

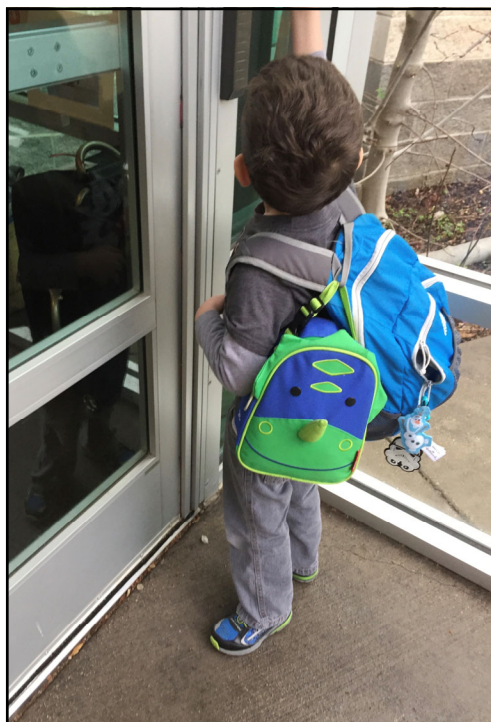


## Autism and Girls: Closing the Gender Gap

Ruth Aspy, Ph.D.  
The Ziggurat Group



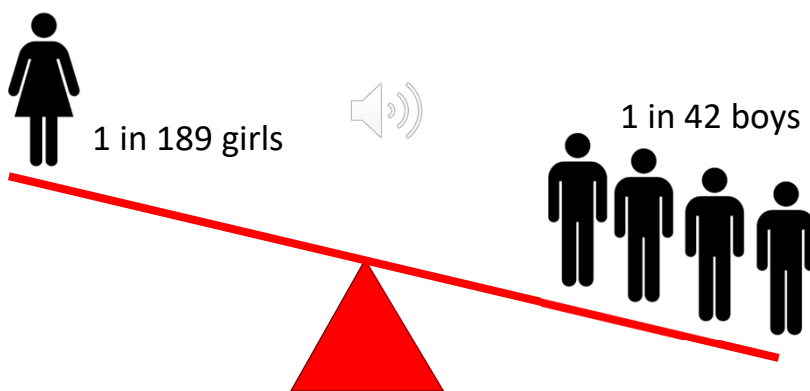
Under-  
identification  
Girls on the Spectrum



## 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



Baio, 2018

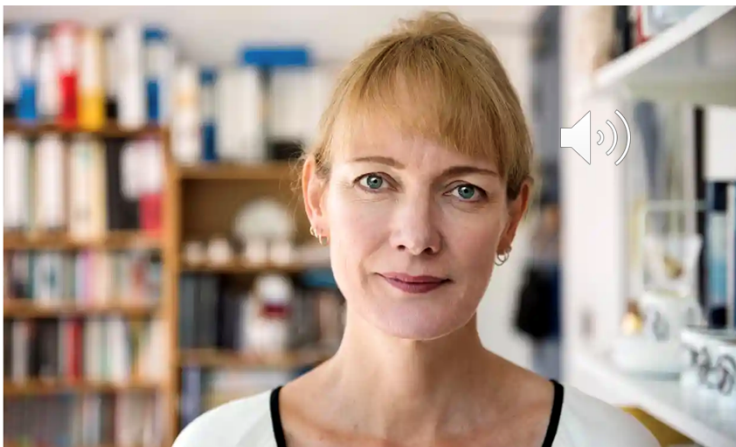
## Identification Gap

- **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.**

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](http://www.huffingtonpost.com/2013/11/26/girls-with-autism_n_4311015.html)

## Thousands of autistic girls and women 'going undiagnosed' due to gender bias

Number of girls and women with the condition in UK may be vastly underestimated, leading neuroscientist says



▲ Prof Francesca Happé. Photograph: Linda Nylind for the Guardian



**Hannah Devlin**  
Science  
correspondent

🐦 @hannahdev

Fri 14 Sep 2018 10.12 EDT

## Male to Female Ratio

Autism 4 or 5:1

←

**Loomes et al,  
(2017)**

Intellectual Disability and ASD 2:1

🔊

Asperger's Disorder 9:1

🔊

Happe's Hypothesis 2:1 (2018)

←

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(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.; Devlin, (2018), Thousands of Autistic Girls and Women going undiagnosed due to gender bias,The Guardian.; Loomes, Hull, & Mandy (2017). J Am Acad Child Adolesc Psychiatry Jun 56(6).

