Gender differences in children and teens with high functioning autism

Dr. Emily Dillon
dillone@kennedykrieger.org

Overview
- Importance of gender differences in ASD
- Overview of recent findings on children and teens with ASD
- Profile of specific research and interpretations
- Current research at CARD
- Summary and questions

Learning Objectives
- Describe current diagnostic criteria of ASD.
- Identify ways in which girls and boys may differ in their expression of ASD.
- Discuss ways in which girls may be missed or delayed in identification under current diagnostic criteria.
- Discuss implications.

N.B.
- Gender one of the things to consider- Not the only thing
- Group differences versus individual variation
- Current focus is on children and teens with high functioning ASD/ no cognitive impairments

Current Diagnosis criteria
- Clinical judgment
- Gold Standards:
  - ADOS-2 criteria:
    - Social Affect
    - Restricted and Repetitive Behavior
  - Changes from the DSM 5 revisions to be reflected in the ICD- to be released in June

On the DSM 5- Dr. Mandy, UCL:
- It states that the male-to-female ratio of autism diagnoses is 4-to-1 and that this may reflect an underdiagnosis of autistic girls and women, particularly those without intellectual disability. It suggests that this occurs "perhaps because of subtler manifestation of social and communication difficulties" in girls on the spectrum.
Roadblocks to Diagnosis

Feel Different → How may gender expectations influence this process?

Parent/teacher concern → Clinical opinion → Diagnostic tools → How may gender expectations influence this process?

Differences in presentation of ASD symptoms

- Circumscribed/perseverative interests
- Restricted interests in females may be more socially acceptable
- Interests generally align with gender norms

N=208 (28 girls); matched sample N=56

Nowell, Jorgenson & Brown, INSAR 2018

Girls Boys Shared
Arts and Crafts Objects Fictional Characters
Animals Video games Sporty games
Food Geography/Maps Dates/Times
Dinosaurs Signs Music
Natural Disasters Computers TV/Movies
Japanese Culture Mechanical systems

Differences in presentation of ASD symptoms

- Increased camouflaging of ASD symptoms in women and girls with ASD
- “Putting on my best normal”
- Compensation and Masking
  - aim to appear less ASD to others
  - May be unconscious
  - May be helpful, but costly overtime to mental health

(Dean et al., 2006; Hull, INSAR, 2018; Lai et al., 2006; Parish-Morris et al., 2017; Ratto et al., 2017; Yani, Hamdam & Lai, 2018)

Biological effects: Social Motivation Hypothesis

- Social attention in girls with ASD may be less impaired from infancy
- Difference observed in typical development
- In boys with ASD this attentional deficit could then extend to other developmental domains

Dawson, INSAR 2018 keynote; Guy, Zeber & Richards, 2016; Hamper et al, INSAR 2018; Sasson & Touchstone, 2014

Biological effects

- Only in boys with ASD was there a significant inverse correlation of Nonverbal IQ and social language impairment
- Higher IQ = high social skills
- In girls with ASD, social skills were less impaired than the boys, regardless of IQ
- Pattern mirrored in typically development
Socialized effects within typical development

- Parental language amount varies by child gender (Lovas, 2011)
- Is this parental bias or are girls eliciting more language naturally?
- Type of language varies by child gender (Ensor & Hughes, 2008; Kuebli, Butler & Fivish, 1995)
- More emotions to girls at 40 months, effect of later topics initiated by child at 70 months
- Natural same-sex preference in socialization rules vary
- Rewards and punishments of interaction types vary by gender (Rose and Rudolf, 2006)
- Girls consider relationship in conflict resolution
- Women maintain communication with other women most; men communicate with other men least

(Body & Hat, 2008; Couper, 2006; Gilford Smith & Brownell, 2002)

Participants

- 53 students with ASD, (30 girls)
- 9-17 years old
- UK and Ireland
- Mild to no cognitive delays
  - HFA/Asperger's
- Qualitative component to a mixed method study
- Gender differences
- ADOS interviews (30-60 minutes)
  - Semi-structured interviews for pragmatic evaluation
  - Inductive Thematic Analysis (Braun & Clarke, 2006)

Results

- Autism as otherness
  - Two subthemes: the diagnosis as a:
    - Source of Resolution
      - Understanding of the self/relationships or understanding and communication of personal needs or preferences
    - Source of conflict
      - Autism as something that needed to be controlled or be managed in order to function as they would like
    - 21 participants, mainly discussed by the girls

