GIRLS & WOMEN WITH AUTISM SPECTRUM DISORDER

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1. Gender differences across the lifespan
2. Camouflaging in girls with ASD
3. Supporting females with ASD
4. Questions
5. Small group discussions
Does autism present differently in females?

Do females mask ASD symptoms better than males?

Are professionals less likely to diagnose females even if symptoms are apparent?

How can we as family members and professionals support girls and women with autism?
Of those diagnosed with ASD over age 5, girls are diagnosed a year later than boys on average.

Without intellectual disability or challenging behavior, girls are less likely to be diagnosed than boys even with same level of difficulties.
FEMALE PROFILES OF FUNCTIONING

Profile 1 (compared to males)

- Lower cognitive ability
- Greater social communication impairment
- Lower levels of restricted interests
- Weaker adaptive skills
- Greater externalizing problems (irritability, lethargy)
FEMALE PROFILES OF FUNCTIONING

Profile 2:
- More girls with ASD have higher verbal cognitive ability and fluent speech than previously thought
- Less social communication impairment than males (e.g. gesture use)
  - Certain time points?
- Different type of restricted interests
DIAGNOSTIC CHALLENGES

Autism diagnostic measures were developed based on largely male research samples.

Gender differences in parenting: social expectations for girls tend to be higher than boys.

Girls are less recognized at school:
- Teacher rating scales tend to be less elevated
- Less likely to have comorbid ADHD or aggressive behavior
- “Camouflaging”
Restricted and repetitive behaviors seem to be less predictive of ASD diagnosis in females than in males.

McFayden et al., 2018; Hiller et al., 2014
Gender similarities in restricted and repetitive behaviors

- Mixed findings on overall RRBs
- Similarity in sensory differences

McFayden et al., 2018; Hiller et al., 2014
Differences in restricted interests in females

- “Seemingly random” (rocks, pens, stickers)
- Less likely to be screen-time or object related
- More socially directed (People/animals vs. objects/symbols)
Multiple studies show similarities in social communication and interaction across *diagnosed* males and females.
- Particularly true for children diagnosed in preschool.
- Function of predominantly male research population or male-developed diagnostic tools?
Mandy & colleagues (2018):

- 7 years: boys’ ASD symptoms > than girls’
- ASD symptoms in females increased between 10 and 16 years
- Of those with “severe” symptom levels, 37% did not show these until age 13
  - 57% of this group was female
The idea the females with ASD are able to mask their social difficulties through mimicking others and using compensatory strategies

- Direct development of compensatory strategies vs spontaneous mimicking
- Goals: To fit in, avoid being negatively viewed or feeling labeled
ALL girls spend more time jointly engaged than boys, even when playing structured games.

Boys with ASD: most time in solitary play.

Girls with ASD:
- Close to peers, weave in/out of activities
- Less sustained engagement: more time “flitting” and in solitary play

CAMOUFLAGING: SCHOOL AGE

Dean et al., 2017
Harrop and colleagues (2018): visual attention to faces as a measure of social motivation.

- ASD and typically developing children ages 6-10

Supports **female protective effect hypothesis** in childhood

- Girls with ASD attended to faces similarly to typically developing girls
- Boys with ASD did not prioritize attention to faces
- General gender difference across both ASD and TD groups
<table>
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<tr>
<th>Domains</th>
<th>Symptoms seen in girls with ASD</th>
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| Social interaction                           | Better conscience of necessity of social interaction  
Desire to interact  
Passivity commonly perceived as shyness  
Camouflaging through compensation strategies  
One or few friends  
Usually taken care of by peers in ES, bullied in MS |
| Communication                                | Directive with peers in play  
Better imagination but repetitive, controlled pretend play w/o reciprocity |
| Restricted, repetitive patterns of behavior, interests, or activities | Restricted interests more related to people/animals than objects |
Typical female friendships:
- Smaller/exclusive groups
- Self-disclosure and intimacy
- Talking in lieu of structured activities

Similarities in female friendships (qualitative studies):
- Definition and importance of friendship
- Friendship activities
- Relational conflict

Sedgewick et al. 2018, Cook et al. 2017
TEEN FRIENDSHIP DIFFERENCES IN ASD

- Fewer, more intense friendships – “let me be myself”
- Social interactions in groups particularly difficult - “too many opinions”
- Some difficulty understanding/discussing others’ expectations in social situations

“I can only be with my friends for so long, and then I want to be by myself”

