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Hide and Seek: Recognizing females on the autism spectrum

Glenis Benson, PhD

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com



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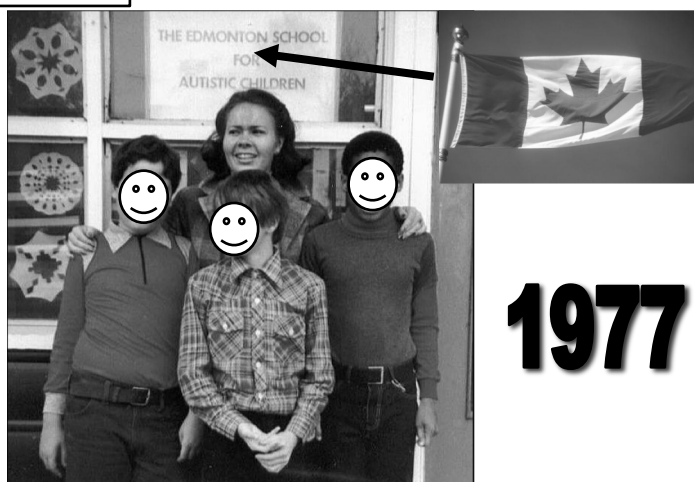
Hide and Seek: Recognizing Girls on the Autism Spectrum

Glenis Benson, PhD

continued

Disclosure:

- This talk does not promote a product

continuedcontinued

continued

HEREIN, Gender is
discussed as binary
Only BECAUSE THE
LITERATURE, CURRENTLY
DOES NOT DIFFERENTIATE

continued

ASC
(Autism Spectrum conditions)
instead of
ASD
(Autism Spectrum Disorders)

Today's agenda

- Prevalence
- Identify rationale for the current ratios of males/females on the Autism Spectrum
- Discuss the pitfalls associated with these beliefs
- Illuminate the distinctions between male/female presentations
- Next steps

Think about 'typical development.'
What do we know about
differences between males and
females with regard to
acquisition/presentation of
communication & social skills?

Gender differences in typical development

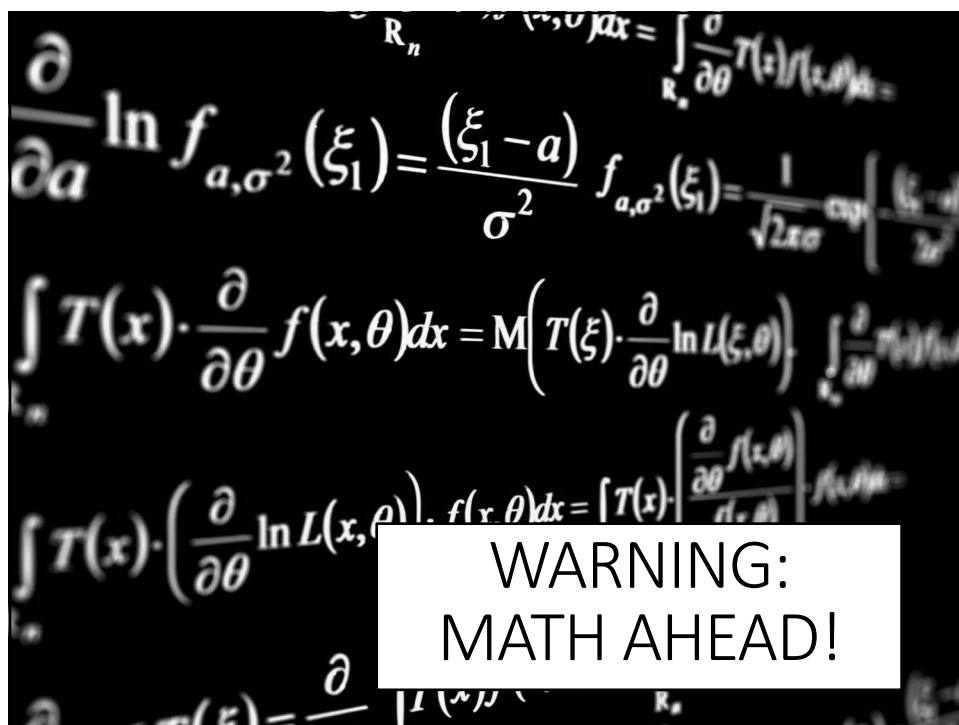
- Sociability and communication present differently in females versus males; females present with *language earlier* and tend to be *more sociable* than males

Attwood, 2015



Historical perspective

- 1943 Kanner (working in the USA) thought there were 4 males/1 female
- 1944 Asperger (working in Austria) initially believed that females were not affected, but then he retracted that statement
- 1981 Wing warned us early on that female superiority in *social and communication areas* (as in their overall development) *may mask the presentation of autism*.



continued

Humor me:

Calculate your ratio of boys/girls on your caseload

continued

1/1?