- Autism as resolution
  - On friendships with other girls with autism
    - "they understand who I am...I help them and they help me. We just know what we’re like, if you know what I mean"
    - 15 years, girl
Autism as resolution
- Knowledge to avoid conflict with classmates
  - "Sometime (other people annoy me), since they keep on cuddling me since I am the youngest in the age group. But I just tell them I need a break and that works"
    - 15 years, girl
- Knowledge to understand others
  - "(friend) comforts me when I’m upset. But (friend), when she’s upset, leave her, and when she feels better, speak to her again"
    - 15 years, girl

Autism as resolution
- Friends in context of response to their ASD
  - "(best friend) is always there for me when I need it...he doesn’t get angry when I do stuff. He doesn’t pick on me cause I am different"
    - 11 years, girl

Autism as conflict
- Many adolescents reported social conflicts
  - Girls: explained their difficulties with their dx and used their dx to explain their treatment by others
  - Boys: overall did not make connection overtly

Autism as conflict
- "and I couldn’t see the difference between her and me. And I think they treated me differently because I was different from other people...and I didn’t realize that until I got older, ‘cause I used to think it was me"
    - 15 years, girl

Autism as conflict
- Feeling of disconnect from others, even those closest to them
  - Positive:
    - "Because of my autism, she (sister) is in care a lot... so she can have time away from me. I think we both like that, especially if we’ve had an argument or something" (smiles)
      - 11 years, girl
Autism as conflict

- Negative:
  - “My nan has always said to me that if I had a boyfriend he had to be normal... he had to be normal... and I said to my nan, ‘I do have friends that are boys’ and she said, ‘are they normal?’ and I said, ‘yes, they are normal’. And then one time, I went to XX (do you know where that is?) on holiday but, he wasn’t like, he wasn’t very nice (to me).
  - 15 years, girl

Autism as conflict

- “This school makes me sad and angry... I just don’t think I should be here. I mean, I know I have “autism” and I would find it hard in a mainstream school but I would prefer it. The people and how the teachers treat you here- childish. They talk to you like you’re a child.
  - 14 years, girl

Autism as otherness

- Boys implied dx but did not state
  - As Conflict
  - About marriage
  - “I’m not exactly suited to having a wife, sometimes I get a little sad, sometimes lazy- not the best qualities! I don’t want to disappoint anyone”
  - 14 years, boy
  - “too much work, too much work for me... having kids, I would regret it... prefer living in house on my own, have a pet so I don’t go insane!”
  - 10 year, boy

Autism as otherness

- “my brother and sister, they get to do all these things in life, and I don’t think my autism should prevent me from doing things I want to do”
  - 16 years, boy
  - “I just want to be alone, to be honest, like many other autistic people”
  - 15 years, boy
  - Inferred resolution

Gender differences

- While both reference ‘otherness’ but feeling less inherently tied to dx in boys
  - Self reflection evident
  - ASD inherent in self or something distinct from self?
  - Age of dx/ process of dx?
  - Boys more insight with age?
  - Girls less delayed in insight

Anxiety and Compulsions

- Rare for outward anxiety or compulsions
  - 12 (4 boys) with anxiety signs
  - 9 (7 boys) with compulsions
  - Descriptions of anxiety/ Compulsions
  - “my worries” / “my needs”
  - 9 girls spoke
  - Triggers of anxiety
  - Management of Compulsions and Anxiety
  - Self-regulation
Experiences of Anxiety and compulsions

- “My autism, it makes me do things”
  - 14 years girl

- “Sometimes I ask a lot of questions. Sometimes I get into people’s business really, but that’s one of my needs...well I have a hard time... that I ask a lot of questions but sometimes I ask questions I might know the answers to and sometimes I think about what the answers might be, but that's sort of hard for me because when I think about what the answer might be, but it might not be right so.”
  - 15 years, girl

Triggers of anxiety

- Girls appear more social in their triggers
  - “Two nights of boarding, it was too much! I couldn’t handle it. Some girls were arguing, I just didn’t like it”
  - 14 years

- Boys more object-based
  - Spiders, exams
  - Even with prompting
  - Two mentions (marriage, and future plans)

- Anxiety not linked to compulsions in ADOS interviews

Differences in coping?

