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- 27 years in Special Education
- 3 Books
 - Girls Under the Umbrella of ASD
 - Mattie's Journey

Overview

- Gender differences
 - Female characteristics of ASD
- Diagnosis
 - First Signs
- Social Skills
 - Friendships
 - Bullying and Girls
- Safety Concerns
 - Dating
- Adolescence and Puberty
 - Touchy subjects
- Self-Advocacy
 - Self-determination
 - Long-term outcomes

Girls and ASD

- 4:1 Autism
- 9-11:1 Asperger Syndrome

"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

Girls and Women with ASD

- Lack of information on girls with ASD
 - "Research orphans" (Ami Klin)
 - Under-diagnosed
 - Diagnosed as adults
 - Poor outcomes
- Differences in boys and girls with ASD
- Provide professional information and personal experiences.
- Give girls a voice
 - Support their uniqueness

*"What are little boys made of?
Frogs and snails,
and puppy-dogs' tails...
What are little girls made of?
Sugar and spice,
and everything nice."*

Gender Differences

Assessment Tools and Diagnostic Criteria

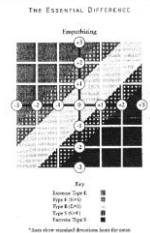
Empathizing vs Systemizing The Essential Difference (Baron-Cohen, 2003)

- 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

Diagnostic Tool: The Autism Spectrum Quotient

- (Baron-Cohen, 2003)
- If I were buying a car, I would want specific information about its engine capacity.
 - If there was a problem with the electrical wiring in my home, I'd be able to fix it myself.
 - I am fascinated by how machines work.
 - In math, I am intrigued by the rules and patterns governing numbers.
 - If I were buying a computer, I would want to know the exact details about the hard drive and processor speed
 - If I had a collection (CDs, coins..) it would be highly organized

Empathizing vs Systemizing The Essential Difference (Baron-Cohen, 2003)



Autism: The Extreme Male Brain

- “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

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
- Attention problems
 - Without hyperactivity
- Lack of focus
 - daydreaming
- Lack of empathy
 - awareness
- Increased anxiety
 - Excessive worrying

Mattie's Journey

- Behavior Meltdowns
- Clothes
 - Too Tight/ Sandpaper
 - Zipper/Buttons/Velcro
 - Weather/Seasons
- Leaving or Going Places
 - Birthday Parties
 - Stores
 - How was your day?
- Out to dinner
 - Waiting (dvd's)
 - Sensory overload
- Bad Language and frustration
 - Hard time articulating
- Odd play and Self-Talk
 - Lining up and re-playing the day

Karen (mother of Rosemarie)

"From the beginning I knew my little girl was different from her two brothers. Rosemarie was happiest when she was on the floor, wearing as few clothes as she could get away with, hovering over a huge sheet of drawing paper. Drawing became her way to communicate and escape from a world that was too complex for us to understand."

Gender Differences

- Girls don't fit the male prototype
 - Girls are rarely fascinated with numbers or have stores of arcane knowledge (Skuse)
- Males have a higher level of activity and behavioral problems
- "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)

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)

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.
- 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

Theory of Mind

- 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 read the listener's level of interest
- Inability to anticipate what others might think of one's own actions
- Mindblindness (Baron-Cohen)

Back to School Ideas!

- Select a comic strip
 - Garfield, Calvin and Hobbs, Zits
- Copy
- White out what is being said
- Copy again and distribute
- Discuss conversation scenarios
 - Have students “put themselves in character’s shoes”
- Discuss emotions
- “Baby Blues” Comic Strip
 - Simulation of classroom

“Under-diagnosing of women with ASD contributes to the marginalization of females. If we do not appropriately identify girls at an early age, women will continue to stay in the background and live in seclusion. They will continue to live in isolation.” (Jean Kearns Miller)

Assessment and Diagnostic Guidelines

- Male- centered profile assessment
- Different symptom expression
- Are we comparing with other boys with ASD or with neuro-typical girls
- Detection ability of assessment tools
- Do assessment tools reflect severity of the disorder?
- Should sex specific norms be used?

Assessment and Diagnosis Guidelines (cont.)

- 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
- Separate Cut-off scores for females?

