

ASD Is Not A Boy's Club: Identifying and Serving Females with ASD

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Gender Gap

For higher functioning forms of autism, the dramatic increase in identification in recent years **applies only to boys**. Girls are **not** being identified at a higher rate (Attwood 2006, Wagner 2006).

Gender Gap

- **One in 54 boys** in the U.S. has been diagnosed with autism, compared to just **1 in 252 girls**. But a growing body of research hints that the significant sex-based differences in autism diagnoses are a result not just of biological differences, but of a **failure to recognize ASD in girls**.

Pearson, C. (2013, November 26). How Girls With Autism Are Being Shortchanged. Retrieved October 16, 2014, from http://www.huffingtonpost.com/2013/11/26/girls-with-autism_n_4311015.html

Gender Gap

- Because there are far fewer girls diagnosed with autism, researchers tend to rely mostly on data from boys. This creates a **self-reinforcing cycle** in which the symptoms of boys are taken as the norm for the disorder, perhaps leading to fewer girls being diagnosed, and thus included in studies.

Rudacille, D. (2011, June 27). Diagnostic tests for autism may miss many girls. Retrieved October 16, 2014, from <http://start.org/news-and-opinion/news/2011/diagnostic-tests-for-autism-may-miss-many-girls>

Male to Female Ratio

Autistic Disorder 4:1

Intellectual Disability and ASD 2:1

Asperger's Disorder 9:1

Attwood's Hypothesis 4:1

(Fombonne, 2009)

Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. Asperger's and girls. Arlington, TX: Future Horizons.

Age of Diagnosis

- On average, ASD diagnosis in females occurred **2 years after caregivers expressed concerns**.
- The average time between first symptoms and diagnosis was **longer for females** than for males.
- Girls with Asperger's are identified **later** than boys
- In **adults**, females with autistic disorder were diagnosed **later** than males

Begeer, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg, & Koot (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 1151-1156.

Late Diagnosis

- According to unpublished results presented at IMFAR, girls with Asperger syndrome are diagnosed on average at 10 years of age, two years older than the average age of diagnosis for boys.

"The consequences of a missed or late diagnosis include social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood."

(Wilkinson, 2008, p.3)

Internalizing Symptoms

*This lack of accurate diagnosis often means that girls develop serious issues, such as **anorexia, depression and anxiety disorders**, as they fail to cope with the stress of unknowingly being 'on the spectrum'.*

Irish Examiner February 06, 2014

Internalizing Symptoms: Girls with ASD and Anorexia

- 18-23% of Adolescent girls with Anorexia also have signs of AS

(Gillberg & Billstedt, 2000)

Consequences of Late Diagnosis

- Group-based social skills interventions that include components targeting **emotion recognition**, emotion regulation, and additional problem solving/coping strategies along with **skills for developing more successful social relationships** have been shown to have an effect on **depression** scores in boys with ASD and their parents (Solomon et al. 2004).

Solomon, Miller, Taylor, Hinshaw, Carter J Autism Dev Disord (2012) 42:48–59

The failure to identify girls has cumulative repercussions. At the individual level, without identification, a girl continues her course of development without critical interventions and becomes increasingly at risk for depression, anxiety, and victimization. At the system level, the failure to identify girls who have ASD perpetuates this failure for future generations.

Gender Differences in Identification

- “. . . Girls are less likely to be identified with ASD even when their symptoms are equally severe” (Russell, Steer, & Golding, 2011, p. 1291).

Russell G, Steer C, Golding J. (2011). Social and demographic factors that influence the diagnosis of autistic spectrum disorders. *Social Psychiatry and Psychiatric Epidemiology*, 46, 1283-1293.

Gender Differences in Identification

- “Clinicians . . . were more likely to classify boys with ASD than girls, even when both sexes had symptoms associated with the disorders documented in educational and clinical records” (Giarelli et al. 2010, p.114).

Giarelli, et al. (2011). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*, 3, 107-117.