Anxiety and bullying

- Both genders report
- Girls describe more open ended
  - “that’s where my trust issue is, cause I guess, I don’t like people to judge me or the things I do so I only let people see a bit of me rather than let people see all of me”
  - 15 years

- Boys concentrate on immediate physical symptoms
  - “anxious is...really hot, heavy breathing”
  - 12 years

Management of anxiety

- “Change of things makes me anxious...I do try to calm down, think of something else (smile) look on the bright side”
  - 14 years, girl

- Costs of social anxiety?
  - Girls more verbal and therefore possibly more able to control their compulsions
  - Boys more flight or fight response (Taylor et al., 2000)

As self-regulation

- “Dad really doesn’t like me head banging...he wants to stop me head banging, cause like he wants me to get to sleep, but I feel like that’s hard on me, cause now I’m delayed in getting to sleep.”
  - 11 years, girl

- “I want people to see my dark side, so ticked off- go into my dark side super form. I start swearing, calling people names...my anger problem, I took too far had to leave”
  - 12 years, boy

- Links to “responsibility code” and behavioural display

As self-regulation

- “If I am not comfortable with what they (the other boarders) are saying, it gets in my head. I don’t like it & makes me do something I don’t want to do. And I just keep it in...it makes my hand tense up, and I’m not in the mood, not in the mood, it’s sort of like, like hit, hit something, but I don’t want to do that. I know that wouldn’t be fair to them”
  - 12 years, girl
Gender differences in self regulation
- Rates of internalizing disorders are higher in girls than boys in typical development
  - (Mendelson, Kubzansky, Datta & Buka, 2008),
- Girls with autism may be at an additional risk with the additional stress of regulation to perceived social norms
- I just start hyperventilating and I can't stop. I can't control my body...it's traumatic. Sometimes it's really small and I get frustrated and sometimes it's really big. I just start crying and I can't control my breathing and I get a bit angry and I kinda start hitting things. And like, I find that people don't really listen to me, when I am having a panic attack and that makes me more upset (15 years).

Experiences of depression
- Feelings of otherness often led to feelings of social isolation and depression
- Girls more common discuss with connection to situation/person/autism
- (I feel sad and lonely) when people don't include me. When they know I'm around and they don't include me, makes me annoyed at the same time...(it's) heart breaking feeling. It feels like my heart torn in two
  - 14 years, girl

Experiences of depression:
- “I used to (feel sad and lonely) at my old school since I got excluded at my old school. People didn’t really talk to me, because of my needs and uh...but not so much at this school”
  - 13 years, girl
- Yet another girl placed the difficulty on herself: “Sometimes I feel like maybe I am not being...helping...participating enough”
  - 11 years

Experiences of depression:
- Boys often more positive
- “Lonely...I do get it all the time, but I don’t take it as the worst year of my life...feeling sad is a normal thing”
  - 14 years

Experiences of depression: Coping
- Subset with limited coping though many can identify what makes them happy
- “I don’t (feel better) I just feel sad and lonely. (little laugh) I don’t really, I just sit by myself and be depressed” (15 years).
- “Usually when I am sad I don’t feel like doing anything...it’s rubbish, it just feels rubbish” (12 years).

Importance of friends
- “Lil helps me with most of my worries as well. She tells me her worries and I tell her mine, so that is quite good” (15 years)
- They also saw their role in the friendship as similarly supportive, “when they’re going through something emotional, especially something I haven’t been through- I don’t know how to support them... I feel really bad that I can’t help them” (15 years)
- “they (her friends) comfort me when I’m upset” (15 years)
Importance of friends

- "Not really (make myself feel better). Sometimes I just have to be sad and sometimes I say 'Can someone make me laugh because I am sad and I want to laugh now and I don't know how'. And then they (my friends) make me laugh and I feel better"
- 12 years.

Current research at CARD

- INSAR 2018
- Differences in social language between girls and boys with autism
- Seen in European and American samples
- While boys are overall more impaired on measures of social language, the question remains of the social cost to both
  - Are girls less impaired or just camouflaging more?

Other resources

- In their own words
  - https://www.youtube.com/watch?v=oZhZ0k1lyF8
- Girls with Autism
  - IT3 documentary https://vimeo.com/199745757

Thank you!

- Questions?
- If you think of anything you like to follow up on or would like additional information, please feel free to email me anytime:
  - dillone@kennedykrieger.org

Evidence for ‘big three’

- Genes
- Environment
- Gender
  - A likely interaction effect
  - Going to focus on Gender but gender is a partial product of genes (sex, etc.) and environment (socialization)