

Detection and Diagnosis of ASD in Females

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Autism in females is often unrecognized and undiagnosed. This article describes the presentation of autistic traits of females and how they differ from those of males with autism. Screening tools for assessing autism in children, adolescents, and adults are identified and described. The process of clinical assessment of females for possible autism are described, including the disclosure of potential diagnoses to the patient.

Michelle is a self-referred, 24-year-old woman complaining of anxiety. Her anxiety impacts sleep and seems to worsen physical GI symptoms. She is appropriately dressed, having come after class, and she is articulate although she takes long pauses to collect her thoughts. She graduated from an excellent college, and she is attending graduate school in English literature and was working part time until recently. She quit her job because her boss frequently yelled at her about not meeting his expectations. She felt he was never clear and constantly changed what he wanted her to do. She felt anxious every day and dreaded going to work. She had quit a prior job because she found it difficult to work in the constant close “team” environment of the office. The team members regularly went to lunch together or out for drinks after work at a noisy bar, neither of which she enjoyed. She felt that her right to a private life and need for time alone were not understood. Michelle lives in her own apartment. Michelle describes herself as a child “always having her nose in a book” and loving reading. She felt she had not fit in socially through all levels of school. She reports few close friendships, although she had friends in school and had been somewhat friendly with a woman in her last job. Parties and family events made her nervous. She didn’t feel that her parents understood her point of view about attending family events, although they were generally supportive of her. She had not dated until college, and then had one relationship that she broke off. Michelle appears to be a serious young woman of high intelligence. She does not display much emotion, despite being obviously upset by her situation. Her descriptions of her experiences are very detailed. When asked about her feelings, she often does not respond beyond saying she was anxious. Is this social anxiety or something more complex? Should a possible diagnosis of autism spectrum disorder (ASD) be considered? What exactly does ASD look like in female patients?



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Clinical Challenge

Incidence and Gender Ratio of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is defined as a neurodevelopmental disorder that is present since childhood (Eckerd, 2018). Age at time of diagnosis ranges from 3 to 18 (and later) depending on the severity of symptoms, ethnic and racial factors, and socioeconomic dimensions. It is estimated that 1 in 59 children meets criteria for ASD (Baio et al., 2018) or 1.7% of children.

Past consensus was that autistic males outnumbered females with a 4:1 ratio (Werling & Geshwin, 2013). However, differing estimates of this male/female ratio has been found ranging downward from 3:1 (Loomes et al., 2017) to 2.6:1 (Wing & Gould, 1979), and 2:1 (Halladay et al., 2015). Some studies estimate that in the less severe range of ASD, the ratio of males to females may be 1:1.8 (Brown et al., 2020).

Diagnostic Criteria for Autism Spectrum Disorder

According to DSM-V, there are two primary diagnostic criteria for ASD. The first is persistent deficits in social communication and social interaction across multiple contexts currently or by history. These deficits can present as problems with social reciprocity (i.e., normal back and forth communication, sharing of feelings and interests, and failure to reach out or respond to social overtures); problems in nonverbal communicative behaviors such as the use or recognition of social cues, gestures, and facial expression; or challenges in developing, maintaining, and understanding relationships. Other nonverbal aspects of communication such as use of and accurate perception of tone of voice are also challenging.

The second area is the use of restricted or repetitive behavior. These might present as stereotyped movements, insistence on sameness or need for routines, difficulties with transitions, rigid thinking patterns, or very restricted interests that are abnormal in intensity or focus. The DSM-V also mentions hyper- or hypo-reactivity to sensory stimuli or interest in sensory aspects of the environment, although this is not one of the two primary diagnostic criteria (American Psychiatric Association, 2013). DSM noted that these characteristics are present from childhood, but symptoms may not be evident until later when social demands exceed the individual's capacity to successfully cope or mask them.

According to the Centers for Disease Control and Prevention (CDC), there is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from other people. The learning, thinking and problem solving of people with ASD can range from gifted to severely challenged (CDC, 2019). ASD is a spectrum or constellation of symptoms and severity of symptoms, so any individual autistic individual may present quite differently (WHO, 1992).

Male Bias in Image of ASD

Multiple causes account for girls/women being under-diagnosed with ASD. However, the male-gendered stereotype of the presentation of ASD symptoms is clearly one factor. The assessment model for ASD in the DSM-V diagnostic system was developed with samples consisting primarily of males. The behavioral traits of males and females with this disorder may differ significantly in terms of their obviousness or the extent to which they deviate from expected behaviors. Put simply, there is a male phenotype expected in the presentation of ASD symptoms, and females present differently than males.

Females are better able to camouflage their autistic traits. As a result, female autistic traits frequently are not identified as due to autism. Their traits and symptoms are misunderstood, and fe-

males are often given different labels and diagnoses. Because females present differently, typical assessment measures often miss females with ASD (Brown et al., 2020).

Severely impacted children of both genders are diagnosed relatively early in elementary school or before. However, children (and adults) with intact intelligence and strong apparent language skills are diagnosed later (and sometimes go undetected altogether). The age of diagnosis is three years later for females as compared to males among those with less severe forms of ASD.

Autistic women report on online chat rooms that doctors (and friends) say, "You don't look like Sheldon," referring to the character on *The Big Bang Theory* television series, whose rigidity, special interests, pedantic speech, lack of tact and "nerdy" appearance are the male prototype of autism. Other TV examples are the character Jerry "Hands" Espenson on *Boston Legal*, Will Graham on *Hannibal*, Abed Nadir in *Community*, and Dr. Shaun Murphy in *The Good Doctor*. The image of an individual with autism in popular culture is a male.