Gender Differences in Identification

- “. . . In the absence of additional intellectual or behavioral problems, girls are less likely than boys to meet diagnostic criteria for ASD at equivalently high levels of autistic-like traits” (p.788)

Dworzynski, K., Ronald, A., Bolton, P., & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 788-797.

Gender Differences in Identification

“This may suggest that girls with ASD are more easily missed in the diagnostic process, and may **require additional problems** to push them over the diagnostic threshold” (p. 793).

Dworzynski, K., Ronald, A., Bolton, P., & Happe, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(8), 788–797.

Level of Functioning and Identification

Two groups:

- Severely impaired girls – readily diagnosed
- High functioning girls – not diagnosed or late diagnosis

Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

IQ and Gender

- Average or above average IQ decreased the chance of an ASD diagnosis **more** in girls than boys. (Giarelli et al. 2010)

Giarelli, et al. (2011). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*, 3, 107-117.

Reasons for Underidentification of Females with ASD

Referral Bias

- Girls with ASD show different and less severe communication and social challenges. Families and professionals often attribute girls' challenges to shyness or anxiety. This can lead to fewer referrals and misdiagnosis (Holtmann et al. 2007)

Holtmann, Bolte, & Poustka (2007). Autism spectrum disorders: Sex differences in autistic behaviour domains and coexisting psychopathology. *Developmental Medicine & Child Neurology*, 49, 361-366.

Instrument Limitations

- It remains possible that a gender bias exists on instruments
- Example - the RBS-R restricted interests subscale refers to objects such as trains, dinosaurs, and toy cars—traditionally male interests.

Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of autism and developmental disorders*, 42(1), 48-59.

Instrument Limitations

- Standardization samples for most instruments include more boys than girls.

Koenig, K., & Tsatsanis, K. D. (2005). Pervasive developmental disorders in girls. In D. J. Bell, S. L. Foster, & E. J. Mash (Eds.), *Handbook of behavioral and emotional problems in girls* (pp. 211–237). New York, NY, US: Kluwer Academic/Plenum Publishers.

Instrument Limitations

- Lack of gender norms may lead to gender bias when “cutoff” scores are used.

Constantino, J.N. & Charman, T. (2012). Gender bias, female resilience, and the sex ratio. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(8), 756–758.

Instrument Limitations

- Screening instruments are not designed to assess for different manifestations of symptoms (e.g., females).
- Therefore, cut off scores should not be applied in the same manner.

Koenig, K., & Tsatsanis, K. D. (2005). Pervasive developmental disorders in girls. In D. J. Bell, S. L. Foster, & E. J. Mash (Eds.), *Handbook of behavioral and emotional problems in girls* (pp. 211–237). New York, NY, US: Kluwer Academic/Plenum Publishers.

Instrument Limitations

- Since ASD presents somewhat differently in males and females, standardized gender-based norms for instruments are needed.

Constantino, J.N. & Charman, T. (2012). Gender bias, female resilience, and the sex ratio. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(8), 756-758.

Diagnostic Criteria

- "It should be borne in mind that the diagnostic criteria were formulated on basis of behaviors and features found in boys" (p.633).
- ASD looks different in females but the diagnostic criteria are based on boys and men.

Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

Gender Related Diagnostic Issues Statement from DSM 5

"In clinic samples females tend to be more likely to show accompanying intellectual disability, which suggests that girls without accompanying intellectual disability or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties."



Camouflage

“ . . . Girls with Asperger’s syndrome may be more difficult to recognize and diagnose due to coping and camouflaging mechanisms, which can also be used by some boys. One of the coping mechanisms is to learn **how to act** in a social setting . . . ” (Attwood, 2007, p.46).

Attwood, T. (2007). The complete guide to asperger's syndrome. London: Jessica Kingsley Publishers.

Camouflage

“The clinician perceives someone who appears able to develop a reciprocal conversation and use appropriate affect and gestures during the interaction. However, **further investigation** and observation at school may determine that the child adopts a social **role** and **script**, basing her **persona** on the characteristics of someone who would be reasonably socially skilled in the situation . . . ” (Attwood, 2007, p.46).