## History and Research

➔

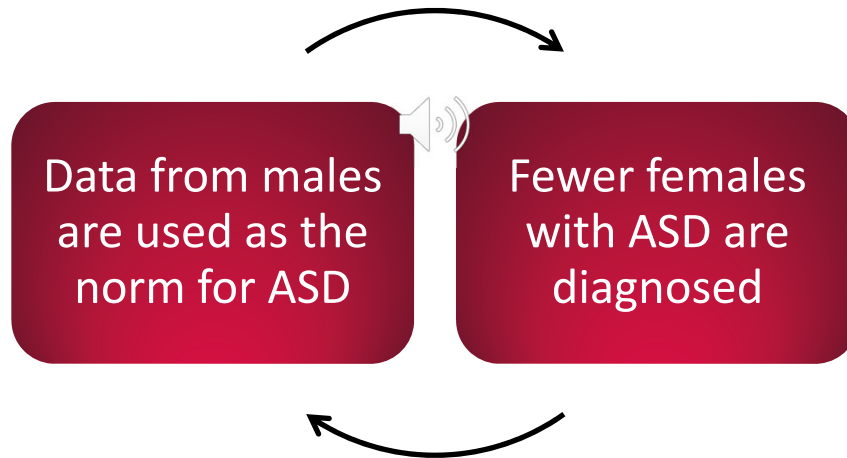
## Bias

- 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)**

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## Self-Reinforcing Cycle



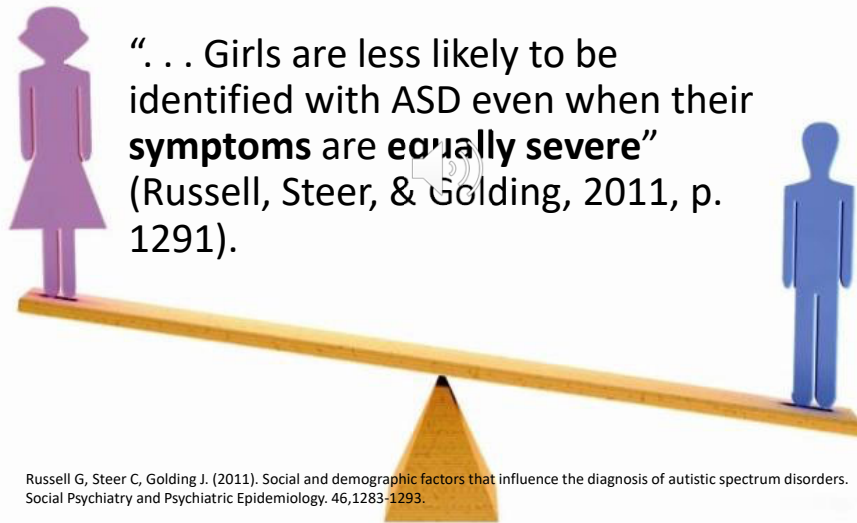
### Level of Functioning and Identification

