

Evidence Base for Identification of Autism in Females and Nuanced Presentations

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Suicidal Thoughts and Behaviors



*"If nothing is wrong with me, why am I failing so miserably? .
.. I'm even miserable at suicide . . . I am terrible at it." P2*

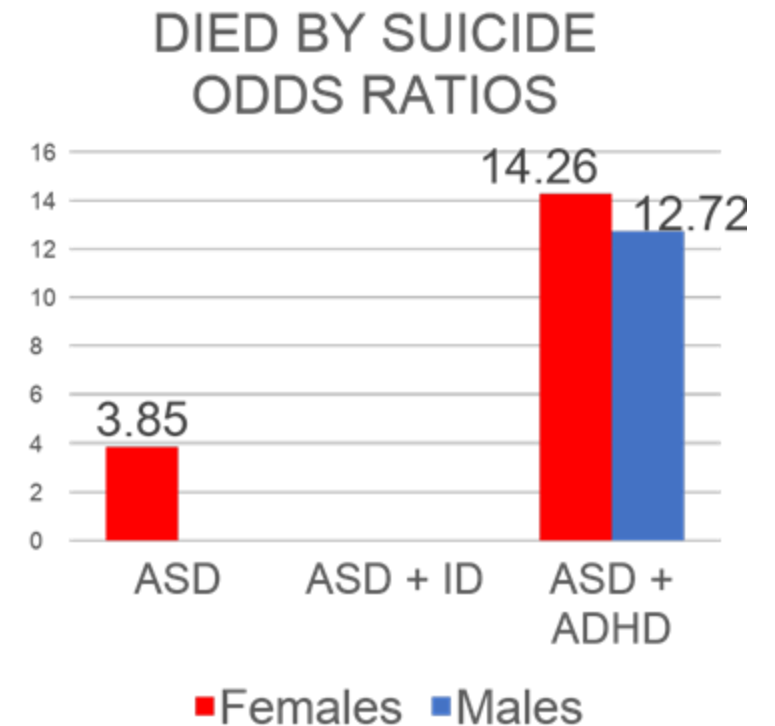
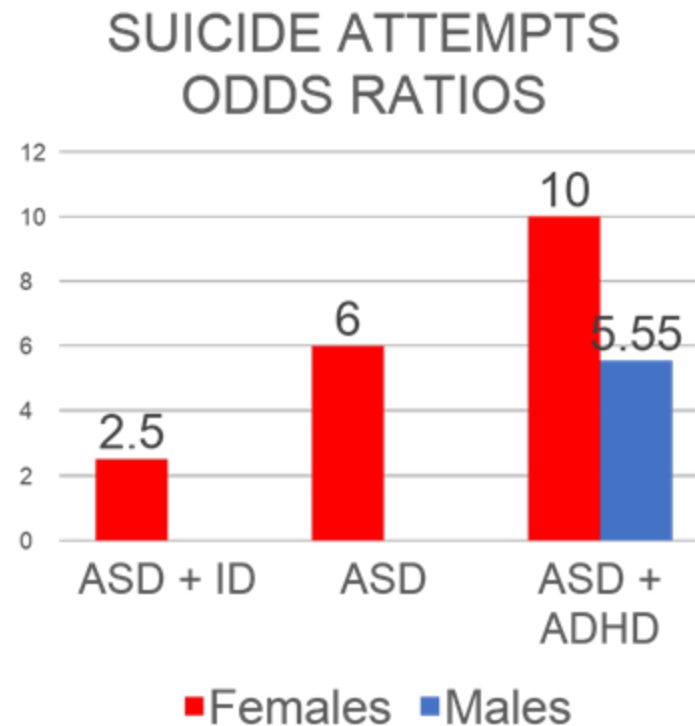


*"My first suicide attempts were a cry for help but then I
Realized that no one will notice because no one did anything
that was helpful anyway." P2*

Individual risk and familial liability for suicide attempt and suicide in autism: a population-based study

Hirvikoski et al., 2019 *Psychological Medicine in SWEDEN*

- $n=54,168$ 1987=2013,
- 43,070 w/o ID, 44% w/ADHD;
- 10,598 w/ID 27% w/ADHD
+ 347,155 relatives
- Controls = 270, 840
+ 1,735,775 relatives



Framed as better alternative to suicidal thoughts and behaviors. Allows for “break” in obsessively rigid thoughts. Serves a sensory function

*I didn't have a voice and no matter what I said no one would care, no matter what I did, no one would care. But by banging my head on the wall I could at least find some kind of release. And the added bonus thing that they could hear me and they could hear me banging myself--like banging the walls. Um to just have some kind of presence in this overwhelming sound-filled world.
[Participant14]*

Self-Harm





“Because we don’t sense danger and can’t. That’s one reason, I think you not reading people to be able to tell if they’re being creepy, you’re that desperate for friends and relationships that if someone is showing an interest in you, you kind of go with it and tend not to learn from others’ safety skills.” (P07)

VICTIMIZATION



“Had I known about Asperger’s, I think I’d have known that I’m more suggestible...and I might not have ended up in the situations that I did.” (P14)

Rudy
Simone

2010



“Whether from our peers or teachers, if we are looked at with an unfriendly, intimidating, or threatening eye, we fold. Alone, we are talented, graceful, witty, and smart, but under such circumstances we curl up like hedgehogs....

Some of us get backed into a corner and we keep retreating until we are out in the parking lot...then we just keep going. In other words, we quit. **Some of us older Aspergirls went from gifted student to high school or college dropout.”**



Missed Potential

“I think women tend to be diagnosed later in life when they actually push for it themselves...when you’re a child, you don’t realise that you’re anxious and depressed... [that] your education is going to suffer because of that and I think that if I had known, and if people had helped me from earlier on, then life would’ve been a whole lot easier.” (Po7)



Wenn Lawson, PhD



Gender Identity/Sexuality

"I don't feel like my body needs a label. Why can't people just be people?" (participant 7)

"I didn't know I was a girl until I was 13. My family sat me down and convinced me." (participant 32)

"I'm no good at being a girl " (FF02)



Spectrum of gender identity and sexuality on
the spectrum

Transgender and Non-Binary

"Increased variance and fluidity in gender expression and identity, as well as sexual orientation and sexual identity" - Lai et al., 2022

- Create a safe and affirmative space and experience for transgender students with respect for names, pronouns, and supports.



Barriers to Identification

A photograph of a weathered wooden fence post in the foreground, with a strand of rusty barbed wire running horizontally across the frame. The post is covered in lichen and moss. In the background, there is a grassy field and rolling hills under a cloudy sky. The text "Barriers to Identification" is overlaid on the left side of the image.

