

SEX MATTERS: UNIQUE PRESENTATION OF AUTISM IN FEMALES AND IMPLICATIONS FOR PRACTICE

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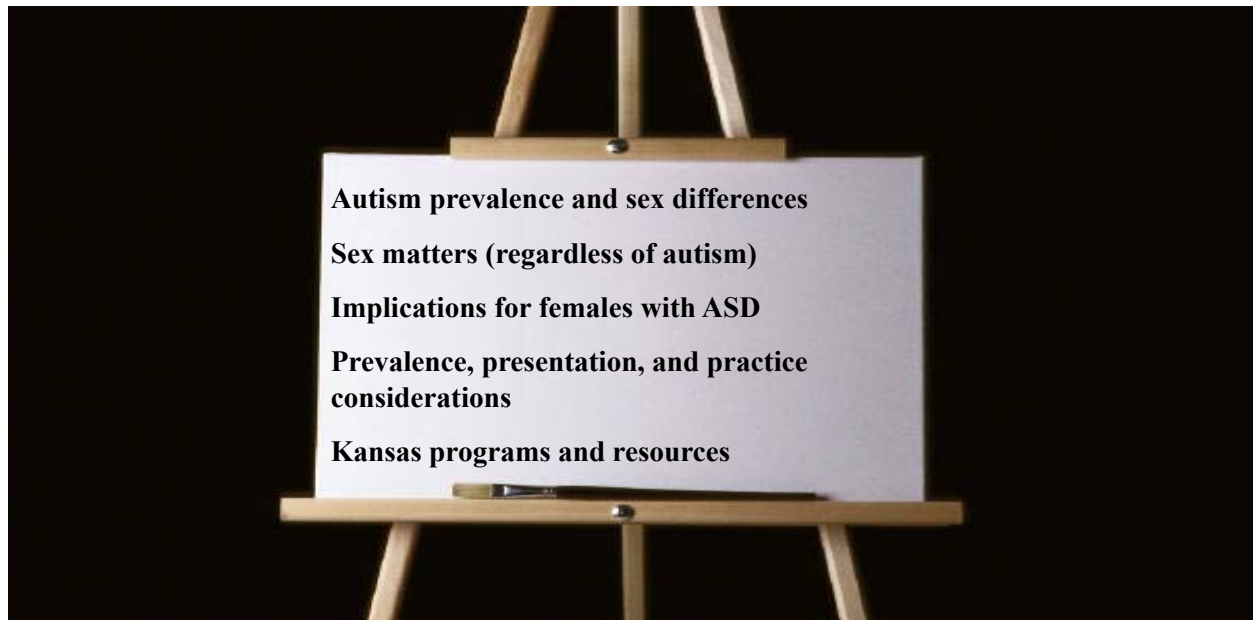
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WHAT YOU CAN EXPECT...YOUR VISUAL SUPPORT

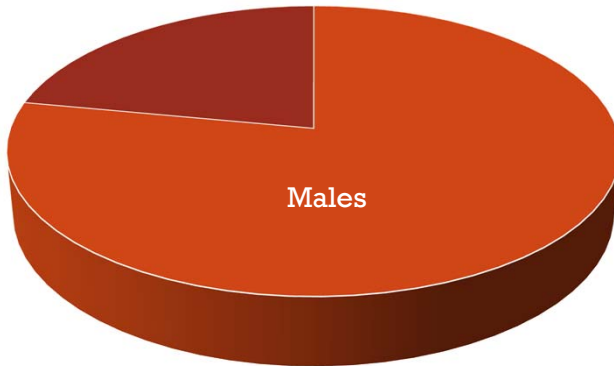


AUTISM SPECTRUM DISORDER (ASD)

- Heterogeneous
- Diagnosis based on criteria defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM)
 - DSM-IV-TR (2000)
 - DSM-5 (2013)



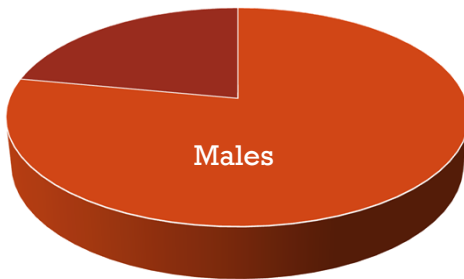
Greater prevalence in males



4:1 – Male to Female Ratio



Greater prevalence in males



Lesser impact on females
in general population
→ decreased focus
→ "female protection"

Frazier, et al 2014



SEX DISPARITY IN DIAGNOSIS

Female Protective Effect - ASD result of multiple risk factors

- Females may require larger “load” for ASD threshold (Lai et al., 2014).

