Autism in Girls and Women

Wednesday, January 24, 2018
Patty Gould-Lucht, BCaBA

Office of Developmental Programs
Bureau of Autism Services
• Mild symptoms of autism - diagnosed, on average, 2 years later than boys

• Women with autism are fundamentally different from men with autism. Autism’s core deficits may be the same, but when the symptoms intersect with gender > lived experience of a woman with autism can be dramatically different.
• **Research Underway**
  - Adapt new methods to diagnose and treat different gender and age with particular interest in understanding girls and boys with ASD as they transition through adolescence and into young adulthood.
  - Develop more effective interventions, treatments and policies specifically focused on supporting women and girls with autism
  - Develop new and innovative kinds of treatments particularly for anxiety and regulating emotions.
Autism in Girls and Women: A Panel Discussion
The NIMH Office of Autism Research Coordination (OARC) and Office of Research on Disparities and Global Mental Health (ORDGMH)

Sept. 2017
Panelist: Kevin Pehphrey, Ph.D., Pam Ventola, Zoe Gross
Kevin Pelphrey, PhD,

- Studying large sample of girls with autism
- Focus on genes, brain function and behavior throughout childhood and adolescence
- **UNIQUE:** Collaborating with ASD Self-advocates to understand and evaluate brain imaging finding and using them with interviews with self-advocates to see if they fit with the experiences of people with autism.

Longitudinal study – Children > adolescence > adulthood
Leading research collaborative

Studying girls and women with autism – over course of childhood through early adulthood.

- Seeking comprehensive type and volume of clinical information
- Asking study participants and families – they know firsthand
- Girls being compared with boys with autism AND typically developing children of both sexes
- Teasing out difference because of autism vs. sex
- Whether autism itself affects sex differences in brain
- How social and biological factors interact in producing gender typical behavior
Large Research Network – 7 sites

NIH Autism Center of Excellence: Girls' (Women's) Neurogenetics Network
Brain Imaging - Brain scans and genetic testing

Findings - Social brain system

- Girls brains activate very well to social stimuli – early social brain development.

- “Everything we thought was true of autism seems to only be true for boys

- Girls with autism different than typically developing girls regarding how brains analyze social info…but not like boys with autism.

- Brains looked like typical boys of same age - reduced activity in regions normally associated with socializing.
  - Activity regions reduced compared to typically developing girls
  - Those same measurement would not be indicative of autism in a boy however.
Brain imaging - Resting State Data

• Resting State Data – Record how brain parts are communicating with one another – no tasks demands, just brain at rest.

• Showed a difference between girls with and without autism and then compared to boys with and without autism.

• Following Wordles show the areas that show brain at rest between girls and boys with autism.
Clinical Perspective

• Pamela Ventola, PhD., Assistant Professor, Yale Child Study Center
Clinical Perspectives

Pam Ventola, PhD, Assistant Professor at Yale Child Study Center and a Clinical Psychologist

- Identify clinical difference between females and males with ASD
  - Brain difference and tie with behavioral differences
- Factors related to misdiagnosed or delayed diagnoses of girls
Prevalence – Boys:Girls

• 4:1; as high as 8:1 in individuals with IQ>70

• Girls diagnosed later than boys
  ♦ Mean age boys - 3 years of age
  ♦ Mean age girls – 4 years of age

1 year difference is a big deal with regards to early intervention for children with ASD.
• Boys and Men: Socialize through activities
• Large stable groups
• Rough and tumble play
• Competitive team games
Girls and women

Girls and Women: Socializing in small groups

- Conversational
- Intimacy through sharing
• Girls w/ ASD compared with boys w/ ASD
  ♦ Lower cognitive abilities
  ♦ More severe social communication deficits
  ♦ Fewer externalizing behaviors
  ♦ Fewer repetitive behaviors/restricted interest
Females and Males with IQ > 70

