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Jolynn L. Haney

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## Autism, females, and the DSM-5: Gender bias in autism diagnosis

Jolynn L. Haney, PhD, LSW<sup>a,b</sup>

<sup>a</sup>Deerfield Data Management, Collegeville, Pennsylvania, USA; <sup>b</sup>Center for Social Work Education, Widener University, Chester, Pennsylvania, USA

### ABSTRACT

Autism is a neurodevelopmental condition thought to occur predominantly in males. Despite limited research, there is evidence that criteria used to identify autism are gender-biased, leaving females with autism undiagnosed or misdiagnosed. This article provides a brief history of autism and an overview of research related to gender bias in autism spectrum diagnosis. In addition, research on DSM-5 autism criteria relevant to gender is reviewed, along with the role diagnostic screening instruments play in perpetuating gender bias. Finally, the sensitivity of DSM-5 criteria to females on the autism spectrum is considered within the context of social work practice and research.

### KEYWORDS

Autism; DSM-5; females; gender bias; social work

In May 2013, the American Psychiatric Association (APA) published its fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). In it, significant changes were made to criteria for diagnosing autism spectrum disorders. Although it is too early to assess the long-term implications of these changes for persons with autism, the revisions have generated interest among clinicians, researchers, and individuals on the autism spectrum. Some researchers contend that the new criteria will reduce the number of individuals diagnosed with autism (Kim et al., 2014; Maenner et al., 2014; McPartland, Reichow, & Volkmar, 2012; Taheri & Perry, 2012); others (Huerta, Bishop, Duncan, Hus, & Lord, 2012; Swedo et al., 2012), however, maintain that the changes will have no material effect on prevalence, but will enable more accurate identification of autism than criteria used in earlier editions of the DSM. Even though Maenner et al. (2014) estimated that autism prevalence might be reduced from 1 in 88 children to 1 in 100 children, because individuals could still qualify for a non-autism diagnosis, the researchers concluded that access to services would not be impacted. Others are not as certain, arguing that persons who no longer meet diagnostic criteria for autism, or are diagnosed with another disorder, might not be eligible for services targeting autism, including early intervention services

**CONTACT** Jolynn L. Haney  [jhaney@deerfielddata.com](mailto:jhaney@deerfielddata.com)  Widener University, One University Place, Chester, PA 19013.

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(Grant & Nozyce, 2013). A critical topic that has not been addressed is what effect the changes to autism diagnostic criteria will have on females, a population historically under-identified and misdiagnosed. This article provides a brief history of autism and an overview of research related to gender bias in autism spectrum diagnosis. In addition, it includes a review of research on DSM-5 autism criteria relevant to gender, along with the role that diagnostic screening instruments play in perpetuating gender bias. Finally, the sensitivity of DSM-5 criteria to females on the autism spectrum is considered within the context of social work practice and research.

## **Autism**

Autism is a neurodevelopmental disorder characterized by significantly and persistently impaired communication, impaired social interaction, and restricted and repetitive patterns of stereotyped behaviors and interests that interfere with an individual's ability to function (APA, 2013). It is considered a spectrum condition, because even though persons with autism share the same core symptoms, the way these symptoms present in each person varies considerably (Veselinova, 2014).

In 1944, Hans Asperger developed a special interest in a number of young patients who demonstrated lack of empathy, had limited ability to form friendships, engaged in one-sided conversations, were intensely absorbed by special interests, and had clumsy motor skills (Frith, 1991). Asperger used the term "autistic psychopathy" to describe what he saw as abnormal personalities (Wing, 1981). A year earlier, Leo Kanner had identified a condition in a group of children with similar social and developmental impairments, which he named "early infantile autism." Both Asperger and Kanner used the term "autistic"; however, compared to Kanner's patients, Asperger's patients showed milder functional impairments (Lyons & Fitzgerald, 2007). All of Asperger's patients, and the majority of Kanner's patients, were male. Noting this, Asperger (1944/1991) commented, "it may be only chance that there are no autistic girls among our cases, or it could be that the autistic traits in females only become evident after puberty. We just do not know" (p. 85).