Attwood, T. (2007). The complete guide to asperger's syndrome. London: Jessica Kingsley Publishers.

Camouflage

Some girls are particularly interested in social interaction. They observe, analyze, and imitate the behaviors of other girls and adopt the “observed persona in their interaction with others ... As such, it appears that **the restricted interests of affected females may actually mask the presentation of their social deficits** (Kirkovski, Enticott, & Fitzgerald, 2013, p.2587).

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. Journal of autism and developmental disorders, 43(11), 2584-2603.

Gender Differences

In contrast to the camouflaging hypothesis, “affected females may present with an altered phenotype against the established diagnostic criteria” (Kirkovski, Enticott, & Fitzgerald, 2013, p. 2586).

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of autism and developmental disorders*, 43(11), 2584-2603.

Gender Differences

- Starting at age 6, females had fewer restricted interests and stereotyped behaviors than males

Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

Gender Differences

Girls on the higher end of the spectrum also have fewer special interests, better superficial social skills, better language and communication skills, and less hyperactivity and aggression than boys (Gillberg & Coleman, 2000).

Gender Differences

- Parents of **boys** are more likely to report that their son "lacks best friends" or "is viewed as a little professor" by peers.
- Parents of a **girl** are more likely to report that their daughter "interacts mostly with younger children" than are parents of boys.
- Based on ASSQ research

Kopp, S. and Gillberg, C. (2011). The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls. A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities*, 32, 2875-2888.

Special Interests

Intensity

Special Interests

- "A girl with autism may be fascinated by horses or by a particular pop star," This isn't unusual among girls, and may not stand out as much as a boy who is obsessed with the Latin names of plants, for example. "But the intensity and narrowness of [her] interest is unusual." Happé.

Special Interests

circumscribed interests may be more **social in nature** in girls

- ☐ Animals
- ☐ Dolls
- ☐ Pop-groups
- ☐ Classic literature
- ☐ Imaginary friends
- ☐ Fantasy Kingdoms
- ☐ Princesses

Strategies and Solutions for Assessment of Females

Guard Against - Mental Prototype Based on Boys

- How is she functioning in her context?
- How is she functioning in comparison to girls with the ASD diagnosis?

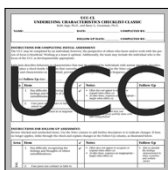
“... In this way, one **guards against using a mental ‘prototype’ for diagnosis** that has been **constructed based on experience with affected boys only**” (p. 229)

Koenig, K., & Tsatsanis, K. D. (2005). Pervasive developmental disorders in girls. In D. J. Bell, S. L. Foster, & E. J. Mash (Eds.), Handbook of behavioral and emotional problems in girls (pp. 211–237). New York, NY, US: Kluwer Academic/Plenum Publishers.

Listen

- Some people operate under the mantra, "If I don't see it it doesn't count."
- Others may be inclined to weigh more heavily there own observations.
- Remember that your own observations are a small sample of time.
- Trust the parents, teachers, and others.

Underlying Characteristics Checklist in Assessment & Treatment Planning for Females



- A descriptive instrument
- Absence of cutoff points helps to focus on the expression of characteristics
- Helps you to "see" the autism
- May be completed by a team
- Self-report in development with Dr. Emma Goodall



The UCC Areas

- Social
- Restricted Patterns of Behavior, Interests, & Activities
- Communication
- Sensory Differences
- Cognitive Differences
- Motor Differences
- Emotional Vulnerability
- Known Medical or other Biological Factors

UCC- Notes Section

UCC-HF
UNDERLYING CHARACTERISTICS CHECKLIST-HIGH FUNCTIONING
Bath Aspy, Ph.D., and Barry G. Grossman, Ph.D.

NAME: _____ DATE: _____ COMPLETED BY: _____

FOLLOW-UP DATE: _____ COMPLETED BY: _____

INSTRUCTIONS FOR COMPLETING INITIAL ASSESSMENT:
The UCC may be completed by an individual; however, the perspective of others who know and/or work with the person of focus is beneficial. Working as a team is optimal. Additionally, the team may include the individual who is the focus of the UCC as developmentally appropriate.