Even when an adult woman suspects she might have ASD, professionals often dismiss the idea when the woman presents it. One woman commented, "When I mentioned the possibility to my psychiatric nurse, she laughed at me."

Differential Female/Male Symptom Presentation

How might the two DSM-V diagnostic criteria for ASD be presented differently by females and males? Autistic traits and symptoms in males and females are generally similar in nature and function, but they present differently. Because autistic behaviors in girls are often misinterpreted, parents and teachers may not give a history reporting clear autistic behavior.

Autistic boys have more repetitive behaviors than girls, and their interests are more atypical. A boy might flap his hands or repeat an odd behavior to self-calm (i.e., "stimming" or self-stimulation). A boy whose fascination is train schedules or who flaps his hands stands out. Girls' interests are generally more gender normative, and a girl whose fascination is with reading, animals, or art does not stand out (Dean et al., 2017; Halladay et al., 2015). Girls pick up on social cues and learn not to "stim." As a result, girls may not meet the thresholds of repetitive behaviors for diagnostic assessments of autism.

In the social environment of schools, girls without intellectual impairment are better able to "hide" autistic symptoms and blend into the social environment than boys (Dean et al., 2017). Boys tend to do activities like sports in larger groups, so an isolated boy is obvious. Female groups are smaller, and girls usually move between groups (i.e., "flit") more than boys. However, non-autistic girls maintained joint engagement even when mov-

ing around. Autistic girls alternated between solitary time and moving around, reflecting their difficulty maintaining social involvement. Girls present differently interpersonally due to their social environment and their ability to imitate social behavior. As a result, girls may not meet the threshold of social impairment for an ASD diagnosis (Jamison et al., 2017).

Autistic girls are generally motivated to fit in and are better able than boys to imitate social behaviors (e.g., camouflage or mask). They can use compensatory behaviors to join groups in ways that make it difficult for untrained adults to observe their social challenges. Girls may learn to make eye contact, imitate facial expressions, and use the strategy of telling stories or anecdotes to continue social interactions, although subtle analysis can demonstrate that there is a tendency toward monologue (Lai & Baron-Cohen, 2015). While the social challenges of autistic girls might not be obvious to an adult observer, their autistic social challenges are evident to peers. Autistic girls can remain physically close to peers and find ways to join groups, but their acceptance by peers is limited. An autistic girl might be allowed to join the jump rope game, but she holds the rope and is rarely invited to jump (Dean et al., 2017). Autistic girls suffer from neglect and exclusion, although they appear to be within social groups.

Females' social challenges due to autism are generally misunderstood and mislabeled. Autistic girls may be perceived to be condescending and rude. For example, autistic individuals tend to tell their perception of the truth irrespective of the social rules of the context. An autistic girl may tell a teacher that an assignment does not make sense (or she may refuse to do it). She may be perceived as having "attitude problems" or as rude. A teenage girl with autism is often perceived as unusual or quirky. She might withdraw from social situations or group work in class based on past negative experiences and be labeled avoidant or oppositional. Her social behavior may be interpreted as selfish, aloof, defiant, self-involved, manipulative and/or attention-seeking, or as anxious and withdrawn—rather than autistic.

Hyper- or hypo-reactivity to sensory input or showing unusual interest in sensory aspects of the environment is mentioned in DSM-V regarding children with ASD. Research suggests that over 90% of children with autism have sensory sensitivities, usually in multiple sensory modalities. "High functioning" autistics have more sensory issues overall and issues in more sensory domains than comparison groups (Leekam et al., 2007).

The disruptive behavior by ASD boys may reflect their reactions to their sensory environment, whether or not sensory issues are identified. Girls who struggle with sensory issues (e.g., noises in school, olfactory or tactile challenges, the visual challenge of bright lights or an overly stimulating environment) are less likely to be understood or believed and their reactions are unexpected. They may seemingly overreact by becoming upset, withdraw-

ing, or refusing to participate in a particular environment, which may be seen as attention seeking, avoidant, or defiant rather than autistic. The behavior of girls with ASD is generally not so disruptive in school that they attract attention.

There are also cognitive characteristics typical of autistic individuals. In the DSM-V system, these cognitive challenges are described under the heading of repetitive behavior: inflexibility, rigid thinking, need for sameness, and difficulty with transitions (American Psychiatric Association, 2013). Autistic individuals can have extreme distress with small changes in task or routine, difficulties with transitions, and expectations of cognitive flexibility such as accepting a different way of problem-solving. These symptoms are found to be similar in males and females. When this kind of behavior is observed in males, it is diagnosed. When presented by females, even at a higher level than males, it is rarely diagnosed as autistic. This behavior in females gets misinterpreted. A girl's failure to shift behavior to different contexts (due to difficulty with transitions) is likely to be noticed but labelled differently. A girl who refuses to put away work on an interesting activity to shift to another task may be viewed as defiant or manipulative rather than autistic.

Other Typical Aspects of Female ASD

There are additional challenges and traits of autism, other than the social deficits and repetitive behavior/cognitions critical to the DSM-V criteria for diagnosing autism. Pragmatic language problems are typical in autism irrespective of the level of language skills and intelligence. Literal thinking has been described as a core feature of autism, as well as lacking appreciation of the need for contextual information in conversation for listener understanding (Geurts et al., 2019). Autistic people of all ages and all genders can have difficulty handling non-literal uses of language such as sarcasm, irony, and metaphor. This does not mean autistic individuals cannot think abstractly; it means that they take language literally, to mean exactly what it says. Innuendo and inferences are missed.

