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

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**WHAT YOU CAN EXPECT... YOUR VISUAL SUPPORT**

Autism prevalence and sex differences
Sex matters (regardless of autism)
Implications for females with ASD
Prevalence, presentation, and practice considerations
Kansas programs and resources

**AUTISM SPECTRUM DISORDER (ASD)**

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

Deficits in social communication and interaction + Restricted and repetitive behaviors, interests, or activities (RRBIs) = ASD
Greater prevalence in males

4:1 – Male to Female Ratio

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

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
<th>Mean age (range)</th>
<th>Co-existing Internalizing</th>
<th>Co-existing Externalizing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females ASD</td>
<td>115 (45%)</td>
<td>6.03* (1-20)</td>
<td>3 (3%)</td>
<td>21 (20%)</td>
</tr>
<tr>
<td>Females No ASD</td>
<td>140 (55%)</td>
<td>6.75 (1-18)</td>
<td>11 (9%)*</td>
<td>56 (46%)*</td>
</tr>
<tr>
<td>Males ASD</td>
<td>532 (52%)*</td>
<td>6.03* (1-21)</td>
<td>29 (6%)</td>
<td>158 (30%)</td>
</tr>
<tr>
<td>Males No ASD</td>
<td>489 (48%)</td>
<td>6.18 (0-18)</td>
<td>26 (5%)</td>
<td>274 (56%)*</td>
</tr>
<tr>
<td>Total Sample</td>
<td>1276</td>
<td>6.17 (0-21)</td>
<td>69 (6%)</td>
<td>509 (40%)</td>
</tr>
<tr>
<td>ASD</td>
<td>647 (51%)</td>
<td>6.03 (1-21)</td>
<td>32 (5%)</td>
<td>179 (28%)</td>
</tr>
<tr>
<td>No ASD</td>
<td>629 (49%)</td>
<td>6.30 (0-18)</td>
<td>37 (6%)</td>
<td>330 (52%)</td>
</tr>
</tbody>
</table>

CCHD
2012-2015
Published Research

82% of participants in published research studies are male

Potential Implications
- Tools → Diagnosis → Prevalence
- Limits knowledge about girls
- Outcomes and generalization

Greater prevalence in males

Greater proportion of males in programs and interventions developed based on male samples
**Reported sex differences.....how does this relate to DSM diagnostic criteria**

<table>
<thead>
<tr>
<th>Develop play skills earlier (associative and cooperative play; play with peers); but boys “catch up”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imaginative and pretend play earlier and sometimes more advanced</td>
</tr>
<tr>
<td>Females often engage in conversation more than males</td>
</tr>
<tr>
<td>Greater use of nonverbal communication</td>
</tr>
<tr>
<td>• “other directed” gaze more often than males</td>
</tr>
<tr>
<td>• increased gestures</td>
</tr>
<tr>
<td>• recognize facial emotion than males</td>
</tr>
<tr>
<td>• variable evidence related to empathy</td>
</tr>
<tr>
<td>Increased complexity of social norms &amp; expectations during adolescence</td>
</tr>
<tr>
<td>• conversation focus on emotional support, facilitative, and relationship based</td>
</tr>
<tr>
<td>• engage in co-action activities that allow for other social behaviors (males = activity based)</td>
</tr>
<tr>
<td>Increased risk for internalizing symptoms (anxiety, depression, low self-esteem)</td>
</tr>
</tbody>
</table>
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

![Bar chart showing findings for different categories: A1 Social-Emotional/Conversation, A2 Nonverbal, A3 Relationships/Play, B1 Stereotyped, B2 Inflexibility, B3 Restricted Interests, B4 Sensory. The y-axis categories are listed on the left, and the x-axis represents a percentage scale from 0 to 100.]
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?

<table>
<thead>
<tr>
<th>Participant Type</th>
<th>Focus Groups</th>
<th>Total Number</th>
<th>Mean Age (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescent Females with Autism</td>
<td>4*</td>
<td>14</td>
<td>15.57 (1.22)</td>
</tr>
<tr>
<td>Adolescent Girls without Autism</td>
<td>4</td>
<td>20</td>
<td>15.85 (1.30)</td>
</tr>
<tr>
<td>Parents of Girls with Autism</td>
<td>4*</td>
<td>15</td>
<td>NA</td>
</tr>
<tr>
<td>Parents of Girls without Autism</td>
<td>2</td>
<td>12</td>
<td>NA</td>
</tr>
</tbody>
</table>

Schuttler et al., manuscript in progress
### Themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Supporting Quotes</th>
</tr>
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<tbody>
<tr>
<td>Limited Social Opportunities and Interactions</td>
<td>“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)</td>
</tr>
<tr>
<td></td>
<td>“I’d say she has online friends, that’s it. She likes to...yeah, that she plays games with and...Virtual friends.” (PA)</td>
</tr>
<tr>
<td>Planning &amp; Coordination Shift</td>
<td>“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)</td>
</tr>
<tr>
<td></td>
<td>“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)</td>
</tr>
<tr>
<td>Increased Complexity</td>
<td>“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.” (FR)</td>
</tr>
</tbody>
</table>

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*
Ascertainment bias

IV Generalizability?

Limited peer pool

Ascertainment bias

IV Generalizability?
Ascertainment bias

Limited peer pool

Gender nuanced skills

IV Generalizability?

Males

→ Exacerbated social communication challenges, heightened risk for internalizing symptoms
Theoretical Framework of “Double Whammy”

Adolescence

Female

Autism

Increased social difficulties and risk for anxiety and depression

A unique intervention to address complex needs of adolescent girls with autism
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

<table>
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<tr>
<th>PROGRAM OUTCOMES</th>
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<tbody>
<tr>
<td>Improvements in social-communication skills, self-perception, and quality of life.</td>
</tr>
<tr>
<td>Satisfaction with program activities and outcomes.</td>
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<tr>
<td>Services and Connections</td>
</tr>
</tbody>
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**WHAT MAKES CNO 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!!!!!**
Meaningful Experiences

Core curriculum components
- Relationship building skills
- Promoting independence in self-care
- Building self-determination

Positive Self-concept (Confidence)
Healthy social/emotional (available for learning)
Implement skills / Engagement
Improved Social Competence
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

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

The Most Powerful Outcome

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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