Under-representation of females

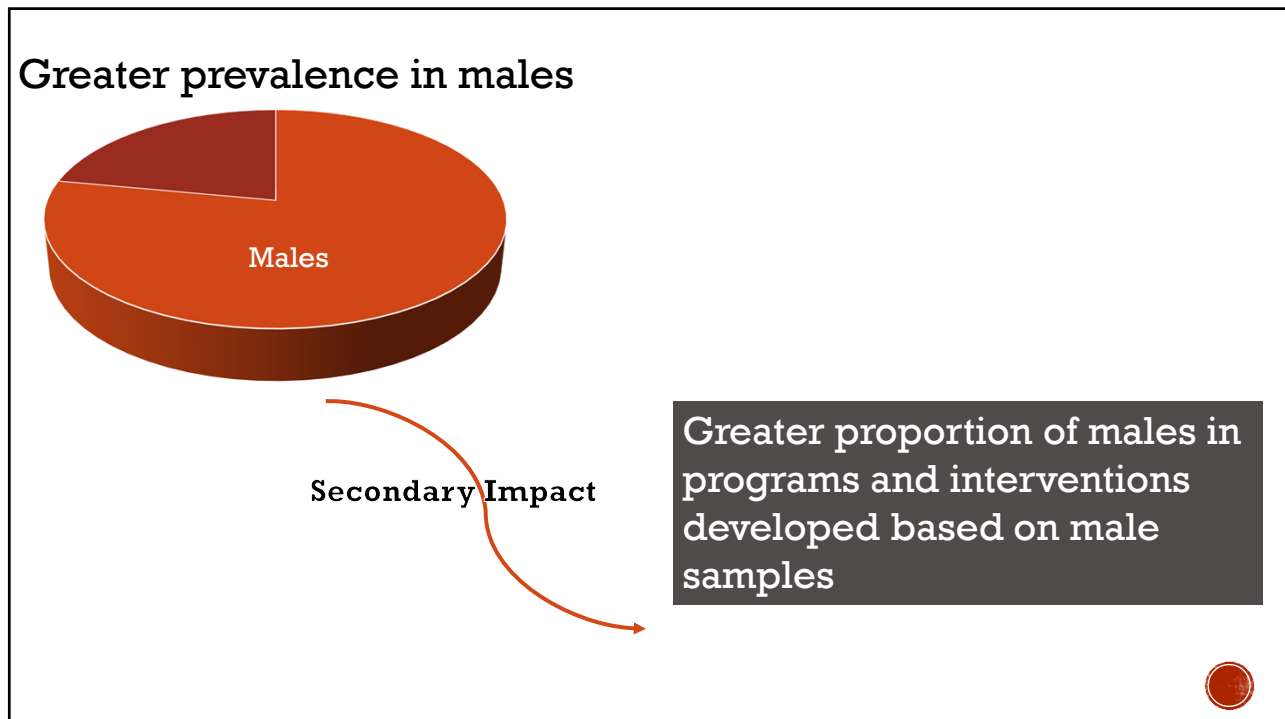
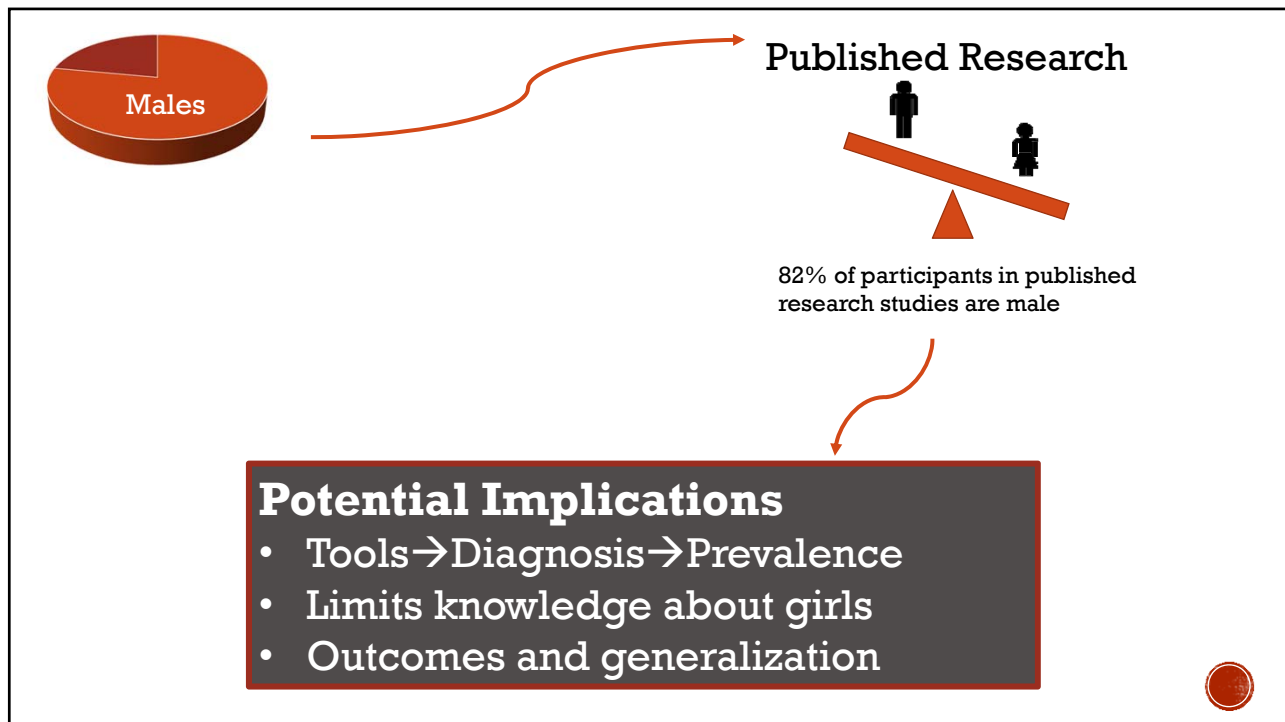
- Higher functioning females “missed”
- Population studies suggest ~ 2.5-3:1
- More likely not to receive diagnosis, delayed (~ 2 years), misdiagnosis (Rivet & Matson, 2011).
- Girls are diagnosed, on average, two years later than boys
- Avg age of a parent concerns significantly younger for girls with ASD