Each item describes behaviors or characteristics that may be exhibited by individuals with autism spectrum disorders. Please place a check beside ALL items that currently apply to the individual. Use the Notes column to describe the behavior and characteristics in more detail, provide specific examples, or indicate frequency, settings, etc.

Projected Follow-up date: _____

Area	Item	✓	Notes	Follow-Up
SOCIAL	1. Has difficulty recognizing the feelings and thoughts of others (mindblindness)	✓	<ul style="list-style-type: none"> • Does not recognize when classmates "bite or "eat her up" • After being corrected at home, she repeatedly asks her parents if they are still angry • In role plays, she can accurately identify the feelings of others 4 out of 10 times 	

UCC - Social

1. Has difficulty recognizing the feelings and thoughts of others (mindblindness)

T: The only one she can identify with is sadness

Special Interests

○ Consider the intensity of interests not just the type.

Misdiagnosis/Comorbidity/ Root Cause

- When anxiety, depression, eating disorders are present, consider possible underlying characteristics or cause
- Consider the possibility that ASD accounts for the symptoms ascribed to another given diagnosis
- Use Occam's Razor

Recognize canned speech as a form of camouflage

- Listen for misused, misplaced, awkward phrases that may be "canned"
- Don't repair too quickly
- Discuss non-preferred topic

"But she wants friends"

- Distinguish social interest from social competence

Expand ASD Awareness

- Help parents, teachers, and health care providers to identify the “red flags” of ASD – warning signs should not be ignored in females
- Consider referrals for females that are “shy” or “anxious” but do not display significant behavior problems

Training and Experience

- Use cutoffs flexibly.
- Use clinical judgment.
- Use the diagnostic criteria flexibly.

Training and Experience

- “Diagnostic criteria are offered as guidelines for making diagnosis, and their use should be informed by **clinical judgment**.” p 21
- “Although some mental disorders may have well-defined boundaries around symptom clusters... we have come to recognize that the **boundaries between disorders** are more **porous** than originally perceived.” p 6

APA DSM-5

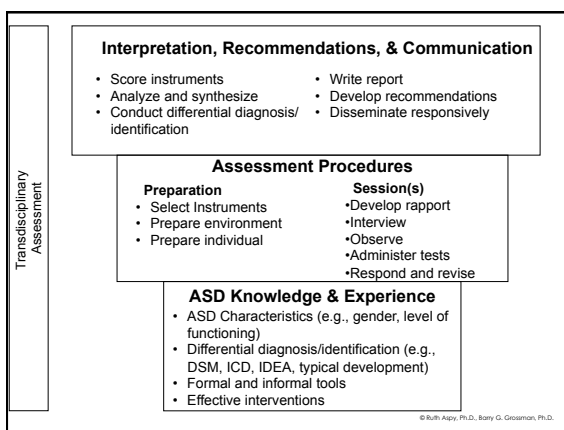


Need for Quality Clinical Training

- “...**cut-off scores** should not be viewed as similar to a standard score, such as an IQ score. Rather, these scores should be used as a clinical **guide** and taken **in the context of other information** about the child.... **This issue alone emphasizes the critical importance of the need for school districts to invest in providing quality clinical training...**”

(p.270)

Noland & Gabriels (2004). Screening and identifying children with autism spectrum disorders in the public school system: The development of a model process. *Journal of Autism and Developmental Disorders*, 34, 265-277.



Intervention for Females with ASD

Safety and Bullying

- Do not assume that girls and women with ASD know how to recognize or respond to bullying or dangerous situations
- Create safe environment - monitor internet and phone interactions (age appropriate)
- Teach individual how to identify bullying
- Teach internet safety (nudity, "sexting," exploitation, money)
- Teach characteristics of healthy relationships

Other Common Issues

- Anxiety and depression
- Real self vs. playing a part
- Understanding life experiences/need for interpreter
- History of misdiagnosis

Contact Information



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