2/1?

3/1?

4/1?

5-10/1?

continued

Prevalence

- 1/59 per CDC, 2018 and 1/68 per CDC, 2016

Gender ratios:

- 3/1 -4.3/1 boys to girls with Autism (Loomes, Hull, Mandy, 2017)

Do females require a greater genetic load to develop ASC?

(Jacquemont, Coe, Hersch, Duyzend, Krumm, Bergmann 2014)

Gender ratio:

- 3/1 -4.3/1 boys to girls with Autism (Loomes, Hull, Mandy, 2017)
- 10/1 boys to girls with Aspergers (Happe, 2015)

Why the difference between the genders? Hypotheses abound.

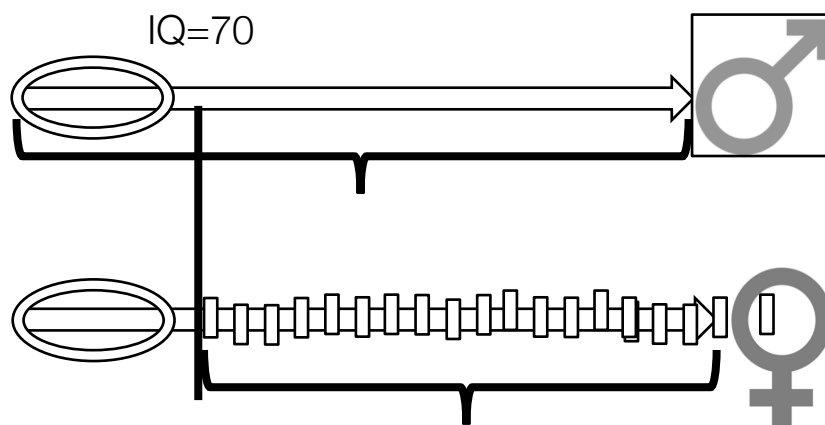
Or...

Prevalence

- 3/1 -4.3/1 boys to girls with Autism (Loomes, Hull, Mandy, 2017)
- 10/1 boys to girls with Aspergers (Happe, 2015)
- What does the above difference show?

Ratio varies as a function of IQ!

Baird et al., 2006; Fonbonne, 2009; Kim et al, 2011; Scott et al., 2002



So why is there a paucity of identified females with average or higher IQs?

- Do they simply NOT EXIST?

“We have a *bias* that autism is a *male condition* because of all the depictions of autism and all the research that is also very *male-dominated*.”

Happe, 2018

In search of an explanation:

- Autism research has focused on males, and therefore the characteristics of this body have become fodder for the generation of diagnostic criteria

**What we know about autism is
actually what we know about
'male autism.'**

Happe, 2015

In search of an explanation: cont'd

- Diagnosticians, when faced with a female in front of them, are pre-disposed to look for males
- When diagnosticians see a female who is struggling socially, the diagnostician tends not to think of autism, but rather they see the secondary characteristics of *anxiety*, and *eating disorders*

In search of an explanation: cont'd

- ***Assessments are biased*** against females insofar as the majority of the research has been conducted, primarily, on males
- Females tend to excel at ***mimicry, masking, pretending, or camouflaging*** their autistic presentation

In search of an explanation: cont'd

- Diagnosticians look for the deficits in *social communication and restricted and repetitive behaviors and interests (e.g., preoccupations, circumscribed interests)*
- And then it becomes 'circular' because the criteria identify characteristics displayed by males, and people believe that ASCs are primarily a male condition, ***REPEAT***

Types of research

- Many studies begin by recruiting individuals who *ALREADY have a diagnosis* of an autism spectrum disorder
- Other studies (epidemiology) begin by screening the general population; they investigate the distribution of a population

Epidemiological studies (which are much more rigorous), go into the population in search of individuals with autism – these ratios show a much higher rate of autistic females.

Loomes et al, 2017

So why is there a paucity of identified females with normal or high IQs?

- Do they simply, NOT EXIST?

NO! We know they exist

So why is there a paucity of identified females with normal or high IQs?

- Do autistic females present sufficiently differently from their male counterparts such that they are not recognized as being on the autism spectrum?



Presentation of characteristics between the genders diverge

- Females without intellectual impairment do NOT present with the same characteristics seen in males with ASC

“We’ve overlooked autism in women and girls and I think there’s a real gender equality issue here,” she said.

“I think we are *missing* large numbers and *misdiagnosing* them too.”