Demographics	N (%)	Mean age (range)	Co-existing Internalizing	Co-existing Externalizing
Females	255	6.43 (1-20)	14 (6%)	77 (34%)
ASD	115 (45%)	6.03* (1-20)	3 (3%)	21 (20%)
No ASD	140 (55%)	6.75 (1-18)	11 (9%)*	56 (46%)*
Males	1021	6.10 (0-21)	55 (5%)	432 (42%)
ASD	532 (52%)*	6.03* (1-21)	29 (6%)	158 (30%)
No ASD	489 (48%)	6.18 (0-18)	26 (5%)	274 (56%)*
Total Sample	1276	6.17 (0-21)	69 (5%)	509 (40%)
ASD	647 (51%)	6.03 (1-21)	32 (5%)	179 (28%)
No ASD	629 (49%)	6.30 (0-18)	37 (6%)	330 (52%)

CCHD
2012-2015





EXAMPLE CLIPS



Reported sex differences.....how does this relate to DSM diagnostic criteria

Develop play skills earlier (associative and cooperative play; play with peers); but boys “catch up”

Imaginative and pretend play earlier and sometimes more advanced

Females often engage in conversation more than males

Greater use of nonverbal communication

- “other directed” gaze more often than males
- increased gestures
- recognize facial emotion than males
- variable evidence related to empathy

Increased complexity of social norms & expectations during adolescence

- conversation focus on emotional support, facilitative, and relationship based
- engage in co-action activities that allow for other social behaviors (males = activity based)

Increased risk for internalizing symptoms (anxiety, depression, low self-esteem)

PRACTICE IMPLICATIONS

- Screening and referral (MCHAT)



Head et al., 2014

(Insert figure)

CONSIDER REFERENCE GROUP

Individuals with
autism scores below
that of those without
ASD

Girls with autism
scored similar to boys
WITHOUT autism.



Do early caregiver concerns differ for girls with autism spectrum disorder?

Little, Wallisch, Salley, &
Jamison, 2016

Insert Figure from caregiver concerns paper

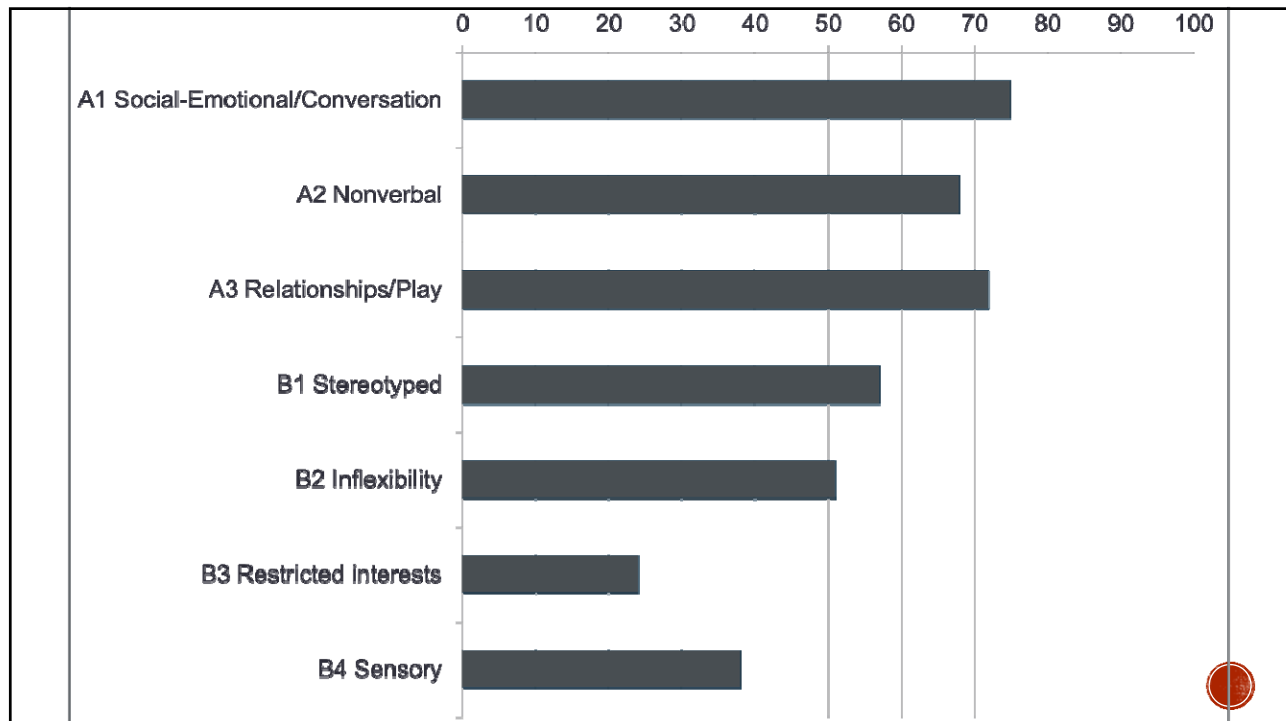


HILLER, YOUNG, & WEBER (2014)

Sample 69 girls, 69 boys w/
HFA (Mean age = 8-9 years)



HILLER ET AL. (2014) DSM-5 FINDINGS



CLINICIAN PERSPECTIVES ON SEX DIFFERENCES

Jamison, Bishop, Huerta, & Halladay, 2017



EXPLORING THE SOCIAL PROFILE OF FEMALES WITH AUTISM

Research Questions:

- How are the interests and social activities of adolescent girls with ASD similar or different from their typically developing peers?
- What are the perceived components of and roles within friendships as described by adolescent girls with and without ASD?
- How do social presentation activities and perceptions (e.g. self-care routines) differ in adolescent girls with and without ASD?