## **Gender bias in autism and Asperger syndrome**

In 1981, Wing conducted a small epidemiological study to examine sex ratios in children with autism who had varying levels of intellectual functioning. Her findings showed significant differences between males and females in what she termed a "triad of language and social impairments" (p. 136). This observation prompted her to recommend further research to understand sex differences in autism. By 1992, evidence began to surface that there might be

a female autism phenotype less likely to be recognized by clinicians, particularly for females who had normal intelligence and milder forms of autism (Kopp & Gillberg, 1992). When Ehlers and Gillberg (1993) conducted a total population study to investigate the epidemiology of Asperger syndrome, their findings revealed a smaller male-to-female ratio than expected. They hypothesized that girls might be better able to employ social skills than boys, thereby minimizing the social impairments characteristic of the disorder, and consequently hindering diagnosis (Ehlers & Gillberg, 1993). Gillberg (1993) examined factors related to autism, including gender, noting that females might be less likely to be referred for treatment or more likely to be misdiagnosed. A total population study by Mattila et al. (2007) also showed a close male-to-female ratio for children diagnosed with Asperger syndrome. Concurring with Ehlers and Gillberg (1993) and Gillberg (1993), Mattila et al. (2007) speculated that females with autism might exhibit superficial social skills, which could interfere with accurate diagnosis. This theory holds that females with autism, especially those with higher cognitive abilities (i.e., normal intelligence), are better able to mimic socially acceptable behaviors than males with autism (Ehlers & Gillberg, 1993; Goldman, 2013; Mattila et al., 2007). Thompson, Caruso, and Ellerbeck (2003) posited that females tend to internalize psychic distress, which manifests as anxiety, mood, or eating problems, whereas males tend to externalize their problems using displays of aggression. Noting that only 2% of autism studies between 2000 and 2002 examined gender differences by analyzing dependent variables separately for males and females, Thompson et al. (2003) concluded that “most of what we believe we know about autism is actually about males with autism” (p. 351). In cases where females have milder forms of autism, diagnosis occurs later than for males (Goin-Kochel, Mackintosh, & Myers, 2006), and when autism is identified in younger females, those females tend to have lower intellectual functioning (Koenig & Tsatsanis, 2005). The fact that more females than males tend to have co-occurring autism and intellectual disability could be an artifact resulting from diagnostic criteria that are less sensitive to females with normal intellectual functioning.

Koenig and Tsatsanis (2005) theorized that sex characteristics factor into identifying autism in children. They warned against “using a mental ‘prototype’ for diagnosis that has been constructed based on experience with affected boys only” (p. 229). Hartung and Widiger (1998) observed that if the expression of symptoms of a disorder differs by gender, the development of diagnostic criteria will be biased toward the gender that externalizes psychic distress and exhibits socially unacceptable behavior. Clinical accounts of persons with Asperger syndrome have been based on individuals referred for therapeutic intervention after they demonstrated social inappropriateness. For example, Asperger’s original cases were referred to his clinic after they exhibited overtly aggressive behaviors, opposition to authority, and

inappropriate conduct in school and at home (Asperger, 1944/1991). Wing's clinical account of Asperger syndrome in six individuals included only one adult female, who reportedly exhibited overt behavioral misconduct, namely childish temper tantrums, when frustrated (Wing, 1981).

Because the literature on autism supports the notion that autism is a male-dominated disorder, an alternate female phenotype might not be considered during the diagnostic process, particularly if evaluators are biased by their own gender expectations about autism (Goldman, 2013).

### **DSM-5**

Just as more attention was being directed to females on the autism spectrum, the APA made substantive changes to autism spectrum disorder diagnostic criteria in the DSM-5. In the DSM-IV, autistic disorder was one of four categorical diagnoses that comprised a group of disorders named pervasive developmental disorders (PDD) (APA, 1994). In addition to autistic disorder, the PDD group included Asperger's disorder, childhood disintegrative disorder, Rett's disorder, and pervasive developmental disorder not otherwise specified (APA, 2013). These diagnoses were removed from the DSM-5, the term *pervasive developmental disorder* was replaced by *neurodevelopmental disorders*, and autistic disorder was renamed autism spectrum disorder (ASD). The diagnostic criteria for ASD was revised by