Confusion about non-literal language can lead to social embarrassment. The teacher of an autistic girl might say, "get out your books," but not say "and start reading the next chapter," (assuming that this is inferred). The girl with ASD might get out her book but continue doing what she was doing (e.g., perhaps drawing in a notebook). The teacher might then announce to the class that the girl thinks her drawing was more important than the classwork, humiliating her in front of her peers.

Most social rules are inferred rather than stated. An autistic college student might be told by another student "we're having dinner in the dining hall" and not understand that this was an invitation. Her failure to join others for dinner could be seen as aloof or as a lack of interest in getting to know her fellow students. A

young woman attending a party might be asked to “hang out longer” as a polite gesture even though the implied message, “it’s time to leave” is communicated nonverbally perhaps by a glance at a watch. The autistic young woman would take this literally to mean she should stay. By staying, she is committing a social faux pas and might be seen as “dense” and annoying. Others might say, “You can’t get rid of her.”

Comments reflecting literal understanding can be perceived as hostile. I was called by a school to observe a “hostile” student. An example of her hostility was when she asked, “What does this have to do with social studies?” after a teacher showed a funny short film as a break from class. This and other statements did not reflect hostility. They were expressions of her literal thinking and her fixed expectations of what should happen in a social studies class.

Autistic adults often express confusion when non-autistic adults do not mean what they say. Children, on the other hand, are simply confused or embarrassed. Literal language and communication breakdowns can be perceived as a lack of consideration or thoughtfulness. A girl’s mother complains that the grocery bags to be brought in are heavy. The girl does not offer to help. The autistic girl takes the mother’s statement as factual—bags are heavy. If the mother wanted help, she would have needed to say that she wanted the daughter to help carry bags.

Autistic individuals are described as lacking empathy. Research has suggested a differentiation between cognitive empathy, which involves understanding another’s thought process or perspective, and affective or emotional empathy, which is an individual’s emotional response to the distress of others. It has been recently suggested that autistic individuals have deficits in cognitive empathy, but not necessarily emotional empathy (Harmesen, 2019). This may represent an important new perspective.

Adult autistics who communicate online often express sincere empathy and support for each other. They describe their empathic reactions as so deep at times as to be overwhelming. Autistic females may express empathy differently than expected. They may express empathy by attempting to share a personal experience to demonstrate understanding of the situation or they may attempt to “fix” a problem. For example, an autistic girl might respond to the news of the death of a classmate’s pet by sharing a television episode about the death of a pet or by suggesting replacing the pet, not understanding that the expected response is to express sorrow.

Individuals can become overwhelmed emotionally by cognitive, emotional, behavioral, or sensory demands. When overwhelmed, autistic individuals might “shut down” or withdraw, or they might have an emotional outburst, typically called a “meltdown.” These outbursts may seem to others to be “out of the blue,” if the trigger

of the meltdown is not recognized. Thinking about an upsetting situation can generate the same physiological stress response as the situation itself, and a repetitive behavior typical of autism generally is a tendency to perseverate or have repeated thoughts. Perseveration over a trigger can also result in a meltdown, so the trigger might not have immediately preceded the meltdown.

There are positive autistic traits to identify in addition to challenges (Austin & Pisano, 2017). Autistic individuals characteristically are very truthful and feel deeply about honesty and integrity. Children with ASD will often be upset if peers do not follow rules in class. They are frequently passionate about social injustice and adamant about fairness. They are very detail focused, which allows them to make connections and have analytic insights that non-autistic individuals miss, but this can be a challenge when the task is inferring overall intent. This detail focus can lead them to monologue in conversation in order to fully cover an idea, but it also means they explore ideas in depth. Most have high standards for themselves and will work hard to master material. This also can make them frustrated if they cannot perform at the level they expect.

Language Usage in the Clinical Interview Process

When interviewing an autistic person of any age or any gender, it is vital to understand literal use and understanding of language. A girl or woman might be slower to respond than typically expected, as they process language and thoughts. In my experience, a girl or woman may pause for several minutes to think through what she considers a precise response.

Autistic individuals can be confused when asked open-ended questions. The clinician needs to ask specific questions, framed clearly and directly. One needs to pay careful attention to the clinical history of social challenges in acceptance and inclusion by peers. A report of having friendships does not mean that the patient is in reciprocal relationships. Many autistic females describe feelings of loneliness and isolation. Obviously, she will not be aware of social or language cues she has missed, so she may simply be confused and hurt about experiences of rejection. A patient may not report sensory sensitivities or difficulties with changes in routine or transitions unless directly asked, because she does not realize that these symptoms are relevant. The clinician must ask specifically about her experience to discover the stress, pain, and confusion that lies beneath a “high functioning” exterior. Often, undiagnosed women complain that therapists do not believe them or minimize their stress when they describe their difficulties.

The diagnostic interview needs to take into account the past misinterpretation of symptoms and camouflaging behavior. Women often have well-developed skills to mask autistic difficulty

with eye contact, facial expressions, and social interactions. It is important to assess daily and occupational functioning from the perspective of the patient. She may express exhaustion from social interactions, difficulty with sensory issues, and problems sustaining friendships or employment. Some women present with alexithymia, difficulty identifying their feelings.