Happe, 2018

In search of an explanation:

- If females present differently from males, and our diagnostic tools are fraught with 'male' characteristics, *then of course females won't get referred or identified*

Is autism being overlooked in females *because the signs are much clearer in males?*

A growing body of research says
YES!

continued



Invisible Girls

Is autism being overlooked in girls because the signs are much clearer in boys?
A growing body of research says yes.

Nancy Volkens

The ASHA Leader, April 2018, Vol. 23, 48-55. doi:10.1044/leader.FTR1.23042018.48

continued



“Recent research suggests that the number of males and females on the autism spectrum is far *more equal* than previously thought and diagnostic statistics suggest,” she said.

Carol Povey, Director of the National Autistic Society's Centre for Autism, 2018

continued

“The problem is that *professionals often don't understand the different ways autism can manifest* in women and girls, with many going through their lives without a diagnosis and an understanding of why they feel different.”

Carol Povey, Director of the National Autistic Society's Centre for Autism, 2018

So what?



The failure to recognise autism in girls and women was taking a *stark toll on their mental health.*

Happe, 2018

Consequences of not identifying females:

- ASCs go undetected in hundreds to thousands of females with higher intellect, meaning that these girls and women *don't get the help they need*
- Many who go undiagnosed experience secondary mental health issues such as *anxiety, depression and self-harm, inclusive of eating disorders*

Consequences of not identifying females: cont'd

- With late diagnoses, they get *misidentified as schizophrenic or psychotic and then inappropriately medicated* (Happe, 2015)
- 23% of women hospitalized for anorexia nervosa actually met criteria for ASC (Westwood, Tandy & Tchanturia, 2017)

I keep meeting young women, new ASD diagnosis in hand, whose childhood stories read like sequels to "One Flew Over The Cuckoo's Nest." They were medicated, hospitalized, removed from regular schools and placed in "treatment" facilities, abused, bullied... but never diagnosed accurately. At least not with ASD.

Maxine Share

Consequences of not identifying females: cont'd

- Because of their adoption of another persona, and their significant ability to imitate, believe that their '*real self*' is despicable, and then depression sets in
- Because they've learned to socialize, more or less, superficially, they don't accurately read non-verbal or subtle verbal signals, making them very vulnerable to sexual exploitation

Consequences of not identifying females: cont'd

- May be seen only as someone with an eating disorder (ED) without the realization that the ED was preceded by the autism

Eating disorders and autism:

Rationale *is different* from NT females with ED:

- May think they need to be 'thin' to be popular
- May just not want to 'grow up'
- May be focused on number of calories
- May be focused on a specific weight

**Can take on
a 'special
interest'
quality**

If the source of the eating disorder is autism

- Intervention is not going to be optimal because the hypothesis for the eating disorder will be incorrect
- Same treatments won't work for females with autism with eating disorder as NTs with eating disorder

continued



How do they present?

continued



continued

What about the females? Essentially 3 groups

- Shy, introverted girls 'afraid of their own shadow' and they lie low and hope no one notices them (let others talk for them)
- Bull moose-like; are intrusive/intense/annoying
- "I don't get it!" "Let me study their behavior – who's popular?" "What does she wear, how does she talk, what does she talk about, what is she interested in?"

Females are better at
camouflaging
and compensating

What do the females 'look like'?

Extraordinary mimics:

- Observe
- Analyze
- Imitate

They consciously adopt the behavior of people around them

But then the social interaction is a product of *intellectualization* and not by *intuition*

(Attwood, 2015)

Mimicry & imitation
are LESS common
among males

Intellectualization

- Without the benefit of intuition, having to 'observe, analyze, and imitate' is EXHAUSTING
- It's hard to think/listen all the while trying to make eye-contact

What do the females 'look like'?

Extraordinary mimics:

- They try to be who people want them to be
- Some get diagnosed with *multiple personality disorder*
- Imitate voice, speech, accents, facial expressions, gestures hair, fashion, walk, interests
- *"It was as if I became the person I was emulating"*
(Attwood, 2015)

What do the females look like?

- Reading fiction (or watching soap operas) helps learn about inner thoughts and feelings
- These females are good at masking, and mimicking, *at least in public*

(Attwood, 2015)

Masking, imitating, thereby disguising their real selves, is:

- EXHAUSTING
- STRESSFUL
- ANXIETY PROVOKING



What do the females 'look like'?

Special interests

- are unusual ONLY because of intensity and not because of their focus; their interests tend NOT to be out of the ordinary

*Preoccupations (special interests) of females
ARE NOT MUCH DIFFERENT from their peers
who are not affected*

(Attwood, 2015)

'Special interests' in females:

- But these interests are extreme:
- *If interested in horses, may only be interested in facts about horses, not in ever seeing or riding a horse*

‘Special interests’ in females:

- May appear superficially more mainstream;
 - horses
 - dolls (Barbies, American Girl dolls)
 - boybands/Taylor Swift
 - friendships
 - book series/TV series

As opposed to hydraulic lifts, elevators, trains, Nascar, vacuum cleaners etc. that fascinate males

Females are better than
males with age-
appropriate interests and
imaginative play

What do the females *'look like'*?