RESEARCH ARTICLE |  Open Access |    

Exclusion of females in autism research: Empirical evidence for a “leaky” recruitment-to-research pipeline

Anila M. D'Mello  Isabelle R. Frosch, Cindy E. Li, Annie L. Cardinaux, John D.E. Gabrieli

First published: 22 August 2022 | <https://doi.org/10.1002/aur.2795>

Funding information: Hock E. Tan and K. Lisa Yang Center for Autism Research; National Institute of Mental Health; Simons Center for the Social Brain at MIT; National Institutes of Mental Health, Grant/Award Number: F32 MH117933

2:1

1:1

A commonly used screening test creates a gender gap that may hinder diagnosis and treatment for women and girls.

8:1

4:1

**Systematic Exclusion of
Females from Autism Research**



October 30, 2024

Autism Diagnosis Among US Children and Adults, 2011-2022

Luke P. Grosvenor, PhD¹; Lisa A. Croen, PhD^{1,2}; Frances L. Lynch, PhD³; et al

» Author Affiliations | Article Information

JAMA Netw Open. 2024;7(10):e2442218. doi:10.1001/jamanetworkopen.

Relative Increases:

Adults 26-34 = 450%

Female Children = 305%

Male Children = 185%

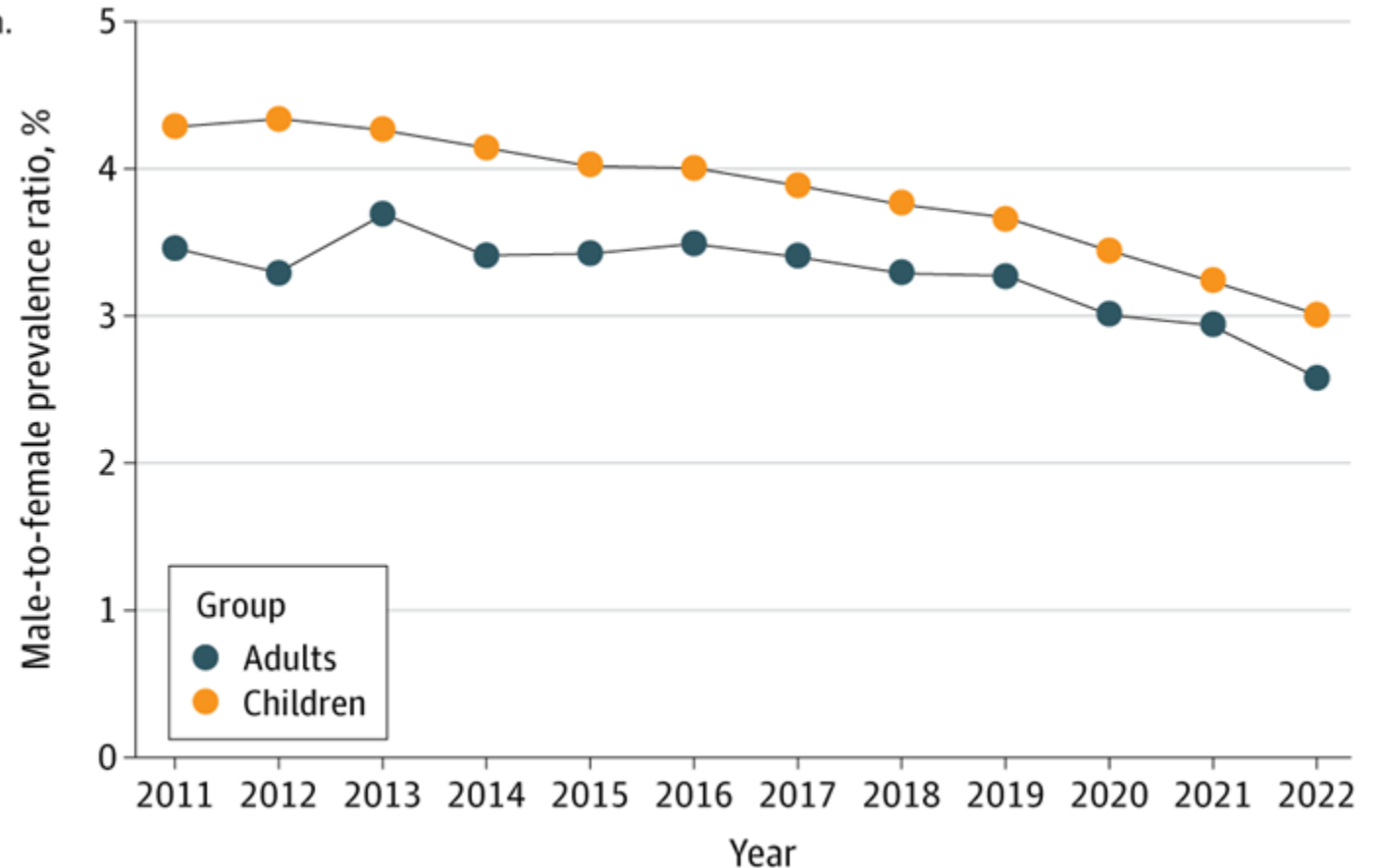
Female Adults = 315%

Male Adults = 215%

Most recent CDC (ADDM)
Prevalence Study:

3.4 : 1 M:F (8 yr olds)

Shaw KA, Williams S, Patrick ME, et al. Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years — Autism and Developmental Disabilities Monitoring Network, 16 Sites, United States, 2022. MMWR Surveill Summ 2025;74(No. SS-2):1–22. DOI: <http://dx.doi.org/10.15585/mmwr.ss7402a1>



Recognition of Girls on the Autism Spectrum by Primary School Educators: An Experimental Study

Alana Whitlock, Kate Fulton, Meng-Chuan Lai , Elizabeth Pellicano , and William Mandy 