#### Two groups:

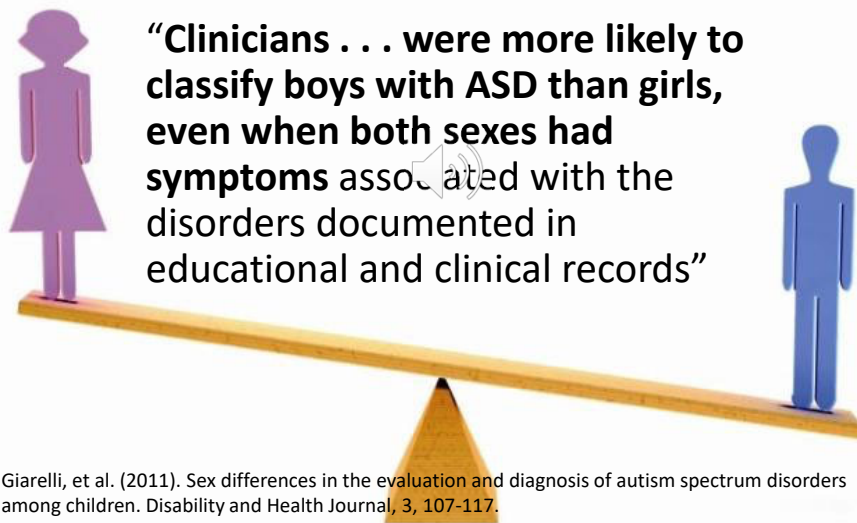
1. Severely impaired girls – readily diagnosed
2. High functioning girls – not diagnosed or late diagnosis.  
(Van Wijngaarden-Cremers et al., 2014)


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



## Sex Differences in Identification



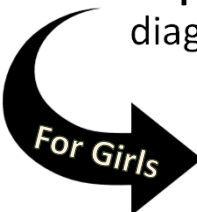


“ . . . In the absence of additional intellectual or behavioral problems, girls are less likely than boys to meet diagnostic criteria for ASD at equivalently high levels of autistic-like traits” (p.788)

Dworzynski, K., Ronald, A., Bolton, P., & 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.


## Sex Differences in Identification

“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).

 **ASD + X = ASD**

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.





Speaker icon indicating audio content.

## Age of Diagnosis

## 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

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.



## 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

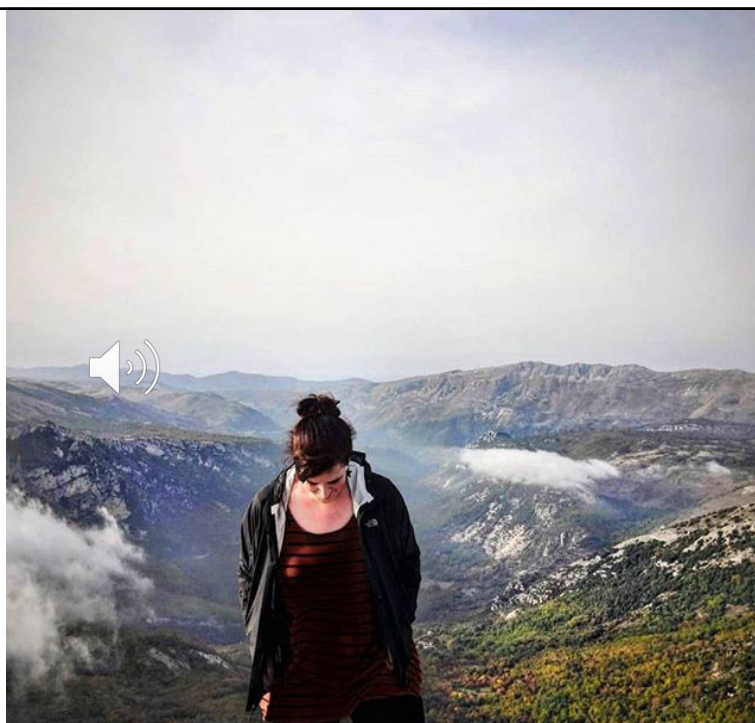
(Wilkinson, 2008, p.3)

