




Girls with ASD


Jennifer Schoffer Closson
Ed D, CCC-SLP



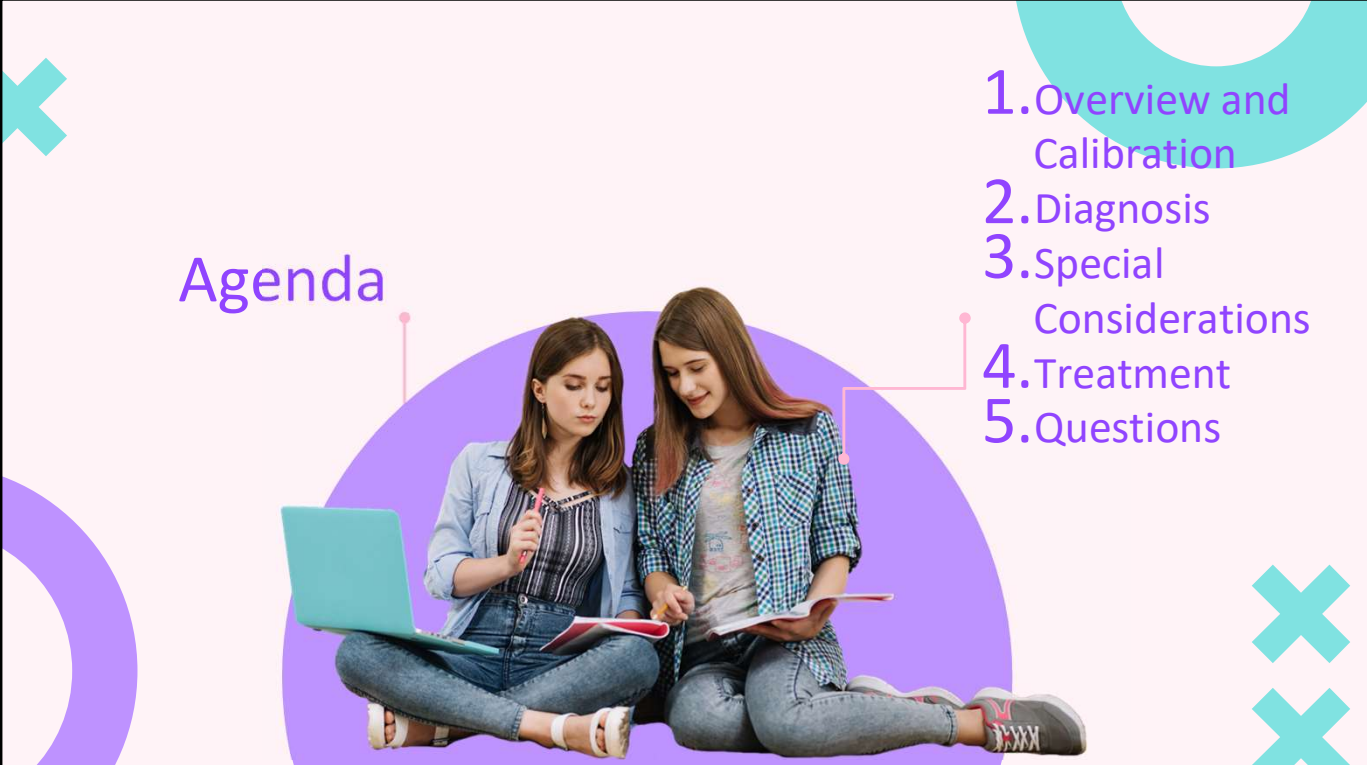
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Thank-you
for having
me join you!