- Girls with ASD
  - More socially isolated
  - Strong interest with consistent with typically developing peers – my little pony, unicorns, princesses
  - Magnitude of interest is what sets them apart
  - Greater internalizing symptoms (anxiety, depression)

- Boys
  - Unusual interest
  - Disruptive behaviors
  - Less socially motivated
Case Example

- 4 y. o. girls with ASD
- Nonverbal skills – quite delayed > 2.5 year level; language skills – 2 year level
- But family and child care providers didn’t detect her differences. She talked’ constantly (but not communication with anyone). Happy **but not engaging** with adults/others.
- Family report dancing a lot; repetitively ‘danced’ around,
- Restrictive interest: Disney princesses n- but at a greater magnitude. (Hard to determine how much interest is too much).
Case Example

- 10 year old girl with ASD
- Nonverbal abilities: below average; verbal abilities: average
- Highly socially motivated, outgoing, and talkative
- No disruptive behaviors
- “Hyper-feminine”
  - Focused on style, celebrities, boys > not able to shift away from topic
- Socially motivated but doesn’t understand nuances
  - Fixated on peers – Learn about peers, follow peers, want to be close to peers (over-bearing to others)
Why missing or delay in diagnosis of ASD in girls?

- Biased towards typical ASD male presentation
- Girls, more than peers, report problems with relationships but teachers report fewer symptoms
- Clinical settings- boys are more active and outwardly atypical
- Boys have more atypical interests and more repetitive behaviors
  - Easier to see repetitive, circumscribed interest when the content is unusual
  - With girls - hard to say how much interest in more typical interest (e.g., princesses) is too much.
## Girls Mask Differences

<table>
<thead>
<tr>
<th>Girls</th>
<th>Boys</th>
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<tr>
<td>- Maintain physical proximity to the group although not engaging with peers ...flitting in and out of social groups</td>
<td>- Adults see boys as being excluded/alone</td>
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<td>- Adults see girls with ASD together with other girls but peers detect differences</td>
<td>- Have trouble initiating and sustaining contact</td>
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<tr>
<td>- Strong interests consistent with peers</td>
<td>- Unusual interests</td>
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<tr>
<td>- Greater internalizing symptoms (anxiety, depression)</td>
<td>- More disruptive behaviors</td>
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Adults with ASD

- Adults with ASD also “camouflage” symptoms
- Use learned jokes, follow social scripts, mimic others’ gestures/facial expressions
- Struggling to fit in
- Adopt persona from fictional character – to camouflage
- Women use camouflaging strategies more readily & often
- Camouflaging may bring increased stress and anxiety; “exhausting to be someone you are not”.
Treatment

- Pivotal Response Treatment (PRT):
  - Effective with social communication development
  - Combines ABA Principles with Motivational Strategies
  - Focuses on targeted areas that will have a large impact and improvement in areas (e.g. reciprocity, social initiation, social responsiveness) – so will get a big response if we can improve these areas of function.
• Study examining Sex difference with PRT Treatment
  ♦ 28 children, 4-7 years., 8 hours a week for 4 months
  ♦ Used adaptive functioning measurement (how they function at home and community)
  ♦ Girls had lower adaptive function than boys initially, but more significant improvement with PRT
  ♦ Brain imaging done afterwards – behavioral findings were mirrored in brain images
By Maia Szalavitz
March 1, 2016
Scientific American

Autism—It's Different in Girls

Autism in Girls

One in 68 children in the U.S. is affected by autism—but new research suggests that current diagnostic methods overlook girls, meaning even more kids may be on the spectrum.

Behavioral and preliminary neuroimaging findings suggest autism manifests differently in girls. Notably, females with autism may be closer to typically developing males in their social abilities than typical girls or boys with autism.

