers with disabilities are not working, and we strive each and every day to connect more people to rewarding careers,” she said.

Unemployment statistics are even high-

er for those on the autism spectrum: 70-90 percent of autistic adults are un- or under-employed.

NYSID is a non-profit membership organization with a mission of “advancing employment and other opportunities for individuals with disabilities.” Through its

statewide network of 160 non-profit rehabilitative agencies and private sector business partners, NYSID helps put the state’s Preferred Source Program into action. A recent Rockefeller Institute of Government report highlights the impact NYSID makes on New York State’s economy: the economic output for every individual hour worked on a NYSID contract is \$86.00, adding \$368.9 million to the state’s economy.

Following graduation from Hoosic Valley High School in Schaghticoke, Chris attended Hudson Valley Community College in Troy where he earned an A.A.S. in business administration, and then went on to achieve a B.A. in journalism at University at Albany, graduating with honors. He discovered his love for writing while working on the student newspapers, *The Hudsonian* and *Albany Student Press*. During his U Albany education, Chris was accepted for an internship at the New York State Writers Institute where he worked with Paul Grondahl (director) and Michael Huber (communications specialist). Huber also taught him in a journalism class.

“Chris Payne was one of the best University at Albany student interns we have had at the Writers Institute in my time here because Chris is a hard worker, he has a wonderfully positive attitude, and he is enthusiastic and dependable. Chris brought a keen intelligence, along with useful analytical

see Career on page 28

Giving Girls a Chance: Educating Females with Autism

By Caitlin Sweetapple, MS
Director of Education
Shrub Oak International School

While autism spectrum disorder (ASD) is more prominent in males, females are also diagnosed at much lower rates (Autism Speaks, 2019). Females diagnosed with ASD require similar services in addition to diverse gender specific supports from their special education teachers and related service providers throughout their school-aged years. This underrepresentation in females with autism is heightened due to diagnostic criteria is catered towards boys (Dworzynski, Bolton & Happé 2012), girls use of linguistic camouflage by mirroring others around them (Parish-Morris et al., 2017), and stronger social skills in girls versus boys with autism (Cridland, Jones, Caputi, & Magee, 2014). Special education teachers need to understand these characteristics and issues with diagnosis so they can alter their practices accordingly to meet females with ASD unique needs.

Compared to males, females on the autism spectrum experience more sensory sensitivities and fewer stereotyped behaviors (Bargiela, 2019). Females are also more aware of their autistic traits, have different special interests compared to males and exhibit fewer socio-communi-



Caitlin Sweetapple, MS

cation difficulties (Bargiela, 2019). Other characteristics that are more often present in females than in males include greater awareness of social interaction, tendency to be controlling, eating problems and better linguistic abilities (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Females’ restricted interests tend to involve people and animals rather than objects and things (Lai et al., 2015). A study completed by Bejerot and Eriksson (2014) found that “tomboyism” and bisexuality

are overrepresented in females with autism versus boys with autism and neuro-typical girls. Special education teachers need to be aware of these gender differences in order to inform their practice for girls on the spectrum.

Cognition in males and females with autism can vary, as females can present with milder interactive behaviors but more autistic traits in adulthood and sensory issues (Lai et al., 2011). Lai and colleagues (2011) also suggested that high-functioning adults with ASD present differently behaviorally based on gender. These characteristics highlight the need for differentiation of instruction of girls with autism in special education services.

One theory regarding sex-differences in females with ASD is the “extreme male brain theory” (Baron-Cohen, 2002, p. 248) which states that the male brain excels at systemizing and the female brain excels at empathizing. Baron-Cohen (2002) argued “autism can be considered as an extreme of the normal male profile” (p. 248) suggesting that females with autism have characteristics of a male brain. Lai et al. (2011) confirmed the existence of the extreme male brain theory. More recently, Ridley (2019) argued that we cannot identify a “male brain.” “A female with autism therefore does not resemble a neurotypical man, she resembles an autistic man. That’s because she has autism, not because she has a ‘male brain,’ ‘extreme’ or ‘otherwise’”

(p. 23). Gina Rippon (2018) agreed with Ridley (2019) in her article stating, “If we could only focus on what brains can do and how they do it rather than the sex of their owners we might have better insights into the links between brains and ability.” If we look at the “extreme male brain theory” through a feminist disability lens, we can alter our assumptions that there is a “male brain” or “female brain” and simply try to understand each individual with ASD as who they are, rather than the make-up of their brain.

Research has shown that teachers may not notice difficulties experienced by girls with ASD in school (Mandy et al. 2012). Stewart (2012) reported that girls with autism experience discrimination in mainstream schools that is not addressed by teachers. Girls with ASD struggle with peer acceptance and benefit from anti-stigma programs in schools (Ranson & Byrne, 2014). School is especially difficult as a female with ASD gets older when social demands become more difficult to understand, social relationships are more prevalent and being around a larger group of people for an extended period of time becomes mandatory (Hendrickx, 2015). Teachers can help with this transition in general but should also recognize that each girl and young woman with autism need individualized support.

see Educating on page 32

Addressing the Psychological Fallout of The Coronavirus Pandemic

By Michael B. Friedman, LMSW
Mental Health Policy Advocate

The coronavirus pandemic in the United States has led to great efforts to prevent the spread of the virus and to prevent fatalities. But the problems that people will face due to the pandemic will go beyond medical issues. In addition, it will be important to address a variety of psychosocial issues. Of particular concern are (1) covering the cost of testing and treatment for all people in the United States for whom testing is medically advisable including people with no health coverage, (2) dealing with the impact of disruptions such as school closures, layoffs, lost income, lack of in-home services, loss of access to social and behavioral health services, difficulty getting food, loss of family caregiving, etc., and (3) dealing with the psychological fallout for those who get the disease, their families, and their caregivers.

This article highlights the behavioral health challenges that will need to be met.

Although it is unlikely that many people will develop new mental or substance use disorders as a result of their experience during the pandemic, some will, and it is likely that many will experience exacerbations of PTSD, anxiety disorders, depression, and psychosis. In addition, many people will experience emotional challenges due to stress,



isolation, confrontation with mortality, and grief. This is of particular concern for the courageous people who will work directly with people who contract COVID-19.

In general, it is important to develop plans for diverse populations including varying social-economic status groups, ethnic and racial groups, household composition, ages, and lifestyles.

Psychological Fallout of a Pandemic

Below is an outline of psychological issues that need to be addressed. It is not

intended to be comprehensive or detailed or to provide specific solutions. That has to happen through planning processes that hopefully will soon address the psychological fallout of the pandemic. The purpose of this document is simply to note areas to be addressed.

Prevalence of Behavioral Health Conditions: Although most people living through a pandemic or natural disaster generally will not develop new diagnosable mental or substance use disorders, some will. Many will experience exacerbations of PTSD, anxiety disorders, depression, psy-

chosis, or substance abuse. And the risk of relapse—especially for people in recovery from addiction—is significant for people experiencing great stress and/or cut off from their usual sources of help.

In addition, a great many people will experience less severe, but very troubling emotional issues. The stress of major disruptions in life and of responsibility for the survival of family and friends can be very difficult to manage. Loss of income can be deeply troubling. Isolation due to quarantine or the loss of in-home supports for people with disabilities can have significant psychological consequences. For some people, confronting mortality may also stir up troubling emotions. And the deaths of people one cares about will undoubtedly result in grief.

Costs of Behavioral Health Care

Although most people in the U.S. have health coverage, behavioral health services are rarely fully covered, and co-pays may be prohibitive. It is essential to cover the full costs of behavioral health services for those suffering from the psychological consequences of the pandemic. This includes eliminating cost sharing in all forms of insurance—Medicare, Medicaid, employer-based health insurance, etc. And it includes covering costs for the millions

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strategic implementation of The Daniel Jordan Fiddle Foundation Adult Autism Endowed Funds. Located in the nation's elite universities, The Daniel Jordan Fiddle Foundation five Adult Autism Endowed Funds each focus on a specific area of adult Autism. [The partnership with Yale Medical School](#), for instance, is the first Fund in the nation dedicated exclusively to support research projects relating to adults living with Autism Spectrum Disorders (ASDs). Helping those with ASD express themselves artistically, [Brown University's Theatre Arts and Performance Studies \(TAPS\)](#) nurtures both undergraduate and graduate collaboration with the Autism community, fighting stigma and revealing the nuances of neurodiverse living. The [Rutgers School of Social Work](#) sends three to four Fellows to work as direct clinicians with family members of autistic adults and develop a web-based resource guide for families to use nationwide. At the [University of Miami through The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the Center for Autism and Related Disabilities](#), model programs focus on job training and attainment, workplace support and social skills development. Yet these efforts would be naught without extensive public policy advocacy in all levels of government. Thanks to [our gift of \\$100,000, fellows at the Watts College of Public Services and Community Solutions at Arizona State](#) can develop a comprehensive policy agenda serving the needs of adults with ASD and their loved ones

through [The Daniel Jordan Fiddle Foundation Center for Public Policy](#) located at [First Place](#) in Phoenix, Arizona.

"We blaze trails that aim to inspire the world to embrace the fact that Autism is a lifelong challenge, that neurodiversity is valued as a matter of human rights, and that the public and private sectors have an obligation to create the supports and services necessary for all individuals diagnosed with Autism Spectrum Disorders to live their best life possible," said Linda Walder. The opportunity to present this vision not only opened doors to a whole new world but successfully inspired the international and Chinese-based audience to view Autism as a lifelong journey with promising destinations as diverse as those who have been diagnosed. The Daniel Jordan Fiddle Foundation's person-centered initiatives and programs have already helped countless adults with ASD lead fulfilling lives, and assuredly will for generations to come around the world.

