Girls Under the Umbrella of ASD

Lori Ernsperger, Ph.D.
&
Danielle Wendel

Overview

- Introduction
- Diagnosis
  - First Signs
- Gender differences
  - Female characteristics of ASD
- School age years
  - IEP Considerations
  - Social Skills
  - Bullying prevention
  - Sensory Integration
- Adolescence and Puberty
  - Touchy subjects
- Advocacy and Self-determination
  - Transitioning
  - Long-term outcomes

Why We Wrote the Book

- 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 women and girls a voice
  - Support their uniqueness

Diagnosis

- **Mattie**
- **Earlier Diagnosis**
  - Looked right through you
  - Walked after 18mths
  - Meltdowns zero-boiling
  - "She'll grow out of it"
  - Christmas Picture
  - Diagnosed at 5
  - Neuro-psychologist
  - Spent time testing
- **Initially Traumatic**
  - Very little information about girls with ASD
  - Relief and Validation

Girls and ASD

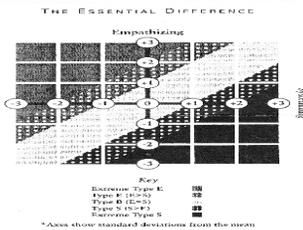- 4:1 Autism
- 10:1 Asperger Syndrome

"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

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

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

Think-- Pair -- Share

- Review the Questionnaire
- Select appropriate answer and score
- Are you more Empathizing or Systemizing?
- How does this impact diagnostic tools for autism spectrum disorders? Male centered questions.

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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

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

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)
- "Due to the misconceptions and stereotypes, many girls and women with autism are never referred for diagnosis, and so are missing from the statistics." (Gould, 2008)

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)

"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?

Off to School

- IEP Considerations
- Social/ Communication
- Bullying Prevention
- Sensory Processing

IEP Experience from a Parent's Point of View

- Danielle's 1St IEP Story
- Current IEP
  – Student attended
  – Strengths & Weakness
  – Support
    • Lunch
    • Getting from class to class

IEP Team

- What can we do as a team to bring out the student's abilities
- Focus on their strengths and motivators
  – Student Profile
- Allow some flexibility in the curriculum to incorporate the child's motivators so they succeed
- Role of the parent
- Placement decisions
  – Special education placement is dominated by boys, therefore a lack of opportunity to make female friends
  – School team is responsible for determining peer models

Student Profile

- Create an individual student profile consisting of:
  – Strengths and weaknesses
  – Medications
  – Reinforcement
  – Stress hierarchy and triggers
  – Topic of special interest
  – One page

Transitions

- Field trip to receiving school or grade
  – Take pictures for a scrapbook
- Spend time walking around while students are in session
- Sensory Factors: noise, movement in hallways
- Lockers: adaptations with practice
- Visit the school a week before school starts
  – Get the schedule early
- P.E.
- Request copy of books for the following year to review over the summer
- Daily agenda

Homework

- What is the value of Homework?
- **The Homework Myth: Homework increases student achievement.**
  - The link between homework and student achievement is far from clear. There is no conclusive evidence that homework increases student achievement across the board. Some studies show positive effects of homework under certain conditions and for certain students, some show no effects, and some suggest negative effects. (Center for Public Education)
- Student's with AS experience great emotional stress in school, they need solitude
- Determine if homework can be completed during school hours/ **Important for parents**-minimal amount to reinforce that they understand assignment
- Create a Homework Schedule:
  - Checklist
  - Time
  - Modifications

Homework Adaptations

- Size: # of items
- Time: more time
- Input: Adapt the way instruction is delivered-visual aids
- Output: Adapt how the learner responds
- Difficulty: Allow calculator or Mult. table

- Participation: Adapt how the student is involved
- Level of Support: Peer buddy
- Alternate Goals: Adapt curriculum goals and focus on the social goals
- Use computer/ type writing assignments
- Graphic Organizers: Webbing, bubbles

Graphic Organizers
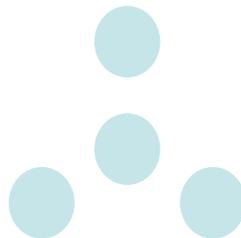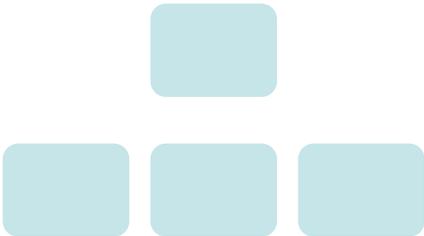
Social and Communication Skills

- "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
- Video Modeling
  - Model Me Kids
- Role-Play
- Direct Instruction
- Scrapbook of emotions
- Games "Cool-Uncool"
- Incidental Teaching
- Social Stories

Hidden Curriculum

- Passing Notes- Mattie
- Unwritten rules in classrooms
  - Brenda Smith Myles
- The hidden curriculum makes the unwritten rules more explicit to students
- List a 3-5 unwritten rules in schools

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
- 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

Peer Buddy System: Girls Rule

- Select and train peers
  - Teacher selection
  - Parent permission
- Create supervised activities
  - Lunch Pals
  - Extracurricular groups
- Peer Selection
  - Calm personality
  - Sense of humor
  - Ability to deflect teasing
  - Moves easily amongst peer groups
  - Has many stable friends
  - Consistent personality

How to Respond to A Bullying Attempt (Gray, 2003)

Step 1: Relaxation techniques/peaceful images/ stress management

Step 2: Say one sentence well

Examples?