70% recognized
male traits

65%
recognized female
traits **w/male name**

55% recognized
female traits
w/female name

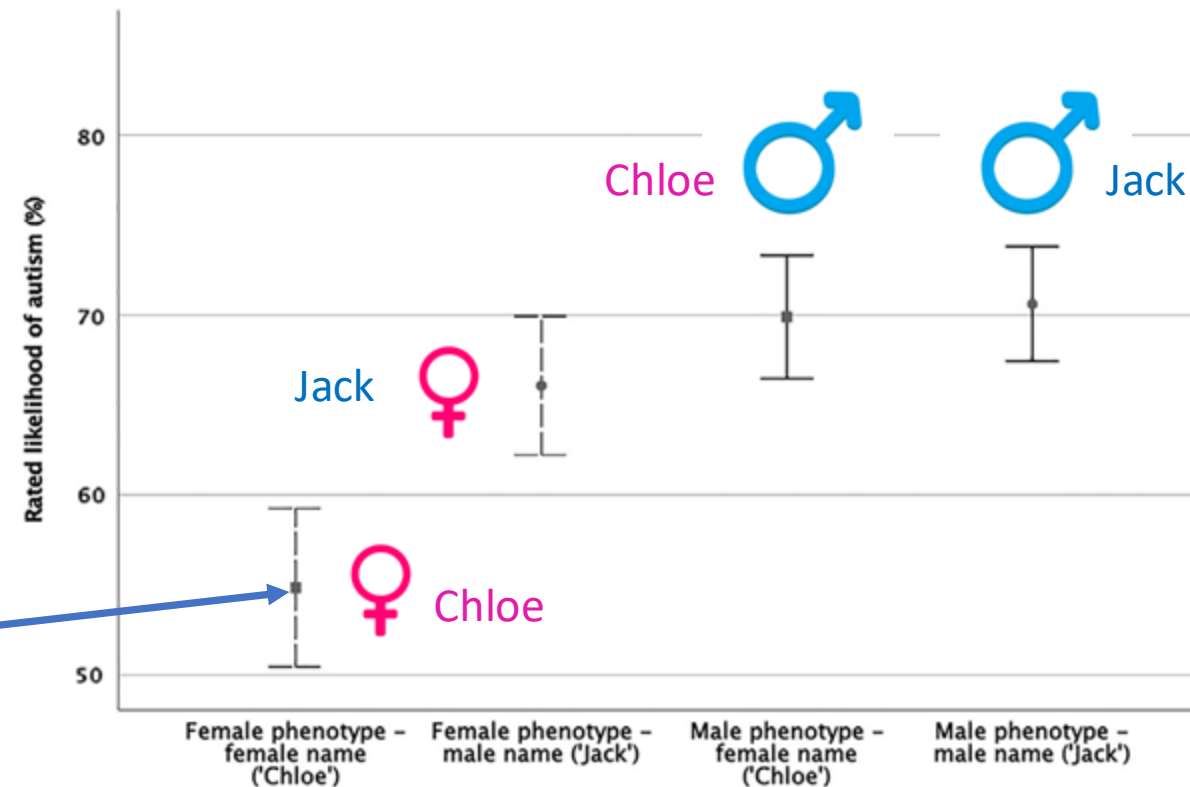


Figure 1. Rated likelihood of autism diagnosis as a function of vignette phenotype and gender (mean, 95% CI).

Likelihood of Seeking Help from School Psych

Only 42% would seek help from school psych regarding female traits with female name

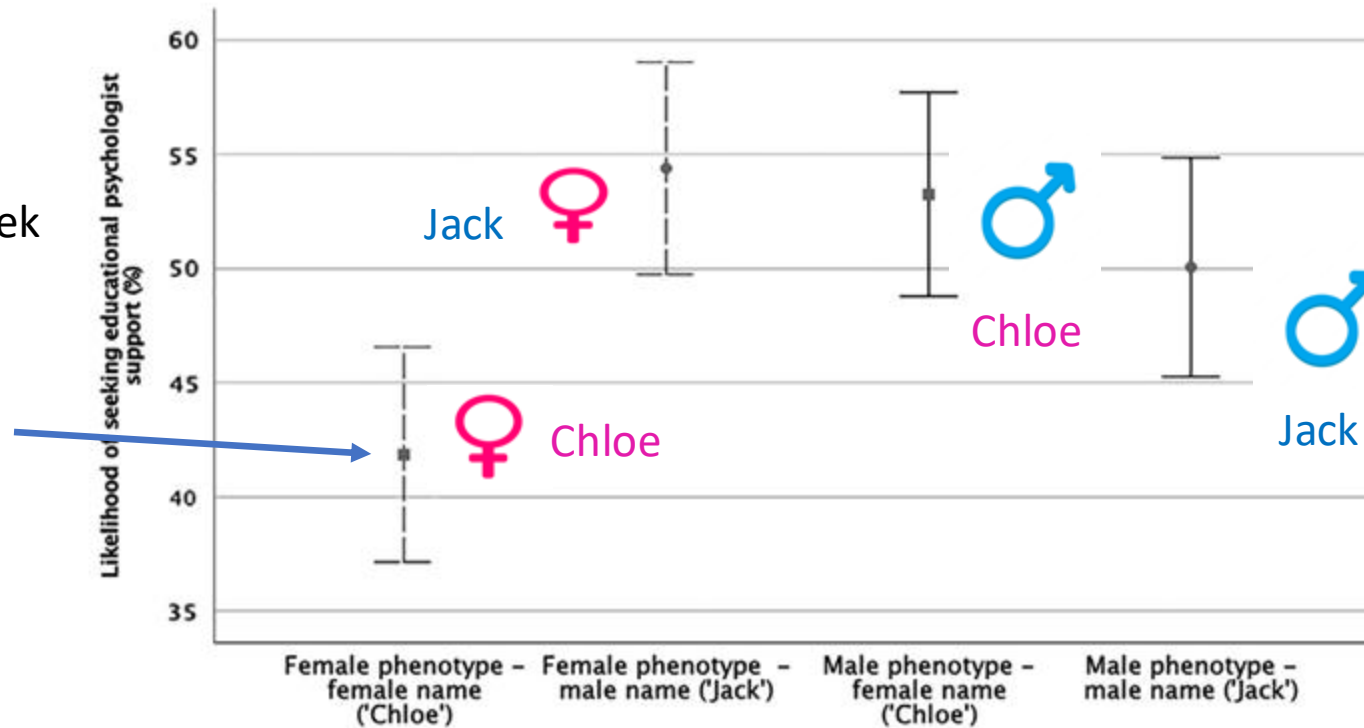


Figure 2. Likelihood of seeking support from an educational psychologist by vignette phenotype and gender (mean, 95% CI).

We use the wrong comparison group

- Autistic girls are more different from neurotypical girls.

≠

- Autistic girls are more similar to neurotypical boys.

?

The mistake most people make is to compare an autistic girl to an autistic boy. They are not much alike and not a suitable comparison. They will almost always look different, people will draw the wrong conclusion.