- (1) converging the diagnostic groups previously subsumed under the category of PDDs into a single diagnosis of ASD; (2) merging the social and communication impairment symptom domains required for the diagnosis of autism into a single domain, thus reducing the symptom domains involved in diagnosis from 3 to 2; (3) expanding the "restricted, repetitive behaviors" symptom domain to include abnormalities in sensory processing; and (4) relaxing the age at onset criterion. (Hazan, McDougle, & Volkmar, 2013, p. 740)

According to an early status report prepared by the APA neurodevelopmental disorders work group (Swedo, 2009), the changes were designed to reflect the dimensional nature of autism as being a condition that exists on a single spectrum, improved diagnostic accuracy, and, unlike prior DSM editions, give clinicians a way to describe individuals with autism in greater detail and include "gender and cultural factors" (para. 4).

These revisions, in particular the removal of Asperger disorder from the DSM, triggered mixed reactions from researchers, clinicians, and autism self-advocates (Giles, 2014; Kapp, 2012; King, 2014; Linton, Krcek, Sensui, & Spillers, 2014; Mayes et al., 2014; Perry, 2014; Spillers, Sensui, & Linton, 2014; Tsai & Ghaziuddin, 2014; Tsai, 2013). In addition to opinion, commentary, and speculation, a few studies attempted to project outcomes by conducting retrospective case reviews using proposed DSM-5 autism diagnostic criteria

(Huerta et al., 2012, 2012; McPartland et al., 2012; Taheri & Perry, 2012). To date, just two studies have conducted prospective analyses comparing final DSM-5 criteria to DSM-IV (APA, 1994) criteria for diagnosing autism (Kim et al., 2014; Mayes et al., 2014). As yet, there appears to be no research focusing on gender bias using DSM-5 diagnostic criteria to identify ASD in females. In the absence of gender specific research, it might be possible to systematically review existing research on the DSM-5 autism criteria to examine the sensitivity of DSM-5 in identifying females on the autism spectrum. It is worth mentioning that although DSM-5 provides little guidance regarding gender bias issues, it does include a statement that females with autism might not be diagnosed due to gender differences, and that “girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestations of social and communication difficulties” (APA, 2013, p. 57).

Although the DSM-5 field trial publications do not detail sex differences between DSM-5 and DSM-IV autism diagnostic criteria, other evidence suggests that DSM-5 criteria do not identify females with autism any better (or worse) than DSM-IV. For example, Huerta et al. (2012) examined existing clinical records to estimate the sensitivity of proposed DSM-5 criteria, compared to DSM-IV criteria, for autism spectrum disorders within three phenotypic subgroups of children. In the gender subgroup, the researchers found that diagnostic sensitivity for females ranged from 0.88 to 0.93. Sensitivity for males was very similar, ranging from 0.89 to 0.92. Although the sample in this study might not have been representative, the implication is that DSM-5 criteria are only slightly less sensitive than DSM-IV criteria, and that they are no less sensitive for females than males. McPartland et al. (2012) found that a slightly higher percentage of females met criteria for autism diagnosis than males (63.2% vs. 60.4%) using proposed DSM-5 criteria to diagnose participants from DSM-IV field trials. Although they did not analyze by gender, Taheri and Perry (2012) found that 63% of previously diagnosed children met proposed DSM-5 criteria for autism, with lower percentages occurring in children with higher intellectual functioning and better adaptive skills.

In 2014, Kim et al. conducted a prospective, epidemiological study using DSM-IV and final DSM-5 criteria to diagnose autism in children from a South Korean community. Like Huerta et al. (2012), the researchers concluded that males and females were equally affected by the changes to autism diagnostic criteria. They calculated a 2.5:1 male-to-female ratio using DSM-IV diagnostic criteria versus a 2.7:1 male-to-female ratio for children diagnosed using DSM-5 diagnostic criteria (Kim et al., 2014). Similarly, Mayes et al. (2014) found DSM-5 criteria to be slightly less sensitive for identifying autism compared to DSM-IV criteria, but did not examine sensitivity by gender.