Often patients with autism are thought to be resistant to therapy or noncompliant if they do not answer questions quickly or if they reject the suggestions or comments of the clinician. It is important to understand that the communication challenges between autistic and non-autistic adults are a two-way process (Milton, 2012). The patient is being challenged to understand the clinician. In turn the clinician has to try to understand the perspective of the autistic patient and needs to check if their understanding is accurate. This can help avoid a breakdown in communication.

The clinician needs to understand how the social, behavioral, and cognitive autistic symptoms mentioned in DSM-V present in school, work, or at home at different developmental stages (and by gender). Because of the multiple diagnoses given to a child previously, parents may not see their daughter as having issues due to autism because her problems have never been explained in such a framework. Presenting problems may have been construed as behavior that is oppositional, resistant, stubborn, and defiant, or that she is anxious and depressed. She may be seen as having social problems because she is not invited for play dates or does not fit in.

Measures and Screens for Females With ASD

Often by the time women with ASD are adults, they have been in therapy numerous times focusing on anxiety, depression, borderline traits, obsessive-compulsive disorder (OCD), or ADHD—but not autism. They often have been given multiple diagnoses. They may have had multiple trials of medication.

With children, if autism is suspected, referral for testing by a psychologist or developmental pediatrician using instruments designed for assessing ASD is the usual protocol. Tools such as the Social Responsiveness Scale, Second Edition (SSRS-2) and Test of Pragmatic Language can pick up deficits in pragmatic language. Girls with high levels of autistic difficulties as measured by the SSRS-2 are less likely than equivalent males to meet autism diagnostic criteria clinically, even if they undergo an autism assessment that meets current standards for best practice. Even “gold standard” assessment such as the ADOS can miss girls (Mandy & Lai, 2017).

The first screener for the female autistic presentation in children and adolescents was recently developed (Ormond et al., 2018) in a pilot study involving 232 females. The questionnaire has two forms, one for children 5–12 years of age (GQ-ASC 5–12

years) and another form for adolescents 13–19 years of age (GQ-ASC 13–19 years). These screening tools are used to interview caregivers of children and adolescents. They are available at the website of Minds & Hearts () under “resources.” These tools are not standardized stand-alone diagnostic measures with reliability studies but are based in extensive work at autism centers.

Assessment screening tools for adults also exist. Such tools include the 50-item Autism Spectrum Quotients (AQ) available at the Autism Research Centre site and the AQ was found to have a sensitivity of .95, specificity of .53, positive predictive validity of .84, and negative predictive validity of .78 in a study by the developers (Woodbury-Smith et al., 2005). Another tool is the 80-item Ritvo Autism-Asperger Diagnostic Scale-Revised (RAADS-R), which is available online (<https://www.aspietests.org/raads/questions.php>). The latter is self-scoring, with the thresholds for an autism diagnosis. A study by its authors suggest good validity and reliability (Ritvo et al., 2011). These tests should be completed with the clinician present and available to discuss the results (and possibly follow up with further evaluation).

The Adult Asperger Assessment (AAA) is a structured clinical interview available at the Autism Research Centre site (https://www.autismresearchcentre.com/arc_tests). It can be a useful guide to making an ASD diagnosis in adults (Baron-Cohen et al., 2005). Like other diagnostic instruments, there may be a bias in the AAA toward the male phenotype. Women who seem more successful socially or professionally may still warrant an ASD diagnosis based on autistic symptoms and ongoing social struggles even if they don’t meet threshold cutoffs.

Additional development and research is needed on diagnostic screeners for autism. A recent review suggested that adult measures for autism (ADOS, RAAD-SR and AQ) were all in the poor to fair range in terms of specificity and sensitivity (Conner et al., 2019).

So-Called Levels of Severity

ASD diagnoses are differentiated by severity levels in the DSM system, ranging from severe to “mild.” There is a tendency to refer to autistic individuals who have normal intelligence and who present well as “high functioning.” Females whose autistic diagnosis is missed are especially likely to be considered high functioning. However, there is no level of autism that is not in need of support (American Psychiatric Association, 2013).

Clinicians need to understand that the designation “high functioning” is usually based on outside observation of someone’s presentation and not on the experience of the patient. Many “successful” autistic women complain that their therapists do not take their internal struggles with autism seriously. The assumption is often made that someone on the autism spectrum

who is high functioning does not need support in daily life. This is simply untrue.

The belief that high functioning autistic people do not need help is challenged by the reality of the lives of many of these autistic adults. Their intelligence, reading and writing skills, and speaking abilities do not obviate the other challenges of autism. The impact of problems with social reciprocity, inflexibility, pragmatic language, executive functioning, and sensory hypo- or hypersensitivity can be significant. This is the focus of treatment with many women with ASD.

There is an 85% unemployment rate of college graduates with autism (Pesce, 2019). This is the highest level of unemployment of any disability group. Many who get jobs are unable to sustain them because the social, sensory, and behavioral demands of the workplace do not accommodate autistic employees. Failure to achieve successfully in employment, loneliness, and misunderstanding are typical experiences for many autistic adults. There are high rates of depression and anxiety. There is a much higher rate of suicidality among women with ASD than other women in the general population. One study suggested autistic females committed suicide three times more often than non-autistic females (Kirby et al., 2019). Predictors of suicidality among women with ASD include high intelligence, self-harming behaviors, camouflaging, and unmet needs for support (Cassidy et al., 2018).