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Agenda



1. Overview and Calibration
2. Diagnosis
3. Special Considerations
4. Treatment
5. Questions

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Jennifer Schoffer Closson
Ed D, CCC-SLP



Instagram

Owner/Member of YETI Consulting LLC

- Autism Specialist
- 11 years Public Schools
- 13 years University of Montana
 - Instructor, clinical educator
- 7+ years private practice

● Areas of interest: Autism, neurodiversity, cleft palate, secondary transition, clinical education, pedagogy

● Disclosure: YETI Consulting LLC will be compensated for this training

YETI Consulting LLC

406-698-3658

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Intervention Principles (Schoffer Closson)



Everyone deserves respect

Every person has a program, it is our job to figure it out (individualized programs)

Assessment is ongoing

Assume competence (make the least dangerous assumption)

Behavior is usually communication

Neurodiverse affirming practice: Helping people move effectively and efficiently through the world



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Girls with autism
have a different
experience than
boys



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Autism Spectrum Disorder (ASD) Overview

Center for Disease Control

- 1 in 36 people have ASD
 - In the year 2000 it was 1 in 150
- reported to occur in all racial, ethnic, and socioeconomic groups
- more than 4 times more common among boys than among girls
- Words like “Asperger,” “Pervasive Developmental Disorder,” “low or high functioning” are no longer used when diagnosing
- Social Communication Disorder was added to DSM-5



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What is Neurodiversity?

Harvard Health

- Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

The term includes:

- Autism
- ADHD/ADD
- Dyslexia
- Stuttering
- TBI/Acquired Neurodiversity
- Dyscalculia
- Dyspraxia
- Dysgraphia
- Tourette/Tic Disorders
- Depression/Anxiety
- Apraxia of speech
 - Plus much more



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DSM 5 ASD Diagnostic Criteria

- For an ASD diagnosis, an individual must show deficits in 3 of 3 social communication areas:
- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
 - 1. Deficits in social-emotional reciprocity
 - 2. Deficits in nonverbal communicative behaviors used for social interaction
 - 3. Deficits in developing, maintaining, and understanding relationships
- Source: American Psychiatric Association, 2013



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DSM Diagnostic Criteria continued...

- AND an individual must demonstrate 2 of 4 restrictive, repetitive patterns of behavior:
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
 - 1. Stereotyped or repetitive motor movements, or use of objects, or speech
 - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus
 - 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
- Source: American Psychiatric Association, 2013



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Severity Levels

- Once it has been established that a person meets the criteria for autism, a severity level is established according to the DSM-V
- Terms like “High Functioning Autism” and “Asperger Syndrome” are no longer used with the new diagnostic criteria that came out in 2013
 - Even though these terms are not used with new diagnosis, people that have been diagnosed with these terms may still identify by them
 - Essentially it means that they are level 1
- The following is a review of each of the levels:



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Severity Level 1

Requiring Support



Social Communication

- Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others.
- May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Restricted, Repetitive Behaviors

- Inflexibility of behavior causes significant interference with functioning in one or more contexts.
- Difficulty switching between activities.
- Problems of organization and planning hamper independence.



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Severity Level 2

Requiring Substantial Support



Social Communication

- Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and has markedly odd nonverbal communication.

Restricted, Repetitive Behaviors

- Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts.
- Distress and/or difficulty changing focus or action.



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Severity Level 3

Requiring Very Substantial Support



Social Communication

- Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Restricted, Repetitive Behaviors

- Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres.
- Great distress/difficulty changing focus or action.



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What is Autism and What is Not:

- Autism is impaired social interaction and restricted interests and/or repetitive behaviors
- Many co-existing conditions
- Some current co-existing conditions were once part of the diagnosis
 - At one time were part of the diagnosis (i.e. language delay – DSM 4)
 - May be reference in and educational classification (i.e. expressive or receptive communication)
 - Remember social/pragmatic skills is classified as communication



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Common Associated Conditions of ASD

<https://www.sciencedirect.com/science/article/pii/S1750946713001207>

Often thought of as part of the diagnosis, but just very common co-existing conditions:

- Language delay/disorder
- Gastrointestinal disorders
- Sensory dysfunction
- Seizures/epilepsy
- General anxiety disorder
- Anxiety

Other Associated Conditions:

- Intellectual disability
- Fragile X syndrome
- ADHD
- Clinical Depression
- Bipolar Disorder
- Obsessive compulsive disorder
- Tourette syndrome
- Tuberous sclerosis
- Visual problems