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Gender Gap from page 1

challenging when looking at females with ASD, given their underrepresentation in literature and the poor understanding of their unique and distinct needs. Hellemans et al. (2007) identified that studies investigating the experiences of individuals with ASD have largely focused on males. Many researchers and clinicians are recognizing the need for more nuanced and individualized assessment of females with ASD, so that diagnosis can be more precise and treatment can be more tailored.

Mademtzi et al. (2018) explored the unique educational and therapeutic needs of girls and young women with ASD. Through parent focus groups, Mademtzi et al. (2018) identified that while females with ASD often experience challenges similar to those of males with ASD, there are additional challenges specific to being a female with autism. These challenges include navigating their desire to build friendships with neurotypical female peers, understanding how to maintain such friendships with others, fearing exploitation in a romantic relationship, experiencing barriers to the accessibility of services due to later diagnosis, and female-specific puberty issues. These outcomes are consistent with previous conclusions (Cridland et al. 2014) in relation to challenges for females with ASD.

Cridland et al. (2014) investigated the



Jennie Labowitz, MS, NCSP, BCBA

experience of adolescent girls with ASD through semi-structured interviews. Based on the findings, the researchers made a number of recommendations for practitioners. Clinicians need to increase their awareness regarding how ASD may present in a female as compared to males with ASD, in order to likely facilitate earlier access to services (Attwood, 2012). Additionally, interventions should target development and maintenance of peer relationships. Clinicians can support females with ASD by addressing social skills and communication, to prevent social isolation that may often ensue (Muller et al,



Maggie Haag, MEd, BCBA, LSW

2008). Furthermore, participation in gender specific groups may be helpful given the unique challenges faced by females with ASD (Nichols et al. 2009). Increased opportunity for female peer relationships can be structured through female-specific social groups.

There is a large body of evidence for the use of applied behavior analysis (ABA) as the most effective treatment for ASD. This is true regardless of gender, however there are many interventions implementing the principles of ABA that practitioners can use depending on the presenting issue. Paying careful attention to the specific issues that may impact females with ASD, and choosing interventions that will best suit these issues when working with females with ASD, is important as we move forward as a field. Additionally, better understanding how ASD impacts males and females differently may help professionals best support individuals with ASD as they go through the complexities of maturation.

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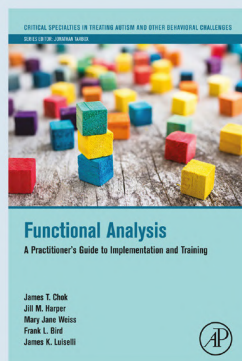
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Considerations for Social Awareness as a Critical Domain in Autism Intervention

By Alan Schnee, PhD, BCBA-D
Nexus Autism Intervention Services

When I first meet parents whose young child was newly diagnosed with ASD, most suffer in saying the same thing: “It is very difficult to engage my child,” “I can’t get my child to pay attention to me.” And, if parents are able to “connect,” the connection is often fleeting.

While the literature is replete with considerations for developing social skills (Gates, Kang, & Lerner, 2017), little attention is given to the formation of social awareness. Social awareness as a critical domain in early intervention for children with autism is concerned with establishing the relevance of others so that children regard their comings and goings, doings, gestures, attention (gaze, point), location, mistakes, and perspective. There are a variety of platforms and strategies that can be employed to fortify social awareness so that children act and learn in relation to US; to enhance learning as a function of increased engagement. In this article, a few illustrative examples and strategies will be offered.

A Basic Strategy:

Avoiding the “Explicit Reference Trap”

Much of early intensive behavioral intervention (EIBI) is directed toward



establishing language abilities (Leaf & McEachin, 1999; Lovaas OI. 1987, Taylor & McDonough, 1996) with an emphasis on teaching children to use and respond to specific linguistic referents (e.g., “Get the red ball”, “Put the car under the table”). While this is essential, it overlooks the need to have children also learn to use and respond to non-specific linguistic referents.

When intervention routinely incorporates and intersperses non-specific referents, as it should since this is a fundamental

aspect of our linguistic practice, children are forced to consider the person speaking and not just their words.

Exercises that utilize Selection-Based Imitation (SBI) (Lund, 2004, Lund and Schnee, 2018) leverage the use of deictic terms in order to fortify social awareness. SBI can also be used to strengthen other language abilities, memory, executive function and shared and shifting attention. Below is one example of how it may be used.

Fortifying Social Awareness: Shifting Between Instruction Modalities

(this is a modified version of an exercise found in Lund and Schnee, 2018)

Setup: Pictures are placed on a wall(s). Matching pictures are placed on the child’s desk and corresponding items are distributed around the room. Child is seated at the desk; instructor is standing by the wall.

Procedure 1: Point to a picture on a wall. Present random instructions:

- “What’s this?” (Pointing to picture on the wall)
- “Touch same” (Pointing to picture on the wall child touches matching item on their desk)
- “Touch this and this” (Point to two pictures on the wall consecutively, child touches matching items on their desk)
- “Bring me this” (Point to picture on the wall, child retrieves it)
- “Bring me the (ball)” (No point)
- “What color is the car” (Pointing to car on wall)

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Assessment from page 16

The presence of one or more of these factors may moderate and/or overshadow the individual’s primary set of symptoms (i.e., ASD) and result in a delay in diagnosing ASD. Therefore, **increasing awareness** and **knowledge** of risk factors and how symptoms present is critical.

A second consideration is for those professionals on the “front lines” (i.e., pediatricians, school personnel, counselors). These professionals should consider adopting **screening practices** that can increase earlier identification. This can include the use of one or more methods of assessment such as record review, interview, and the administration of a valid and reliable rating scale. These considerations can be applied to any condition that warrants early (or earlier) identification such as behavioral health conditions in youth with ASD (e.g., Magyar & Pandolfi, 2009).

Dr. Magyar, a NYS Licensed Psychologist & NYS Board Certified Behavior Analyst in Rochester, NY, provides diagnostic assessment and treatment services to adolescents and adults with autism spectrum disorder (ASD). She focuses much of her practice on the assessment and treatment of females with ASD. Visit her website for information on her services and for contact information: www.magyarpsychservices.com.

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may mask other symptoms), females with ASD face more social, friendship, and language demands than males with ASD, and that females with ASD can exhibit patterns of restricted interests and repetitive behaviors, as well as social and communicative problems that are deemed more socially acceptable as compared to the patterns seen in males with ASD (Lai et al, 2015; Rynkiewicz et al, 2016; Dean et al, 2014). This theory also accounts for the findings that females with ASD in general present with more severe behavioral, emotional, and cognitive problems compared to males (Frazier, et al, 2014; Holtmann et al, 2007; Horiuchi et al, 2014; Stacy et al, 2014). Further, Hiller and colleagues (2014) found that females were more likely to show an ability to integrate non-verbal and verbal behaviors, and initiate friendships, and exhibited less restricted interests. Teachers reported fewer concerns for females with ASD than for males, including concerns about behaviors and social skills. These data support the idea that that females with ASD may “look” different from the considerable “classic” presentation of ASD and may also present as less impaired in an academic setting.

The vast differences associated with gender presentation in ASD require that clinicians involved in diagnostic work become more cognizant of these broader phenotypes and adjust their assessment practices accordingly to better detect females presenting with atypical symptoms that still fall on the autism spectrum. Notably, many common diagnostic tools lack sensitivity to such a presentation. To that end, it is important to recognize that generally speaking, the evidence base, and hence the diagnostic criteria for ASD in itself comes from research among male-predominant samples (e.g. Edwards et al, 2012; Watkins et al, 2014). Therefore, while the efforts to study this area further are prominent, it is important to be mindful of the fact that existing assessment tools and diagnostic criteria likely contain sex/gender bias (Evans et al, 2018). Without addressing the neurological and diagnostic challenges pertaining to these sex/gender issues, any research in this area will be influenced by the underlying problem of not knowing how ASD should be defined and diagnosed in males as compared to females (Lai et al, 2015).

Currently, the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) is arguably the most commonly relied upon diagnostic instrument for ASD. The ADOS-2 is a semi-structured observational assessment designed to evaluate aspects of communication, social interaction, and stereotyped behaviors and restricted interests (Lord et al, 2000; 2012). In contrast to what has been documented with regard to the strong differences in the prevalence of ASD, differences between the sexes in the phenotypic presentation of ASD have been found to be much smaller in size, with inconsistencies in the findings with regard to severity level of the core symptoms, as well as age and general level of functioning. For example, some studies have found no significant differences between sexes with regard to the behavioral presentation of ASD on the ADOS (e.g. Lord et al., 2000; Lord et al., 2012; Ratto et al, 2017), while others have reported some differences (e.g. Lai et al., 2015).

In order to examine these inconclusive findings further, Tillman et al (2018)

looked at data containing 2684 individuals with ASD from over 100 different sites across 37 countries. Children and adults were administered one of four ADOS modules (modules are determined by expressive language level). The Autism Diagnostic Interview, Revised (ADI-R) was also administered as well as a general intellectual ability instrument, such as the Wechsler Intelligence Scale for Children, or a different measure depending on age and verbal capabilities. Effects of sex were determined after excluding non-verbal IQ as a predictor. No main effect of sex was found for ADOS symptom severity, or on the specific ADOS subscales. Females showed lower scores on the RRB scale with increasing age. This result is similar to previous meta-analytic research on small-scale studies as well as large-scale studies (Van Wijngaarden-Cremers et al, 2014; Mandy et al, 2012; Supekar & Menon, 2015; Wilson et al, 2016; Charman et al., 2017). The researchers concluded that this adds to the current body of literature that supports the notion that females with ASD show lower levels of RRBs than males, but exhibit a more similar autistic phenotype to boys in relation to social communication deficits across ages (Tillman et al, 2018). Thus, it is possible to surmise that females with ASD are being under-identified as a result of exhibiting fewer RRBs. Notably, research has found that clinicians are hesitant to diagnose ASD without the presence of RRB (Mandy et al, 2012), as the diagnosis of ASD in the DSM-5 requires at least two types of RRBs. Lai et al. (2015) made the case that females with ASD may simply be exhibiting different RRBs rather than fewer, and it is possible that these less common forms of RRBs are being missed during diagnostic assessments.