Behavior Problems (or not)

- *“Back in the day they didn’t really help me, they just put me down to really being a naughty child” (FF11)*



"I was unbearable with my mother, but at school I was perfect." (P09)

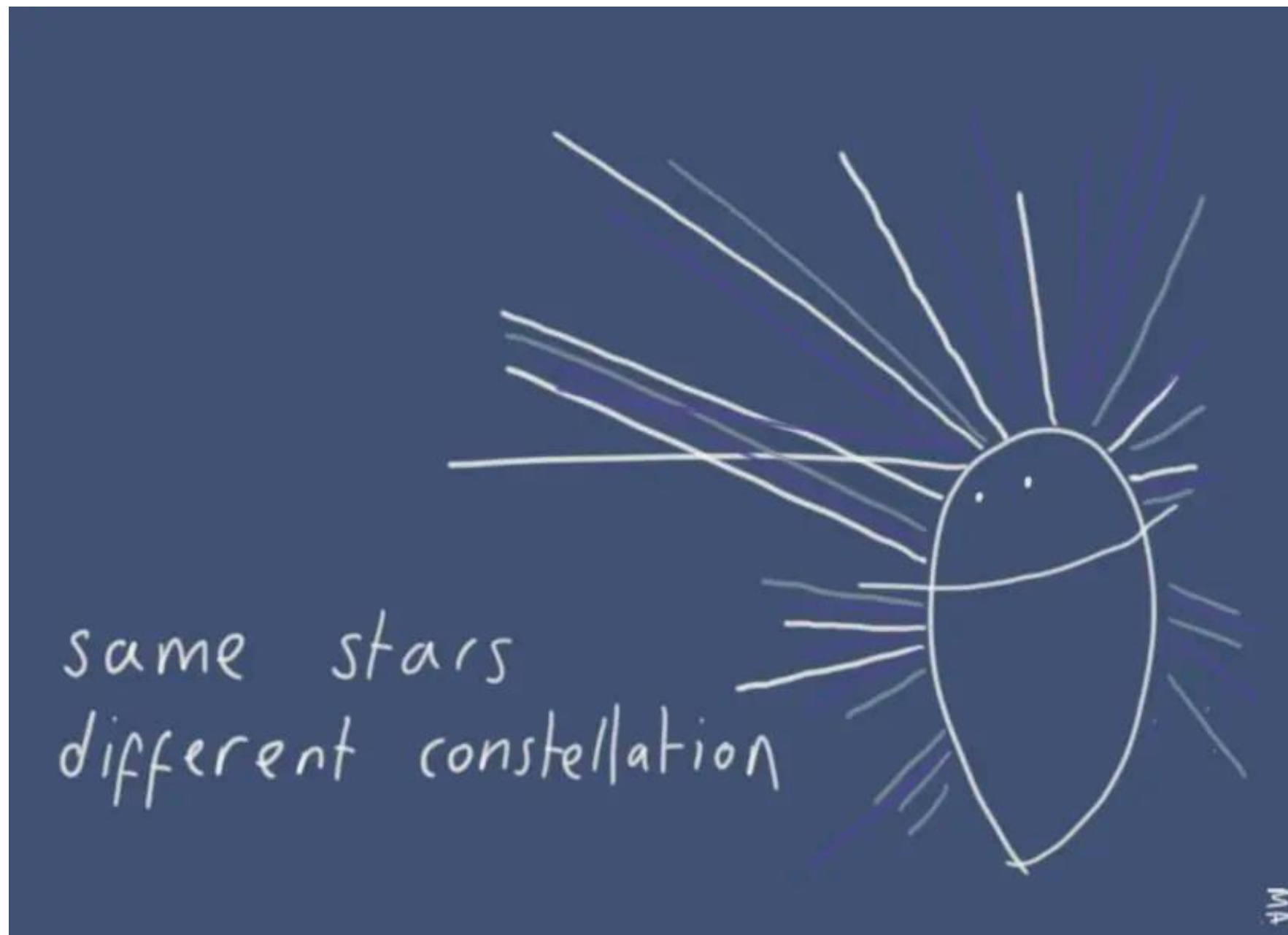
“The reward for trying hard to be normal was to be ignored because you were acting normal and I look at stories online of kids who were going off the rails and I think, I should have just burnt more cars” (P09)

Parent Perceptions of Positive Traits Invalidating Consideration of Autism



- Success and competence in some domains does not rule out autism.
- **Look for patterns** in positive traits that may suggest autism traits.

Getting
Better at
Identifying
and
Supporting
Nuanced
Autism



Because of the overlap in symptoms across diagnoses, it is not unusual for an individual with ASD to be misdiagnosed with multiple disorder rather than ASD. A concept that may be helpful in clarifying the assessment in these cases is the notion of parsimony.

PARSIMONY

For example, if a clinician finds themselves diagnosing or evaluating a patient previously diagnosed with

ADHD, social anxiety disorder, language disorder, developmental coordination disorder, and sensory processing differences,

it may be worth reassessing the constellations of symptoms and considering if ASD is a more overarching, accurate and parsimonious diagnosis. (Duvall et al., 2021, p. 1181)

Genetic Effect

Explore family histories for evidence of autism, which may indicate a higher genetic load and greater likelihood.

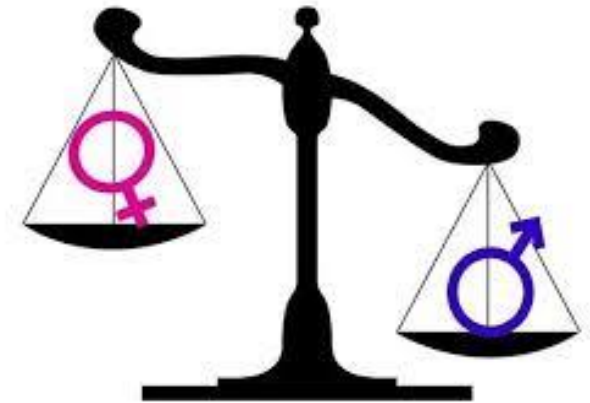
Interviews with *mothers* and teachers



Male Bias in Research & Practice

How to use standardized measures with girls

- Consider sub-threshold results as possibly valid
- Use weight of evidence in a comprehensive evals
- Patterns should be consistent with autism (if not quite at cutoff)
- Variability in cognitive profile (even if all average or above)
- Variability in language abilities or prosody (even if passing as typical)