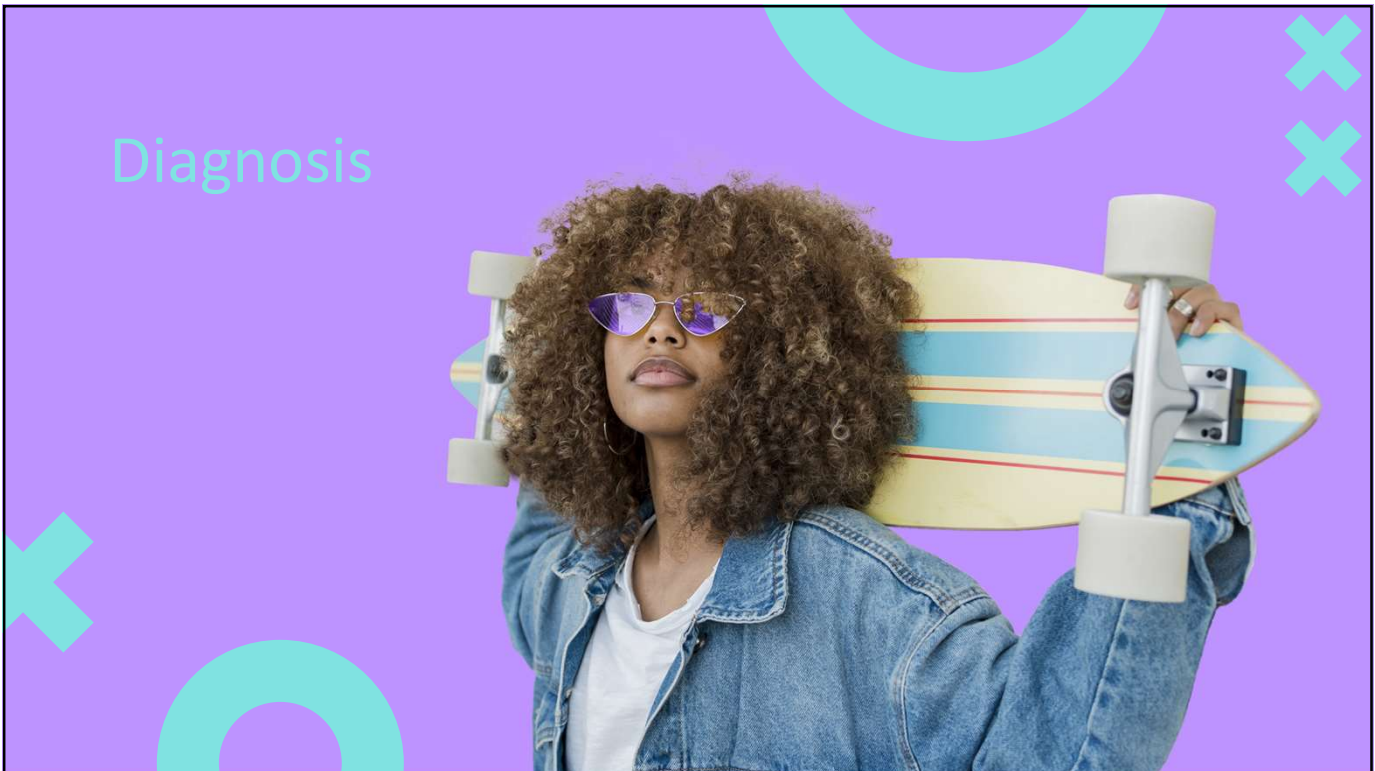


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Questions?

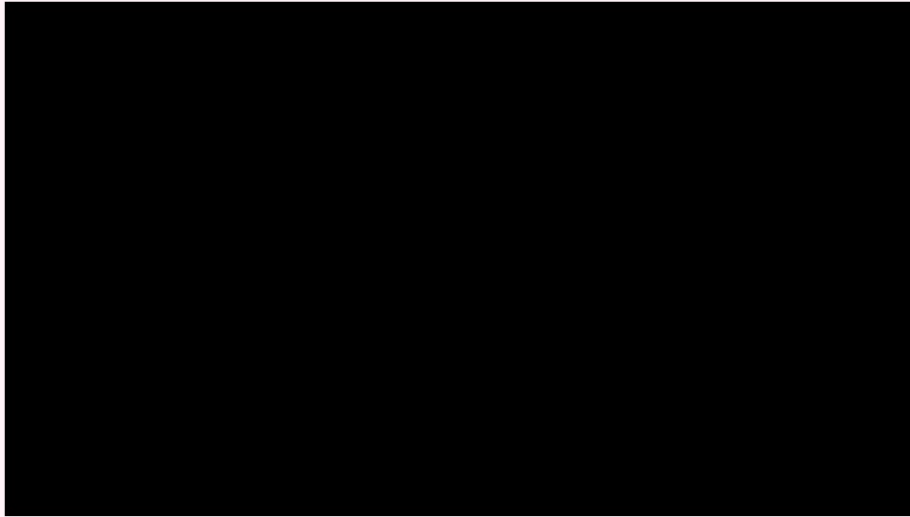
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Diagnosis

