Girls Under the Umbrella of ASD

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Session Objectives

• Identify First Signs
• Review gender differences
• Social Communication Skills
• Strategies for adolescence and puberty
• Plan for self-determination
Goal: Girls Under the Umbrella

• Lack of information on girls with ASD
  – “Research orphans” (Ami Klin, 2006)
  – Under-diagnosed
    • Lack of services
  – Poor outcomes unemployment and housing
• Differences in boys and girls with ASD
• Give women and girls a voice
  – Support their uniqueness
First Signs

- **Mattison**

- **Earlier Diagnosis**
  - “She’ll grow out of it” pediatrician
  - Neuropsychologist
  - Spent time testing to observe symptoms over extended time

- “First hour of diagnostic interview may go well” Baron Cohen (2013)
Girls and ASD

- 4:1 Autism
- 9-11:1 Asperger Syndrome
- Mild ASD (DSM-5)

“Girls are better learners. They are more gifted for the concrete and practical. In the autistic individual the male pattern is exaggerated. It may be there are no autistic girls. We just don’t know.”

Hans Asperger, 1944
First Signs

- Good social imitation skills
  - Pretending to be Normal (Wiley)
- Odd play skills
  - Not overly stereotypical
  - Pretend play
- Passive or lack of initiative
- Non-aggressive behaviors
  - Avoidance behaviors

- Attentional problems
  - Without hyperactivity
- Lack of focus
  - daydreaming
- Lack of empathy
  - awareness
- Increased anxiety
  - Excessive worrying
Empathizing vs Systemizing
The Essential Difference (Baron-Cohen, 2003)

• **Empathizers:**
  - Female Brain
  - Comforting
  - Sensitive to emotions and facial expressions
  - Focus on relationships
  - More cooperative and collaborative
  - Increased communication skills and conversational skills

• **Systemizing**
  - A drive to understand the system and build one
  - Technical and mechanical
  - More aggressive
  - Based on empirical evidence
  - Interest in classification and organizing categories
  - Closed systems: finite, structured, rules
“We shouldn’t assume that autism and Asperger Syndrome will look the same in both sexes” (Baron-Cohen, 2008)

Male Tendencies:
- The male pattern of systemizing is exaggerated to the extreme.
- How does this impact females with ASD?
- Compare females with ASD to other females
- Review Chart
  - Autism Spectrum Questionnaire
  - Cut-off scores are biased towards males
Gender Differences

• Girls don’t fit the male prototype
  – Girls are rarely fascinated with numbers or have stores of arcane knowledge (Skuse)
    • Horses or ballroom dancing

• Males have a higher level of activity and behavioral problems
  – Due to Testosterone (Baron-Cohen)

• “Males demonstrate aggressive, acting out behaviors and are more likely to be identified. Whereas, girls who are compliant and quiet are over-looked and underdiagnosed.” (Jean Kearns Miller)
Asperger’s and Girls
featuring
Tony Attwood and Temple Grandin
Gender Differences (cont.)

- Underdiagnosing girls is due to our reliance on the **male prototype**. If girls exhibit the male features of autism or the male externalized behaviors, they are identified earlier. (Kopp & Gillberg)

- “Whenever girls act in a sensitive manner toward people around her or her community, she is praised and her behavior is reinforced. I discovered early on that I could win people over if I did nice things.” (Zosia Zaks)

- Principles ABA?
- “nice” behaviors are reinforced
Research

• Head and Body Size Differences
  – *Autism Research* July, 2013

• Professor Esther Ben-Itzchak, Israel
  – 50\textsuperscript{th} percentile for males
  – 43.4 % for females – head size compared to typically developing girls
  – Preliminary results
  – Additional neurological conditions were found
    • Epilepsy
    • Co-morbid conditions
Additional Research

• Twin Study (Ronald & Robinson, 2013)
• February, 2013
• *Proceedings of the National Academy of Sciences*
  – Fraternal twins
  – Preliminary finding: Girls had “protection” from autism risks
  – Girls were not diagnosed unless the were “loaded up to the gills with risk factors.” (Ronald, University of London)
  – “Could be clinical gender bias as clinicians are more primed to look for male characteristics...to get diagnosed as a girl you have to be more impaired”” (Robinson, Harvard University)
“Missed Diagnosis or Misdiagnosis”

• Dr. Judith Gould
• National Autism Centre: Lorna Wing Centre
• Girls are more able to follow social actions by delayed imitation. They observe and copy other children.
• Girls with ASD are on the periphery of social activities
• Socially immature
• Girls have a lack of social reciprocity and tend to control play
  – Theory of mind deficits
Theory of Mind

- Theory of Mind is the ability to read the beliefs, desires, perception, and intentions of others in order to understand and predict behavior.
- Inability to negotiate friendships and responding to intentions
- Girls with ASD have difficulty with emotional understanding, sarcasm, irony, “white lies” and non-literal speech.
- Inability to anticipate what others might think of one’s own actions
- Mindblindness (Baron-Cohen)
- Sally-Anne Test
Theory of Mind

• Girls failed the “Sally-Anne” test
  – Ability to understand and read other people’s thoughts and feelings
  – Girls had a greater impairment in ToM (Nyden & Gillberg)
• Girls with ASD have a limited ability to “Mind Read”
• Girls with ASD appear insensitive to other people’s feelings
• Why would girls fail the Sally-Anne test in greater numbers than boys?
Organization for the Study of Sex Differences (OSSD): April, 2013