Understanding the phenotypic differences in the presentation of autism is critical for diagnosticians for several reasons. It is crucial to understand that aspects of the diagnostic criteria for ASD may present on other ways in females though not be elevated on standard measure scales. As a result, those who do not receive an appropriate diagnosis will subsequently not receive an appropriate intervention. Beyond the obvious concern associated with females on the autism spectrum not receiving intervention associated with their autism symptomatology, there are a range of other mental health concerns that may dually go unaddressed. Higher functioning adolescents with ASD, which is often the presentation consistent with females that get “missed” in the diagnostic process, are at greater risk for developing depression (Greenlee et al, 2016) and anxiety (Steensel, Bogels, & Dirksen, 2012). Adults with high-functioning ASD are also at increased risk for suicidality (Hedley et al, 2017). More recent, emerging research suggests that while those with ASD may be able to mask their symptoms the majority of the day and thus not reach the diagnostic threshold in scandalized measures, doing so causes them significant distress and puts them at increased risks for such co-occurring mental health concerns.

The under-diagnosis of ASD in females with ASD lends itself to a population of women who end up wondering “what is wrong” with them.) Females who do not have the opportunity to understand themselves in the context of neurodiversity tend to waste time and efforts on imitating and trying to fit-in (Bargiela et al, 2016). They are at far greater risk of bullying, as well as being taken advantage of socially,

with subtle difficulties in perceiving and responding appropriately to social cues rendering them inept in certain situations that require a degree of social assimilation. These females have missed out on the benefits of early intervention, most often in the social realm, and can be plagued with identity issues later in life as they try to play catch-up in light of a new diagnosis. The timely identification of ASD can mitigate some of these risks and problems by improving the quality of life, increasing access to services, reducing self-criticism, and helping to foster a positive sense of identity. As such, diagnostic experts have a responsibility to continue to stay abreast of research developing in this area and adjusting their assessment practices accordingly.

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Medicaid Managed Care Is Essential for Persons With Intellectual and Developmental Disabilities

By Arthur Y. Webb
Executive Director
New York Integrated Network for
Persons with Intellectual and
Developmental Disabilities (NYIN)

In New York State, persons with intellectual and developmental disabilities are one of the last groups of Medicaid recipients to be included in the State's coverage under Medicaid managed care. Close to 5.8 million of the 6.2 million Medicaid recipients are enrolled in Medicaid managed care. For the I/DD field, New York spends over \$8.0 billion for approximately 125,000 persons. Over 90% of the spend level is for long-term services and supports mostly covered by a home and community-based waiver.

At the outset of this article, it is important to state that the field of I/DD is facing a severe fiscal crisis of its own. The field has not had a cost-of-living adjustment for nine years.

Since 2012, New York State has been developing an appropriate plan for Medicaid managed care (MMC) for the I/DD field. Delays have occurred because of concerns of advocates, providers, and families. State officials have concerns about the cost of starting-up MMC for the field of I/DD and the actuarial analysis that did not show any



Arthur Y. Webb

savings from MMC.

However, the State Office for Persons with Developmental Disabilities (OPWDD) has recently released a new draft of a revised plan. Over the past two years, OPWDD has been focused on two distinct areas: (1) improvement in care management processes using a home health model—as a first step towards managed care; and (2) creation of a policy framework for

the implementation of provider-led managed care.

A new draft version of the New York State Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards to Serve Individuals with Intellectual and/or Developmental Disabilities in Specialized I/DD Plans – Provider Led (SIPs-PL), which is referred to as the Qualification Document, was released for stakeholder review and comment.

In July 2018, DOH and OPWDD launched an enhanced care management program to support individuals with developmental disabilities and their families. This program consolidated more than 350 agencies providing Medicaid Service Coordination into seven regional provider-controlled Care Coordination Organizations (CCOs) providing Health Home Care Management under the federal program. At the same time, these CCOs expanded the role of new care managers, moving from OPWDD service-centric Individualized Support Plans (ISPs) to integrated and coordinated health and habilitative services through an expanded Life Plan. Approximately 100,000 individuals transitioned to this new model.

I want to address why Medicaid managed care is essential for persons with I/DD. MMC works for the field of I/DD because:

- It moves from a fee-for-service fragmented services world to a comprehensive plan and integrated funding model.
- It integrates the long-term services and supports (LTSS) with medical, behavioral and access to the full range of Medicaid benefits.
- It promotes the use of experienced providers of I/DD services to manage a comprehensive plan.
- It builds in service and resource flexibility through the use of a Life Plan that is not constrained by the current siloed service limitations.
- It brings the field of I/DD into the broader health reform agenda of the state and the marketplace.
- It puts pressure on the field to develop and measure the success in quality of care and general well-being of persons with I/DD through the use of value-based payment models.

I understand the reality of how hard it is to build Medicaid managed care for special populations having been directly involved

see *Managed Care* on [page 30](#)

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Coronavirus from [page 8](#)

- Identification and important documents (insurance, birth and marriage certificates, and special-needs forms)
- A few changes of clothes
- iPad or phone with charger to smooth or comfort along with headphones
- Ear plugs, headphones or eye shades
- An ID bracelet and autism information cards to explain behaviors to others.
- Collect non-perishable foods that meet any dietary needs or restrictions (if that is not allowed in quarantine areas, create list to provide to medical staff)

- Bring all medications for child or adult with autism to ensure consistent dosing
- Use Hurricane/Blizzard preparedness protocols and checklist as additional resources

In Case of a quarantine or medical emergency, keep the following in mind:

- Keep routines as close as possible to a "typical day."
- Using a word, picture, or picture-word schedule, make substitutions where necessary. If school is closed, replicate the schedule as close as possible with academics or homework practice and other school activities such as snack, story time, lunch, etc. where possible.

- Explain to the child in a factual, positive way why these changes have occurred and that it's important to stay safe and healthy
- Like all of us, your child will want to know when they can resume the lifestyle they were used to. If you know, then count off the days until that happens on a calendar.
- Similarly, it will be important to explain to a child why a parent or other family member is quarantined away from home should that happen. As your elected representative, I am fully supporting additional staffing and equipment for the New York State Department of Health to prepare for a coronavirus response here in New York State. The Depart-

ment of Health is also working with our local health departments and hospitals to review protocols and procedures and help ensure they're prepared.

Please note: Every case may be different. Please check with our local or state health officials for more specific protocols including any special assistance needed during an emergency. Should you have questions call the dedicated hotline at 1-888-364-3065, also check this dedicated website for updates and resources at <https://www.health.ny.gov/diseases/communicable/coronavirus/> For assistance, call me at (518) 382-2941, send me an email at santabarbara@nyassembly.gov or visit <https://nyassembly.gov/mem/Angelo-Santabarbara/> at any time. Also keep your eye on up-to-date information provided by the [CDC](#).

Dating from page 14

community often becomes impractical for many, at least where finding prospective relationships is concerned. This is evidenced by the general lack of success of most Aspie online dating sites and services. Consequently, neurodiverse relationships need to be encouraged and facilitated as much as possible.

One other issue that is particular to many autistics is the tendency to fixate on one person as a romantic interest. Not only have I experienced this in my own life, but will never forget the time when, at an autism conference, I actually overheard someone telling the story of a young autistic person who had done exactly the same thing that I had done in my own youth so many years earlier! I since heard similar stories at various other autism community events and gatherings. This problem is further compounded by the inability of autistics to discern, let alone understand, the other person's real intentions. All of this can result in embarrassing and painful situations, and even lead to accusations of stalking (which can have serious legal consequences). Those working with autistics trying to find relationships need to be aware of this issue and able to recognize when it is happening; prompt intervention should then take place accordingly.

Finally, on a personal note, I have both

experienced and observed the common situation of being drawn to someone who, for whatever reason, is not entirely appropriate or compatible, while being oblivious to others who might have far greater relationship potential. While this can certainly happen to anyone, autistics, who often do not properly appreciate the other person or understand the situation, are far more likely to be susceptible to this. They need to be made aware of such.

Potential Hazards

Along with the basic issues, there are a number of hazards that can affect anybody, but to which autistics are especially susceptible; as such, they need to be made aware of these and how to spot them, so that they are better able to recognize and avoid them. As is so often the case, they involve various forms of deception. Exploitation of many kinds is tragically very common and can range from financial to sexual to otherwise having the person do things not in their best interest (performing uncompensated labor or engaging in illegal activities). Autistics, who so often are looking for friendships and especially romantic partners are often targeted in this manner because they desperately want to believe these deceptions and are somewhat if not entirely oblivious to their dangers.

There are also numerous schemes which may not have as severe consequences but

are nevertheless embarrassing and painful for those who fall prey to them; once again, autistics are far more likely to be victims of such. These usually involve people pretending to be interested in the victim for reasons ranging from simply "playing games" (as happened to me at various times since adolescence) to deliberate attempts to embarrass and humiliate the victim. Once again, autistics are often unable to see what is happening, let alone understand why this is being done to them.