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ASD in Females Looks Different



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Why are Females with ASD not Recognized?

- Difference in the expression of some characteristics
- Masking
- Referral bias based on gender
- Instruments limitations

Let's talk about these...



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Girls are Diagnosed Less than Boys

- 4 boys are diagnosed for every one girl
- Experts suspect it should be more like 2 boys to every one girl
- CDC 2020
 - 1/144 girls
 - 1/34 boys



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Why?

Gender Bias

- Females are largely excluded from research
- Reduces the number of girls diagnosed (Devlin, 2018)
 - Symptoms have to be stronger to be recognized
- Girls often have to have additional conditions to get diagnosed
 - The co-existing condition is what gets them consideration

Girls: ASD + Coexisting Condition = ASD

Boys: ASD = ASD



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Hmmmm

- Girls are often diagnosed later than boys
- On average 2 years after the caregiver expresses concern
- Time between the first symptoms and diagnosis is on average 2 years later than boys
 - In adults, women receive their diagnosis later than men



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Results?

- Failure to diagnose will result in a delay in services
- This can lead to
 - Social isolation
 - Peer rejection
 - Lower grades
 - Increased risk of depression/anxiety
 - Increased risk of victimization



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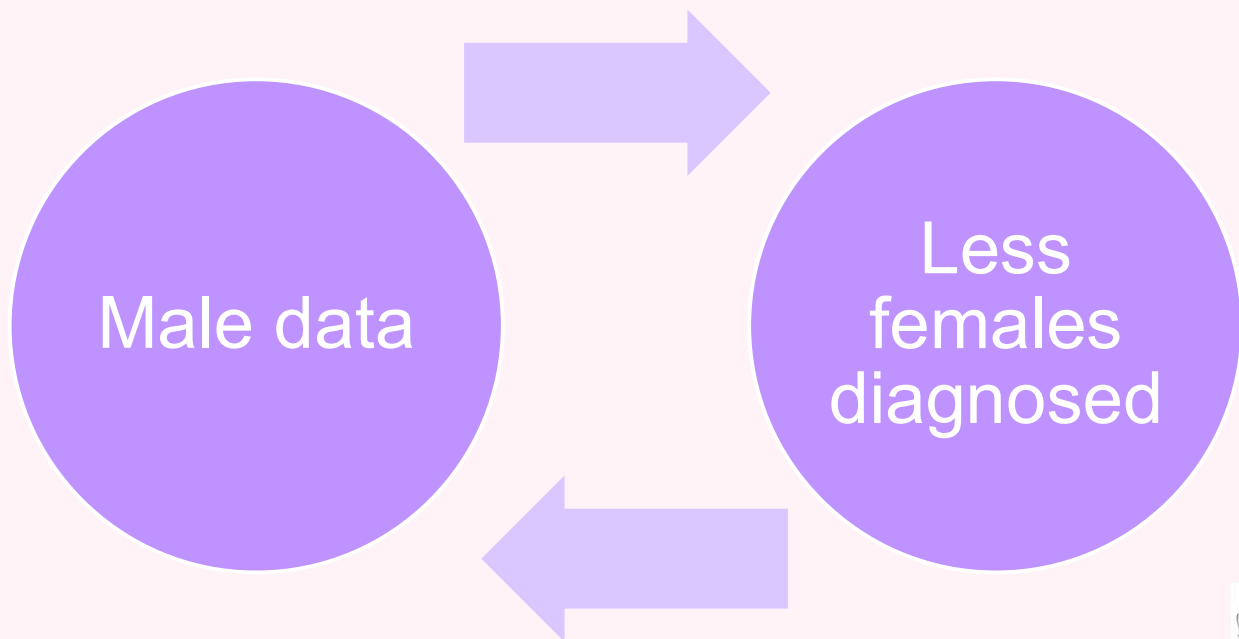
How did this happen?