“It depends on the day, I need a lot of de-stress time. I would not be able to socialize two days in a row.”
TEEN FRIENDSHIP DIFFERENCES IN ASD

- More conflict and more often the victim
- Difficulty knowing how to manage conflict successfully
- Less sense of competition with friends
- Social exclusion reported to affect girls, but parents even more so

Sedgewick et al 2018, Cook et al. 2017
Hull and colleagues (2017): Self-selected sample of 92 adults with ASD diagnosis

- Most adults with ASD, including males, used camouflaging of some sort for assimilation and connection
  - Expressed hope for less need for camouflaging as education/acceptance increases
- Some evidence that females are more successful than males at camouflaging
- Vast majority reported unwanted consequence of camouflaging
  - Exhaustion
  - Being inauthentic
FIRST PERSON ACCOUNT
IMPLICATIONS FOR DIAGNOSIS

- Use multiple tools, mixed method (clinical and parent report)
- Some value found for using ADI-R and ADOS together
- Look for specific response styles rather than relying primarily on cutoff scores
- Caution in females with higher verbal abilities in particular; subtler symptoms

(Lai et al., 2011)
FEMALE SPECIFIC TOOLS

Autism Spectrum Screening Questionnaire - GIRL (ASSQ-GIRL) (Kopp & Gillberg, 2011)
• Added subset of 11 female specific questions to ASSQ-REV
• Discriminated well between cases and non-cases; girls with ASD vs. girls with ADHD
• Needs further validation in large community samples

Questionnaire for Autism Spectrum Conditions (Q-ASC) (Attwood et al., 2011)
• Parent report of autism symptoms
• 8 subcomponents identified
• Preliminary results support ability to distinguish between boys and girls
### SUPPORTING FEMALES WITH ASD

**Social Skills**
- Building and maintaining relationships
- Recognizing emotions
- Bullying

**Health**
- Mental health
- Healthcare access
- Diet and exercise

**Life Skills**
- Hygiene
- Puberty and menstruation
- Sex education

(Mademtzi, Sing, & Koenig, 2018; Cummins et al., 2018)
SUPPORTING SOCIAL SKILLS

- Group format, ideally involving peer mentors without autism
- Education regarding romantic relationships, dating
- Address being a victim of bullying
- Social Skills Training: evidence-based practices
  - Girls Night Out
  - PEERS
• Targets (1) Relating to others, (2) Self-care, and (3) Self-determination in social competence and self-perception
• Uses a variety of empirically-based strategies to teach and reinforce concepts
  – Peer mediated
  – Video modeling, Modeling and role play, Visual supports
  – Reinforcement, Goal setting/monitoring, In-vivo coaching, generalization
• Results: Participants reported significant improvement in perceived social competence, self-perception, and quality of life
PEERS

- *PEERS and PEERS for Young Adults* (Laugeson & Frankel, 2011)
- Positive effect on parent and self-reported social skills, autism symptoms
- Recent evaluation of gender differences in outcomes from PEERS participation showed similar effects across males and females

McVey et al., (2017)
MENTAL HEALTH

• Higher rates of **anxiety, depression, OCD, and epilepsy** than males with autism

• Adolescence and mental health
  – MH concerns more likely to have adolescent onset
  – Females affected more significantly by struggles experienced through social relationships

• Teens and women shown to use MH services more than males
  – More likely to use psychiatric and emergency department services

(Croen et al., 2015; Holtmann et al., 2007; Maddox et al., 2017; Tint et al., 2017)
HEALTHCARE ACCESS

- Medical providers: limited knowledge and education on autism and autism in females

- Adolescent girls and women with ASD need to follow **same schedule** of recommended health screens as girls and women without ASD
  - **myhealthfinder Widget** ([healthfinder.gov/FreeContent/PreventiveServices/](http://healthfinder.gov/FreeContent/PreventiveServices/))

- Women have self reported **anxiety** while waiting in waiting rooms, when communicating with provider, describing pain and health needs
  - Once distressed, much harder to communicate needs

*(Lum, Garnett, & O’Connor, 2014; Tint, Weiss, & Lunsky, 2017)*
Supports to consider for medical and mental health visits

- Call ahead and discuss accommodations
- Time of appointment
- Make priorities with provider
- “About me” fact sheets
- Bring security items, music, preferred people