Social Skills

Social and Communication Skills

- “To recognize and use a range of different behaviors to interact and negotiate through verbal and non-verbal means”
- Families and school personnel must explicitly teach to each of these deficit areas
- Increase positive outcomes and independent living and employment

"My memories of school were far from what can be considered normal. Many nights I lay crying in bed, afraid that one of my school pencils might not be sharp enough. I was frustrated because I absolutely had to walk with my desk partner when switching classes and was not permitted to walk alone. The slight cracks between the adjoining desks bugged me. Lunch time in itself was hell. I was afraid that I would miss recess or class afterwards. Therefore, I would pick two classmates every day and ask them to sit beside me at lunch and play with me at recess. This was my typical day." Rosemarie

Instructional Techniques for Social/Communication Skills

- Pictures
 - Magazines
- Video Modeling
 - Model Me Kids; www.modelmekids.com
 - Conversations; Executive Functioning; Friendships
- Role-Play
- Direct Instruction
- Scrapbook of emotions
- Social Stories
 - Social Narratives

8 Steps for Teaching Social Skills

- Step 1: Identify the necessary social skill
- Step 2: Identify skills that are valued by the student
- Step 3: Teach in the natural setting
- Step 4: Include as part of the **everyday** curriculum

Steps (cont.)

- Step 5: Identify on-going opportunities to practice new skill
- Step 6: Provide feedback
- Step 7: Teach students to self-monitor
- Step 8: Use a variety of instructional techniques

Mattie and Friendships

- **How to make friends**
 - Making friends was a challenge at times. (Junior High)
 - Now that I am in High School it is much easier.
- **What worked**
 - Complimenting
 - Focus on friends and talk about "their" interests
 - Realize that you can have more than one friend
- **What didn't work**
 - Talking about my interests
 - Over obsessive
 - Give friend space
- **Picking the wrong friend**
 - If someone says "Hi" it doesn't always mean they are your friend
 - Quick to judge because someone gave you some attention
 - Thinking that they were your friend and realize that they just might be bullies.
- **Social skills classes**- I liked going to social skills classes when I was younger. As I got older, they seemed weird to me.
 - **What I learned from the classes:**
 - Start and stop conversation
 - Not to interrupt/Listen
 - How close to stand (Hula Hoop)
 - Taking turns

Bullying and Social Skills

- Girls with ASD are prone to bullying due to their uniqueness and being alone
- Staff can create a "Circle of Friends" or a peer buddy system to help insulate from Bullies
- Rebekah Heinrichs "Perfect Targets"
- School-wide Zero Tolerance
 - Increase supervision in target areas
 - Carol Gray's Guide to Bullying

Bullying and Girls with ASD

- Verbal insults
- Social exclusion/ silent treatment
- Subtle and indirect
- Refusing to be friends
- Gossiping
- Teacher's may inadvertently bully students
 - Stop daydreaming
 - You are lazy
 - Look at me

“School was hell wrapped in a hot winter fur. This one girl at school never wanted anything to do with me. All of my attempts to play with her resulted in rejection. As the school year progressed, my peers started to use my idiosyncrasies against me for their own fun.” Rosemarie

Adolescence and Puberty

- Body changes
 - Sensory Issues
- Puberty
- Menstruation
- American Girls Series
- Self-Advocacy
- Self-Determination
- Transitioning
- Employment

Mattie's Journey

- **High Expectations**
 - Raise the bar
 - Otherwise they stay stagnant
- **Repetition (Target)**
 - Over and Over
 - Teachable Moments (Dinner)
- **Follow Through on Behaviors**
 - Structure (Bad Language)
 - What to Expect (Laps)
- **Transitions/ Treasures**
 - In the car/Home
 - Toys/ Books
 - Special Place (Funky Town, Danielle's Diner)

Mattie's Journey Cont.

- **Validate/ Listen**
 - Write it Down
 - Sit and Listen
- **Allow Limited Time**
 - Self Talk/ Designate a Place
 - Odd Play
 - Discuss Interest
 - Twilight
 - Transition Back!!!

Girls and Puberty

“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)

Girls and Puberty

- The Goal: The student will initiate basic hygiene routines at home as well as in school
 - Quote: Temple Grandin, "It is perfectly fine to be a little eccentric but dirty or ragged is not acceptable."
- Start early and educate
 - Books "Taking Care of Myself" by Mary Wrobel
 - American Girl Books
 - What is dirty and what is clean?
 - How do we stay active and healthy?
- Keep it Simple- do not complicate the information
- Practice-over and over
- Find teachable moments- it is not a one time only
- Create a daily personal hygiene checklist
 - School personnel can assist parents in creating a checklist

Personal Hygiene Checklist

Date:

Shower	
Use Shampoo and Conditioner	
Shave Under Arms/ Legs (Nair)	
Comb hair thoroughly	
Put on deodorant	
Brush teeth for 2 minutes	
Put on clean bra and underwear	
Put on clean clothes	
Look in the mirror	

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
 - Hospital offers classes
 - 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

Menstruation Story (shortened version)

1. Mattie's body is changing. She is getting bigger and growing taller. Hair is growing in her private area and under her arms.
2. When Mattie has her period blood will come from her privates. This is okay.
3. At first, I might be scared and upset when I see the blood.
4. All big girls, mommies, and adult women have periods.
5. A period comes every month for 5 or 6 days and then it will stop.
6. During my period, I will wear pads in my underpants. The pads may feel funny, but they will keep me clean.
7. I am a big girl now. I will do a good job with my period.