- First descriptors of ASD were in the 40s
 - These were observations of primarily boys
- Because diagnosis is based mostly on male subjects
 - The symptoms described align more with males
 - Therefore, more males are diagnosed
 - Marginalizes female in the diagnostic process
 - Perpetuating that more males are diagnosed than females
- Result is gender biased exclusion
- Result is more males being included in research



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Diagnostic Cycle: Self-reinforcing



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DSM-V: Social Communication

Three out of three of the following persistent deficits in social communication and social interaction

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviors used for social interaction
3. Deficits in developing, maintaining, and understanding relationships



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What this looks like for females

- Less severe communication challenges
- Less severe social challenges
 - Largely due to masking
- Friends – clingy/obsessed (where boys are viewed as aloof/withdrawn)
- Less hyperactivity and aggression

Referral bias

- Dismissed as shyness, anxiety, etc.



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DSM-V: Restricted, Repetitive Patterns of behavior, Interests, or activities

Two out of four of the following restricted, repetitive patterns of behavior, interests, or activities

1. Stereotyped or repetitive motor movement, use of objects, or speech
2. Insistence on sameness, inflexible adherence to routine, or ritualized patterns of verbal or nonverbal behavior
3. Highly restricted, fixated interests that are abnormal in intensity
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment



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What it Looks Like for Females

- Level 1 – less restricted interests
- Restricted interests are less prominent than male counterparts
- This can result in a failure to refer for assessment



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Interests: Girls tend to have interests that are typical to girls

Males

- Biology
- Trains
- Space
- Dinosaurs
- Currency
- Robotics

Females

- Disney princesses
- Animals i.e. horses/cats...
- Fantasy fiction
- Pop stars
- Social media
- Dolls



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Special Interests

- Not the interest that will be telling
 - The intensity of the interest
 - If it manifests in interfering behavior



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Limitations of Diagnostic Materials

- More boys represented in standardization
- Lack norms separated by gender
- Screeners are geared toward males

Take-away: Do not rigidly adhere to testing to form your impressions.



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Autism in Girls Checklist

Possible presentations

These may change in intensity depending on environmental/ social/health context. They will not all be present in one individual, but a significant number of ticks would suggest a referral for assessment might be helpful.

Friendships: lacks best friend/has just one or two intense friendships/fixates on one person/controlling or domineering/on the edge of things socially/imaginary friend/teased or bullied by peers /shy/timid/passive/flitting from group to group

May struggle with group work.

May obsess about possibility of a relationship particularly a love interest or feasible new friendship.

Strengths: May be very loyal



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Maturity: different to peers; sometimes immature – may have special object for comfort e.g. teddy bear – may play with younger children - or older children

Strengths: Sometimes very mature

Intense interests that are very specific and restricted [may be similar to most girls e.g. books/animals/dolls/celebrities/fashion but more passionate, intense and repetitive and less imaginative]- likes to talk about one particular topic but may be very factual
May have rich fantasy life – may be misinterpreted as psychosis

Strengths: Specialist in-depth knowledge which gives huge pleasure

School work: difficulty with starting work in lessons or with stopping work that is unfinished – lack of interest in lessons - issues with homework.

Difficulty with change and or transitions

Forgetful – disorganised

Wanting things to be certain

High standards/perfectionist/may spend a long time on work -horror of failure = mental burnout

Strengths: May be model student

May produce work of very high calibre



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Misunderstanding social norms– failure to recognise status/authority – rude to teachers; correcting adults and their peers; may not know how to be a ‘child’, rejecting play with other girls preferring boys

Strengths: Different take on what really matters – sometimes refreshing!