The Clinical Neuropsychologist

2022

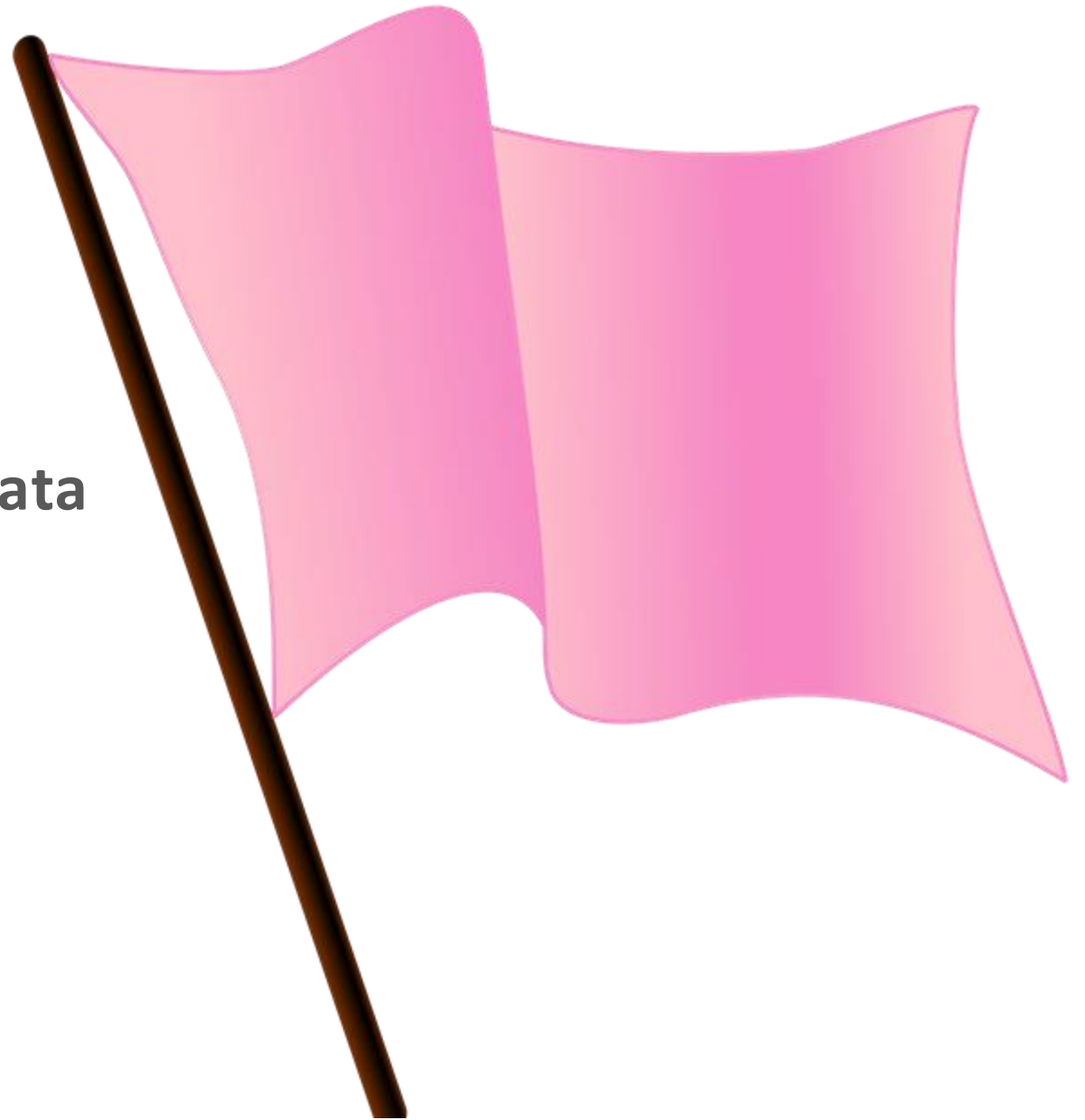
ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/ntcn20>

A road map for identifying autism spectrum disorder: Recognizing and evaluating characteristics that should raise red or “pink” flags to guide accurate differential diagnosis

Susanne Duvall, Kira Armstrong, Ambreen Shahabuddin, Caroline Grantz, Deborah Fein & Catherine Lord

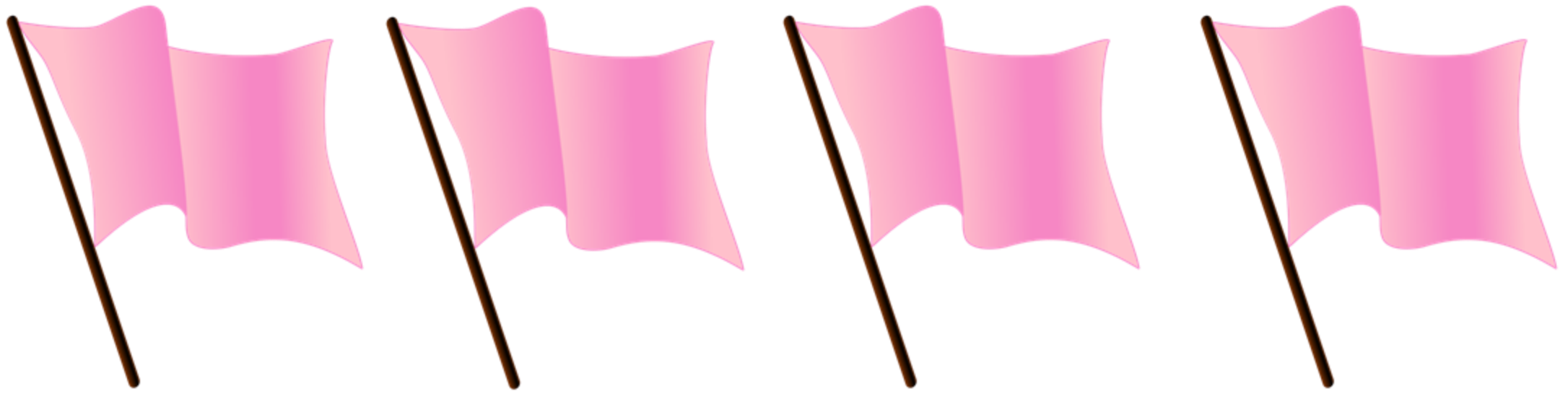
Different Profiles and Patterns

- Patterns of traits
- Red or pink flags in assessment data
- Lower restricted interests and behaviors, (intense interests and stimming)
- More sensory sensitivities,
- Executive functions issues,
- Mild language or motor issues



Milder, Less Apparent Differences – not Deficits

- Pink flags should not be dismissed, *especially* if there are many of them.