## Diagnostic screening instruments

Although there are a number of screening tools designed to identify autism, the value of these instruments for females on the autism spectrum is questionable. Like diagnostic criteria, autism screening tools have been developed based on the male phenotype. Kopp and Gillberg (2011) attempted to address this issue by identifying and evaluating 18 items believed to be sensitive to the female autism phenotype. They added these items to the Autism Spectrum Screening Questionnaire (ASSQ), an instrument developed by Ehlers, Gillberg, and Wing in 1999 to screen for Asperger syndrome and high-functioning autism. Kopp and Gillberg's preliminary findings suggested that several items on the newly named ASSQ-Revised Extended Version were more sensitive to females with autism and were able to discriminate between autistic and non-autistic females. For example, item response analysis revealed that, compared to boys, girls tended to respond affirmatively to four questions on the ASSQ-REV: avoiding demands, difficulty competing daily activities due to repetitive behaviors, interacting mostly with younger children, or having a different voice or speech (Kopp & Gillberg, 2011).

The ASSQ-REV merits further research, ideally in coordination with studies evaluating the sensitivity of DSM-5 criteria to females with autism. For example, in the previously discussed study conducted by Kim et al. (2014), because the researchers used the original ASSQ to screen participants, it is possible that females were underrepresented in their study. Without using a gender-sensitive screening tool, ascertainment bias can confound accurate prevalence rates and sex ratios in epidemiological investigations.

## Implications

Practice specialty notwithstanding, there is a strong likelihood that social workers will encounter individuals with developmental conditions in their practice (Whitaker, Weismiller, & Clark, 2006); yet, little is known about social workers' competencies in working with the autistic population (Preece & Jordan, 2007). Although it is not realistic to expect social workers to be experts on all special populations, it is reasonable to assume they have sufficient knowledge to conduct informed assessments, and can direct clients to other professionals with expertise in meeting the needs of individuals on the autism spectrum.

Practicing without up-to-date or accurate knowledge can pose a substantial risk for psychic harm to persons with autism. Maloret and Sumner (2014) described the case of a young woman, "Sue," who entered mental health services for depression treatment at age 14, but was not diagnosed with Asperger syndrome until age 17. In the interim, she was prescribed medication for anxiety, depression, and insomnia, and was subjected to treatments



contraindicated for autistic persons hypersensitive to external stimuli. The client recounted:

One mistake that sticks out in my mind occurred on the day my therapist told me that they were considering placing me in a hospital for my own safety. I remember crying and repeating “I don’t want to go to hospital” over and over again. I was terrified of being placed in a foreign environment, away from my family and friends. I thought that I would be unable to see them and would become even more isolated. My anxiety increased until I was unable to verbalise my feelings or worries, which made it harder for others to support me. The thought of being taken away from my parents and home, and put somewhere completely new was horrible. For someone who, like me, has an autistic spectrum condition, change is difficult at the best of times; in the vulnerable state I was in, the suggestion that I would be taken away from my support network at home was almost too much to bear. (pp. 24–25)

The implication is that if Sue had been accurately diagnosed at age 14, either her depression might not have progressed to clinical levels, or she might have been directed to services delivered by a professional skilled in treating depression in individuals with autism, thereby avoiding 3 years of unnecessary emotional turmoil. What is important to keep in mind is that diagnostic criteria are guidelines, at best. Therefore, the larger issue may not be whether diagnostic criteria are biased, but rather whether evaluators can recognize and advocate for accurate diagnosis in females who have autism spectrum conditions. Doing so requires practitioners who are able to apply diagnostic criteria critically and to self-reflect about their own gender stereotypes.

At present, aside from the previously discussed ASSQ-REV, there are no other known gender-sensitive autism assessment instruments being tested, however keeping informed about new developments in this area of research is essential in order to inform social workers about new assessment tools. Additional research is needed to determine how new and existing autism screening and assessment instruments fare in differential item analyses, so that practitioners can be aware of the potential for gender measurement error when using these instruments. These steps toward developing social workers’ knowledge about autism and gender can inform practice and are consistent with social work’s strengths-based approach and ecological perspective. Social work educators are ideally positioned to pass this knowledge along to those of their students interested in gaining more knowledge about autism. A qualitative study of female health profession students’ attitudes about working with people with autism included 10 social work students (Werner, 2011). The author noted that:

Students reported that lack of information may contribute to an avoidance of working with this population. For example, “There is not much fondness of working with this population. This is reflected in the fact that there are no relevant courses within the School of Social Work, while there are courses on working with



children and adolescents. Thus, the subject does not receive enough credit and is not appealing” (Social work student 3). (p. 133)