Communication - may have been referred for Speech and Language therapy; struggling with following verbal instructions; poor at chit-chat; difficulty with open questions; overuse of stock phrases; taking things literally; selective mutism; may be exhausted by social interaction ; not initiating conversations ; reluctant to answer questions in class
Difficulties with appropriate facial expressions and responses - may laugh inappropriately – infrequent use of gesture

Strengths: May be able to learn ‘scripts’ successfully


Some girls with autism have exceptionally good expressive language

Different behaviour at home to school e.g. anxious at home but ‘fine’ at school


Find it very difficult to get up in the morning and ‘face the world’; trying hard to fit in at school but this comes at a cost: exhausted and emotional when safely at home




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<p>High levels of anxiety – may be misdiagnosed with mental illness – but may also develop mental health problems [e.g. depression, self-harm, OCD, demand avoidance]; emotionally upset for apparently trivial reasons; catastrophizing; ‘meltdowns’[shouting, aggressive] or ‘shutdowns’ [silent, head on desk, avoiding interaction, unable to communicate, blank stare, looking into space, withdrawn]</p>
<p>Obsessive – organising things endlessly, doing the same thing repeatedly e.g. line up toys [rather than play imaginatively with them] Strengths: Ability to persist with something</p>
<p>Lack sense of personal identity e.g. not sure how to describe themselves beyond physical appearance Over apologetic – appeasing others Strengths: Freedom from social constraints</p>



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<p>Gender may lack certainty about gender; may reject ‘feminine’ clothing preferring comfortable practical clothes; no interest in hair or make-up; Tomboy type; desire to present as male Strengths: Freedom from social constraints</p>
<p>Sensory processing differences [noise/touch/light...] e.g. dislike having hair brushed or washed, dislike hand dryers, sensitive to clothes, resistant to hugs and kisses, need warning that someone is going to touch Flicks fingernails, picks skin, rubs hands, paces, clears throat Eating issues: limited diet; eating disorder Poor personal hygiene Strengths: May find great pleasure in certain sensory experiences</p>
<p>Intense- may come across as opinionated; strong need to be right, Strengths: Strong sense of justice</p>
<p>Copying others - studying people – watching in playground or on films/videos [repeatedly] and ‘act out’ what she has seen; practises what she is going to say, play may be about practising rather than having fun; lacking in spontaneity Observe and copy behaviour – may use repeated script when meeting people - mask the autism Analytical rather than intuitive Strengths: Observant</p>



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Social Responsiveness Scale, Second Edition (SRS-2)

- Identifies the presence and severity of social impairment within the autism spectrum and differentiates it from that which occurs in other disorders

** Caution, this instrument uses stigmatizing language like “behaves in ways that seem strange or bizarre” and “is regarded by other children as odd and weird” etc.



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Adult Repetitive Behavior Questionnaire (RBQ-2)

- Ages 18+
- Measures restricted and repetitive behaviors, such as routines and rituals, repetitive motor behaviors, sensory interests, and repetitive actions with objects



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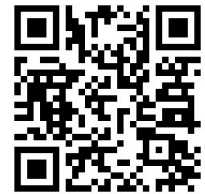
Underlying Characteristics Checklist - Self Report

- Adolescent (UCC-SR-ADOL) Ages 12-18 and Adult (UCC-SR-ADULT) Ages 18+
- Identifies characteristics in areas of social, restricted patterns of behavior interests and activities, communication, sensory, cognitive, motor, and emotional vulnerability with an Individual Strengths and Skills Inventory for each area



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CAT-Q



- The CAT-Q measures the degree to which you use camouflaging strategies. The more you camouflage, the more of your autistic proclivities you are likely able to suppress. As such, a high camouflaging score can also account for lower scores on other autism tests. So if you don't currently meet the diagnostic criteria but you still think you have autistic traits, then this could be why.



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CAT-Q

The CAT-Q measures camouflaging in general, as well as three subcategories:

- **Compensation** — Strategies used to actively compensate for difficulties in social situations.
 - Examples: copying body language and facial expressions, learning social cues from movies and books (see [Autism & movie talk](#)).
- **Masking** — Strategies used to hide autistic characteristics or portray a non-autistic persona.
 - Examples: adjusting face and body to appear confident and/or relaxed, forcing eye contact.
- **Assimilation** — Strategies used to try to fit in with others in social situations.
 - Examples: Putting on an act, avoiding or forcing interactions with others.



