Autism and Girls: Closing the Gender Gap

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Girls on the Spectrum
Identification 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).

Prevalence

1 in 189 girls

1 in 42 boys

Baio, 2018
Identification Gap

- **One in 42 boys** in the U.S. has been diagnosed with autism, compared to just **1 in 189 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**.

Female to Male Ratio

Table of Ratios:

- Autism: 4 or 5:1 (Loomes et al., 2017)
- Intellectual Disability and ASD: 2:1
- Asperger's Disorder: 9:1

Bias and Research History:

- Early descriptions based on boys
- Girls and Women outnumbered in Research
  - Research studies have often used male-only participants.
  - Eight to one male to female participants in brain imaging studies

“This means that what we think we know about autism from research is actually just what we know about male autism.” (Happe, 2018)
Data from males are used as the norm for ASD

Fewer females with ASD are diagnosed

Self-Reinforcing Cycle

Two groups:

1. Severely impaired girls – readily diagnosed

2. High functioning girls – not diagnosed or late diagnosis.
   (Van Wijngaarden-Cremers et al., 2014)

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


Sex 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”

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)


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

For Girls

ASD + X = ASD
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 (average of 2 years)
- In adults, females with autistic disorder were diagnosed later than males

Nicola Clark – diagnosed in her 40’s

“Many women remain undiagnosed until their 20s or 30s... If a woman has had children, is in a relationship, is interested in make-up, music, fashion, or in my case doing stand-up comedy, this level of sophistication apparently makes diagnosis ‘less clear cut’. At worst, it apparently makes autism seem ‘nonexistent’.

From *Girls and Autism* by Carpenter, Happe, and Edgerton (2019)

The consequences of a missed or late diagnosis

- social isolation
- peer rejection
- lowered grades
- greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood

(Wilkinson, 2008, p.3)
Cumulative repercussions of the failure to identify girls with ASD

- **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 perpetuates this cycle for future generations.

Reasons for Underidentification of Autistic Females
ASD Sex Differences: Brain Structure


Girls on the spectrum 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.

Sex Differences

Girls on the higher end of the spectrum also have

- fewer special interests
- better superficial social skills – “clingy rather than aloof”
- better language and communication skills and
- less hyperactivity and aggression

(Gillberg & Coleman, 2000)

Lower Levels of Restricted Interests

- Research of equivalence of autism symptoms domains in autistic males and females using the Social Responsiveness Scale (SRS) and the Autism Diagnostic Interview – Revised (ADI-R) found that cognitively able females on the spectrum had **substantially lower levels of restricted interests, this difference could not be accounted for by measurement bias.**

- Starting at age 6, females had fewer restricted interests and stereotyped behaviors than males
Less prominent restrictive /repetitive ➔ not referred/misclassified

➢ Our findings raise the possibility that girls with less prominent [restricted/repetitive behaviors] may **miss being tested for ASD or get misclassified** as having **social communication disorder** . . . Regardless of the potential impact on diagnosis, our findings point to a need for further research on the development of clinical instruments that are better tailored towards autism in females.

Instruments

• possible gender bias

• Example - the RBS-R (The Repetitive Behavior Scale-Revised) restricted interests subscale refers to objects such as trains, dinosaurs, and toy cars—traditionally male interests.


Instrument Limitations

• **Standardization samples** for most instruments include more boys than girls.

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

• **Screening instruments** are not designed to assess for different manifestations of symptoms (e.g., females).


"I was working with a 10-year-old girl who had lots of features of autism but when we used the diagnostic tools that are available, she didn’t score up," she explains. Even though it became very clear that this girl was autistic, she was unable to get her official diagnosis.

- Jess Commons (April 2, 2019)
Characteristics of Autism?

- **No**
  - She’s a girl so no referral

- **Yes**
  - She’s a girl so doesn’t meet the cut offs
  - She meets cutoffs, but she’s a girl – assign a comorbid condition

**No Diagnosis**

**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.

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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.”

Strategies and Solutions for Assessment and Program Planning for Females
Guard Against - Mental Prototype Based on Boys

- How is she functioning in her context? Compare to NT females.
- 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)


Listen: Some people operate under the mantra, “If I don’t see it it doesn’t count.”

- Trust parents, teachers, the individual and other informants.
- Remember that your own observations are a small sample of time.
Decision Making Process

Clinical Judgment

Interview Data

Diagnosis/ Identification/ Recommendations

Observations

Test Data

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 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

<table>
<thead>
<tr>
<th>Area</th>
<th>Item</th>
<th>Notes</th>
<th>Follow-Up</th>
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| 1.   | Has difficulty recognizing the feelings and thoughts of others (mindblindness) | ✓ | ● Does not recognize when classmates tease or "put her up"  
 ● After being corrected at home, she repetitively 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

Consider the intensity of interests not just the type.
UCC - Restricted Patterns of Behavior, Interests, and Activities

14. Has eccentric or intense preoccupations/absorption in own unique interests

*Over 12,000 texts per month*

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UCC - Restricted Patterns of Behavior, Interests, and Activities

14. Has eccentric or intense preoccupations/absorption in own unique interests

T: Books, fascination with small things on the floor, origami, animals

P: Intensely absorbed in reading and arts and crafts
UCC - Communication

25. Has difficulty with rules of conversation (e.g., interrupts others, asks inappropriate questions, makes poor eye-contact, has difficulty maintaining conversation)

T: Doesn’t carry on a conversation unless prompted – doesn’t initiate
T: Talks about baby sister all the time

Consider:
Misdiagnosis/Comorbidity

When anxiety, mood disorders, eating disorders are present, consider possible underlying characteristics or cause.
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 topics

Distinguish social interest from social competence

“But she wants friends”
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

• “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
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)