"I cursed God a lot. I remember calculating how many periods I would have to struggle through in my lifetime for no reason, as most women have so few children for the number of years of menstruation they have to endure."

(Masilamani, *Women from Another Planet*)

Public vs. Private Issues

- The Goal: The student will demonstrate an understanding of personal topics, which she can and can not talk about with others
- Identify what topics are for home and what topics are for school
- Identify specific school personnel that are appropriate for discussions on private issues
- Parents and school personnel should be in agreement on where and with whom

Advocacy and Self-determination

Girls with ASD who are empowered with self-determination and advocacy skills have higher employment rates and earn a higher wage after graduation. (Test, Karvonen, Wood, & Algozzine, 2000)

Self-Advocacy

- Self-determination allows Women with ASD to advocate for their own needs and determine their destiny.
- Provide Disability awareness, facts about ASD and resources
- Define terms
- Acceptance of Disability
- Identify strengths and weaknesses
 - Problem-solve weak areas
 - Discuss limitations

Mattie's Journey

- **Mattie's profile:**
- **Mom's Cell number is (702)**
- Any Questions or concerns please call mom or e-mail her.
- **All about me:**
- I am so excited to be here at Spring Valley High School!!
- I love to learn new things and I am really smart!!
- I am an excellent writer and I love to write stories and poetry!!
- I am obsessed with Twilight!!!
- I am in love with "Edward Cullen" From the Twilight Movies!!!
- I am a Social Butterfly and I make friends really fast☺

Mattie's Journey

- **Things to help me in school: Modifications and Accommodations**
- Directions are hard for me, so I might get lost the first few days of school.
- I need a calculator to help with math.
- Sometimes I have a hard time with too much homework, but I always try and do what I can.
- I need a quiet testing Environment, noise can be very frustrating.
- Also I might need a little more time on testing days.
- Please provide a study guide for tests/quizzes a week in advance, so I can study hard and pass!!
- I really need extra time to study!!
- I might need to possibly retake tests at times.
- Non- Verbal cues to redirect, please!
- I will have a Notebook/Planner to keep track of assignments/tests.☺
- Thanks for being patient with me, I will do my best!!
- Go Grizzlies!!!!
- I Love Spring Valley High School!!!!

Self-Disclosure

- Public vs. Private
- *The 411 on Disability Disclosure* (www.ncwd-youth.info)
 - workbook
- Who and when to tell?
 - Friends? Employers? The custodian?
 - Develop a list
 - Discuss negative reactions and discrimination against people with disabilities.
 - Role play how and when to disclose
 - Create and write out a short description of the disability-script
 - Respect her decision

"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

- Employment
 - Unemployment for Women with disabilities has increased
- Quality of Life
- Independence
 - Fading support
- Start Early
 - Middle school

Mattie's Journey

- **Volunteer**
 - St. Vincent's Soup Kitchen
 - Autism Picnic
 - Spring Preserve
 - Library
 - Special interests (books, animals, hospital, nursing homes)
- **Why it is important**
 - Learn time management
 - Learn people skills
 - Appearance/Appropriate
- **Community**
 - Mattie's 14th Birthday Wish
 - Oprah Show Inspired

Work Place Social Skills

- Bureau of Labor and Statistics: Skills required for successful employment:
 - Honesty
 - Teamwork*
 - Motivation
 - Strong Work Ethic
 - Analytical Skills
 - Flexibility*
 - Computer Skills
 - Time Management*

How to Find Work That Works for People with AS (Hawkins, 2004)

- Employment
 - Job Coach or Voc Rehab
 - Contact even if they do not qualify
 - Do they provide training? How to get a job 101?
 - Local resources
 - Internet search or autism and supported employment
 - What not to do? Identify challenges
 - Be direct and concise about job roles
 - "Say what you mean and mean what you say.....
But do it in 15 words or less." Gail Hawkins

"Kids with ASD need a lot of preparation and training, training that needs to be part of elementary, middle, and high school education." Temple Grandin

Mattie's Journey

"Please do not use Autism as an excuse or your child will stop growing. Teach and educate your child so that they can grow up feeling confident and able to handle necessary life skills."