Another danger frequently reported by news media is that of online scams involving "relationships" in which the victim has never even met the perpetrator, who pretends to be romantically interested and gains their confidence to the point where they comply to requests for substantial amounts of money. This has happened on numerous occasions, often to people who are intelligent, highly educated, and nowhere on the autism spectrum. There have even been instances of more sophisticated deceptions where this was actually done in person by con artists. It is truly frightening to think of how vulnerable an autistic person, who is longing for it to be true and unable to see the deception, might be to such a scam.

The emergence of online dating poses a variety of questions for the autism community. Having made use of it a few times in my life, I had occasion to give this some thought. As a young engineering student

in the 1970's and a strong believer in the potential of modern technology, I was very impressed by the advent of "computer dating" as it was then known and quickly seized on an opportunity to participate. It certainly did not live up to its promise – the results were greatly disappointing. The very idea that any technology can identify suitable partners for people is nothing less than absurd. More recently, though, people became accustomed to communicating and even meeting online and, as such, many now do so. Still, online dating is nothing more than a venue for people to meet, and not a substitute for deficits in skills otherwise required to form and maintain relationships. Autistics need to be made aware of this.

What Needs to be Done?

Those of us on the autism spectrum, like everyone else, have a need for romantic companionship, yet are challenged by precisely those things that are required in the pursuit of such. Those who work with the autism community need to appreciate this situation and understand our challenges as best as they possibly can. Above all, the importance of this issue to so many in our community needs to be more widely recognized and actively addressed.

Karl may be contacted at kwittig@earthlink.net.

Awareness from page 23

- "What color is this?" (Pointing to item on wall)

Procedure 2: Same set-up as in procedure 1 except pictures are now placed on two different walls and items are also placed inside and outside of the room.

The exercise above includes layered demands on attention (to task and to others), working visual memory, executive function and serves to fortify social awareness. Children are required to attend to the instructor; to that which the instructor attends and to is required to track the instructor as they move about the room. By mixing instructions, children learn to switch flexibly between different kinds of instructions.

Fortifying Social Awareness: Using Ambiguous Point

The use of deictic terms can be used also to intentionally confound children in order to ensure that they learn to 'check back'... to 'check in' with us in order to obtain more information. This can be achieved with the use of an 'ambiguous point' as illustrated in the example below:

Setup: Place several of the same items (e.g. two-three cars) very close to each other, a few feet away from the child. Stand next to the child.

Procedure: Point toward the array of cars and say, "Bring me that car." At first the child will likely select one of the cars. When they do, say something like, "No." We say this in order that the child will stop what they are doing and turn back to us in order get more information. This exercise requires that children learn to 'check back' with us in order to select the item that 'we

have in mind.' Linguistic targets which 'fall out' under these circumstances might include teaching children to learn to ask, "Which one?" when confronted with such ambiguity.

Fortifying Social Awareness: Using Sequential Matching

(this is a modified version of an exercise found in Lund and Schnee, 2018)

Once a child has learned to match, we can leverage this basic ability to foster social awareness using sequential matching.

Set up: An assortment of items is placed within arms reached of the child. These items correspond to an array of pictures on the table in front of the child.

Procedure: The child is instructed to match the items with the corresponding pictures. The instructor "sabotages" the child's ability to complete the task by removing some of the items. This forces the child to ask the adult for the matching item. (We do not use this exercise to introduce 'requesting,' only to bring other abilities into further use.) Thus, once the child asks for the needed item, additional abilities are 'folded in.'

Therefore, when a child asks for the item, we can direct the child to get it by pointing to its location:

- "It's over there."
- "It's under that table."

Or we can direct them to other persons:

- "Alan has it."
- "Mommy has it."
- "She has it."

Thus, we can see how various social dimensions are packed into a simple matching exercise so that children are required to refer to our point or to seek other persons out.

Fortifying Social Awareness: Spatial Considerations

Common EIBI programs such as "bring me" or "give to" can be employed to fortify social awareness and social pragmatics. For example, to fortify the relevance of others in a simple 'bring me' exercise, we can move from the location from which the instruction was given. This can be exaggerated so that children are forced to find us, if we conceal our location (partially or completely; concealed behind a wall or piece of furniture or even if we leave the room). Also, if you refer back to the first exercise, "Shifting instruction modalities," the purpose of placing items on two walls in Procedure 2 is so that children are forced to track our movements stressing social awareness.

Summary

A variety of strategies and platforms can be employed to establish and fortify the relevance of others in the lives of children with autism and should be considered a critical domain for intervention. Common exercises can be used as vehicles in this effort. This article touched on only a few things to consider, but much more can be done to effectively foster social awareness in children with ASD.

Alan Schnee, PhD, BCBA-D, has been treating children with autism for almost 30 years and is co-author of *Early Intervention for Children with ASD: Considerations*. For questions or comments, contact Dr. Schnee at as@nexusais.com. For more

information go to www.nexusais.com.

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AUTISM SPECTRUM NEWS DESK

Largest-Ever Genetic Study of Autism Yields New Insights

By Dr. Francis Collins
The National Institutes of Health (NIH)

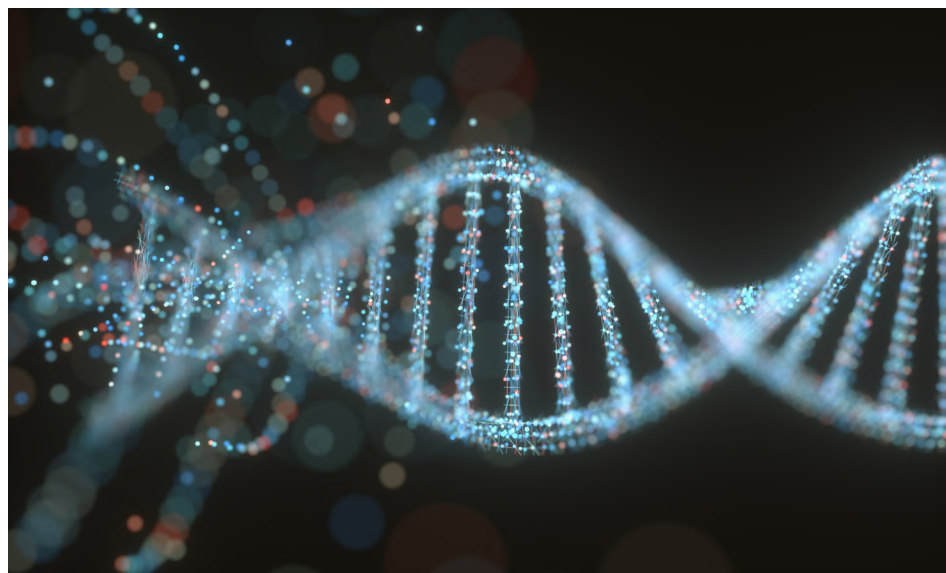
Anyone who's spent time with people affected by autism spectrum disorder (ASD) can tell you that it's a very complex puzzle. The wide variability seen among individuals with this group of developmental brain disorders, which can disrupt communication, behavior control, and social skills, has also posed a huge challenge for researchers trying to identify underlying genetic and environmental factors. So, it's no surprise that there's been considerable interest in the recent findings of the largest-ever genetic study of ASD.

In a landmark study that analyzed the DNA of more than 35,000 people from around the world, the NIH-funded international Autism Sequencing Consortium (ASC) identified variants in 102 genes associated with increased risk of developing ASD, up from 65 identified previously. Of the 102 genes, 60 had not been previously linked to ASD and 53 appeared to be primarily connected to ASD as opposed to other types of intellectual disability or developmental delay. It is expected that this newfound genetic knowledge will serve to improve understanding of the complex biological mechanisms involved in ASD, ultimately paving the way for new approaches to diagnosis and treatment.

The study reported in the journal *Cell* was led by Joseph Buxbaum, Icahn School of Medicine at Mount Sinai, New York; Stephan Sanders, University of California, San Francisco; Kathryn Roeder, Carnegie Mellon University, Pittsburgh, PA; and Mark Daly, Massachusetts General Hospital, Boston, MA and the Broad Institute of MIT and Harvard, Cambridge, MA. These researchers and their teams faced what might seem like a rather daunting task.

While common genetic variants collectively are known to contribute substantially to ASD, rare variants have been recognized individually as more major contributors to a person's risk of developing ASD. The challenge was how to find such rare variants—whether inherited or newly arising.

To do so, the researchers needed to analyze a enormous amount of DNA data. Fortunately, they and their ASC colleagues



already had assembled a vast trove of data. Over the last decade, the ASC had collected DNA samples with full consent from thousands of people with and without ASD, including unaffected siblings and parents. All were aggregated with other studies, and, at the time of this investigation, they had gathered 35,584 unique samples. Those included more than 21,000 family-based samples and almost 12,000 samples from people diagnosed with ASD.

In search of rare genetic alterations, they sequenced whole exomes, the approximately 1.5 percent of the genome that codes for proteins. Their search produced a list of 102 ASD-associated genes, including 30 that had never been implicated in any developmental brain disorder previously.

But that was just the beginning. Next, the ASC team dug deeper into this list. The researchers knew from previous work that up to half of people with ASD also have an intellectual disability or developmental delay. Many of the associated genes overlap, meaning they play roles in both outcomes. So, in one set of analyses, the team compared the list to the results of another genetic study of people diagnosed with developmental delays, including problems with learning or gross motor skills such as delayed walking.

The detailed comparison allowed them to discern genes that are more associated with features of ASD, as opposed to those that are more specific to these develop-

mental delays. It turns out that 49 of the 102 autism-associated genes were altered more often in people with developmental delay than in those diagnosed with ASD. The other 53 were altered more often in ASD, suggesting that they may be more closely linked to this condition's unique features.