(DSM-5-TR, APA, 2022)

Criteria C: Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).



Individuals with autism spectrum disorder may only display the restricted/repetitive patterns of behavior, interests, and activities during the early developmental period, so a comprehensive history should be obtained.

Current absence of symptoms would not preclude a diagnosis of autism spectrum disorder, if the restricted interests and repetitive behaviors were present in the past.

REVIEW



Towards equitable diagnoses for autism and attention-deficit/hyperactivity disorder across sexes and genders

Meng-Chuan Lai^{a,b,c,d,e}, Hsiang-Yuan Lin^{a,b}, and Stephanie H. Ameis^{a,b,c}

Lai, M. C., Lin, H. Y., & Ameis, S. H. (2022). Towards equitable diagnoses for autism and attention-deficit/hyperactivity disorder across sexes and genders. *Current Opinion in Psychiatry*, 35(2), 90–100. <https://doi.org/10.1097/YCO.0000000000000770>



- *Overall, clinical diagnosis is based on the Gestalt*
- *... behavioural-cognitive patterns*
- *... developmental profiles,*
- *... functional and wellbeing impacts ...*

A network diagram is constructed on a white surface using several pushpins and a piece of brown string. The pushpins have colorful, semi-transparent spherical heads in shades of blue, green, red, and yellow. The string is looped around the heads of the pushpins, creating a web of interconnected lines that represent relationships or communication paths. The background is a plain, light-colored surface.

Social Communication Social Reciprocity, and Social Relationships

Heightened *Attention* to Socially Salient Stimuli

- “She has this fantastic moral compass and she always wants to stick up for people” (FP02)
 - Can have intact affective empathy and show sympathy
 - Better at superficial nonverbal communication (possibly exaggerated, inflexible, or not well integrated)
-
- Difficulty reading non-verbal communications
 - Invests large amounts of energy preparing for social interactions, exhausted afterwards
 - Learned and forced eye contact, facial expressions detract from verbal exchanges





CAMOUFLAGING

“I honed something of a persona which was kind of bubbly and vivacious, and maybe a bit dim, because I had nothing to say other than adult novels. So I cultivated an image, I suppose, that I brought out to social situations as my partner’s girlfriend, that was not ‘me’.” (P09)



Camouflaging/Masking is Behavior, not Symptom

- Impression management is not autism-specific nor diagnostic. . .
- Look for:
 - Reports of developmental experiences of intention and efforts to 'camouflage/mask/pass'
 - Cognitive exhaustion due to autistic cognition and executive function challenges, consistent need for recovery time
 - Collateral information of evident autistic features in early years (i.e., childhood), are key to autism diagnostics in this scenario

Lai et al., 2022

TAKE MORE TIME

Social behavioural differences may manifest and become more observable over time during long interactions

- *especially in novel or unpredictable settings*

(Lai et al., 2022)

Repeated assessment sessions over time are likely to illuminate differences in play, conversation, and interests

“Thus, longer assessments, observation in naturalistic settings, and inquiring about any tolls of social interaction may be needed ([Cage and Troxell-Whitman 2019](#); [Hull et al. 2017](#)).” DSM-5-TR



PLAY



Diversity in Autistic Play: Autistic Adults' Experiences E. Pritchard-Rowe, C. de Lemos, K. Howard and J. Gibson Autism in Adulthood 2023 <https://doi.org/10.1089/aut.2023.0008>

Childhood imaginative/pretend play often present

Lining up can be imaginary plan (in my head)

Scripted (even interactive), with limited reciprocity (even with the presence of agency using dolls/figures)

Solitary play can be recuperative

“Flow” is reported (by adults)

Social play takes more energy, more 1:1 and parallel than groups

Lai et al., 2022

Friendships and Social Groups

- Social motivation is present
- Navigating friendships (conflict) is difficult
- Social awareness is present
- Tendency to be naïve about relationships
- Often prefer to be alone or with one friend
- Effort and time required to understand thoughts and feelings of NT peers
- "Flitting"



“When I was being bullied, I was told not to antagonise these girls and actually I was only antagonising them by being myself.”

(P03)

“In secondary school I just got the shit kicked out of me mentally, physically, emotionally, the works, and the teachers joined in.”

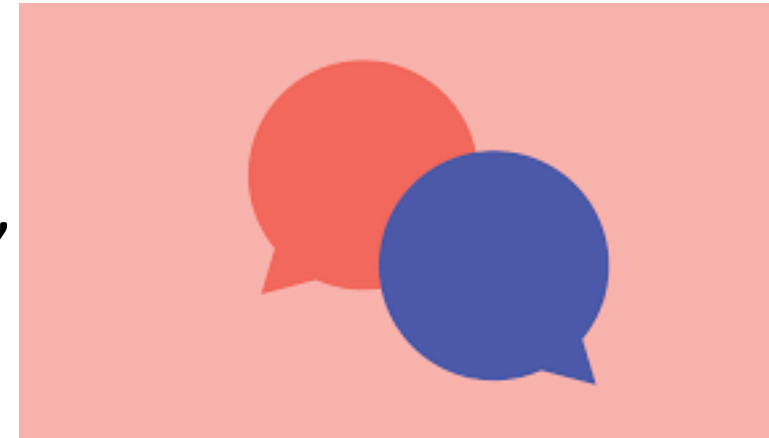
- Gemma (Kanfischer et al., 2017, p. 666)

It was probably the culmination of everything, but the bullying was I think was the catalyst for the breakdown. The trigger that sent her into freefall. -P12 - Mother (Fowler & O'Connor, 2021)

*“[She] has been bullied a lot. I did not know about it going on but because she is different just in her affect and in understanding things. . . A lot of it was at church and I wasn't aware of it . . . I think accumulated overtime to a point where she doubted herself.”
(Participant 22- Mother)*

Richness in language expression

- Conversational reciprocity improves and becomes more natural when talking about interests
- Well-rehearsed - questions as conversation
- Stereotypy may be idiosyncratic language (formal, pedantic, detailed, precise)
- Good structural language ability, especially in expression
- YET, difficult understanding own emotions (alexithymia) and others' emotions, including long processing times or difficulty differentiating emotions





- Prosody
- Good at superficial back-and-forth,
- Not very flexible, but 4-part, 2-way conversations
- Not good in a group
- Trouble shifting topics
- Conversation improves around interests
- Evidence of not understanding social situations, sarcasm, jokes, etc.