Frequent Co-Morbid Diagnoses

Living with the traits of autism is understandably linked to anxiety. Anxiety can be secondary to the social and cognitive demands of rapidly changing situations and expectations, but more than 50% of individuals with autism at all ages are diagnosed with a co-morbid anxiety disorder, specific phobias in children, and generalized anxiety disorder in adults. Social anxiety is principally characterized by performance anxiety or fear of judgement, whereas in autism social skills and the ability to perceive interpersonal cues are often simply lacking (Lai & Baron-Cohen, 2015).

More than 50% of autistic individuals have depressive symptoms and depressive disorders. Screening for depression is important. Autistic adults can have difficulty reporting emotional symptoms, but decreased satisfaction in usually enjoyable activities, changes in energy or concentration, and disturbed sleep patterns can be helpful in making the differential diagnosis. With autistic individuals, higher intellectual ability is linked to better social adjustment (masking) but is also linked to increased depression and low self-esteem. Increased suicidal thoughts and behaviors (with or without associated depression) are reported in 11–14% of children but can be as high as 66% for ideation and 35% for plans or attempts in adults. Rates are higher in adults who also have a diagnosis of depression (Lai & Baron-Cohen, 2015).

Up to 35% of autistic adults are diagnosed with co-morbid OCD; this can be due to misdiagnosis since perseveration and routine are part of the autistic presentation. OCD symptoms are often ego-dystonic for patients with only OCD, while obsessive symptoms are generally ego-syntonic for autistic adults (Lai & Baron-Cohen, 2015).

Differentiation of autism and personality disorders can be difficult, and there is a high occurrence (up to 60%) of autistic individuals diagnosed with personality disorders, particularly schizoid, schizotypal, avoidant, and OCD. This is possibly due to overlapping symptomatology and the failure to consider an autism diagnosis. Borderline personality disorder can be misdiagnosed in women due to difficulties in interpersonal relationship, identity issues, problems with emotional control, and suicidal ideation. Autism should be ruled out before a borderline personality disorder is diagnosed (Lai & Baron-Cohen, 2015).

Attention deficit disorder (ADHD) is diagnosed in both children and adults in as much as up to 40% of autistic adults. In autism, the issues are often difficulty in changing the focus of interest and in switching interest, or in having interest in non-preferred topics. People with ADHD only demonstrate difficulty maintaining focused attention, effort, and at times with hyperactivity (Lai & Baron-Cohen, 2015).

There is confusion between anti-social personality disorder, narcissistic personality disorder, and autism because of the misconception that autistic people lack empathy. Autistic individuals may not demonstrate cognitive empathy but do have affective empathy. Individuals with anti-social and narcissistic personality may have cognitive empathy (i.e., recognizing how others feel) but lack affective empathy, making it easier for them to be callous and manipulate others.

There is a higher incidence of eating disorders in autistic girls and women, as well as a higher incidence of gender dysphoria and transgender identity questioning (Lai & Baron-Cohen, 2015). There are medical conditions frequently comorbid with autism as well, including GI and sleep disorders. Children with ASD are more likely to be diagnosed with Crohn's disease and ulcerative colitis than controls (Lee et al., 2018). Forty percent to 80% of children with ASD have sleep disorders compared to 30% of typically developing children; sleep disorders are also found to be more severe in children with ASD (Bauman, 2010).

The Importance of an ASD Diagnosis for Females

The price paid by undiagnosed autism in females is high. Because they do not look like autistic males and because they camouflage autistic symptoms, they appear to be “normal” (neurotypical)—and they are expected to act and react appropriately. Girls with

ASD are often labeled as “rude” or “lazy,” and they are told to behave more normally. If they are bullied, they are often told that this is their fault due to their overly sensitive or quirky behavior. Their repeated efforts to fit in with peers fail, and they are often rejected by peers. They are subjected to criticism by their parents and teachers, inducing self-blame and low self-esteem. As a result of these experiences of rejection and criticism, they are more likely to be anxious and depressed (Bargiela et al., 2016). Their academic needs are dismissed as avoidant or oppositional.

As girls become adolescents, sexual development can be confusing and distressing. They may not understand pubescent physical changes to their bodies and the hygiene necessary as a result. Formal sex education is generally limited. Informal peer-to-peer sexual education about sexual behavior, norms, and safety is often “missed” by autistic adolescents. They have age-appropriate interests in sexuality but miss cues about flirting. Their desire for acceptance can lead them to misjudge the overtures and intentions of others, so they may be easily manipulated. This puts them at risk for sexual abuse and victimization. There is a high incidence of sexual abuse among females with ASD (Bargiela et al., 2016).

A lack of understanding of the complexity of social expectations for females can lead to the internalization of negative stereotypes (Ballan & Freyer, 2017). Autistic adolescents’ behavior does not always conform to gender expectations of femininity. Females are expected to be cooperative and eager to please others. Experiencing themselves as “unfeminine,” and as having difficulty fitting in with other women, some adolescents with ASD express gender confusion and question their gender identity (Baker, 2002).

Throughout their lives, women with ASD have had their behaviors, sensory, and cognitive differences and other symptoms related to autism misunderstood and labeled negatively. As a result of these expectations there are high levels of internalizing symptoms, such as anxiety, depression, and eating disorders, which may appear as primary diagnoses until a woman is diagnosed as on the autistic spectrum. Once appropriately diagnosed, professionals can help women develop self-understanding and address issues of self-esteem and self-respect. It is then possible to reframe challenges, approach such women realistically, and recommend needed support (Jamison et al., 2017; Bargiela et al., 2016).