Further study also showed that people who carried alterations in genes found predominantly in ASD also had better intellectual function. They also were more likely to have learned to walk without a developmental delay.

The 102 new genes fell primarily into one of two categories. Many play a role in the brain's neural connections. The rest are involved primarily in switching other genes on and off in brain development. Interestingly, they are expressed both in excitatory neurons, which are active in sending signals in the brain, and in inhibitory neurons that squelch such activity. Many of these genes are also commonly expressed in the brain's cerebral cortex, the outermost part of the brain that is responsible for many complex behaviors.

Overall, these findings underscore that ASD truly does exist on a spectrum. Indeed, there are many molecular paths to this disorder. The ASC researchers continue to collect samples, so we can expect this list of 102 genes will continue to expand in the future.

With these gene discoveries in hand, the

researchers will now also turn their attention to unravelling additional details about how these genes function in the brain. The hope is that this growing list of genes will converge on a smaller number of important molecular pathways, pointing the way to new and more precise ways of treating ASD in all its complexity.

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[1] [Large-scale exome sequencing study implicates both developmental and functional changes in the neurobiology of autism](#). Satterstrom FK, Kosmicki JA, Wang J, Breen MS, De Rubeis S, An JY, Peng M, Collins R, Grove J, Klei L, Stevens C, Reichert J, Mulhern MS, Artomov M, Gerges S, Sheppard B, Xu X, Bhaduri A, Norman U, Brand H, Schwartz G, Nguyen R, Guerrero EE, Dias C; Autism Sequencing Consortium; iPSYCH-Broad Consortium, Betancur C, Cook EH, Gallagher L, Gill M, Sutcliffe JS, Thurm A, Zwick ME, Børglum AD, State MW, Cicek AE, Talkowski ME, Cutler DJ, Devlin B, Sanders SJ, Roeder K, Daly MJ, Buxbaum JD. *Cell*. 2020 Jan 23. {Epub ahead of print}

Links

[Autism Spectrum Disorder](#) (NIH/National Institute of Mental Health)

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Mentors from page 10

them figure out how to help themselves. If helping means standing to the side as we flap or squeeze our hands in order to calm ourselves, then you are doing your part to help. I've said it before with self-advocating, but the "Advocating through Asking" approach applies to anyone who wants to help women with ASD.

In order for us to lead independent and fulfilling lives, we need to know how to care for our conditions ourselves. In addition to self-care, we need to learn how to speak up clearly and appropriately when the time comes to self-advocate. IEP meetings and support services don't exist in every space where an Autistic woman might venture into. Any advocate should encourage these women to own their ASD

as a strength and speak up for what they need in terms of care. It is this woman on the spectrum's belief that these tactics are the best way that we can be successful.

If you would like to discuss this approach more, please follow up with me through email at thekatetrammell@gmail.com. For other samples of my work, please review my LinkedIn page: www.linkedin.com/in/thekatetrammell/.

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Puberty from page 14

- Teach them about personal safety and internet online safety
- Always be involved in your child's curiosity, be prepared to discuss and let him/her ask you questions

Professor May Ng, MBBS (Hons), FHEA, FRCPCH, MSc, LLM, PhD, is a Consultant Paediatric Endocrinologist and Honorary Associate Professor at the University of Liverpool, United Kingdom. She completed her undergraduate degree under full scholarship in University of Sydney, Australia and her paediatric training in Australia and the United Kingdom. She was the recipient of the prestigious UK Medical Research Council Fellowship and completed further training to obtain a Masters in Medical Science and PhD degree in paediatric endocrinology and diabetes. Dr Ng also holds a Master of Laws degree and is active in medico-legal work. She is Chair of the UK Association of Children's Diabetes Clinicians, Officer for British Society of Paediatric Endocrinology and Diabetes and Training Advisor for Royal College of Paediatrics. She is in the Diabetes UK Council for Healthcare Professionals and Online Learning Committee for European Society of Paediatric Endocrinology.

She is an active researcher with over 150 publications and has presented at more than 150 scientific meetings. She serves on the editorial board for several international journals including as Editor-in-Chief and as Associate Editor and is a regular invited referee for many high impact journals. She is a clinical lead of multiple national award winning initiatives such as University of Liverpool Alumni Award 2020, Diabetes UK Mary

Mackinnon Award 2018, winner of 2015 Diabetes Quality in Care award, Highly Commended runner up for Diabetes Team of the Year National BMJ Awards 2015, finalist for the HSE Clinical Leader of the year 2015 and finalist in the UK Asian Woman of Achievement Award 2016.

Dr. May Ng is also a book author of [A Journey with Brendan](#), documenting life with her son with autism as both a mother and paediatrician. Her twitter page is [@mayng888](#) and website is [www.paedsdoc.co.uk](#).

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Career from page 20

and computer skills, to his work at the Writers Institute. He acknowledged his autism, but it never defined him or his work. He was respected and liked by our staff, by faculty members and by fellow students. We provided Chris an opportunity, but he was the one who took that opportunity and turned it into something more, the start of a professional career. We always like it when Chris comes back to visit us. His smiling face, positive energy and enthusiasm rubs off on all of us. It is not an exaggeration to say that Chris inspires us. He made the most of his internship and he will have a place in the annals of the Writers Institute as a talented young man who left his mark in a very special way," said Grondahl.

"He's one of the hardest-working people I've ever met. I think Chris's drive stems

from his understanding that he needs to make the most of his opportunities. I miss his presence here in our office. The folks at NYSID are fortunate to have Chris as their newest colleague. He's a great young guy who brings joy to the workplace," said Huber.

Chris' family has been very active with the Autism Society of the Greater Capital Region in Schenectady. Shortly after the Autism Society became a NYSID Member Agency, NYSID reached out to fill two temporary office positions. Janine Kruiswijk, who serves as executive director, immediately thought of Chris and recommended him for one of the open jobs.

"Chris loves communications! He has studied very hard to prepare himself for the field in which he chose to study. Autism can often present with challenges in communication, yet Chris has worked to excel in his career field. He is articulate,

respectful of people's views, and has a great deal of integrity when presenting information. Autism has not stopped Chris from advancing his career goals," she said.

Chris' family that includes Maria (mom), Ray (dad) and Lexy (sister) is proud of him.

"When Chris was first diagnosed with autism, we were told that he may never talk or go to school. Fast forwarding to the here and now, and knowing the struggles that he worked through, we are proud that he graduated with honors from high school and college, and that he found a job that makes him happy," Maria said. "We are grateful that Chris had an aide and teachers that supported him all through elementary, middle and high school. There were times that Chris knew that he was different from other kids at school, but all in all he tried to get along with his class-

mates and at times provided comic relief. In his senior year, Chris and another classmate were voted 'most likely to brighten your day,'" said Maria.

As of right now, Chris plans to spend many years working hard at NYSID and is very grateful to be there. In just a few months on the job, he's become known for concentrated attention to detail and ability to write clever text for marketing projects.

"Throughout the years, my family and friends have created a great environment. They have been very caring and kind to me. Although I may not be a big fan of constructive criticism, my family and friends have shown me ways to improve different aspects of my life. I am grateful to have great family, friends, co-workers, and supervisors."

For more information about NYSID, click here: [www.nysid.org](#).

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Different from page 10

proverbial rooftops to be heard. Be a listener. Be an observer. So many of us have learned to internalize and isolate to survive. You can foster our self-confidence by not dismissing our words, thoughts, and needs as "weird" or "odd" but instead try to listen without judgment to how we interpret the world and observe how completely amazing we can be when we are allowed to freely be our authentic selves.

I remember who I was when I was seven years old. I was feisty, opinionated, silly, sarcastic, loyal, thoughtful, enthusiastic, and overly in love with anything furry. I

lost that girl at eight. I spent years drowning her in various versions of the mask the world required from me. BUT I found her again in my forties, after I had peeled back the onion that being undiagnosed had let grow. I found her there, still feisty, still enthusiastic, still silly, and oh, so very glad to be free.

Becca Lory Hector, CAS, BCCS, is an autism & neurodiversity consultant/author/speaker/advocate based in Colorado. You can find more of her work, sign up for her newsletter, and follow her social media by heading to her website, [www.beccalory.com](#). You can also email her directly at [info@beccalory.com](#).

Fallout from page 21

of people living in the United States who have no health care coverage at all. This includes many self-employed people, day and gig workers, undocumented immigrants, and foreign travelers, among others.

Access to Behavioral Health Services

Access to behavioral health services is limited in the best of times. During a pandemic, it will be more difficult to provide behavioral health services due to:

- Increased need
- Increases in homebound populations due to quarantine
- High staff outages
- Preventive measures that limit allowing people with coronavirus onto treatment sites
- Limited reimbursement for telephonic services and other forms of tele-behavioral health.

Preparation by Behavioral Health Providers

Organizations and private practitioners providing behavioral health services will need to prepare to maintain as much service as possible during a pandemic. This should include planning how to provide services if offices are closed, workers are out due to illness or family responsibilities, etc.

Making sure that people have an adequate supply of medication and adhere to treatment will be critically important to preventing relapse

Of particular concern is payment for telephonic and other off-site services and remaining financially viable if traditional service delivery is impeded.

Management of Risks in Congregate Care and Group Settings

For programs that provide residential services and/or group programs such as day treatment and psychiatric rehabilitation, managing health care risks without locking people out of service will be a particular challenge.

Behavioral Health Services in the Home

Behavioral health services in the home are in short supply ordinarily. If there is a pandemic, this will become a crisis. Home care workers may themselves be out of work due to illness, or they may be unwilling or precluded from entering the homes of people who are quarantined.