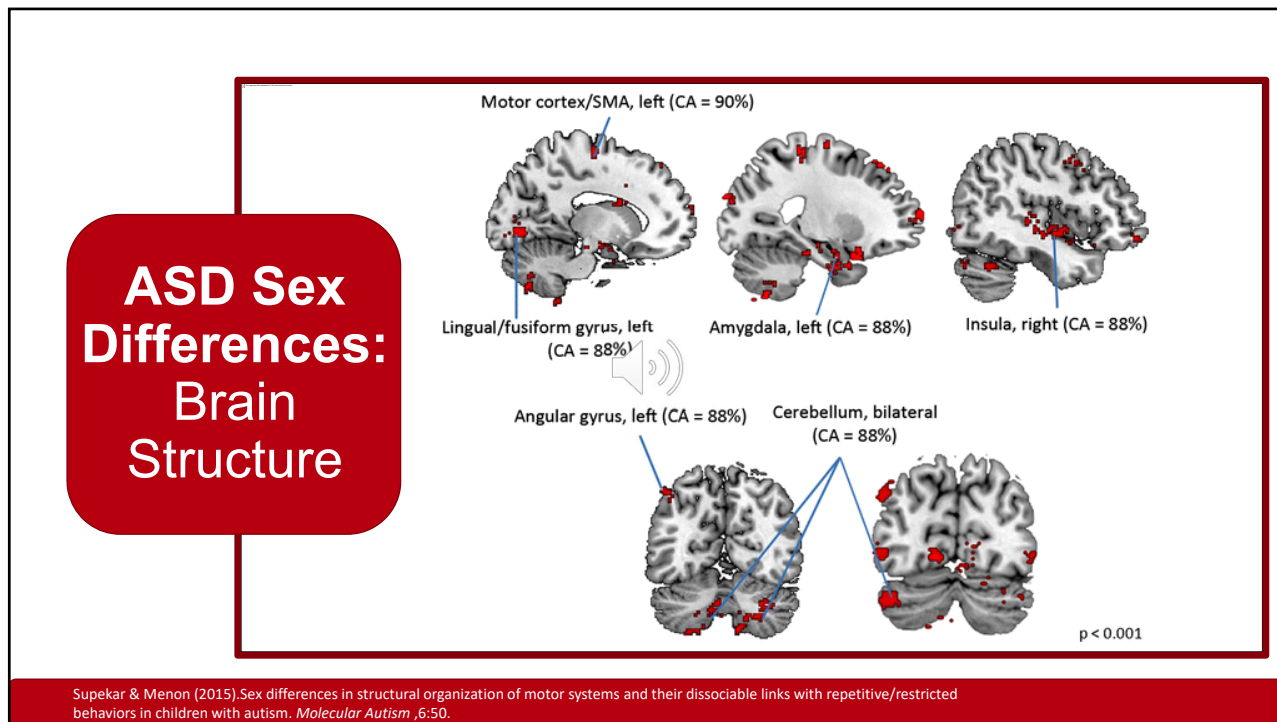


## Cumulative repercussions of the failure to identify girls with ASD

- **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





**Referral Bias**

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.

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

## 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.**

(Frazier and Hardan. Equivalence of symptom dimensions in females and males with autism. [Autism](#). 2016, Aug 7)

- 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.)

