Girls on the Spectrum

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Sex, Gender, Autism

- Sex (Biological) ≠ Gender (Cultural)

- Higher prevalence in boys

- Boys are diagnosed with autism earlier
What I have learned from autistic girls

“I tended to over-communicate all the time because I constantly felt misunderstood or the way I was saying something wasn’t the right way...after I would have a social interaction, I would replay the conversation over and over in my head...this would lead me to frustration...at the time I didn’t realize I couldn’t access that information in my brain.”

-Adult autistic woman

“The thing about being autistic is that you gradually get less and less autistic, you keep learning how to behave. It’s like being in a play; I’m always in a play”

-Temple Grandin

“When I got interested in stuff, I really got interested...it caused a little bit of conflict between me and other students because they thought I was hogging the art table...I was known as the art kid.”

-Female teen with autism
ADDM Report 2023

• Currently 1:3.8 female:male

• For the first time reported, the prevalence for females is >1% (currently 1:87 up from 1:113)

• Identification of the co-occurrence of Intellectual disability is increasing (currently 38% co-occurring), with girls more frequently receiving an additional diagnosis of Intellectual Disability (42% Female compared to 37% Male).
Why are fewer females diagnosed with autism?

- Diagnostic criteria?
- Bias?
- Research Participation?
- Something inherent about being female?
Some of the first descriptions of Autism

Hans Asperger

Leo Kanner

Hans Asperger - Wikipedia

Leo Kanner - Wikipedia
Social reciprocity

Found differences between boys and girls with ASD in:

- Turn taking
- Reciprocal interaction
- Reciprocal flexibility
In general, the literature suggests girls have:

- Fewer RRBs and motor stereotypies
- Less intense interests
- Interests that are more typical/age appropriate
  - Autism
  - Nature/gardening
  - Human body/Psychology
  - Animals
  - Arts & Crafts
Why are fewer females diagnosed with autism?

- Diagnostic criteria?
- Bias?
  - Clinicians biased to see autism in boys?
  - Tools biased towards males?
  - Extrinsic factors?
- Research participation?
- Something inherent about being female?
Clinician Bias

Boys are referred for diagnostic assessment 10 time more often than girls (Wilkinson 2008)
Are measures bias?... probably not

• Some studies report that females exhibit an increased number and severity of autism symptoms (Frazier & Hardan, 2017).

• Conversely, others report less severe autism traits and fewer symptoms in females (Backer van Ommeren et al., 2017; Beggiaoto et al., 2017).

• Yet other studies have found no sex differences in autism symptomatology (Frazier & Hardan, 2017; Pisula et al., 2017).
Measure bias, cont’d

Original Investigation | Pediatrics

Analysis of Race and Sex Bias in the Autism Diagnostic Observation Schedule (ADOS-2)

Luther G. Kalb, PhD, MHS; Vini Singh, MPH; Ji Su Hong, MD; Calliope Holingue, PhD; Natasha N. Ludwig, PhD; Danika Pfieffer, PhD; Rachel Reetzke, PhD; Aiden L. Gross, PhD, MHS; Rebecca Landa, PhD

ORIGINAL PAPER

Sex Differences on the ADOS-2

Hannah M. Rea1 • Roald A. Øien2,3 • Frederick Shic4,5 • Sara Jane Webb1,4 • Allison B. Ratto6

Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis

Aaron J. Kaut,1 Amy M. Shui,2 Sheila S. Ghods,2 Cristian A. Farmer,3 Amy N. Esler,4 Audrey Thurm,3 Stelios Georgiades,5 Stephen M. Kanne,6 Catherine Lord,7 Young Shin Kim,2 and Somer L. Bishop2

https://doi.org/10.1007/s10803-022-05566-3

doi:10.1111/jcpp.13242
Diagnostic Considerations

Clinicians should be aware that females may present with a more nuanced presentation

- Superficial social skills (conversational reciprocity, use of facial expressions, naivety)
- Interest in social relationships, but may not be accepted
- Gender-normative repetitive behaviors (e.g., animals)
- Sensory dysfunction can lead to eating problems or clothing choices not fitting gender stereotypes
- Symptoms may present later due to masking
- Clinicians should probe the individual (as appropriate based on language/cognitive level) for masking
Why are fewer females diagnosed with autism?

