



Practical Tips for Working with Young Women on the Autism Spectrum

By Eva Mendes, LMHC, and Eric Endlich, PhD, IECA Associate (MA)

With Greta Thunberg being chosen as *Time* magazine's 2019 Person of the Year, young women on the spectrum are gaining greater visibility. And as children are increasingly being diagnosed with autism, independent educational consultants (IECs) are likely to encounter more students on the spectrum in their caseloads. But much of what people know—or think they know—about autism is based on a predominantly male presentation, so it is important to learn about the unique needs and challenges of females on the spectrum.

Difficult Diagnosis

Autism is often not the first diagnosis that females receive when seeking help. Males are diagnosed with autism spectrum disorder (ASD) at least three times as often as females, perhaps in part because ASD is harder to detect in females. Clinicians and ASD specialists strongly suspect that there are many undiagnosed autistic females in the population. Autism expert Tony Attwood estimates

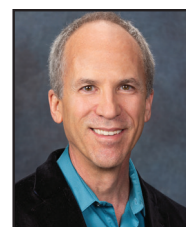
“we are currently detecting and diagnosing about 50 percent of children who have Asperger’s syndrome” (2007, p. 46).

Many young women on the spectrum have been labeled as intellectually gifted or carry other diagnoses, such as anxiety, depression, ADHD, eating disorders, borderline personality disorder, or bipolar disorder. Some receive a series of diagnoses for years before they stumble across the autistic profile—sometimes at the suggestion of a partner or clinician—and then obtain the correct diagnosis later in life. In addition to those who have been misdiagnosed, many have additional comorbid conditions (e.g., autism plus depression or anxiety). According to Haley Moss, a young autistic attorney prominent in the neurodiversity movement whom we interviewed for this article, “Women don’t present the same way as young men on the spectrum—women get overlooked. They don’t get diagnosed, or they get diagnosed later. They go through diagnostic roulette.”

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Depending on where you live, finding adequate resources can sometimes present a major challenge. Many clinicians have little experience with autistic females, and as a result, women sometimes become discouraged with the assessment process. Women who are seeking evaluations have sometimes been told that they “can’t be autistic” because of their eye contact, vocal inflections, or social network. There is some evidence to suggest that women are more likely than men to self-identify, as opposed to obtaining a professional diagnosis (Wake, Endlich, and Lagos, forthcoming).

Hidden Symptoms

Research suggests that young women learn social skills differently from males. They may experience more pressure to conform to social expectations, and they may be less likely to exhibit aggressive behaviors that draw attention. Their autism might also be harder to detect because they may mimic their nonautistic peers more successfully than males. Unfortunately, this chronic masking or “camouflaging” can lead to increased depression, fatigue, and stress.

In addition, young women don’t always fit the “geek” stereotype. Although it may be true that a disproportionate number of autistic students choose STEM fields of study, at least half of those on the spectrum select other pursuits. Intelligent, quirky young women may have more socially acceptable interests than young autistic men, including animals, astrology, musicians or

other celebrities, poetry, environmental activism (think Greta Thunberg), or even fashion.

If you suspect that a young woman is autistic, consider referring her to a specialist to get a diagnostic evaluation, preferably to someone who is familiar with the female presentation of autism. Even if the student or family isn’t interested in a formal assessment, it’s still a good idea to suggest appropriate supports and resources, at least for the comorbid conditions, such as anxiety.

Working with these students may require a great deal of patience to ascertain their true wants and feelings. According to Moss, “What we say isn’t always what we mean. There’s a compliance culture: you’ll say yes when you want to say no. You want uncomfortable situations to be over. You’ll say you’re fine if you’re not.” Reviewing neuropsychological testing, if available, can help an IEC understand a student’s cognitive and emotional styles to establish an effective working relationship.

College Selection

It’s not unusual for young autistic women to struggle with adjusting to college life, and many fail to graduate as a result. Therefore, it’s crucial to guide them in picking the right educational institution. Some students do better when they start at community colleges or commuter schools so that they can learn to handle college-level coursework before dealing with the challenge of independent living. Those who plan to move away from home may wish to avoid large “party” schools or

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institutions that are overly focused on socializing and sports and instead seek out small colleges with more individualized attention. Depending on their interests, they may thrive in academically oriented colleges with strong arts or science/engineering programs. Because of potential naïveté and difficulty reading social cues, they may be at increased risk for exploitation and should become familiar with safety trainings and resources, regardless of which colleges they attend.

Disclosure Decision

The decision about whether and when to disclose a diagnosis to a college is highly individual. Sometimes a student will mention the diagnosis during the application process to qualify for a support program or to explain something unusual (e.g., a temporary drop in grades because of depression). If a student will require accommodations in college, she should be prepared to provide documentation, such as recent neuropsychological testing, soon after admission. The college's disability and accessibility office can guide the student through this process. Depending on her difficulties with social interactions, one option is for her to seek a single room in a residence hall as an accommodation. Many young women on the spectrum are also attached to and soothed by animals and can benefit from having an emotional support animal or residing on a pet-friendly campus.

In considering accommodations and supports, keep in mind that the student may downplay her needs. Moss noted, "I don't think I was honest with myself about what supports I needed. When you're young you want to believe you can take on the world. My roommate thing was a disaster. They offered a single room, but I said no. I didn't want to be different or be an outcast." It may be necessary for an IEC to gently challenge a student who is resisting supports and services that may be key to her success in college.

On-Campus Supports

Young autistic women often struggle with on-campus living, challenged by the social aspect of having to live with roommates, sensory sensitivities that may be exacerbated by dorm living, a lack of social-emotional support, and executive functioning issues. IECs should assess students' college readiness and determine the type and level of support needed. Students may need not only accommodations but also a variety of supports, including counseling, executive function coaching, and social skills groups. Some colleges have dedicated autism support programs with all those components, allowing one-stop shopping for services; a list of such programs can be found at topcollegeconsultants.com. 

References

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Wake, Wilma, Eric Endlich, and Robert Lagos. Forthcoming. *Older autistic adults: The lost generation*. Shawnee, KS: AAPC.

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