Telehealth in various forms will be essential to serve people who are homebound. There will need to be changes in the reimbursement rules regarding telehealth services to cover these costs.

**Michael B. Friedman, LMSW****Psychological Support for Health Care Workers**

The stress of providing health care for people with a highly contagious and possibly fatal disease is enormous. Staff burn-out is common. The people who do this courageous and vital work often need help themselves to manage the stress they live with.

Telephonic and On-line Information and Referral and Crisis Intervention

There are a number of telephonic and on-line information and referral and crisis intervention services. These hotlines and helplines will need to be prepared to respond to needs related to COVID-19. It will be particularly important for them to maintain information in real time about service closures and service availability.

There is a national Disaster Distress Helpline (1-800-985-5990; Text: "Talk-WithUs" to 66746), but there needs to be increased public awareness and additional funding to handle greater volume.

It will also be important to provide public information about mental and substance use conditions that can arise during a disaster and how to deal with them.

Training for People Providing Services During a Pandemic

It will be important to provide training for people providing services regarding how to manage psychological and behavioral issues during a crisis. This includes primary health care providers, EMTs and other first responders, staff of social service and other helping organizations, staff of congregate facilities including community residences, assisted living, nursing homes, shelters, etc.

Training is also essential for behavioral health personnel regarding the physical aspects of the virus.

Impact of "Disruptions"

Disruptions such as school and workplace closures, canceled events, etc. will

be emotionally difficult for people with adequate financial and other resources. They will create great emotional challenges for people who will be devastated by the disruptions, such as people who live from paycheck to paycheck or from day-job to day-job and for people for whom stability is key to well-being such as those with mental disorders, those in recovery from addiction, those with dementia, family caregivers, and others.

For these populations, assistance needs to be available to provide childcare, adequate income support, and essential services. They will also need psychological support.

Behavioral Health Services in Community Settings

One of the lessons of responding to behavioral health needs during a disaster is that it is critical to provide psychological support (such as mental health first aid) in community settings where people seek help for other reasons. This includes houses of worship, food banks, senior centers, etc.

Addressing Issues of Particular Populations

Behavioral health conditions vary from population to population. In preparing for the psychological fallout of coronavirus, it will be necessary to make special provisions for certain of these populations including:

- Adults with long-term psychiatric disability, who are likely to be particularly challenged by disruptions of service and poor access to medical care
- People in recovery from addiction, for whom relapse is a distinct possibility due to great stress and/or loss of access to treatment and supports, such as sometimes daily self-help groups.
- Children and adolescents, for whom services are in short supply in the best of times
- Older adults, who are at highest risk of mortality if they contract coronavirus and may experience increases in existential anxiety and demoralization
- People with dementia, for whom environmental disruptions and changes in routine are especially challenging
- People with developmental disabilities such as autism or intellectual disability, for whom disruptions of routine can also be extremely troubling
- Family caregivers, who are under great stress and suffer burn-out in the best of times
- People who are living in isolation, who are at high risk of mental disorders
- People in grief, of whom there will be an increasing number if the pandemic is severe.

Effective Communication of Information for the Public

Although much information is available about the coronavirus pandemic, it does not adequately address psycho-social concerns, nor does it appear to be guided by psychological insights about effective behavior change communication.

In general, communication of public information needs to be geared to varying social-economic status groups, household composition, ages, and lifestyles.

This includes placing information where diverse populations will see/hear it, not just on websites and reported in the news. This should include public service announcements on TV, radio, and social media.

Particular attention needs to be paid to how to reach such populations as people who are homeless or otherwise estranged, people who are poor or otherwise disadvantaged, people who do not speak English or Spanish, people with impaired vision or hearing, and more.

Public information also needs to address what people need to know to take personal action including what symptoms call for testing and how to seek testing. These questions are especially important for people without personal physicians, including people who use emergency rooms, urgent care centers, and the like.

In addition, messages regarding preventive actions, such as staying home from work, and preparations for quarantine, including stockpiling food and other necessities, need to address people who have no sick leave and/or insufficient income and savings and not only those who have a regular source of income and adequate savings or employee benefits.

In general, messaging should be designed to avert dysfunctional anxiety as well as to avoid the implicit ageism of providing reassurance by noting that young healthy people are not at significant risk of death due to COVID-19; only old and sick people are.

Plans Are Needed Now

No doubt, meeting the medical issues of the COVID-19 pandemic is the highest public health priority. But people will suffer not just from the illness but also from lost income, lack of essential services, and from behavioral health challenges including mental and substance use disorders and difficult emotional disturbance.

Plans are needed now to take on the psycho-social challenges of the pandemic as well as the medical needs.

Michael B. Friedman, LMSW, has been a mental health policy advocate for over 40 years. He was Director of the Center for Policy and Advocacy of the Mental Health Association of NYC when he retired in 2010. He continued teaching at Columbia University School of Social Work until 2019 when he re-located to Baltimore to be closer to his grandchildren.

Managed Care from page 25

in creating plans for special populations including for persons with HIV/AIDS and for the frail elderly. I also understand that there are a few national models we can look to where plans in other states have successfully rolled out special plans. So, the evidence is limited to support the use of managed care for populations like those with I/DD.

What gives me some sense of confidence in taking on managed care for the I/DD population is the recent success of rolling out the comprehensive care management program under the federal health home requirements and funding. These Care Coordination Organizations are all provider collaborations covering close to 100,000 persons and were rolled out in record time in partnership with OPWDD. Both of these factors are core ingredients in implementing managed care. While the CCOs have only been operating for 20 months, and it is too early to declare a complete success, they show what can be done using a partnership between providers and the state.

I would also point to a start-up specialized managed care plan called Partners

Health Plan (www.phpcares.org). Partners Health Plan is New York State's only fully integrated duals advantage plan dedicated to serving individuals with intellectual and developmental disabilities and their families. By combining coverage and provider networks for Medicare, Medicaid, and IDD services, Partners is able to provide its members a cohesive, easy-to-navigate plan of care that is tailored to each individual's needs. This is a small federal and state demonstration with 1700 enrollees (March 2020).

It gives me some pause in looking at the experience of how the behavioral health field has fared in being integrated into managed care. This experience has been very slow and fraught with implementation issues and is, perhaps, several years from fulfilling the promise of managed care for persons with behavioral health needs.

In the face of these initiatives, there are legitimate concerns raised by I/DD stakeholders and they are the following:

- Isn't the timing of rolling our managed care out of line in the face of the state fiscal crisis?

- What is the source of funding for starting-up new plans?
- Will existing general Medicaid managed care organizations that already cover 5.8 million recipients be used if I/DD experienced providers can't step up because they don't have deep pockets?
- How can providers engage in developing managed care in the face of a fiscal crisis?
- Shouldn't the state and the field complete the successful transformation of the CCOs, which is the first step for managed care, before putting the whole field at risk under managed care?
- What is the basis for VBP in the field of I/DD since there is no consensus on quality indicators and there is a complete lack of data to understand utilization, quality and cost of care?

Okay, I can hear stakeholders yelling out **Yes** to these concerns. However, in my optimistic approach to life, and with my ex-

perience of 18 years in state public service and 25 years as a provider and consultant, I would say that you have to start somewhere to build the future. And, if we want to control or shape the future we have to act. So, let's start building the foundation for managed care because it is the most effective and efficient way to better use public funding to meet the needs of persons with Intellectual and Developmental Disabilities.

Arthur Y. Webb was the former commissioner of OMRDD (now OPWDD) from 1983 to 1990 and Executive Director of Division of Substance Abuse Services (now OASAS) from 1990 to 1992. Mr. Webb has held several senior executive positions in government and the nonprofit sectors. For the last ten years, he has been a consultant working with numerous nonprofits to translate public policy into innovative solutions. Presently is the Executive Director of the New York Integrated Network for Persons with Intellectual and Developmental Disabilities (a nonprofit collaboration of 12 providers). Contact: arthur@arthurwebb-group.com or 917-716-8180.

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Menstrual Care from page 15

confusion for some students as to when the skills need to be performed.

ABA-Based Instructional Strategies

Applied Behavior Analysis (ABA) uses evidence-based strategies to systematically teach new behaviors. Task Analysis and Chaining are common ABA instructional approaches. Task Analysis involves breaking a task down into sequential component steps that can be targeted for instruction. Chaining involves sequentially teaching these steps through use of prompts and differential reinforcement. Menstrual care skills have been effectively taught using these approaches in a number of studies (Esroy, Tekin-Iftar, Kircaali-Iftar, 2009 and; Veazey, Valentino, Low, McElroy, LeBlanc, 2016).

At AHRC NYC schools, instruction using task analysis and chaining has been provided both using dolls and in vivo training with the student. Instruction using dolls can include a simulation of a soiled pad with food coloring. Task analysis steps include removing and properly disposing of the soiled pad, replacing it with a clean one, and following proper hand washing procedures. Similar strategies can be provided during in vivo training depending upon the support needs of the student. Repeated instruction on specific task analysis steps is provided using modeling, a prompt hierarchy, and response feedback, including error correction or reinforcement. Video modeling can also be considered as a potential option for instruction. Consideration needs to be given as to whether instruction will only take place during menstruation, or also will be provided at other times. Providing more frequent instruction

facilitates faster learning, but may cause confusion for some students as to when the skills need to be performed.

Some students may require ongoing additional supports to achieve greater independence. Visual strips of the required steps can be provided to serve as a visual prompt, thereby removing the need for adult-delivered prompts. Adding visual structure by color coding the bottom of the pad and the center of the underwear to show pad location also has been helpful. A visual schedule can be used to cue the student on when and how often the pad should be changed. Where possible, pad change times should fit into the normal break schedule of the student's day. Adding technology in the form of a vibrating watch can be another helpful approach for cuing students to change the pad at set times. To encourage independence and self-management of menstrual care, the student can be taught how to use a calendar and/or an app to plan when her period is due.