Participant Type	Focus Groups	Total Number	Mean Age (SD)
Adolescent Females with Autism	4*	14	15.57 (1.22)
Adolescent Girls without Autism	4	20	15.85 (1.30)
Parents of Girls with Autism	4*	15	NA
Parents of Girls without Autism	2	12	NA

Schuttler et al.,
manuscript in progress



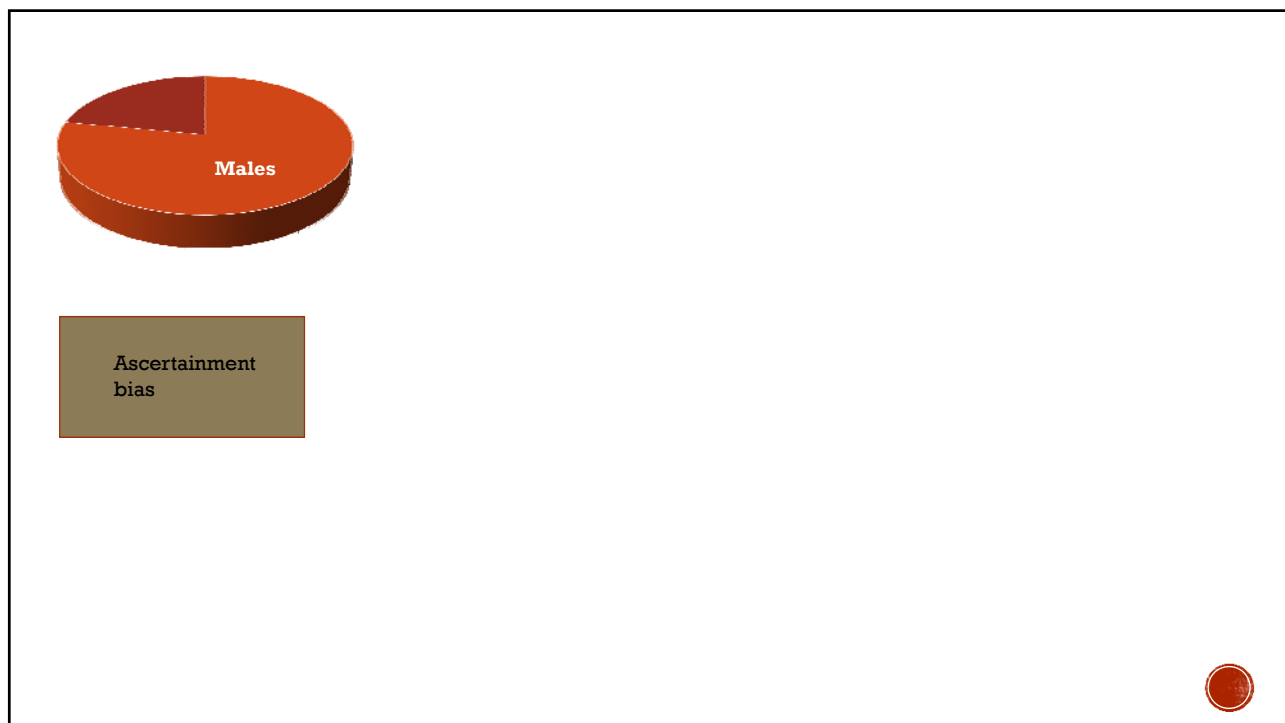
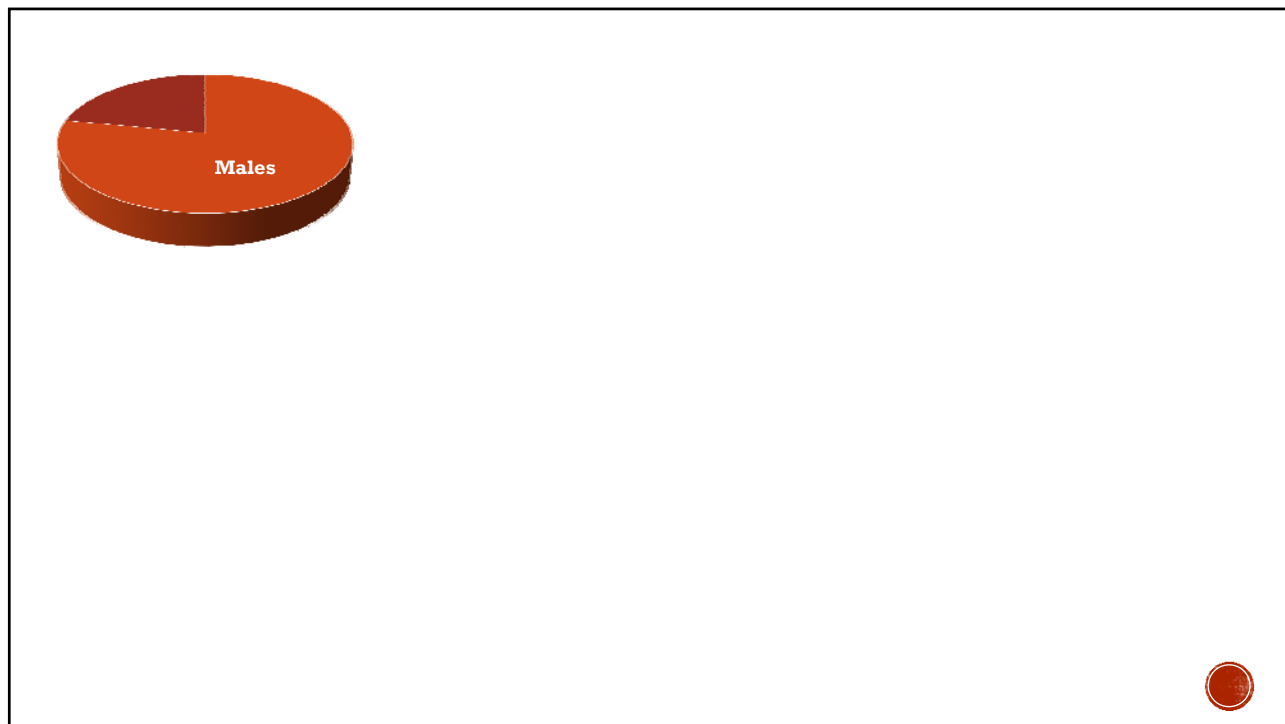
Themes	Supporting Quotes
Limited Social Opportunities and Interactions	<p>"She will plan with a friend several times, but it's been like gaps, you know. You're talking about one or two times a year, you know." (PA)</p> <p>"What our daughter, it seems like she may have a few little friends when she was a little younger, but now it seems like the older she's getting she's less and less friends." (PA)</p> <p>"I'd say she has online friends, that's it. She likes to...yeah, that she plays games with and...Virtual friends." (PA)</p>
Planning & Coordination Shift	<p>"There is a vicious cycle that happens - you want to get in on the group activities, and when you attend those activities, you make plans for the next activity - sort of a FOMO effect - you want to attend so you know what's happening next you stay in the "group" and in the "loop." (NA)</p> <p>"...so you're hanging out with like your high school friends and oh like my grade school friends want to do something, .. we all do something and meet each other." (NA)</p> <p>"my parents drive her we go and get her and then to go to the movies and then her mom usually takes me home sometimes." (FA)</p> <p>"She wouldn't invite the kids, but she would direct me to organize with the parents." (PA)</p>
Increased Complexity	<p>"Well elementary school, it was more of like a small world to me, but when you get to high school it's a much more bigger world, there's more different people and it's more complicated and in high school you have more complicated relationships." (FA)</p>