Women have the same autistic traits as children and adolescents. They present with symptoms of anxiety, depression, and eating disorders. Woman with ASD may have neurotypical partners. Sexual intimacy may be challenging because of sensory issues or because of lower sexual desire. However, many autistic women appear to be “normal” wives and mothers, unless the clinician

inquires about inward struggles that go on due to social, sensory, and behavioral demands.

The qualitative experience of adult autistic women was recently explored in a small sample of female patients (Milner et al., 2019). The thematic analysis was important and worthy of exploration by the clinician with female patients in an age-appropriate manner. One expected critical factor was patients’ experiences of attempts to fit into expected behavior in their social milieu. All spoke of struggles in making and keeping friendships. They found coping with “normal” social demands exhausting. Many described working so hard for so long at keeping up a social mask (i.e., trying to maintain neurotypical social behavior) that they were exhausted and that they couldn’t remember their own authentic identity. They struggled with the expectations of female gender roles: that they be soft-spoken, intuitively empathic, nurturing, and socially adept. They struggled with others’ lack of acceptance of their differences, and the lack of support for social, cognitive, and executive function challenges. Their typical blunt truthfulness, missing cognitive empathic cues, literal thinking, need for clearly expressed expectations, difficulty handling cognitive or behavioral transitions, and missed social cues were interpreted as negative attributes and not autism.

Coping strategies included spending time alone, as well as depending on routine and camouflaging autistic behavior. Sensory sensitivities were significant in their lives, as were their experiences of times when they were so overwhelmed by emotional and sensory situations that they needed to shut down or they became extremely upset. They felt it was important for others to understand that these behaviors reflected being overwhelmed; these behaviors are not manipulative but were caused by emotional overload.

Most patients described feeling gullible and at risk of being taken advantage of. Women can miss the nonverbal warning signs of a sexual overture or the nonverbal cues that they are likely to be exploited or misled. Yet, all spoke of the positive aspects of autism, including having a unique perspective of the world, a sense of identity as being different, and a strong sense of justice (Milner et al., 2019).

In a small study of 14 successful women with late diagnoses of autism, the authors analyzed detailed accounts of their experience to find common primary themes (Bargiela et al., 2016). The women’s stories yielded five common themes. All of the women had been repeatedly told that they were not autistic, although they were evaluated for mental health problems, primarily anxiety, depression, and eating disorders. Mental health professionals had discounted their autistic symptoms.

They discussed the risks of having a late diagnosis; a significant number of those in the sample experienced sexual abuse and

intense self-criticism and judgment by others. They found that when these women were diagnosed, it helped them foster a positive sense of identity. These women had higher social motivation and more internalizing problems than men.

All the women studied expended a great deal of effort pretending to be normal to fit in with peers. They described this as wearing a mask or taking on a persona in social situations. Sometimes social mimicry was unconscious, since these women had practiced these behaviors for so long. They reported that this experience was exhausting and that they felt they lost a sense of authentic identity. These women also felt pressured to gender stereotypes and felt inauthentic when they adopted them. They had difficulty navigating relationships with typical friends and found online communication easier (Bargiela et al., 2016).

These women described a pattern of passivity that led them to unhealthy relationships and high-risk situations. Nine out of 14 experienced sexual abuse in relationships. They were unable to read others' intentions toward them and had not learned skills for self-protection. They described a desperation for acceptance based on past exclusion that made them vulnerable to exploitation. Some had so little understanding of social rules that they didn't know they could say "no" to a situation until it was too late. However, over time, many learned to be assertive, and having an autism diagnosis encouraged them to be proactive.

Sharing an ASD Diagnosis With a Woman

The disclosure of a diagnosis of autism is somewhat challenging, regardless of the age or gender of the patient. With children, the diagnosis is shared with the parent and the family decides with the clinician how best to disclose it to the child (Eckerd, 2019). Helping parents understand autistic behaviors can alleviate blame and lead to useful solutions to problems at home.

Often teenagers are the least accepting of the diagnosis (Eckerd, 2019), which is a developmentally typical reaction. While understanding of autistic traits can potentially enhance self-knowledge, reduce self-criticism, and validate the need for support and accommodations, teenagers do not want to see themselves as different from peers and often hope that their differences will go away in time. Some clinicians recommend disclosing the diagnosis to teenagers even if it produces a depressive reaction; others recommend waiting until the teenager asks questions indicating a desire to understand differences and difficulties with peers.

One would always share consideration of a diagnosis of autism with an adult. Many women describe relief at being given a diagnosis in terms of enhancing a sense of identity, making sense of past difficulties, and recognizing self-understanding and the potential for self-advocacy. For those who have been searching to understand themselves, a diagnosis can explain a lifetime of try-

ing to fit in, rejection, and confusion. This understanding can have positive practical consequences. For example, understanding of autistic symptoms can help improve the relationship between partners or within families by recognizing the need for clear communication and realistic expectations. The diagnosing clinician can validate the patient's needs, such as taking a break from sensory overstimulation, requiring alone time after social stress, and needing clear expressions of expectations rather than inferences.