Mattie Wendel

References

- American Association of University Women (2004). *Women and girls with disabilities*. Washington D.C.: AAUW Educational Foundation and National Education Association.
- Attwood, T. (1999). *The pattern of abilities and development of girls with Asperger's Syndrome*. www.tonyattwood.com.
- Attwood, T. (2007). *The complete guide to Asperger's Syndrome*. London: Jessica Kingsley Publishers.
- Attwood, T. (2006). *Asperger's and Girls*. Future Horizons.
- Banks, M., & Koschak, E. (2003). *Women with visible and invisible disabilities: Multiple interactions, multiple issues, multiple therapies*. New York: Haworth Press.
- Baron-Cohen, S. (1995). *Mindblindness*. London: The MIT Press.
- Bissag, V. (2006). *Bullying among girls: Frieded or foes*. *School Psychology International*, 27(5), 535-551.
- Crompton, V. & Kessler, E. (2003). *Saving beauty from the beast*. Boston, MA: Little, Brown and Company.
- Cutler, E. (2004). *A thorn in my pocket*. Arlington, TX: Future Horizons.
- Debbaut, D. (2003). *Safety issues for adolescents with Asperger Syndrome*. In L. Holliday Willey (Ed) *Asperger Syndrome in Adolescence* (148-178). London: Jessica Kingsley Publishers.
- Ernsperger, L. (2003). *Keys to success for teaching students with autism*. Arlington, TX: Future Horizons.
- Ernsperger, L. & Stegen-Hanson, T. (2004). *Just take a bite: Easy, effective answers to food aversions and eating challenges*. Arlington, TX: Future Horizons.
- Fine, M. & Asch, A. (1988). *Women with disabilities*. Philadelphia, PA: Temple University Press.
- Frith, U. (Ed). (1991). *Autism and Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Gillberg, C. (1991). *Clinical and neurobiological aspects of Asperger Syndrome in six family studies*. In U. Frith (Ed), *Autism and Asperger Syndrome* (123-146). Cambridge, UK: Cambridge University Press.
- Grandin, T., & Barron, S. (2005). *The unwritten rules of social relationships*. Arlington, TX: Future Horizons.

References

- Gurian, M. (2002). *The wonder of girls: Understanding the hidden nature of our daughters*. New York: Atria Books.
- Gurian, M. & Stevens, K. (2004). *With boys and girls in mind*. *Educational Leadership*, 62(3), 21-26.
- Hawkins, G. (2004). *How to find work that works for people with Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Helfrich, S., & Weinstock, C. (2003). *Women with visible and invisible disabilities*. *Women and Therapy*, 26(2), 81-81.
- Hurblatt, K. & Chalmers, L. (2004). *Employment and adults with Asperger Syndrome*. *Focus on Autism and Other Developmental Disabilities*, 19(4), 215-222.
- Kopp, S. & Gillberg, C. (1992). *Girls with social deficits and learning problems: Autism, atypical Asperger Syndrome or a variant of these conditions*. *European Child and Adolescent Psychiatry*, 11(1), 89-99.
- Lomdale, S. (1997). *Women and disability*. New York: St. Martin Press.
- Lord, C., Schopler, E., & Revicki, D. (1982). *Sex differences in autism*. *Journal of Autism and Developmental Disorders*, 12(4), 317-329.
- Lynch, R. & Gussel, L. (1996). *Disclosure and self-advocacy regarding disability-related needs: Strategies to maximize integration in postsecondary education*. *Journal of Counseling and Development*, 74(4), 352-364.
- Miller, J.A. (2003). *Women from another planet: Our lives in the universe of autism*. Bloomington, IN: A Dancing Mind Book.
- Nichols, Shana (2009). *Girls Growing up on the Autism Spectrum*. Jessica Kingsley Publishers.
- *Resources for Rehabilitation* (1998). *A women's guide to coping with disability*. Lexington, MA: Resources for Rehabilitation.
- Russo, H., & Wehner, M. (2001). *Double jeopardy: Addressing gender equity in special education*. New York: State University of New York Press.
- Russo, H., & Wehner, M. (2002). *Gender matters: Training for educators working with students with disabilities*. Newton, MA: Education Development Center.
- Shaw, V. (1999). *A girl's guide to what's happening to your body*. New York: Rosen Publishing Group.
- Simone, Rudy (2010). *Aspergrits*. Jessica Kingsley Publishers.
- Smith, T. (1997). *Sexual differences in pervasive developmental disorders*. *Medscape Psychiatry and Mental Health e-Journal*, 2(3).
- Sugar, G. & Lewis, T. (1996). *Preferred and promising practices for social skills instruction*. *Focus on Exceptional Children*, 29(4), 1-16.
- Willey, L. H. (1999). *Pretending to be normal: Living with Asperger's Syndrome*. London: Jessica Kingsley Publishers.
- Willey, L. H. (2012). *Safety Skills for Asperger Women*. Future Horizons.
- Wing, L. (2001). *The autistic spectrum: A parent's guide to understanding and helping your child*. Berkeley, CA: Ulysses Press.
- Zaks, Z. (2006). *Life and love: Positive strategies for autistic adults*. Shawnee Mission, KS: Autism Asperger Publishing Company.