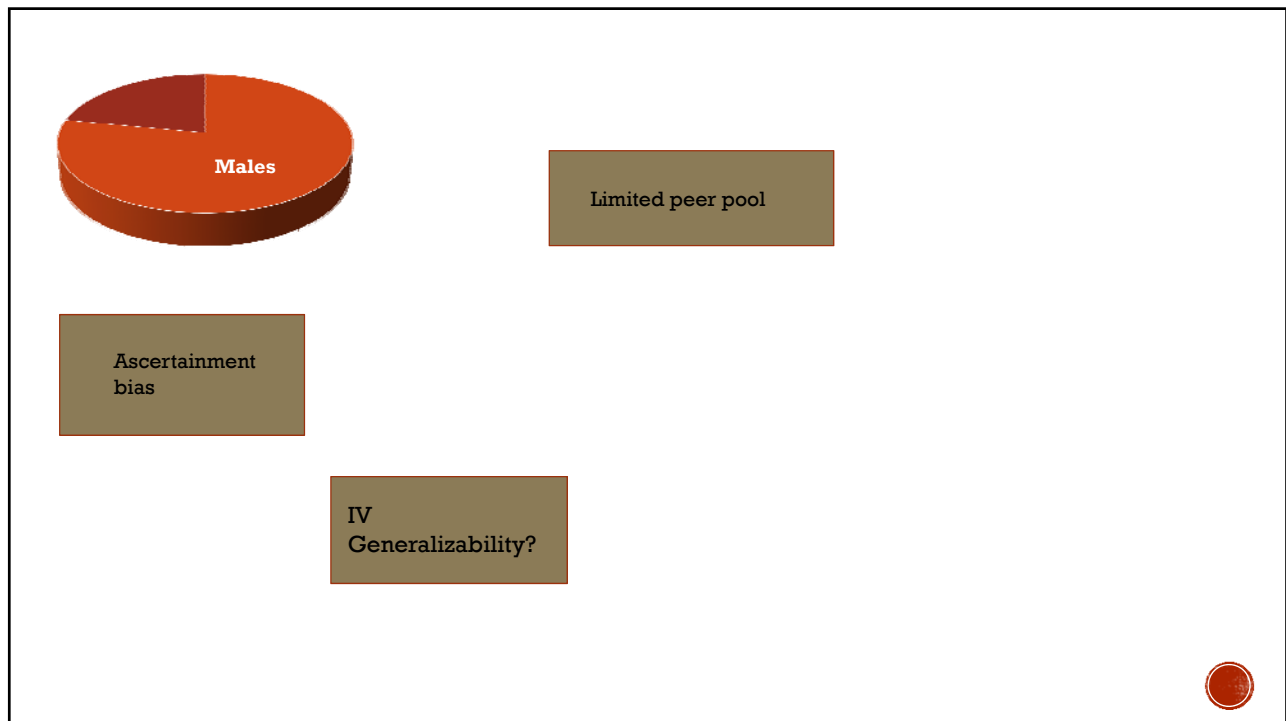
Examining social competence, self-perception, quality of life, and internalizing and externalizing symptoms in adolescent females with and without autism spectrum disorder: a quantitative design including between-group and correlational analyses.