Step 3: How to say it?

Inflection/ non-verbal skills/ voice control

Walk away

Steps for Addressing Bullying

- Teach how to react to bullying and practice new skills
- Develop the girl's talents and strengths
- Join a group with similar interests
- Teach age-appropriate social skills and other ways to fit in
  - American Girls Series

Beyond Bullying

- Sexual Harassment and Bullying
  - Some research suggests that up to 83% of girls with developmental disabilities will be sexually harassed or even sexually abused
  - Young women with ASD require specific guidance on sexual harassment
    - Private vs. Public
  - Personal Safety guidelines should be established between home and school
  - www.autismriskmanagement.com

Beyond Bullying

- Cyber-bullying:
- 27% of a girls in a recent study reported cyberbullying
  - School policy: computers and cell phones
  - Social Networking: My Space
    - Girls with ASD are often seeking friendships on-line
    - Personal Information/ What to share?
    - Safety guidelines
  - Bullying Beyond the Schoolyard: Identifying, Preventing and Responding to Cyberbullying (Hinduja & Patchin)
  - www.cyberbullying.us
    - Worksheets/crossword puzzles and scripts
  - Schools must teach prevention and can be found negligent

"Thank You, Mr. Falker," by Patricia Polacco

- The book demonstrates how students and teachers work together to help the main character with a disability to grow.
- Read this book to ASD's girl's classmates approximately two weeks into the school year.
- Do not involve ASD girl in this discussion.
- Compare character of book to ASD girl – that neither one is sick or contagious, their brains are just wired differently.
- Discuss ASD girl's strengths among her classmates. (great reader, good friend, sweet.)

Role of the Teacher

- Set up Classroom Environment for Success (Elementary)
- Set up Rotation Stations
- These stations allow the students to experience hands-on the ASD girl's perception of her surroundings.
  - Auditory Station
  - Tactile Station
  - Visual Station

Auditory Station

- Materials Needed: Radio
- Instructions:
  - Turn on Radio Really Loud
    - Explain how this demonstrates how a normal voice may sound magnified for a girl with ASD.

Tactile Station

- Materials Needed: None
- Instructions:
  - Children Sit In Circle with Teacher
    - One at a time, each child pokes the next child in the arm.
    - When it becomes the teacher's turn, the teacher will pretend to punch the next child in the arm.
      - This demonstrates how a poke or gentle touch could feel firm or strong to an ASD girl.

Visual Station

- Materials Needed: Magnifying Glass
- Instructions:
  - Children Sit in Circle with Teacher
    - Instruct children to look at each other one at a time through the corners of their eyes.
    - Teacher's turn: Use magnifying glass to look at nearby child and over-react loudly at child by saying, "I don't like your mean look and stop looking at me."
      - This demonstrates how an ASD girl's perception of someone's facial expression could be misinterpreted.

How Peer Understanding Leads to Acceptance

"When Mattie returned to the classroom, I could see my students sitting up with pride that she was in our classroom. It was obvious that they cared about her. With the passage of time, I enjoyed watching the respect for Mattie cultivate and grow. By the end of the school year, she had achieved the "Golden Rule Award," and we all learned that autism was not such a scary word, but just person at a time."

Ms. Charest

Adolescence and Puberty

- Body changes
  - Sensory Issues
- Puberty
- Menstruation
- American Girls Series
  - Create teachable moments

- Self-Advocacy
- Self-Determination
- Transitioning
- Future Outcomes

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
- Start early and educate
  - What is dirty and what is clean?
  - How do we stay healthy?
- Keep is Simple- do not complicate the information
- Practice-
- 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

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

"My physical development was a complete shock. Although I had been given the "talk" by my mother, it was an explanation from a medical textbook and I could talk knowledgeably about the progesterone and such but I made no connection between information and what was happening to my body." (Masilamani, *Women from Another Planet*)

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
- 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.

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
- Identify strengths and weaknesses
  - Problem-solve weak areas
  - Discuss limitations

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

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

"Kids with ASD need a lot of preparation and training, training that needs to be part of elementary, middle, and high school education if they're going to have any kind of life after they get out of school."

(Temple Grandin, Unwritten Rules of Social Relationships)

Findings and Conclusions

- Maintain high expectations
- Seek Knowledge
- Plan for the Future
- Embrace Uniqueness
- Create a Network of Support