Girls with autism may be harder to diagnose for several reasons, including criteria developed specifically around males and overlapping diagnoses such as obsessive-compulsive disorder or anorexia.
• More likely to get different, random diagnosis
• Visit more doctors to obtain clarity/diagnosis
• Sometimes told, ‘you have a girl, it’s not autism
• Criteria based on data most entirely from studies of boys

• Thought that girls were, on average, more seriously affected

• Criteria missing girls and adult women – symptoms look different (Effecting 1 in every 68 child - 4:1 – boy / girl ratio)

• Some undiagnosed or given other dx - ADHD, OCD, Anorexia
2014 - Cleveland Clinic (Thomas Frazier) assessed 2,418 children with autism; 304 of them girls.

Girls:

- Likely to have low IQ
- Serious behavior problems
- Less obvious signs of restrictive interest
  - Topic areas of interest more similar to neurotypical girls
Recent systematic reviews and meta-analyses suggest that females with HFA report poorer overall levels of sexual functioning and experience more sex-related problems and harassment than males with HFA and TD counterparts.
• **Objective of this study:** quantitatively investigate sex differences in sexual development and sexuality in males and females with High Function Autism (HFA), in order to confirm qualitative accounts that suggest poorer sexual and romantic functioning for females in this group.

• **Participants consisted of:**
  - 232 individuals with HFA (97 males; 134 Females; 1 unreported [$M = 25$ years]) and
  - 227 non-clinical controls (66 males; 161 females [$M = 27$ years]).

• **Results:** analyses confirmed the hypotheses that females with HFA would report poorer levels of overall sexual and romantic functioning and adverse sexual experiences across a range of sexuality domains than males with HFA.
• **Results:**
  • Analyses confirmed the hypotheses that females with HFA would report poorer levels of overall sexual and romantic functioning and adverse sexual experiences across a range of sexuality domains than males with HFA.
  • Females are subject to a range of adverse experiences their pursuit of a healthy sexual development and sexual life.
• Autism characteristics differ by gender, studies find
BY SARAH DEWEERDT
27 MARCH 2014

• Two studies published lend support to the notion that autism looks different in girls than it does in boys, making it harder to recognize and diagnose in girls. The studies reflect growing suspicion in the research community that the underlying biology and the experiences of girls with autism may both be distinct.
• Study 1: March issue of the *Journal of the American r.*

• The researchers report that autism characteristics in girls depend on their level of intelligence. “On the lower end, they tend to have more social communication impairment and lower cognitive ability” than boys who have the disorder, says study leader Thomas Frazier, director of the Center for Autism at the Cleveland Clinic in Ohio. “On the higher end, they have fewer restricted interests.”
The newest edition of the *Diagnostic and Statistical Manual of Mental Disorders*, the DSM-5, overtly acknowledges that females with autism may have features that differ from those of males with the disorder.

One of the most striking features of autism is its gender ratio. Males are four times more likely than females to receive an autism diagnosis, and at the high-functioning end of the autism spectrum there are as many as nine males for every female.
Organization for Autism Research (OAR) – RESEARCH FUNDED, 2017

Square Pegs in Round Holes: Investigating How Diagnostic Practices Fail to Identify Females with ASD
Researcher: Jonathan Sterling Beck
Brigham Young University

- Securing study participants
- Study will include interviews with girls and women who experience ASD symptom and about their developmental trajectories in school, family, and social situations.
- Data will be valuable for modifying standard assessment tools to be more sensitive to females and more likely to lead to an appropriate diagnosis and treatment.
Adolescence can be a confusing time for any young girl, but for a girl with autism, “trying to make friends and not understanding why the friendships aren’t lasting, or why you’re not being included when people are making plans” can be incredibly isolating. “You’re aware enough to know that you’re failing, basically.”

There is almost nothing to give adolescent girls the kind of emotional support that only comes from true companionship.
The truth is though, someone who is neurodiverse in some areas of their brain, will also be no different to your average person in other areas of their brain.

You see, the autistic spectrum looks something more like this.