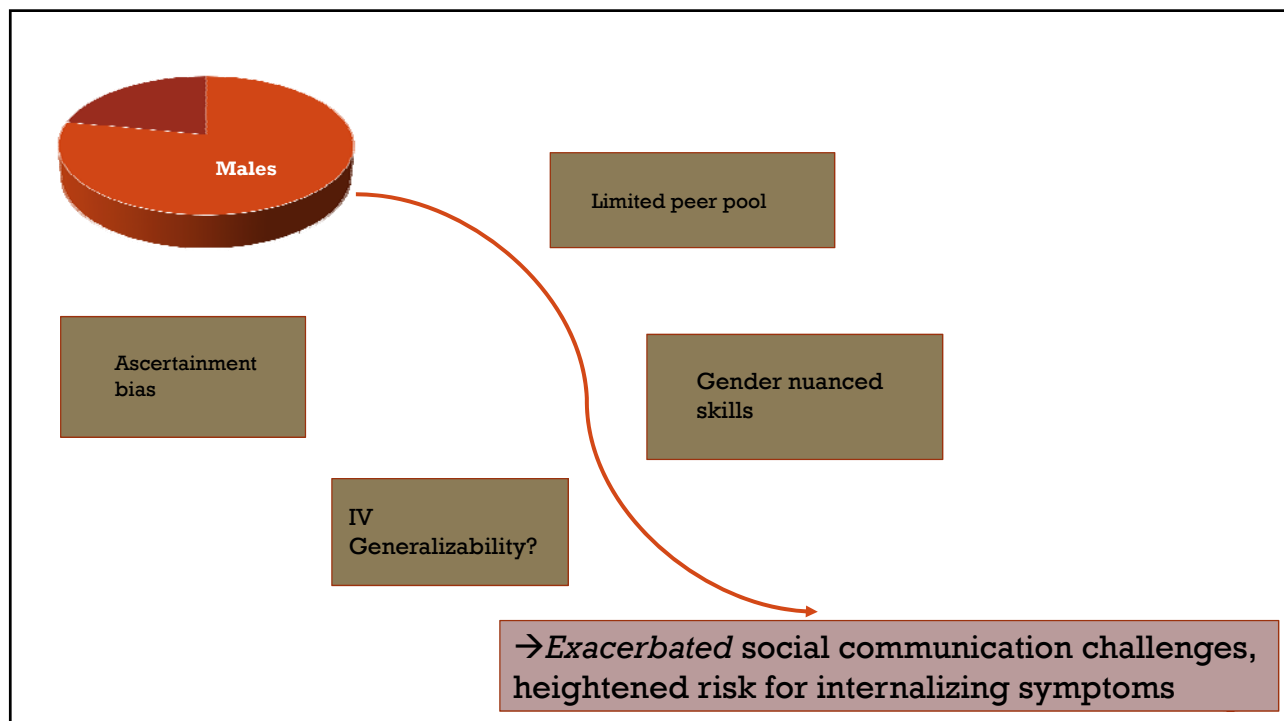
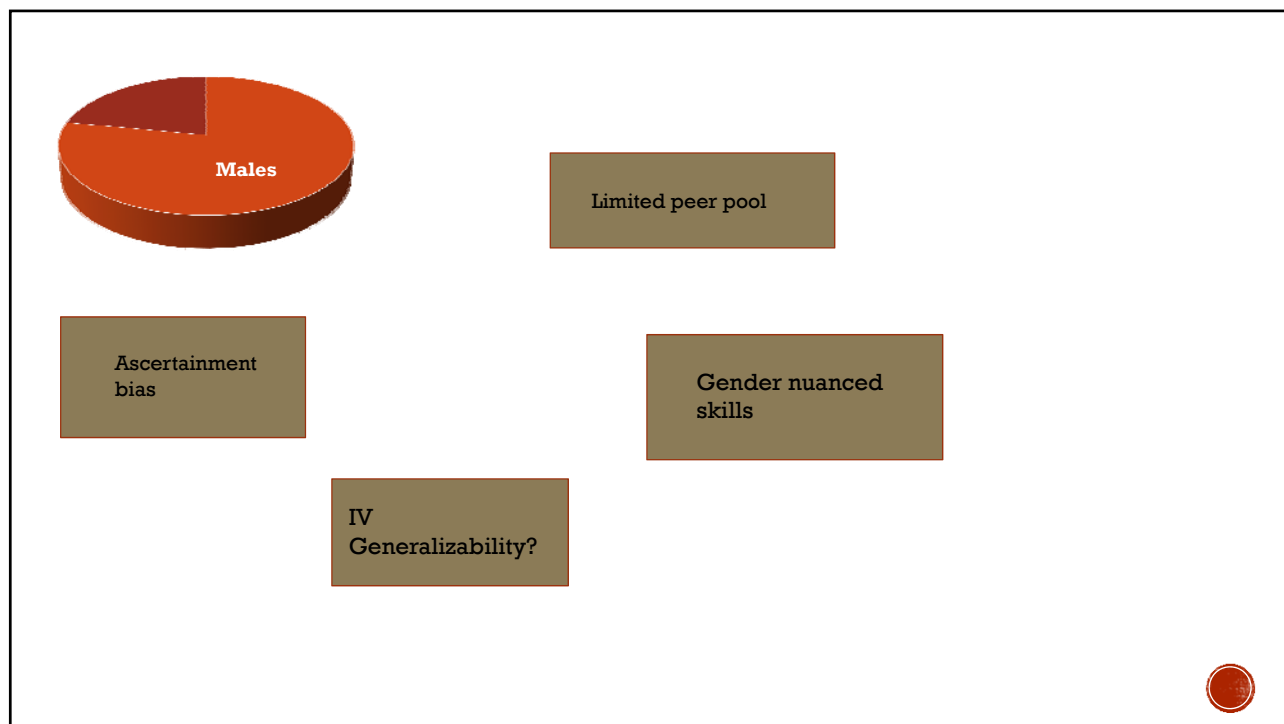
Insert figures and caption from Jamison & Schuttler, 2015)