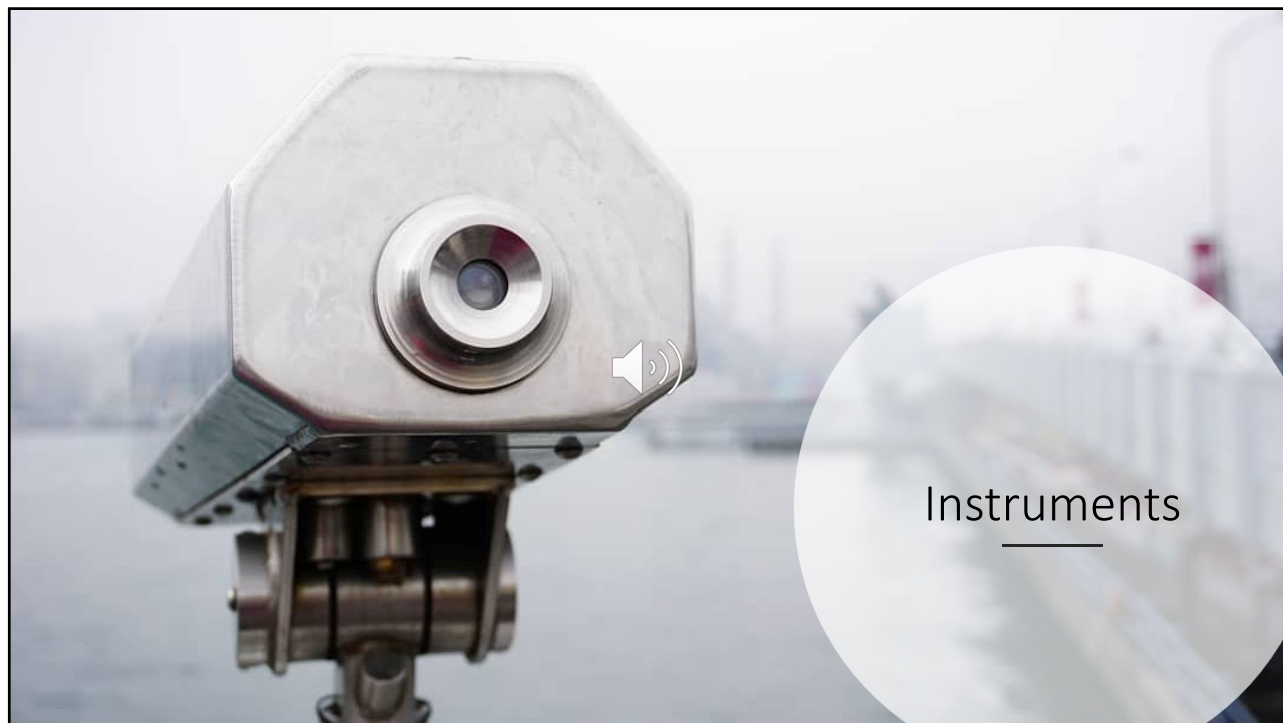


Less prominent restrictive /repetitive → not referred/misclassified

- 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.**

(Supekar & Menon (2015). Sex differences in structural organization of motor systems and their dissociable links with repetitive/restricted behaviors in children with autism. *Molecular Autism* ,:6:50.)

Supekar & Menon (2015). Sex differences in structural organization of motor systems and their dissociable links with repetitive/restricted behaviors in children with autism. *Molecular Autism* ,:6:50.





## 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.


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.
- **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).

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.

Constantio, 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



"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)



Copy & Paste  
Hidden Asperger's – Girls  
with Asperger's  
TEDxDunLaoghaire

Niamh McCann

<https://www.youtube.com/watch?v=QY2ctCuTWPw>





## 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.

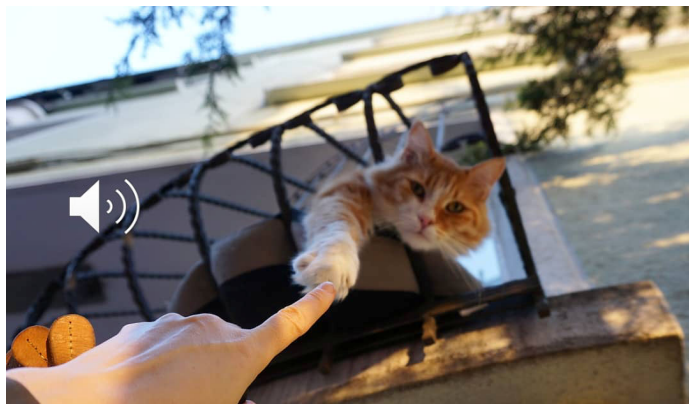
Van Wijngaarden-Cremers et al. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44-627-635.

## 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.”*



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?