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Interview Questions

Parent, caregiver, teacher

- Describe the child's friendships
- Describe the child's maturity in comparison to other girls her age
- Describe the child's interests
 - How intense are these compared to age and gender peers?
 - Do interests create interfering behaviors?
- What does schoolwork look like?
- How does the child do with social expectations outside of peer relationships? (i.e. teachers, adults, age peers)
- What does the child's communication look like?



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Interview Questions

Parent, caregiver, teacher

- Does the child behave differently in different situations? (i.e. home, school, childcare, etc.)
- Does your child experience anxiousness? If so, please describe this.
- Does your child obsess over things? If so, please describe this.
- Describe your child's personal identity.
- What does your child's sense of gender look like?
- Does your child experience any sensory needs such as seeking or avoiding certain experiences?
- What is your child's intensity level? Can you give examples?
- Does your child copy others and emulate them? Please describe this.



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Please consider...

- When considering a referral
 - Do not compare to boys on the spectrum
 - Do compare to typically developing female peers
 - Do they stand out in comparison
 - Social difficulties
 - Communication difficulties
 - Restricted interests
 - Intensity? Interfering?
 - Repetitive behaviors
 - Functioning compared to gender peers



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Please consider...

- When evaluating
 - Seeing is not believing
 - Masking may make it very difficult to see telltale signs
 - Listen to them
 - Interview them
 - Interview the people that know them
 - Look for recurring themes
 - Trust your informants
 - Give weight to your interview



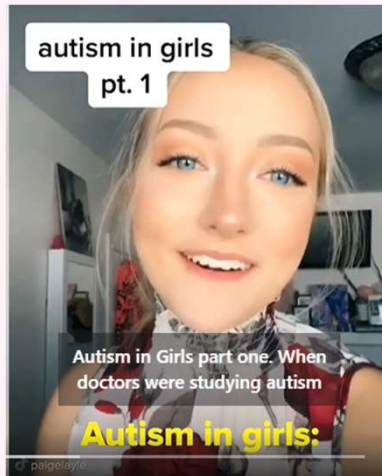
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Special Considerations



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Girls with ASD



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Masking/Camouflaging

- Done to hide symptoms
- Neurotypical people are reluctant to interact with people with ASD (Sasson, 2017)
- People mask because they do not want to be perceived as different
 - Some people equate different as less than
- Reduces bullying/rejection
- Increases employment opportunities



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Masking/Camouflaging



- EXHAUSTING!
- Use of scripts and imitation to assimilate
- Can require significant recovery
- Some people hold it together all day
 - Then they may act out or shut down when they get home
- Can lead to mental health challenges
 - Depression
- Makes evaluation difficult
 - Symptoms are masked – not a true representation
 - Standardized tests may miss the actual presentation of ASD
 - Interview questions may be more effective than observation



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Co-existing Conditions



- ADHD
- Depression
- Obsessive Compulsive Disorder
- Sensory processing disorder
- Anxiety
- Mood disorder (most common – 36%)
- Eating disorder
- Self-harm associate with a disorder
- Emotional/behavioral concerns



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Co-existing Conditions

- Level 1 – higher incidence of mood disorder
- Depression likelihood increase with age through adolescence
 - Post puberty = higher risk
 - May show feelings in different ways
 - Need help recognizing and labeling emotions
 - Others and self
- People with ASD have higher risk of depression and suicide
 - Girls with ASD experience this more than boys
 - Social challenges, bullying, masking, sexual abuse, and gender dysphoria may be contributors



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Co-existing conditions

- 8 year olds: 69% had 4 or more co-existing conditions
- 4 year olds: 53% had 4 or more co-existing conditions
- Concerns
 - ASD will eclipse the other conditions
 - Conditions will eclipse the ASD



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Special Interests

- Do not discourage or undermine
- Find peer groups around interests
- Consider future employment
- How can this be part of a reinforcement?



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But they want friends...