As social workers acquire more knowledge about females on the autism spectrum, practice guidelines can be developed to work with this population. At present, social workers have, as resources, a multitude of autobiographies and memoirs authored by women on the autism spectrum. One well-known author is Temple Grandin (1996); however, other women, whose lived experiences can inform social work practitioners, include Jean Kearns Miller (2003), Liane Holliday Willey (1999), and Dawn Prince-Hughes (2004), to name a few. Practitioners can also reference the work of clinicians, such as Dr. Tony Attwood (2006), who has specialized in mental health services for females with autism, and Dr. Judith Gould (Gould & Ashton-Smith, 2011), another pioneer in addressing issues faced by females on the autism spectrum, have also published on this topic. Social workers can attend workshops and trainings, such as those sponsored by the Initiative for Girls and Women with Autism Spectrum Disorder Autism Program at the Yale Child Study Center. In general, when working with females with autism, social workers should be cognizant of their own biases and stereotypes about gender, as well as stereotypes about autism, particularly regarding sociality. For example, Lorna Wing (1981) noted that “girls tended to appear superficially more sociable than the boys, but closer observation showed that they had the same problems of two-way social interaction” (p. 120). It is not necessarily the absence of communication or social skills that signals autism, but rather whether the individual has the ability to use and sustain use of those skills across different life situations.

As is the case with the general population, individuals who have autism are prone to anxiety, depression, and other behavioral health concerns (Ghaziuddin, Ghaziuddin, & Greden, 2002; Lugnégard, Hallerback, & Gillberg, 2011; Sterling, Dawson, Estes, & Greenson, 2008), which may need professional attention. When presented with a female client who has an autism spectrum condition, social workers must recognize that autism may not necessarily be “the problem.” Yet, they must be able to recognize autism, and implement interventions that consider the characteristics of this condition. For example, females with autism may be hypersensitive to touch, sound, or light, which contraindicates therapies that aggravate the senses. Furthermore, for many individuals, autism represents a different cognitive style, not a disorder; therefore, practitioners should help females focus and build on the strengths and opportunities that autism offers to them, rather than pathologizing their condition.

Practitioners should also be aware that a new disorder—Social (Pragmatic) Communication Disorder (SCD)—was introduced in the DSM-5. A differential diagnosis recommendation in the DSM-5 suggests

that SCD should be considered in cases where individuals have social and communication deficits, but do not show evidence of restricted and repetitive patterns of behaviors, interests, or activities that are necessary to make an ASD diagnosis (APA, 2013). Grant and Nozyce (2013) reported that although the APA neurodevelopmental workgroup for DSM-5 acknowledged that clinical trials using the revised criteria showed that some cases lost the autism spectrum disorder diagnosis, in clinical field trials “there was a net 14% increase in diagnosed cases because of the use of the SCD diagnosis” (p. 588). In other words, the neurodevelopmental disorders workgroup asserted that even though some individuals lost their autism diagnosis, they still met the criteria for SCD (Swedo et al., 2012). The addition of SCD into the DSM-5 is significant because SCD is classified as a communication disorder, not as an autism spectrum disorder. As Tanguay (2011) noted, the diagnostic criteria for SCD are strikingly similar to the criteria for ASD, which means that females with autism, who are already difficult to identify, could be at greater risk for being misdiagnosed with SCD. Practitioners should be aware that females diagnosed with SCD would not be eligible for the protections of autism insurance mandate laws, which require private insurance carriers to cover payment for services, such as speech therapy and applied behavioral analysis, provided to persons with an autism spectrum diagnosis.

## Conclusion

Ever since Kanner and Asperger first described autism more than 70 years ago, autism has evolved from being considered a rare and relatively obscure disease affecting 4.5 in 10,000 children (Lotter, 1966) to a commonly diagnosed disorder affecting 147.1 in 10,000 children (Centers for Disease Control and Prevention, 2014). Thought to occur primarily in males, and defined by behavioral symptoms affecting social and communication abilities, autism may well be one of the most complex, mysterious, and misunderstood phenomena of the twenty-first century. Now that gender differences in autism have finally come to the attention of researchers and therapists, the time is ripe for social workers to learn more about autism in order to become effective clinicians and advocates for females on the autism spectrum.

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