Repetitive behaviors:

- Females don't have as much repetitive behavior as males

(Attwood, 2015)

What about the females?

- Different presentation
- Females often diagnosed with something different
- Not diagnosed with ASCs until much later in life, if at all!

What do the females 'look like'?

Social behaviors:

- Many females want to socialize more than their male counterparts
- Social and communication skills in females are advanced over the male counterparts in early years
- This is replicated in the ASC population; social skills in females with autism is better than that of male counterparts

(Attwood, 2015)

What do the females 'look like'?

Social behaviors:

- They look like the worrier and often are ***dxd with anxiety disorder before anything else***
 - May be too anxious to attend school or to go out
- Often viewed as ***too much, too sensitive, too rigid, too intense*** resulting in diagnoses of Bipolar Disorder (BPD) or Obsessive Compulsive Disorder (OCD)

What do the females *'look like'*?

Play behaviors:

- May engage in more or less normal play, they tend not to role play. They may arrange the play things to be visually pleasing like preparing a 'tea party' but be annoyed if someone then pretends to partake of the tea, thereby disturbing the scene

They can hide in plain sight!

- The ability to imitate allows ASC females to *'appear' more social so they tend not to stand out socially to the same degree as do males*
- Melding the two domains of social communication and special interests, females with autism, *can have, as their special interest, the imitation of social behaviors and expectations*

You need to look for:

(Ami Klin, 2018, from Volker in ASHA Leader)

- More age-appropriate intense interests.
- “Pretend play” that is actually repetitive or strict.
- Possibly at-age or above-age language use, but perhaps echolalia or differences in receptive/expressive language.
- Less obvious self-stimulation behavior, as the girl may have replaced her natural self-stimulation with something more socially acceptable.
- Exhaustion after social stimulation (school, playgroups).

You need to look for, cont'd:

(Ami Klin, 2018, from Volker in ASHA Leader)

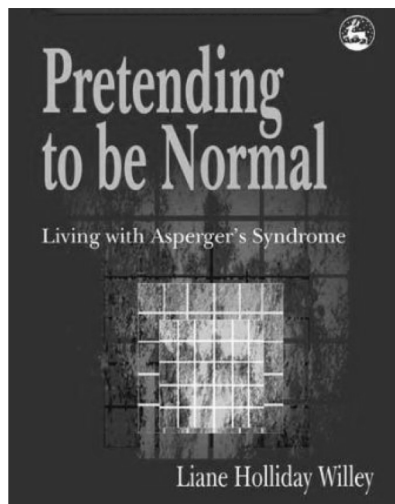
- “Jekyll & Hyde” behavior—following rules at school and being the “ideal student,” then coming home and melting down or having tantrums.
- Sensory issues—intolerance of crowds or of certain sounds or textures, for example.
- Difficulty with conversation skills and social engagement—turn-taking, staying on topic, initiating and contributing to the conversation.

Getting a diagnosis

Getting the diagnosis:

- Many come to it after their child's diagnosis

continued



LIANE HOLLIDAY
WILLEY, PHD

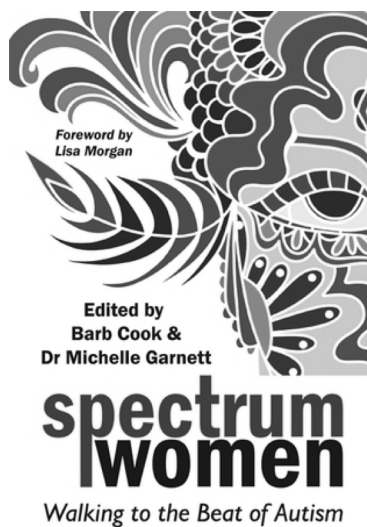
- sought diagnosis after her daughter was diagnosed
- studied human behavior in college had a posse of girl friends who guided her behavior

1999

continued



19 chapters
each written by
an autistic adult
female



continued

Getting the diagnosis:

Experience relief!

- When highly intelligent they'll *exclaim* "*does this mean I'm not stupid?*"
- An explanation for why they've never 'fit' in

#SheCantBeAutistic was used by thousands of women around the world to show how their autism was either misdiagnosed, or rejected altogether, due to the gender stereotypes which dominate the diagnostic criteria.

Pinto, 2017

continued

Attwood thinks it's
more like 2/1

continued

If that's not the ratio you
claimed, in the beginning...
seek them out!

continued[®]



 **Hide and Seek**