Women may also experience initial distress at a diagnosis, resulting in mourning and a period of depression (Baker, 2002). The patient may feel that the diagnosis signals failure of her hope to ultimately be accepted and fit in. For her, accepting a diagnosis is giving up the dream of normality. It is important to emphasize that having a diagnosis gives her the opportunity to use her strengths and create strategies for problem areas.

A primary concern with disclosure is the impact of the diagnosis on the self-esteem of the patient. Sharing the diagnosis requires follow-up to help the individual process the information and decide upon how best to proceed. Since patients usually present with anxiety, depression, or other concerns, it is important to discuss support and treatment.

It is important to present a balance of the woman's challenges and strengths. She may not have had others value her strengths and interests, and she may not have valued them herself. She needs to value her integrity, her cognitive strengths, and her empathic nature. I have a married autistic (previously called Asperger's) patient. She was undiagnosed until her early 30s. We discussed the ways her autistic traits impacted her relationship with her spouse and extended family. For example, she did not realize she needed to greet them (say "hi") and explain her exit before she left. She needed family members to be clear if they had a request and she needed some routine. On the other hand, her autistic trait of deep empathy and loyalty was evident. Her husband developed a neurological condition that was progressively becoming worse when they were married less than a year, and she never considered leaving him or complaining. Her spouse repeatedly thanked her for standing by him and realized some people might have left. She was deeply valued at work for her insights that often were far beyond those of her co-workers, and at times they asked her to solve problems that confounded others. However, when she presented to her team, she often needed time to think and compose her thoughts to answer questions. Both her capability and her slow response time were characteristics of her autism.

It is important for the patient to understand both the usefulness and the limits of strategies she has used—as well as the impact of constant stress. Some of the books suggested for clinicians, parents, and patients (see Table 1) demonstrate that there are solutions to life on the autistic spectrum.

The clinician exploring the diagnosis of autism in women needs to be aware that different perspectives of autism are being shared by some researchers and by many autistic adults themselves. Some researchers use the terminology *autism spectrum condition*, emphasizing a holistic picture of cognitive strengths and empathy as well as the challenges and the heterogeneity of the presentation of autistic traits. They suggest that autistic individuals are differently “wired” in processing rather than having an illness to be cured. They feel the term “disorder” focuses only on disability (Lai & Baron-Cohen, 2015). The concept of “neurodiversity” is also relevant.

From the neurodiversity paradigm perspective, different neurocognitive ways of functioning would not be pathologized, but would be seen simply as different. There isn’t a right way and a wrong way to function. The idea of a “right” way would be a social construction; it would be no more correct than thinking there is a “right” gender. In the neurodiversity model, the “problem” with autism is less autism itself than the lack of acceptance and accommodations to neurodiverse functioning, which results in stress, rejection, and other consequences.

“Neurotypical” means having a neurocognitive style accepted by a society as “normal.” This is the idea that there are multiple neurological profiles (autism and ADHD as examples) as well as what is considered “normal” or “neurotypical.” People are neurodiverse, having different patterns of functioning. Adult autistic individuals supporting the neurodiversity model strongly oppose the view that they “have autism” (i.e., are a person with autism) as opposed to “being autistic” (i.e., are an autistic person). They feel that autism is a vital part of their functioning and identity, and they believe that many aspects of autism are problematic primarily because they are not accepted or accommodated by the neurotypical world. They feel that neurotypical people tend to attribute disability and a lack of capability to autistics.

The “neurodiversity movement” is a social justice movement, largely supported by autistic adults, that they should have the same degree of respect and inclusion as neurotypicals. They feel that an understanding of autism necessitates listening to the experiences and ideas of autistic adults themselves, rather than having neurotypical “experts” assuming understanding on their own. Autistic adults often provide a very different perspective on the nature and experience of being autistic.

The “Invisible” End of the Spectrum

What about women who present with autistic traits that the clinician feels do not sufficiently meet the criteria for an ASD diagnosis? The terms “autistic tendencies” and “broader autism phenotype” have been used to refer to a sub-clinical autism category (Baker, 2002; Gerds & Bernier, 2011). If the decision is made against making a diagnosis of autism because of a concern with

scientific accuracy despite the presence of autistic traits, the explanation of these traits is critical to the patient. For the woman or girl (and parents, if one is evaluating a child) these traits may be the key to understanding extremely difficult life experiences, providing support, and planning appropriately (Baker, 2002).

Women need to understand social challenges because there are ongoing moral judgments of women who fail to observe expectable reciprocity and social rules. In a 1960s study cited by Baker, there was almost universal moral outrage when social expectations were breached, such as not using the appropriate greeting or inappropriate participation in an ongoing conversation (e.g., talking too long, giving too many details, expounding on a subject of interest.) The woman or girl may be struggling with a life-long experience of being on the receiving end of such outrage. Any information leading to self-understanding is important. Many women just below the diagnostic threshold identify more with the autistic community than with those considered “normal” or neurotypical. These women find others with autism helpful in understanding their experience and finding strategies for handling life situations (Baker, 2002).

Discovering a supportive online community can be enormously valuable to patients and parents. For patients diagnosed with autism (or with a subthreshold autistic syndrome), the validation and support of others with similar experiences may be the first time they have felt understood. Learning the experiences of other parents can be extremely helpful. Autistic adults feel that sharing their understanding is important because they have lived experiences similar to those of the child. Many autistic adults oppose Applied Behavior Analysis, which is considered evidence-based treatment in the professional community. They feel that extinguishing autistic behaviors and teaching neurotypical behaviors has long-term negative consequences. There is controversy when the opinions of autistic adults and professionals differ regarding appropriate treatment for children. It is important to encourage parents to read about different perspectives and to choose what they feel is best for their child.