Adolescent girls with ASD evidenced significant internalizing symptoms compared to boys with ASD and TYP girls. –Solomon et al., 2012

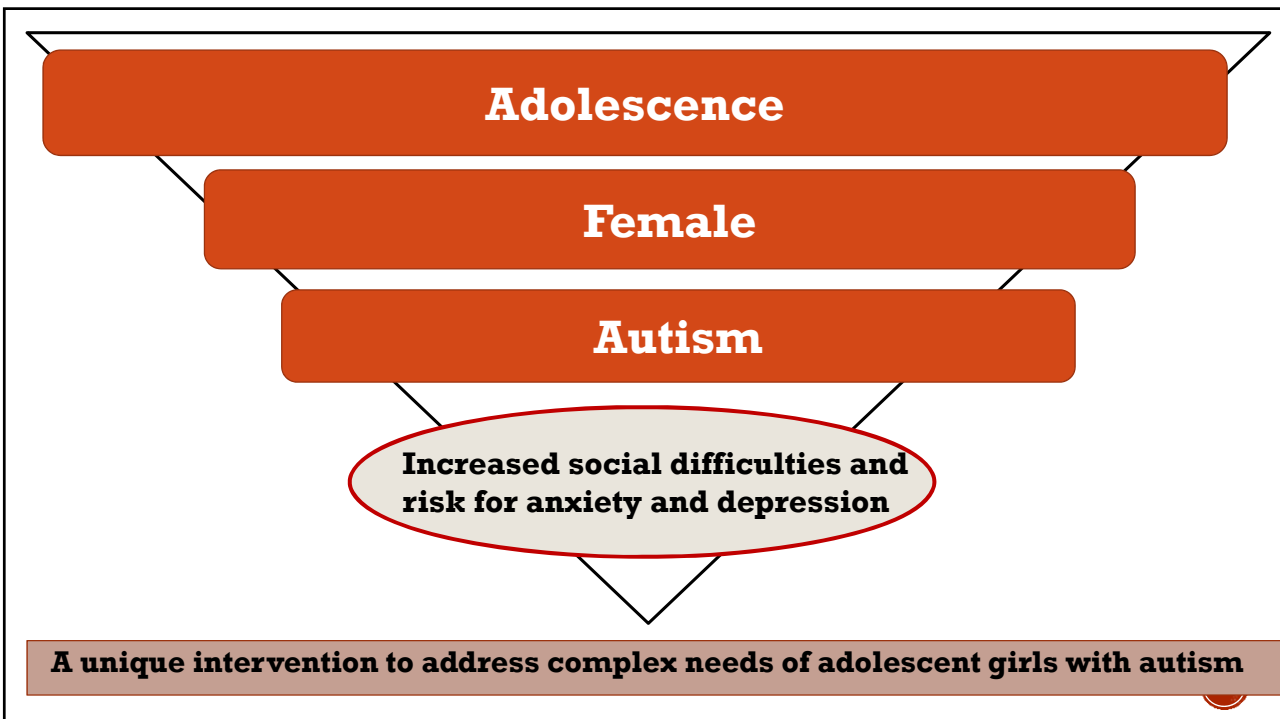
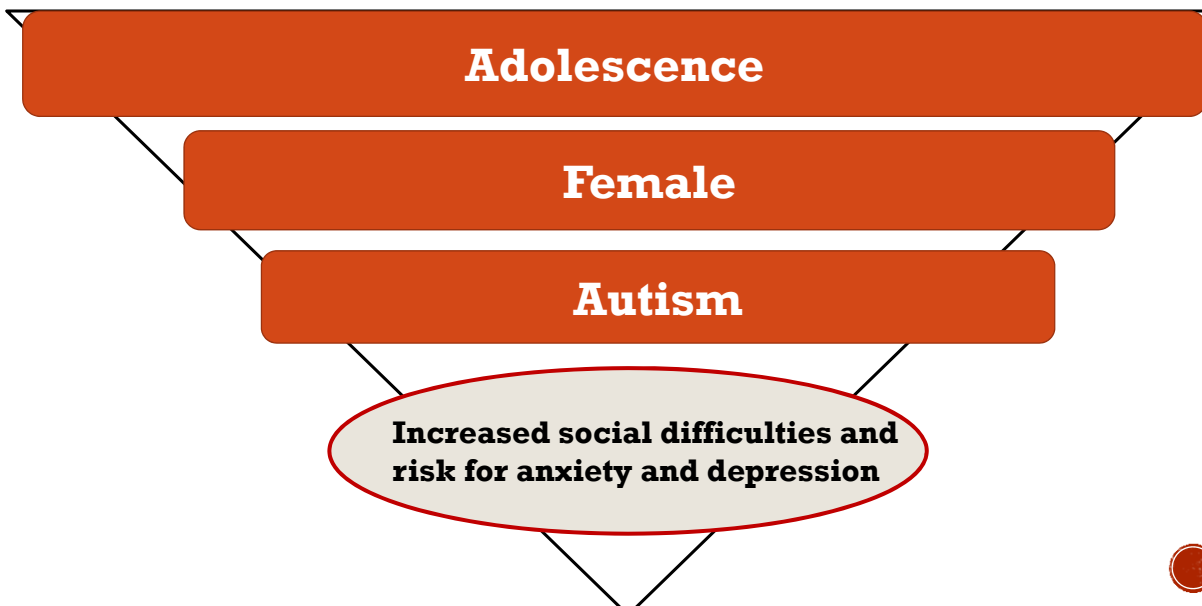