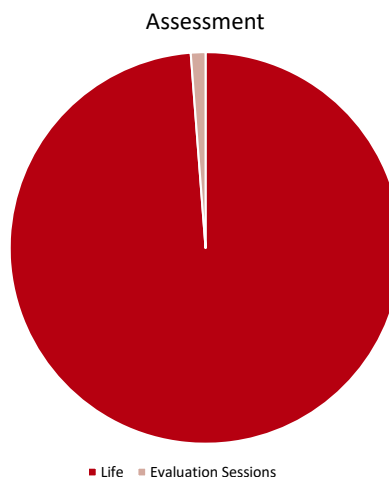


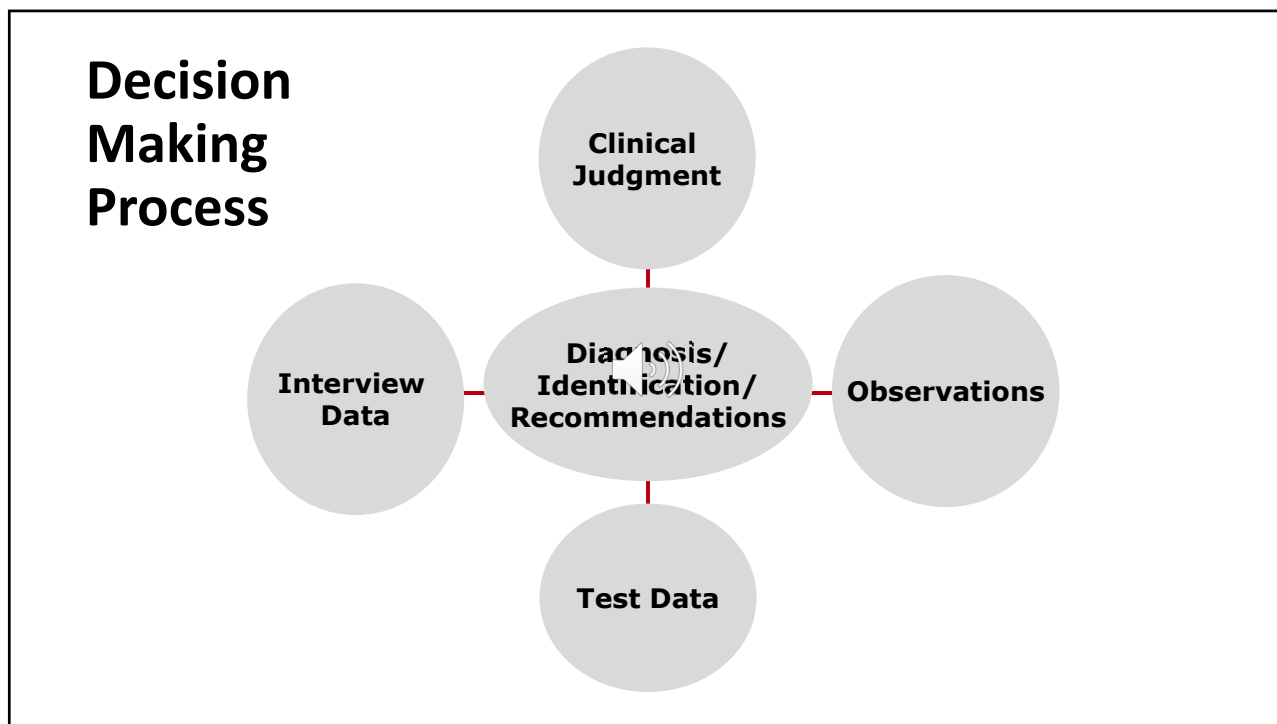
“... In this way, one **guards against using a mental ‘prototype’ for diagnosis** that has been **constructed based on experience with affected boys only**” (p. 229)

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.

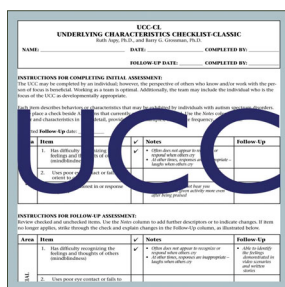
Listen: Some people operate under the mantra, “If I don’t see it it doesn’t count.”

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



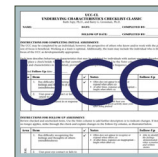


## Underlying Characteristics Checklist in Assessment & Treatment Planning for Females



- 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



**UCC-HF**  
**UNDERLYING CHARACTERISTICS CHECKLIST-HIGH FUNCTIONING**  
Ruth 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"> <li>• Does not recognize when classmates tease or "set her up"</li> <li>• After being corrected at home, she repetitively asks her parents if they are still angry</li> <li>• In role plays, she can accurately identify the feelings of others 4 out of 10 times</li> </ul>	


## UCC - Social

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

**T: The only one she can identify with is sadness**




## 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*

## 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)



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.

## Tri-State Autism Spectrum Disorder Webinar Series



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