Treatment for ASD

Treatment for children, teens, and women with ASD is complex and beyond the scope of this article. One excellent reference for cognitive therapy for adults with ASD is Gaus (2007). There are many curricula for teaching social skills to children on the spectrum, although there needs to be awareness of the difficulties with masking when a child is expected to act “normal” all the time.

There is a need for increased acceptance of neurodiverse behavior and for education of parents and professionals to help the girl navigate the neurotypical world with success and without having negative self-esteem or a loss of individual identity and self-acceptance. It is vital that girls and adolescents are educated

Table 1

Resources

<p>Recommended books for clinicians, parents, and teachers</p>	<p>Simone, R. (2010). <i>Aspergirls: Empowering Females with Asperger Syndrome</i>. Jessica Kingsley Publishers, London and Philadelphia.</p> <p>Cook, B. & Garnett, M. (Ed.). (2018). <i>Spectrum Women: Walking to the Beat of Autism</i>. Jessica Kingsley Publishers, London and Philadelphia, PA</p> <p>Gaus, V. (2007). <i>Cognitive-Behavioral Therapy for Adult Asperger Syndrome</i>. The Guilford Press, New York, NY</p> <p>Hendrickx, S. (2015). <i>Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age</i>. Jessica Kingsley Publishers, London and Philadelphia, PA.</p> <p>Notbohm, E. (2005). <i>Ten Things Every Child With Autism Wishes You Knew</i>. Future Horizons Publisher, Arlington TX.</p> <p>Sakai, K. (2005). <i>Finding Our Way: Practical Solutions for Creating a Supportive Home and Community for the Asperger Syndrome Family</i>. Autism Asperger Publishing Company Shawnee Mission, KS.</p> <p>Winter, M. (2003). <i>Asperger Syndrome: What Teachers Need to Know</i>. Jessica Kingsley Publishers, London and Philadelphia, PA.</p>
<p>Organizations with available resources</p>	<p>The Asperger/Autism Network (https://www.aane.org). AANE is a recognized non-profit organization based in the northeast US, which provides both services at locations and online. These services include free consultations, parent and patient support and coaching, life map services which include job coaching, online support groups, and webinars for autistic individuals, parents, and professionals. There is a sliding scale of fees.</p> <p>Global and Regional Asperger Syndrome Partnership (https://grasp.org/). GRASP is a multidimensional resource created by autistic individuals. They offer both online membership and regional membership for those wanting to join support groups across the US. Online they provide blog posts, information about resources, educational programs, and research for adults, teens, and families. They also have coaching for autistic adults and a Facebook discussion group.</p>
<p>Facebooks groups and other websites</p>	<p>Professionals, parents, and autistic adults should be aware that Facebook groups run the gamut from being very anti-autistic to being intolerant of people asking “politically incorrect” questions from a neurodiversity perspective. These groups were chosen as offering a variety of perspectives in a supportive environment:</p> <p>Mums On the Spectrum provides support for autistic mothers.</p> <p>Autism Support and Discussion Group has neurotypical and autistic moderators. It provides information and support for parents.</p> <p>Autism Awareness offers support for parents.</p> <p>Neurodiversity Newsstand has discussions for parents, professionals, and autistic individuals.</p> <p>Actually Autistic Adults and Allies is a support group from a neurodiversity perspective.</p> <p>Websites for adults include Aspergers101.com, Autistic Woman (https://autisticwoman.weebly.com) and The Aspergian (https://theaspergian.com) for articles by neurodiverse writers.</p>

in sexuality and in safety since peer-based learning is often difficult for them.

Psychoeducation is critical because the child and parents or adult would be unaware of the etiology of many of the symptoms and suffering that is secondary to autism. This also applies to negative labels attributed to the child or adult that need to be reframed as reflecting autistic versus purposeful behaviors. Social skills, relationships, and job coaching are often necessary to help the child or adult navigate daily experiences, and appropriate accommodations need to be made.

Take-Home Points for Clinicians

1. Autistic girls and women are significantly underdiagnosed, even if previously examined with “state of the art” assessments.
2. Autistic females present differently from autistic males. They can mask social deficits, and repetitive behaviors are less common. Interests can seem normal. The presence of autistic traits is not explored, and an autism diagnosis is either not considered or is considered and dismissed out of hand.
3. Autistic girls and women are frequently misdiagnosed and medicated for disorders based on a misinterpretation of the individual’s presentation of diagnostic ASD symptoms or based on symptoms that are iatrogenic and based on previous misdiagnosis. Diagnosing co-morbid disorders and missing ASD is common.
4. Autistic girls are generally mislabeled and criticized. Parents and teachers often blame them for behavior due to autistic symptoms. As a result, these girls do not receive the understanding, accommodations, and support they need.
5. Females who present with normal intelligence and who perform adequately or well in daily life may still be struggling with significant autistic symptoms, presenting as internalizing problems such as anxiety, depression, and eating disorders.
6. Women with autistic traits require support to be successful in relationships and employment. Autistic adults have the highest rate of unemployment for any disability group, despite many individuals with high intelligence and college or advanced degrees.
7. Undiagnosed women without support are at risk for anxiety disorders, depression, and suicide due to experiences of rejection, criticism, blaming, and resulting low self-esteem and self-worth.

References available at NationalRegister.org