- Rebecca Burgess, Comic Redesigns the Autism Spectrum to Crush Ster The Mighty
Intense Focus/Interests

Sensory Sensitivities

Planning/Executing

Communication

Social Skills
Support Opportunities Underway

A few programs/places supporting girls/women with autism:

- **Yale School of Medicine** – Initiative for **Girls** and **Women with Autism** Spectrum Disorders at the **Yale Child Study Center**

- **Falicity House - New York City**, non-clinical program just for women with autism. Place to meet, socialize, pursue interests, learn, create, connect to resources, find supportive people and to laugh. [https://felicity-house.org](https://felicity-house.org)

- **Girls Night Out – Kansas City** - Rene Jamison, assistant clinical professor at University of Kansas Medical Center.
  - Focus: teaching adolescence and women about good hygiene and dress (often neglected - sensory issues; hygiene perceived as unimportant) and chance to be with others females for sharing and friendship.

- **Minds and Hearts Clinic – Australia** – Tony Atwood. Groups for girls/women, how to develop friendships, work with peers
Resources and References

National Institutes of Health (NIH) Autism in Girls and Women
A Panel Discussion: Kevin Pehphery, Ph.D, Pamela Ventola, Ph.D and Zoe Gross
https://videocast.nih.gov/summary.asp?Live=26146&bhcp=1

Scientific American – Mental Health. Autism – It’s Different in Girls, Maria Szalavitz, March 1,
https://www.scientificamerican.com/article/autism-it-s-different-in-girls/

Spectrum News. Adolescence unmasks autism traits in girl, Jessica Wright, March 13, 2017

The Mighty – Rebecca Burgess, Comic Redesign the Autism Spectrum
https://themighty.com/2016/05/rebecca-burgess-comic-redesigns-the-autism-spectrum/
Minds and Hearts – Dr. Tony Atwood, leading expert on autism, Chairperson, Senior Consultant, Principal Psychologist and supervisor of staff team. http://www.mindsandhearts.net

YouTube Channel: Autism Hangout w. Dr. Tony Atwood
https://www.youtube.com/user/autismhangout/search?query=girls+with+autism


Research studies being conducted on females with autism:

The Autism Site
http://blog.theautismsite.com/anorexia-correlation/
http://blog.theautismsite.com/anorexia-correlation/
• **The Lost Girls**. Apoorva Mandavilli in Spectrum. Published online October 19, 2015 [https://spectrumnews.org/features/deep-dive/the-lost-girls](https://spectrumnews.org/features/deep-dive/the-lost-girls)

• Autistic Self Advocacy Network: [http://autisticadvocacy.org](http://autisticadvocacy.org)
• Autism Women’s Network: [https://autismwomensnetwork.org](https://autismwomensnetwork.org)
• Academic Autism Spectrum Partnership in Research and Education: [https://aaspire.org](https://aaspire.org)
ASERT Statewide Resource Center

- Statewide Toll-free Number: **877-231-4244**
  - Offering live assistance from ASERT’s Resource Center Specialists
- Website: [www.PAautism.org](http://www.PAautism.org)
- ASERT Outreach Specialists
  - Available to attend conferences, support group meetings and community events to promote autism awareness and provide resources
  - to provide information and support to families
  - to facilitate connections between individuals, families, professionals, and providers throughout the Commonwealth
How to ensure you have all the information to do your job as a provider

• Have you visited the ASERT website (www.paautism.org)?
  – Did you create profiles for the participants you support?
  – Did you sign up to receive the ASERT monthly newsletter?
  – Do you follow ASERT on facebook or twitter?
• Are you signed up on BAS list-servs (all providers and SC specific)?
  – Are you receiving Admin Notices and Communications via the list-serv?
• Do you visit the online training platform (www.myodp.org) and save all pertinent documents and watch trainings? Do you participate in live training opportunities?
• Do you communicate with the Regional and Clinical Reps to ask questions and share participant concerns?

If you have questions on any of the above, please contact the Provider Support Mailbox (ra-basprovidersupprt@pa.gov)