Effective instruction needs to plan for generalization of the skills involved in menstrual care. Once basic steps are mastered, instruction should plan for variations across material and settings. An example of variation in material would be use of different types of pads, such as those with and without wings, light flow pads, etc. Variation in setting would include skills needed to dispose of the soiled pad in public restrooms, as well as in school and at home.

Desensitization

One aspect of menstrual care not addressed by research is the refusal of some girls to wear sanitary pads due to sensory sensitivities. In such cases, a desensitization approach can be effective in order to gradually expose the student to wearing the

pad. Having the student wear increasingly larger or thicker sections of pads over a period of time can increase tolerance to the sensation of the pad. Begin with a very small, thin section of the pad and gradually increase size and thickness as the student's tolerance improves.

In summary, preparing girls for independent menstrual care requires that they achieve both knowledge and skill acquisition. Menstrual care requires new skills in a private body area, thus requiring enhanced planning and sensitivity for instruction. The generally accepted practice is to begin this preparation prior to the onset of menstruation. The timing of instruction onset can be a joint decision between parents and professionals, with parents giving guidance based upon signs of physical maturation. For a small minority of students, it may be felt that providing early instruction may heighten anxiety and the tendency to fixate. In such cases, instruction may be delayed until the onset of menstruation. While greater research is needed on the topic, current evidence and experience supports the use of multifaceted, evidence-based approaches. AHRC NYC schools have found the use of Social Stories, ABA instructional strategies and desensitization programs to be effective in helping students to increase menstrual care knowledge and skills.

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Lisa Barzotto is a certified school psy-

chologist and board-certified behavior analyst (BCBA) who works for the New York City Department of Education. Previously, she worked for 10 years as the school psychologist of AHRC New York City's Brooklyn Blue Feather Elementary School. Lisa's interests include behavioral interventions in Autism Spectrum Disorders (early identification and intervention, parent and teacher training, coping strategies for managing anxiety, and social skills interventions) as well as dissemination of 'best practices' in ASD interventions in schools and the community.

For more information, visit www.ahrcnyc.org.

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Unique Needs from page 6

“Activities with structure, like using Roberts Rules or something...to help us know when to talk”

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). Yet school age girls with autism show problems maintaining friendships (Hiller et al., 2014) and find it harder to manage social conflict (Sedgewick, Hill & Pellicano, 2019). Girls with autism also report more experiences of relational aggression (Sedgewick et al., 2016). As adults, women with ASD face unique challenges because of societal expectations of women's social behavior (Bargiela, Steward, & Mandy, 2016). As a result, the social gaps between adult women with ASD and their non-ASD peers may be 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; McCormick et al., 2020). Such differential access to formal diagnoses 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 women in general (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 in need of 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 comfortably share experiences and build connections. To provide such opportunities, 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. A careful use of visual supports is required; 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 that social communication needs can be varied. At the group level, this can be accomplished via a menu of programs that caters to diverse needs and interests, including experiences that are rich in opportunities for discussion as well as those designed for participants who prefer hands-on activities. Program content should also be informed by the current context and interests of the women. Differences in social motivation are also important factors that affect participation. Thus, identifying special interests, as well as understanding previous negative experiences, is essential for supporting the individual. Additionally, programs will require participation and staffing models that can account for changing support and 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 between a woman and staff member, with ongoing follow-up as needed. Programming is varied and includes 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 pre-planned modifications with an eye towards facilitating diverse forms of 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 format of the program activities; program 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.

For more information about Felicity House, please visit www.felicity-house.org.

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Yes She Can from page 17

Each person's success may be defined differently however, all trainees participate in identifying their goals and the steps involved in reaching those goals. Goals may include working towards mastering a specific skill or it may include being aware of how you present yourself in the world.

We recognize that there are different expectations for men and women. Men who are unshaven and casually dressed are likely to be more accepted than women who have not brushed their hair and wear more casual clothing. For many young women on the spectrum beginning to understand how their hygiene and appearance impact how they are perceived and what kind of impression they make often becomes an important goal. Presenting with appropriate hygiene is challenging for many. Matter of fact conversation, visual stimuli, taking perspective about how others react to poor hygiene and availability of toiletries lends itself to honest, caring and genuine feedback. We encourage individual style and choices with increased knowledge about the impact their choices have

in their lives in the world. Confidence comes with increased self-awareness and realistic feedback.

Recognizing the stress created when plans or routines change is particularly important for women who are working so hard to keep their anxiety and uncertainty under control. At Yes She Can we explain why business priorities change and the value of trainees being part of the team to meet management goals. Developing strategies to manage changes in expectations becomes important. One of those strategies might be taking a short break. We accept the need for a break and acknowledge that most employees take informal breaks throughout the day (a trip to the bathroom or water cooler). We talk about self-soothing strategies, (listening to music, playing a quick game on-line, working on a word puzzle) and getting back to work. We ask participants to identify how much time they think they need to decompress and set timers accordingly to return to work. Learning how to manage anxiety is a critical and transferrable skill.

Teamwork is emphasized, knowing that each trainee may have differing abilities to

take on different parts of the work. When business priorities are met, the team can see the collaborative successes as well as the individual efforts that went into meeting the goal. Trainees can experience pride in knowing that they contributed to and can be relied upon to work towards the accomplishment of a goal. Confidence comes with knowing the value of their contributions.

Confidence also comes from external reinforcement of repeated successes. Increased knowledge and self-confidence begins to allow for more independent decision making and ultimately generalization of skills to other settings. Our curriculum includes regular assessments which capture the data measuring skill development. Our trainees apply their skills they gain at work to their home and community lives. Families report on the confidence and skills their daughters develop, and how life-changing the program has been.

Lesli Cattan is Director of Training at Yes She Can, a nonprofit dedicated to helping young women with autism develop transferable job skills leading to employ-

ment and greater independence. Yes She Can operates its job skills training program at Girl AGain boutique. We welcome visitors to see our program in action at Girl AGain boutique, located at 4 Martine Avenue, White Plains, NY 10606. For more information, visit www.YesSheCanInc.org and www.GirlAGain.com.

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Toolkit from page 8

Family Engagement for [Devereux Advanced Behavioral Health](http://www.devereux.org), one of the nation's oldest and largest nonprofit provid-

ers of behavioral healthcare, and serves as a family representative on several special needs boards in the community, locally and nationally. In addition, she participates with other patients and families in efforts

supported by the American Board of Pediatrics Foundation and the Autism Speaks Autism Treatment Network to address children with special needs and the importance of quality care.

To learn more about Devereux Advanced Behavioral Health, visit www.devereux.org. To learn more about Devereux's autism programs and services, visit www.devereux.org/autism.

Educating from page 20

Some of the general ways that special education teachers can assist in schools are putting support in place before the start of the school year, staff training in how ASD manifests differently in girls, teach non-academic skills, pre-teach lesson contents, and bring her interests into the curriculum (Hendrickx, 2015). Interviewing with special education teachers can help us to further understand whether these supports are being put into place to meet the unique needs of girls with ASD.

Jamison and Schuttler (2017) created a social skills and self-care curriculum for adolescent females with autism call the "Girls Night Out Model (GNO)." "GNO is a social skill and self-care program designed to address the unique needs of adolescent females with ASD/DD with goals to improve their social-emotional health" (Jamison & Schuttler, 2017, pp. 112). Their goal is to create a safe space to learn new skills, empower girls to be more independent and create and conquer individualized goals (Jamison & Schuttler, 2017). They have received positive feedback from students and parents on their program, and the progress girls have made. These practitioners suggested educators focus on social competence, behaviors related to development, gender differences, and self-determination (Jamison & Schuttler, 2017).

There is a significant need to develop awareness and skills in special education teachers working with females on the autism spectrum in order to support their specific needs (Baldwin & Costley, 2016). Girls with ASD have reported feeling misunderstood by their teachers due to their autistic characteristics (Bargiela et al., 2016). It's time we change that narrative.

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Understanding from page 12

IQ score $t(51) = -.24, p = .81$; Nonverbal IQ scores $t(51) = .08, p = .94$; and Verbal IQ scores $t(51) = -.50, p = .62$. There was a significant difference between females with ASD and non-ASD females regarding the mean standard score difference between Nonverbal and Verbal IQ scores $t(51) = 2.17, p = .04$. Females with ASD had a significantly greater discrepancy between their Nonverbal and Verbal IQ scores than females without ASD.

Results from this project do not support prior research that suggests females with ASD are more cognitively impaired than males with ASD. When females with ASD were compared to non-ASD females, females with ASD had significantly more discrepant Nonverbal and Verbal IQ scores than females without an ASD diagnosis. These discrepancies indicate that females with ASD do not perform uniformly across nonverbal and verbal cognitive tasks in the same way that non-ASD females do. These findings provide new information about the cognitive profile of females with ASD, which had been lacking in previous literature. With these novel findings, we are beginning to better understand females with ASD.

Females with ASD are considered difficult to diagnose (Hull et al., 2017). However, when females with ASD have co-occurring cognitive impairment (e.g., IQ <70), their developmental concerns may be more apparent. Thus, prior conceptions of females with ASD having lower IQ scores than males with ASD may be a result of a diagnostic bias. In the typically developing literature, females are significantly more social than males (De Goede et al., 2009). Head and colleagues (2014) found a similar trend in children with ASD: females with ASD showed significantly stronger social skills than males with ASD. Females with ASD, however, are significantly behind their typically developing female peers in regard to their social skills. Further complicating the matter, females with ASD have social skills that are on par with

typically developing males (Head et al., 2014). Females with ASD have significant deficits in their social skills, but these deficits may not be as striking as males with ASD, since females with ASD are viewed as being just as social as typically developing males.