Theoretical Framework of “Double Whammy”



Overview and preliminary evidence for a social skills and self-care curriculum for adolescent females with autism: The Girls Night Out model.

Jamison and Schuttler, 2015

PROGRAM OUTCOMES

Improvements in social-communication skills, self-perception, and quality of life.

Satisfaction with program activities and outcomes.

Services and Connections

WHAT MAKES GNO UNIQUE?

➤ **Targets adolescent females w/ ASD!**

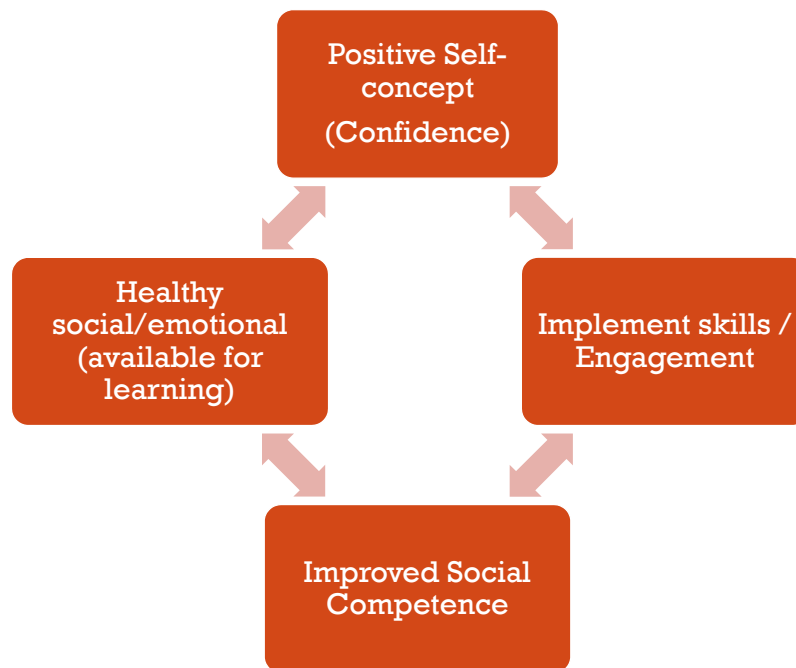
- Social skills & self care curriculum unique to girls/women.
- Skills taught & practiced within naturally occurring, age relevant activities and settings.
- “Peer mediated”
- Utilizes empirically based strategies
- Focuses on strengths & empowerment.
- Includes formative & summative assessments
- Establishes partnerships w/ community
- **Buy in!!!!**

Photo

Meaningful Experiences

Core curriculum components

- Relationship building skills
- Promoting independence in self-care
- Building self-determination



The Impact So Far...

"We need GNO for 10 years at least!"

"These girls nights just keep getting better & better"

"I almost did not sign her up because of the cost...but it was the best money I've spent on her IN YEARS!"

"....it made me get more interaction with people and get out of my comfort zone"

"this girls night out is the most fun I've ever had."



COMMUNITY WIDE IMPACT

13 GNO Skills Groups
(162 Sessions)

+

14 Community Events

More than **38** trained facilitators (medical students, graduate students, fellows, community volunteers)

Over **65** Community Partners

Including over **100** girls with autism and 125 peer volunteers!!!



Programs & Supports Across the Lifespan



Connecting Families, Creating On-Going Social Opportunities, and Providing Expanded Supports



The Most Powerful
Outcome

**Meaningful and Sustainable
Impact.....Changing the Course!**

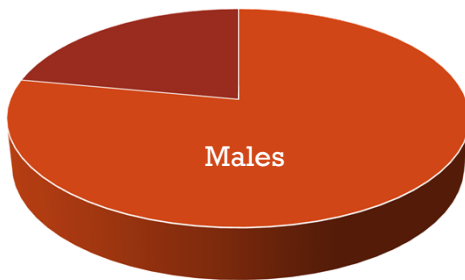


PRACTICE IMPLICATIONS

- SCREENING
- REFERRAL
- MEDICAL HOME
- FOLLOW-UP



Take home message and challenge



Influence the pie!

- Consider female presentation
- Evaluate your practice
- Tell your friends!

Consider implications and how you can influence the trajectory!



IMPLICATIONS FOR PRACTICE

QUESTIONS?? COMMENTS???

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