- Focus of the OSSD symposium
- Protection for girls with ASD?
- Do sex chromosomes provide extra protection?
- Different levels of sex hormones
- Study of epigenetics: how the body turns genes on and off based on non-genetic factors or environmental influences
- Updated Autism Speaks
Additional Research: IMFAR

• 2013 International Meeting for Autism Research: Focus on Females and ASD
  – “It (girls) is the white elephant in the room” (Huerta)

• Sanders, Yale
  – Genetic difference may explain 20-50% of the difference in rates

• Dr. Kevin Pelphrey, Yale University
  – $15 million grant from NIH
  – Girls are more severely effected
  – “But is the diagnostic criteria male-based”

• Klin, Emory University
  – Girls engage differently, more eye contact
In response to the IMFAR Meeting posted on-line

• “This is fantastic. I am ‘unofficially’ an Aspie because it is difficult for me to get tested because I love to talk to people but do not have quality friendships. I have a daughter on the spectrum. I was diagnosed with PTSD, which is not correct.”

Happily Eccentric Blog

• *Initiative for Girls and Women with Autism Spectrum Disorders*: Yale Child Study Ctr
  – Follow-up research
  – Kathy Koenig, Director
Additional Research

• *Journal of American Academy of Child and Adolescent Psychiatry* (Happe, June 2013)
• “clinicians miss autism in girls”
• Gender bias in diagnosis due to male stereotypes
• Diagnostic “overshadowing” or pre-determining diagnosis aligned with “female typical condition”:
  – Anxiety, PTSD, or eating disorders
• Will the DSM-5 increase or decrease diagnosis in girls and women?
New Research

• *Brain*: Journal of Neurology (August, 2013)
• Dr. Meng-Chhuan Lai
• Brain Imaging focus on neuro-anatomy
• Autism affects different parts of the brain in females
• Sub-group autism by males and females in order to progress towards understanding the mechanisms that cause autism.
Conclusions and Findings

• Must address diagnostic tools
  – Cut-off scores
  – “Girls are often on the threshold that separates individuals with clinically significant impairment” (Robins, 2013)

• Increase professional training
  – Pre-service training for clinicians

• Data Base of Female characteristics
Gender-Based Assessment Tools

• Most psychological instruments do not include any analysis of gender differences.
• Gender-based assessment tools would include specific norms or scoring.
• It is recommended that psychologists (or other professionals diagnosing ASD) utilize instruments which have evidence of positive gender based performance information.
• Including separate scoring and norms.
Conclusions and Findings

• Specific symptoms may manifest in later years; re-evaluation may be necessary
• Avoid comparing girls with typical male profile
• Strongly assess for social-communicative deficits as girls will not typically display aggressive, acting-out behaviors
• Family Interviews on the ADI-R are very important and may weigh heavier than the ADOS scores
Traits of Girls with ASD

• Rudy Simone
• Author and International consultant
• “Aspergirls”
• Social Skills

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“Girls may behave very differently in schools and suffer social confusion and isolation on the playground but may appear quite differently at home, the opposite of cooperative and complaint”

- Tony Attwood
  - Meltdown at home, where it is safe
- Friendship with only one girl and can become quite intense
- She may be described as a “tomboy” and play with boys
Hidden Curriculum  (Brenda Smith-Myles)

• Social communication skills in girls may differ and require unique assessment and intervention strategies

• Giving a compliment
“Men and women are judged differently when it comes to personal appearance. While the world tolerates a little sloppiness from men, women are under pressure to look attractive. Women on the spectrum who do not put themselves together in a way society expects are often viewed as childish, disorderly, or rebellious and not accorded the respect or taken seriously.” (Zosia Zaks, p. 301)
Grooming and Dress

- Teaching Methods
  - Review methods from Social skills
- Checklists for Grooming
- Task Analysis
  - What are the steps?
  - 5-8 steps
Puberty and Menstruation

• The Goal: The student will demonstrate a clear understanding and independence during her menstrual cycle.
• We have an obligation to teach and help our girls understand
  • Practice with different products
• Reduce fear and stress
• Start Early: Look for signs
  • 11- year old girl
• Break it into small steps
• Create a Personal Story
  – “I’m Growing Up”
Self-Advocacy

• Self-determination allows Women with ASD to advocate for their own needs and determine their destiny.
  – Find value in their strengths
• Provide Disability awareness, facts about ASD and resources
• Identify strengths and weaknesses
  – Problem-solve weak areas
  – Discuss limitations
  – Create a Powerpoint or Art Project
“It took me several years to admit that I had issues. After all the research my mom had shown me, I could definitely see that I had tendencies. But the part that I didn’t see eye-to-eye with the experts is that I believe Asperger Syndrome is not a disorder. It is a Gift.”

Ashley
Girls Rule: The Future Is Bright

• Networking and Outreach in the Community
  – Seek role models in the community
  – Mentoring Programs

• Special Interests
  – Volunteer opportunities

• Employment
  – Teach Work Place Social Skills
  – Teach Money Management and Time Management
  – Following Orders and Cooperation
  – How to avoid annoying your co-workers