- Making friends is hard
- Maintaining friends is hard
- Social-emotional reciprocity can be a barrier
- Poor nonverbal communication can contribute
- Bullying can be confusing
- People use them
- Conflict
 - Lack skills to avoid, navigate, and repair
- Black and white thinking causes barriers



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Anorexia

- Growing concern
- Failure to diagnose ASD may contribute to increased of anorexia in that person
- Devlin, 2018, 23% of women hospitalized for anorexia met criteria for ASD
 - 35% of those that went to clinics for treatment of anorexia met criteria for ASD
- When ASD and Anorexia co-occur
 - Recovery rates go down
 - Mortality rates increase
 - Making correct diagnosis of ASD critical



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Treatment



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Strategies



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Girls with ASD:

1. Be thoughtful about your language and communication style
 - Let your students be heard and accommodate accordingly
 - Take time for discussion and include interests
 - Celebrate achievements
 2. Value social interests
 - Group or arrange people with preferred social group
 3. Be flexible as an instructor
 - Add visuals to support understanding
 - Structure routines and things that can be consistent
 4. Consider sensory needs
 - Including clothing specifics, lighting, shorter spurts of engagement (20 min)
 5. Reduce sensory stimuli
- If these do not work – talk to the learner to see what would work for them and individualize accordingly.



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Sharon DaVanport: What Every Autistic Girl Wishes Her Parents Knew (2022)

- Believe in her possibilities
- Express your love and support
- Teach her about social skills
- Don't make her feel broken
- Respect her for who she is
- Talk about everything (including sex)
- Help her find her autistic community



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Evidence-Based Practice

- Antecedent-based interventions
- Social narratives
- Video modeling
- Modeling
- Structured play groups
- Prompting
- Technology aided instruction and intervention
- Reinforcement/differential reinforcement
- Scripting
- Visual supports
 - Etc.: The National Professional Development Center on Autism Spectrum Disorders



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- Brain research for our learners with autism tells us that we need...
- **M:**
- More repetitions for learning
- **M:**
- More visuals
- **M:**
- Motivators that work for the learner



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Treating the Co-Existing Conditions

- Interventionists that understand autism as well as the co-existing conditions
 - Willing to get trained
 - Know what is autism and what is the disorder
 - Know how autism can influence the disorder
 - Positively for the purpose of treatment
 - Negatively and choosing strategies to avoid negative outcomes
- Neurodiverse Affirming Interventionists
 - It's the idea that individuals have differences in their abilities and how they interact with the world around them – differences which are not considered to be deficits that need to be “fixed”. (TherapyWorks, 2022)



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Community Education

- Provide education on how to make our spaces more inclusive for people that experience neurodiversity and/or autism
- This can include topics like
 - Making sensory friendly spaces
 - Reducing anxiety through modified classroom expectations
 - Using Universal Design for Learning
 - Providing options
 - Being flexible – teachers, peers, etc.
 - Bystander training
 - LGBTQ+ training
 - Trauma informed training



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Should I Suggest That They Mask?

- Research is showing that masking is significantly taxing
 - Can lead to more mental health challenges
 - Imagine if every day you had to act like something you were not – like a dog or a flight attendant....it would be exhausting
- Females with autism want to be heard
 - Find out their feelings about masking
 - Find out if there are times when they will choose to mask over others
 - Support their masking plan
 - Teach them how to take breaks
 - Teach them “outs” for when the social becomes too much
 - Provide options like “today I am just listening” or individual vs group options for school work, etc.



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Female MOSSAIC Participants:

- Special interests present differently
- We mask differently
- More bias: Stimming is less socially acceptable for girls
- We mask to have friends
- Feel better when I am not masked
- Always Always use trauma informed care with girls
- Can be very quiet when overwhelmed, do not dismiss this as shy
- The more severe the ASD the more likely to be an outcast
- Offer and accept requests for breaks
- Do not deny fidgets please



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Trauma Informed Care

1. Safety
 - Physically and psychologically safe
2. Trustworthiness and Transparency
 - Transparency, and with the goal of building and maintaining trust
3. Peer Support
 - Shared experiences are integral into service delivery
4. Collaboration
 - Power differences are leveled to support shared decision-making
5. Empowerment (voice & choice)
 - Strengths based intervention and belief in resilience and the ability to heal from trauma
6. Humility and Responsiveness
 - Biases, stereotypes, and historical trauma are recognized and addressed



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Questions

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Thank-you
so very
much!

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