The social camouflaging theory is emerging in ASD research, and it supports the phenomenon of under-representation of females with ASD. Social camouflaging encompasses multiple coping strategies used to hide one's social difficulties, such as masking and compensating (Hull et al., 2017). Social camouflaging is seen in both males and females with ASD; however, affected females have higher camouflaging scores than affected males and camouflage their symptoms more often than males (Lai et al., 2017). Societal expectations potentially impact autistic females' higher rates of camouflaging. Females with autism spectrum disorder feel the need to camouflage more - and by doing so, appear more social - but it is to their own disadvantage. Females adept at camouflaging risk being overlooked and under-diagnosed (Gould & Ashton-Smith, 2013).

While social camouflaging may appear beneficial in the immediate context, it can have long-term detrimental implications. Females - typically developing or with ASD - are at an increased risk of having anxiety and depression, especially during adolescence (Green et al., 1996). People with ASD are also at an increased risk of developing co-occurring psychopathology (Skokauskas & Gallagher, 2012). Females with ASD are an especially vulnerable population given this compounding risk.

An upcoming study at the Center for Autism and Related Disabilities will explore how camouflaging behaviors may impact females with ASD. The study purports that camouflaging has a negative impact on the lives of females with ASD, and it will investigate the use of camouflaging behaviors in women with ASD compared to men with ASD and typically developing women. The study will further explore how camouflaging behaviors may impact

the lives of women with ASD, specifically in regard to their mental health, quality of life, and substance use. Understanding of camouflaging is only beginning and further work is needed on outcomes related to these behaviors. Despite growing evidence of gender differences in social presentation and expectations, prevalence of mental health disorders, and quality of life issues, there is a lack of research on outcomes for females with ASD.

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For more information, visit the website www.aane.org or contact the facilitators:

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

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For more information, contact the facilitators:

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

Hormones from page 11

Existing health problems are reported to worsen in this premenstrual (luteal) phase of the cycle. Examples common to women with autism are epilepsy, asthma, sinusitis, and chronic depression (see Table 1 on page 11).

As there are no specific tests for the diagnosis of PMS, monthly charts illustrating occurrence of symptoms are necessary to diagnose the syndrome. Documenting signs and symptoms of PMS can present a challenge for health care providers of women with developmental disabilities. Often the history is either unobtainable or incomplete. PMS Assessment is best approached when charting of symptoms daily consistently occurs over a three-month interval. Bergen's Promise, a care management organization within the New Jersey Children's System of Care, serves a large population of individuals with autism. Through an integrated pediatric behavioral health home, the organization utilizes menstrual tracking tools, adapted from the Managing Menstruation resource from the Queensland Centre for Intellectual and Developmental Disability (Taylor, Carlson, Griffin, & Wilson, 2010), to encourage consistent charting.

Those who experience PMS often have symptoms which are typically associated with hypoglycemia, such as headaches, sweating, fainting and dizziness. These women frequently binge or crave chocolate and salty foods such as potato chips.

Women with autism PMS or PMDD may experience a symptom-free interval characterized by tremendous amounts of energy followed by a low energy time interval: relaxation and regular exercise are a must.

As women with autism age, hormonal fluctuations can impact physiological, psychological/behavioral, and cognitive dimensions of wellbeing. The transition to menopause can be divided into three phases: Premenopause, Perimenopause, and Postmenopause.

In Premenopause, hormonal fluctuations become more pronounced although the cycles remain regular. As there is a decrease in serotonin and endorphin withdrawal, menstrual migraines and mood changes become more evident. Insulin sensitivity brings on food cravings and appetite changes. If a woman with autism experiences PMS symptoms these will become more severe. Water retention, GI symptoms, breast tenderness, and heart palpitations may also occur.

In Perimenopause, the hormones of estrogen and progesterone decrease with a subsequent change in the length of the cycle and change in monthly flow. There is a further decrease in serotonin, endorphins, dopamine and estrogen brain receptors resulting in mood changes, headaches, insomnia, fatigue, and forgetfulness.

Insulin sensitivity continues to enhance food cravings and appetite changes. There is also a decrease in thyroid activity, metabolic rate and subsequent weight gain. Hot flashes, heart palpitations, skin changes (including vaginal dryness) and formication (a sensation like insects crawling on an area of skin may occur).

In Postmenopause, the woman with autism may experience some of the same symptoms of Perimenopause but to a lesser degree. Bone loss (osteoporosis) and risk of heart attack increases in this phase. Abdominal fat and an increase in waist to hip

ratio also occurs.

In general, women with autism are not adequately prepared for these menopausal phases. Menstrual knowledge is commonly addressed as a hygiene issue for this population and their caregivers. Information given by the health care provider to women with autism regarding PMS/PMDD, premenopause, perimenopause and both surgical (hysterectomy-induced) and natural menopause often is scant or non-existent. It is interesting to note that in the US, education and income level are related to the likelihood of having a hysterectomy.

This group and those helping them make decisions need to be aware of the risks and benefits of Hormone Replacement (HRT).

Now that women with autism are routinely living past menopause, this aspect of life needs to be part of the health promotion strategies for this population.

The interactions of psychological, sexual, physical, vocational and recreational decisions concerning the perimenopausal and postmenopausal phases are complex and powerful. Approaches to hormonal changes effect mental health, energy levels, the cardiovascular system, bone strength, sexuality, and potential cancer risk. It is in this context that female self-advocates and all persons involved with the health and well-being of women with autism should become aware of the effects of hormonal changes during the luteal phase of menstruation (Premenstrual Syndrome), the Premenopausal phase, the Perimenopausal phase and Postmenopausal phase. Knowledge regarding health status and disease risk during these stages is essential. Increased awareness and assessment are the first line of implementation and should be

implemented to promote optimal health in the continuum of hormonal passages for all women with autism.

Jan Schlaier, EdD (c); FNP-BC, is Director of Health Services and, Jacqueline Berko, RN BSN, is a Behavioral Health Home Nurse at Bergen's Promise. We would like to thank Dean Pastras, CEO of Bergen's Promise, for his leadership in providing integrated healthcare to Bergen's Promise. For more information, please visit www.bergenspromise.org.

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Supporting from page 12

Mary, a member of our job development staff, went to the popular restaurant Texas Roadhouse in New Rochelle, NY, a business where we did not have an existing relationship. Mary brainstormed with the manager for an opportunity for Carlie to roll silverware before the restaurant opened.

In the beginning, Mary was onsite with Carlie often, helping her put together a structure, schedule reminders and implement all that she learned during her time with Project SEARCH. After seeing how well Carlie was doing at her job and how she was positively impacting the work environment, Texas Roadhouse contacted Mary about giving Carlie additional tasks. Carlie now is also responsible for filling salt and pepper shakers, cleaning windows, ledges and menus, prepping butter and brown sugar containers and preparing coloring books and crayons for kids. She is truly flourishing.

Alex – Employment Program

Through ACCES-VR and our supported employment program, Alexandra began working with M Group Consulting, LLC, one of the largest independent financial services firm in the tri-state area, in October 2018. It's a very clerical, serious office environment, and Alex was hired for data entry and scanning documents. Her employers entrust her with their data and important documents, so it is imperative that she was taught the skills and given the supports to be successful in this, her first job.

In addition to job skills, our employment program helps Alex and all of those we support with adjusting to how to be an employee. From learning to become more independent, how to talk to co-workers and supervisors, how to respond to feedback from your bosses and general office protocol, we are dedicated to giving those we support strategies on how to be successful in every area of the workplace. After more than a year at M Group Consulting, Alex is doing wonderfully at her job and her employers truly value her.

The Choices Volunteer Group

For almost two years, four young women from our Choices Neighborhood program – including Haley, Jennifer and Samantha who have autism - have volunteered at The Manor Club in Pelham, NY, which was founded in 1913 when a group of women rescued the club after the previous organization began to struggle financially.

Every Tuesday, the Club hosts a luncheon for its members, and our volunteers assist in various tasks including preparing the food and dining area, registration, service and clean up. This has given them an opportunity to learn employment skills and to socialize with fellow Choices group members, as well as female members of the club.

One of the most important skills the girls have learned from this work is the structure of a workday, from arriving at work at 9:30 a.m., having lunch at 11:15 a.m. and leaving at 2 p.m. They also learn important communication skills that have a positive impact on every aspect of their lives.

In Conclusion

It is abundantly clear that with the right education, training and support, young women with autism can become highly regarded and respected employees and contributors to their community. It is through our experience and observation that there are certain social engagement skills that young women need in and out of the workplace, such as meaningful social interactions with their peers. It is abundantly clear, however, that more research is needed to better assess and improve ways we can best prepare women with autism to succeed in the workplace.

Recognizing and nurturing the potential of young women with autism is key to successful program outcomes. It is our expectation that organizations across the country continue to dedicate more resources and research to transition services to help the next generation of women with autism join and flourish in the workplace.

Tibi Guzmán is the Executive Director and CEO of The Arc Westchester, the largest agency in Westchester County, NY, supporting individuals with developmental disabilities, including those on the autism spectrum, and their families. She has been a part of The Arc's leadership team for more than 14 years, overseeing different aspects of the organization. Ms. Guzmán has two sons and a B.S. from Fordham University, an M.P.S. from The New School for Health Service Administration and an M.A. in Economics from Fordham University. She was named one of

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