(Autism Speaks, 2019; Tint et al. 2017)
Exercise promotion

- Consider fun options, involve in decisions
  - Horseback riding, Wii fit, swimming, Special Olympics
- Reward healthy behaviors and choices
- Create structured schedule and routines for healthy habits
- Model healthy behavior using family, peers

Women Be Healthy (Lunsky, Straiko, & Armstrong, 2003; Parish et al., 2012)
HEALTHY EATING

• Maintain structure around meals to promote socialization
  – Avoid allowing meals in bedroom or in front of TV
• Reward healthy choices
• Create food menu presenting an array of choices
  – Once unhealthy options are gone, not available again until next week
• Offer choices between two foods to provide control
HYGIENE: PUBERTY AND BEYOND

• Directly address the need to increase personal hygiene as girls enter puberty
• Provide extra support to readjust bathing and self-care routine to encourage increased hygiene habits
  – Structured visual and verbal supports to introduce new hygiene habits
• Follow through on expectations to maintain habits
Reassure that this is a normal part of life and only temporary

• Use calendars or period tracking apps
• Keep sanitary pads stocked in an assigned area in bedroom or bathroom
• Role play and model using sanitary pads
• Track mood before and after period

Cummins, Pellicano, & Crane (2018); Mademtzi et al. (2018)
• Direct discussion is important
• Discuss why some people get married or live with one person, using family and friends as examples
• Distinguish between appropriate examples (family, friends) and non-examples (TV relationships, pornography) or relationships and behavior
SEXUAL ABUSE

• Don’t delay conversation about safe versus unsafe behavior
• Teach ways to say “stop” and “no” in response to unwanted touch
  - What is an ok vs. not ok touch?
• Teach accurate names of private body parts
• Be aware of warning signs

https://www.autismspeaks.org/recognizing-and-preventing-sexual-abuse
• Higher incidence of ASD diagnosis in individuals with anorexia (diagnostic overlap)
• As girls enter adolescence, body image may become a worry
  – Stress that all bodies are different
  – Discuss body images as displayed in media and provide appropriate models for body image

(Stewart et al., 2017; Bitsika & Sharpley, 2018; Jermakow & Brezezicka, 2016)
Parenting stress significantly higher in parents of individuals with autism than parents of individuals with other diagnoses.

Higher chronic strain reported in parents of adult women than adult men with ASD.

(Bronfenbrenner, 1979; Tint et al., 2017; Hayes & Watson, 2013)
Identity:
  – Prefer person versus identity-first language?

Defining strengths
  – Involve in identifying what those strengths are
  – Involve in identifying own quality of life

Promote self-efficacy
  – Facing challenges and adverse life events have been reported as beneficial (Webster & Jarvis, 2017)
  – Promote independence by surrounding female with people who believe in her
1) Address diagnostic challenges
   • Refine tools for verbally fluent girls and women in larger groups

2) What characteristics of autism are sex/gender dependent vs. independent?

3) How is the likelihood of developing autism linked to gender?

4) What etiological-developmental mechanisms of autism are implicated by sex/gender and sex/gender differentiation?

(Lai et al., 2015)
AREAS FOR FUTURE RESEARCH

4) Do differences in gender still persist when conducting research with large, equally sized gender groups?

5) Further development of empirically-based interventions for females
   • Emphasis on females with co-occurring severe – profound ID

6) Involve more sophisticated measurement techniques (e.g., eye tracking, neuroimaging) for identifying males versus females’ responses to intervention
Interested in a social skills group for female children or adolescents with ASD?

- Spring 2019
- Research study of social skills curriculum for ASD
- For more information/to be added to interest list: ejf3u@virginia.edu
- Sign-up sheet today
LOCAL OPPORTUNITIES

University of Virginia Autism Initiative
Curry.virginia.edu/star

Coming in Spring 2019: Autism DRIVE
– UVA autism research registry
– Interactive database of state and nationwide autism resources
– Portal for accessing professional trainings
QUESTIONS?
PART 2: DISCUSSION
SMALL GROUP DISCUSSION QUESTIONS

Service access
What were your experiences in accessing diagnoses and services for yourself, your family member, or someone you know with autism?
Development
What strategies have you found helpful for coping with developmental changes during:
• Childhood?
• Adolescence?
• Early adulthood?
Camouflaging

Have you seen camouflaging? How have you or someone you know “camouflaged”? Does it help or hurt?
SMALL GROUP DISCUSSION QUESTIONS

**Strengths**
What are her/your strengths? What are her/your affinities?

How can we support and use these affinities to promote independence?
THANK YOU!

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