• Diagnostic criteria?

• Bias?

• Research participation?
  • Most past research includes mostly male participants?

• Something inherent about being female?
Potentially problematic interactive cycle

- Females diagnosed with ASD less frequently
- Girls present differently with ASD?
- Fewer females available for research
- Less known about female ASD profile
The impact of heterogeneity on Research

- Research can be more accurate with more participants
  - WHY? Individual studies try to apply information about those who participate in a single study to the entire population of people in the group in the study, therefore, some study designs are best applied when there are more participants

- Heterogeneity = variability in symptom presentation

- Heterogeneity can complicate the ability to apply research findings to populations
Example

Does medicine X treat strep throat?

People with all types of strep

Medicine X does not treat strep throat

What researchers yet don’t know is that Medicine X doesn’t work for Strep A. They included people with both Strep A and Strep X (more with Strep A). People with Strep A confused the results. Conclusion was incorrect.
Potentially problematic interactive cycle

- Females diagnosed with ASD less frequently
- Girls present differently with ASD?
- Fewer females available for research
- Less known about female ASD profile
But there may be an increasing identification of females with Autism

DOI 10.1007/s10803-014-2053-6

Time Trends Over 16 Years in Incidence-Rates of Autism Spectrum Disorders Across the Lifespan Based on Nationwide Danish Register Data

Christina Mohr Jensen · Hans-Christoph Steinhausen · Marlene Briciet Lauritsen
Why are fewer females diagnosed with autism?

- Diagnostic criteria?
- Bias?
  - Clinicians biased to see autism in boys?
  - Tools biased towards males?
  - Extrinsic factors
- Research participation?

- Something inherent about being female?
  - Intrinsic factors
  - Genetic protection?
  - Camouflaging?
Intrinsic and Extrinsic Factors

- **Intrinsic**
  - Timing of developmental milestones
  - Intelligence
  - Medical concerns
  - SCQ

- **Extrinsic**
  - Urbanicity
  - Income
  - Age of parent-report first concern
  - Parent-reported first concern

SPARK Sample (all autism)
- N = 18,042
- Males n = 14,334
- Females n = 3,708

Ages 18m to 18y
Intrinsic factors

- Females more delayed on motor milestones (1-3 months in sitting without support, crawling, and walking)

- Males more delayed on language milestones (1-2 months in using words, combining phrases, and using complex sentences)
  - Females slightly lower on parent report of autism symptoms (SCQ)
  - Females more likely to have ID

Dillon et al. 2021
Extrinsic factors

• More females in lower income brackets (but not urbanicity)
• No difference in age at first concern
• Boys increased ADHD, girls increase mood concerns

• Parents noted first concerns for females:
  o late walking, mood, social
• Parents note first concerns for males:
  o change or skill loss, late speech, repetitive bx
Intrinsic and Extrinsic Factors (Take Aways and Next Steps)

- Supports developmental sex differences in ASD for females:
  - Later motor milestones
  - Better language
- …that can lead to delayed identification (and access to services):
  - 4 months longer to dx
  - Diagnosed 4 months later
- How do differences in co-occurring condition presentation impact?
Rule-Outs

- Receptive/Expressive Language Disorder
- ADHD
- Anxiety
  - Specific Phobia
  - Social Phobia
- Intellectual Disability
- Learning Disability
- Giftedness
My child doesn’t have friends…

Autism
- Limited nonverbal socialization
- Limited spontaneous seeking to share enjoyment
- Limited social reciprocity
- Rigid in social interactions, directing play

ADHD
- Interrupts and intrudes on others
- Talks excessively
- Difficulty playing quietly
- Does not listen when spoken to directly
- Difficulty sustaining attention to tasks or play
Co-occurring conditions

- Receptive/Expressive Language Disorder
- ADHD
- Anxiety
  - Specific Phobia
  - Social Phobia
- Intellectual Disability
- Learning Disability
- Giftedness
Sex Differences in Co-Occurring Symptoms