“I honestly didn’t know I was doing it [social mimicry] until I was diagnosed, but when I read about it, it made perfect sense. I copy speech patterns and certain body language.” (P05)



Intense or Special Interests

- *Content of circumscribed interest can be typical to neurotypical and gendered contexts (e.g., Fantasy, animals)*
- Unusual for her age (e.g. dolls, My Little Pony)
- Often become more evident in adolescence as peers outgrow them

Imaginary Worlds

- I have an imagination and I just kinda live in it a lot.
- Um, especially when I was little and that was not as, you know, as strange to like, play pretend and stuff like that.
- So, I'd make up these incredibly elaborate worlds and then I'd find people who'd go along with it with me and then, but then they would kind of mature to a point and they'd be done.
- And they'd be done with my worlds and they'd be done with me.

(Unpublished study)





“So she loved things about dragons, she loved things about horses. . . I don't know if she identified with the characters or she separated them, but she would become somewhat attached to them, . . . almost like they were real people.”



Sensory Sensitivities

Sensory Intolerance



“The sensory issues are just, it’s the most difficult thing in the world and it’s so distressing and it really does make a difference between I think um having life quality or not for me” (FF18)

Listen -- Sensitivity to Sound

- “We can’t go there any more”
- Covers ears at sudden or loud noises; flaps, turns circles, and acts out in odd ways when stressed by too many visual or auditory distractions;
- Shows ill temper or illness at parties, theme parks and other large-group activities;
- **Misophonia**
- Sensory overwhelm



Eating Disorders and Autism – Different Etiologies, Different Treatment Needs



"I feel like I've lost control of my head, so I'm refusing to eat or drink anything. . . I hope that I will finally be able to die if I keep refusing to eat or drink water." -

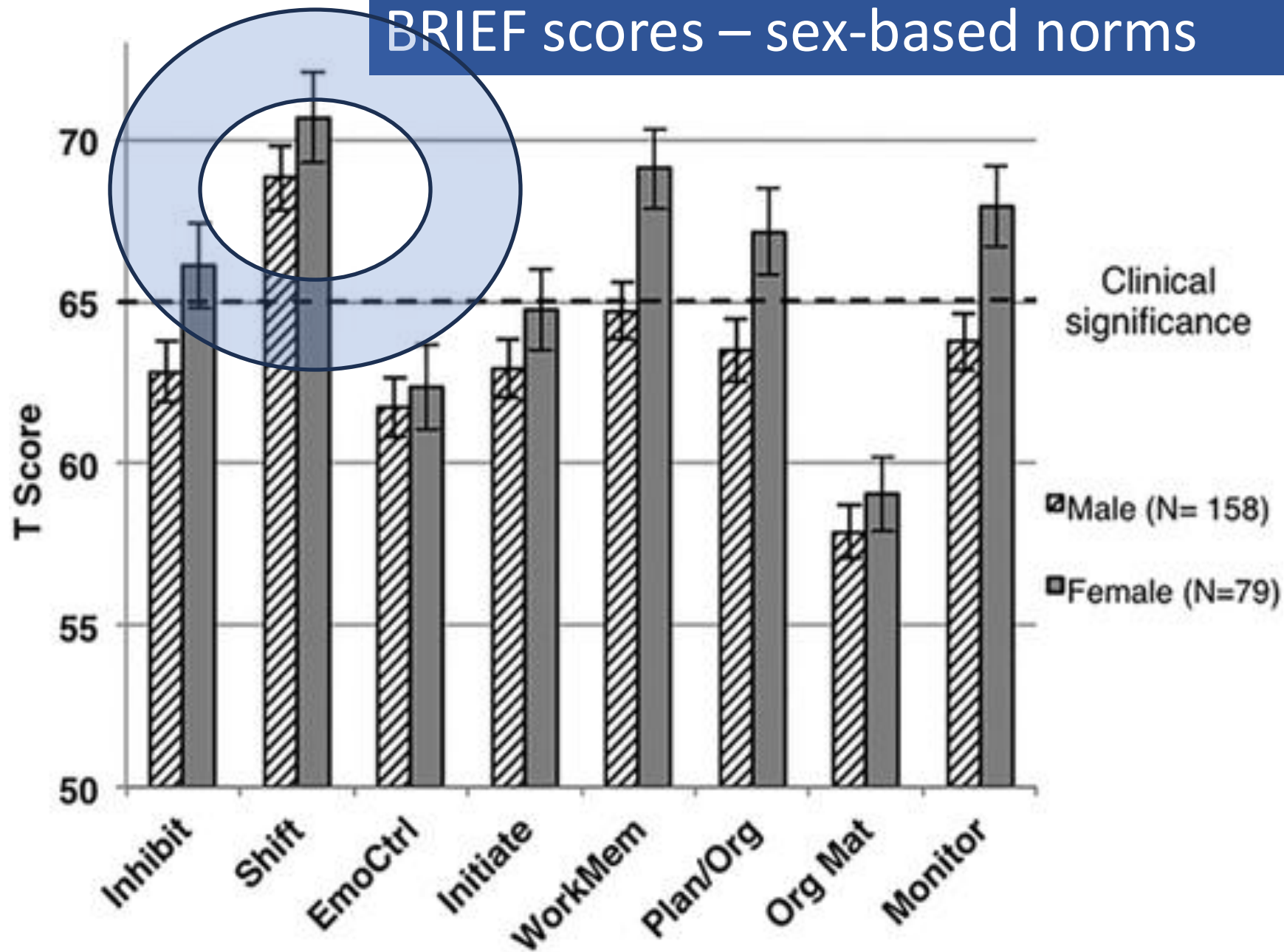
"It all boils down to the fact that if anyone had connected the dots between autism and eating disorders, if I had found your work earlier, if the professionals who were supposed to be experts in the field had known what autism even looks like in girls or women . . . we might have saved Kathryn's life. --Rebecca" - O'Toole (2018), p. 255

Rigid – Executive Function

“So yes, even when she knows she has something that she wants to do or has to do, it’s hard for her to switch gears and do it. And it’s impossible for someone else to make her.”