- N=25,078
  - Ages 6-18
    - Males n = 19,681
    - Females n = 5,397

- Developmental and medical history
- Looked at social, RRBs, and motor

Co-occurring attention-deficit/hyperactivity disorder and anxiety disorders differentially affect males and females with autism

Ericka L. Wodka, Julia Parish-Morris, Robert D. Annett, Laura Carpenter, Emily Dillon, Jacob Michaelson, So Hyun Kim, Rebecca Landa, the SPARK Consortium, and Stephen Kanne
Demographic differences

<table>
<thead>
<tr>
<th>Sex distribution</th>
<th>Overall</th>
<th>ASD Only</th>
<th>ASD+ADHD</th>
<th>ASD+Anx</th>
<th>ASD+ADHD+Anx</th>
<th>Subgroup Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female – N (%)</td>
<td>N=25,078</td>
<td>N=10,804</td>
<td>N=7,707</td>
<td>N=2,045</td>
<td>N=4,522</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5,397 (21.5%)</td>
<td>2,536 (23.5%)</td>
<td>1,268 (16.5%)</td>
<td>595 (29.1%)</td>
<td>998 (22.1%)</td>
<td></td>
</tr>
<tr>
<td>Male – N (%)</td>
<td>19,681 (78.5%)</td>
<td>8,268 (76.5%)</td>
<td>6,439 (83.5%)</td>
<td>1450 (70.9%)</td>
<td>3,524 (77.9%)</td>
<td></td>
</tr>
<tr>
<td>Sex ratio vs. ASD Only</td>
<td>Reference</td>
<td>More males*</td>
<td>More females*</td>
<td>ns</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\[ \chi^2 = 211.87^* \]
Females with co-occurring anxiety, diagnosed after age 8 compared to males who were diagnosed around age 6, and delay mostly impacted mostly by co-occurring ADHD.

Wodka et al., 2022
Key Findings by Group

Parent Report ASD Symptoms

Parent Report Motor Skills

Parent Report Repetitive Behaviors

Wodka et al., 2022
Co-Occurring Conditions (Conclusions)

• Males over-represented with ADHD, females with Anxiety

• Co-occurring conditions delay ASD diagnosis, particularly anxiety in girls

• Co-occurring conditions reduce sex differences in reported ASD symptoms (SCQ)
• Co-occurring ADHD leads to greater reported motor difficulties
• Co-occurring conditions impact RRBs differently by age

Wodka et al., 2022
Co-Occurring Conditions (Take Aways)

• School-age females with autism at highest risk for underestimation of autism related symptoms

• Across ages, be careful to probe for social communication symptoms, RRBs, and motor problems in females with autism alone, or with co-occurring Anxiety or ADHD
Why are fewer females diagnosed with autism?

• Diagnostic criteria?
• Research participation?
• Bias?
  • Clinicians biased to see autism in boys?
  • Tools biased towards males?
  • Extrinsic factors

• Something inherent about being female?
  • Intrinsic factors
  • Genetic protection?
  • Camoflauing?
Female protective theory

• Hypothesizes that females require greater environmental and/or genetic risk than males to express the same degree of autistic characteristics, and, hence, that females are ‘protected’ from autistic characteristics relative to males with a comparable level of risk factors (Robinson et al. 2013).
Camouflaging

• Some autistic individuals learn/implicitly develop the ability to compensate, mask, and assimilate (can be conscious/unconscious) to fit in social situations
  • All people camouflauge in some way, but for those with ASD it is exhausting and ongoing and can cause anxiety/distress

• Examples include mimicking facial expressions of others in interactions, forcing eye contact, suppress discussing interests or repetitive behaviors

• Can delay recognition/diagnosis
Conclusions

• Females are under-recognized on the Autism Spectrum

• There are multiple contributing factors, involving both intrinsic and extrinsic characteristics

• Co-occurring mental health conditions are more common in females and can further delay ASD diagnosis
References

• American Psychiatric Association. (2013). DSM-5 Diagnostic Classification. *Diagnostic and Statistical Manual of Mental Disorders.* [https://doi.org/10.1176/appi.books.9780890425596.x00diagnosticclassification](https://doi.org/10.1176/appi.books.9780890425596.x00diagnosticclassification)


References


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Thank you and Questions

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