BRIEF scores – sex-based norms



White et al., 2017
(Lauren Kenworthy)

79 girls
158 boys
matched data

IQ 106(20)

ADOS II(4-5)

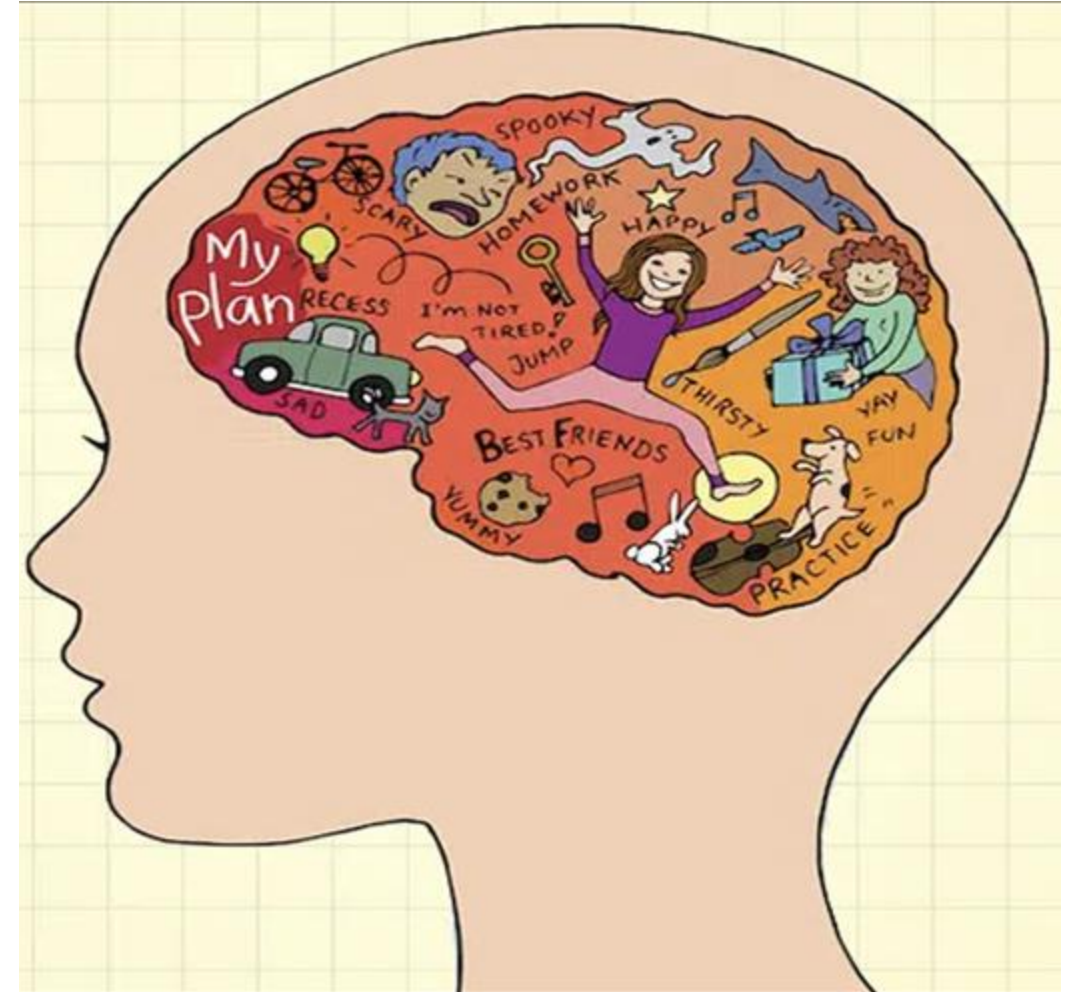
Insistence on Sameness

self-critical
Anger compelled
unrealistic
Perfectionism
strive self-esteem
realistic expectations

- *Can be perceived as perfectionism or preoccupation with details*
- *Can manifest as strictly following rules, 'black and white' thinking, or insisting on believed truth*

Assess for Executive Function

- **Gendered (binary) norms are available**
- Be sure to include Self-report versions if old enough
- INTERVIEW her!
- Direct assessment of Executive Function (D-KEFS, etc.) may show competencies that don't exist in real-world situations
- Interviews and observations can also illuminate executive function issues that screeners might miss or raters might not notice.



Cognitive Differences

- +Variable memory skills- sometimes excellent, sometimes a challenge
- +Variations in cognitive profile- consider what types of skills are represented
- +Goes “deep” in topics of interest
- +Rigidity in thought patterns and connections
- +Logical mind
- *NOTE: CARS-2 HF may be a good way to include Cognitive and Adaptive comparison in a scored measure.*



Sensory and Executive Function and Motor and Hygiene

- Possible sensory intolerance (hair)
- Many, many steps for basic hygiene
- Smells, textures
- Routine disruption
- Transitioning from other activities
- Motor skills – braiding, combing,
- Dressing, putting on a bra





It's kind of like a duck on water you know it's calm on the surface but sort of paddling really hard underneath (FF13)

Autistic Burnout

Assessing Burnout

Engagement with circumscribed interest can also be exhausting

- *Despite superficially intact functioning, can easily feel exhausted due to impression management efforts*
- *Context dependence of functioning is not uncommon: e.g., keeping oneself together in public (e.g., at school, workplace) but experiencing/expressing substantial emotion regulation challenges (e.g., burnout, meltdown) in private settings (e.g., at home)*



Assessment Approaches

-Standardized measures need to be supplemented substantially **with interviews and observations.**

-**Don't make assumptions about function based on cognitive or language skills- assess those areas**



-Adjust interviewing style

-Reduce open-ended questions

-Especially for suicidality, eating disorders, etc.



Evidence exists that borderline or sub-threshold results are significant for girls

- **Social Responsiveness Scale, Second Edition**
 - Fewer symptoms required for significance for girls
- **Autism Spectrum Questionnaire (AQ)** has different (fewer symptom) cutoffs for females (16 and older) AQ-Adolescent (12-15)
- Even in the general population, females have lower autism trait scores than males

Meet Asteria, Princess and Paladin



Girls and Women on the Autism Spectrum

Girls and Women on the Autism Spectrum

[Books](#)[Videos](#)[Links](#)[Webinars](#)[Podcasts](#)

Hi there, my name is Chloe Rothschild. I am 23-years-old and I have autism. I am on a mission to help advocate and teach others about autism and what it's like from my perspective so that they can help individuals with autism. As a member of the OCALI advisory board, and a young woman with autism, I am pleased to welcome you to OCALI's Autism Awareness site. This year the main focus will be on girls and women with autism. I hope you find the information OCALI has to offer helpful. Thank you for helping spread autism awareness and most of all, acceptance.

Chloe Rothschild
OCALI Advisory Board Member
Autism Advocate
Young Woman with Autism

- OCALI <https://www.ocali.org/project/Girls-and-Women-on-the-Autism-Spectrum>
- OCALI AIM Module on Girls <https://autisminternetmodules.org/>

Online Resource

Peter Gerhardt & Amy Gravino



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