12<sup>th</sup> Annual School Healthcare Training Event

# Autism and the Role of the School Nurse

Jessica Weeks, Ph.D. February 29, 2020

# Learning Objectives

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Understand and better identify the characteristics of autism spectrum disorder

Become familiar with the diagnostic process and tools used to evaluate individuals with ASD

Increase understanding of intervention options and how to support the student and school team

Better understand the implications of ASD in relation to the role of the school nurse

### National Prevalence of ASD

- Most current estimate of autism prevalence is
  1 in 40 for children between the ages of 3 and 17
  - Data from the 2016 National Survey of Children's Health
  - Previous CDC estimate from 2014 was 1 in 59
    - Data from 8 US monitoring sites
    - Only took data from children 8 years of age

Kogan, M. D. et al., (2018). The prevalence of parent-reports autism spectrum disorder among US children. *Pediatrics*, *142*(6) e201741. DOI: 10.1542/ peds.2017-4161.61; Xu, G. et al., (2019). Prevalence and treatment patterns of autism spectrum disorder in the United State, 2016. *JAMA Pediatrics*, *173*(2). 153-159. doi:10.1001/jamapediatrics.2018.4208

### Autism Spectrum Disorder

DSM-5

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, *ranging*, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- 2. Deficits in nonverbal communicative behaviors used for social interaction, *ranging*, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- 3. Deficits in developing, maintaining, and understanding relationships, *ranging*, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

## Autism Spectrum Disorder



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, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day.)
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/ temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

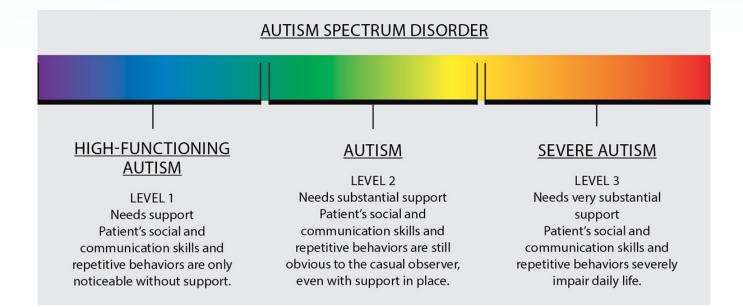
### Autism Spectrum Disorder



- c. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- d. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning
- e. These disturbances are not better explained by intellectual disability or global developmental delay. The disorders frequently co-occur; to make comorbid diagnoses of ASD and intellectual disability, social communication should be below that expected for general developmental level.

### Remember, it's a spectrum

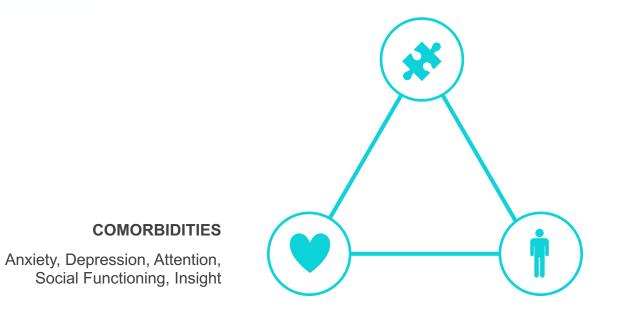
"Once you've seen one person with autism, you've only seen one person with autism."



### 3 Key Assessment Areas

#### **CONFIRM DIAGNOSIS**

Does the child meet ASD criteria



#### **BROADER DEVELOPMENT**

Speech, motor, academics, medical, genetic

### Best Practice Diagnostic Assessment

Based on three main sources of information



Early Development

Description of course of development



### **Current Behavior Patterns**

Detailed information about current social difficulties and repetitive, restricted patterns of behavior



#### **Direct Observation of Behaviors**

Observation of social approach, reciprocity, and RRBs

# Early Developmental History

Red Flags in Development

Early social behaviors

- No babbling
- Not responding to name by 12 months
- Not pointing to objects to show interest by 14 months
- No gesturing (by 16 months, 16 gestures)
- Not playing pretend games by 18 months
- Attending to parts of objects more than using them for functional or pretend play
- Increasingly atypical affective expression
- Few joint attention gestures

# Early Developmental History

Measures:

Autism Diagnostic Interview-Revised (ADI-R)

- Most reliable standardized measure to obtain an early developmental history of an individual suspected of having an autism spectrum disorder
- Most widely used diagnostic instrument in autism research
- Comprises 93 questions summed into 3 functional domains
- Focuses on developmental history at ages 4-5

Social Communication Questionnaire

(SCQ)

- Item content is directly related to the diagnostic algorithm items of the ADI-R
- 40-item rating scale completed by parent or other primary caregiver (must be familiar with developmental history)
- Lifetime version assesses period between the individual's 4<sup>th</sup> and 5<sup>th</sup> birthdays

ADI-R; Rutter, Lecouteur, & Lord, 1994; SCQ; Rutter, Bailey, & Lord, 2003

# Current Behavior Patterns







### Interviews

### Parents Teachers

### Therapist

- How does the individual relate to their peers?
- What range of affect does the individual show?
- What does their speech sound like?
- How is conversation with the person?
- Are there current sensory sensitivities or interests?
- What are their interests? How do they engage in these?
- Does the individual show rigidity or difficulty with transitions/change?

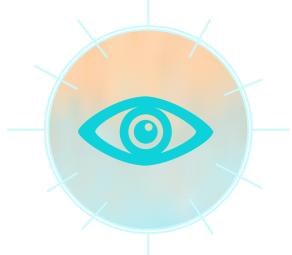
### **Rating Scales**

BASC-3 – Atypicality; Withdrawal; Autism Index SRS-2 – Pre-k, Child, Adult ASRS – Standardized on national sample SCQ – Current Form or Lifetime Form (front side)

# Direct Observation of Behaviors Why the ADOS-2?

- Standardized structure provides observation
  - Activities, materials, and hierarchical presses
- Corresponds to DSM-5 diagnostic criteria
- Strong diagnostic validity
- Excellent sensitivity and specificity for detecting presence of ASD vs nonspectrum disorders
- Can be used for anyone who is ambulatory and has a nonverbal mental age of 12 months
- Required by some insurance providers

# Direct Observation of Behaviors What are we looking for?



Create a natural, social environment to observe:

- Social interaction
- Communication (verbal and nonverbal)
- Play and imaginative use of materials
- Stereotyped/restricted behaviors
- Affect and insight into relationships

## School Definition of ASD

### Arizona Department of Education

Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section. A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied. [34 C.F.R. § 3 00.8(c)(1)]

### In order to qualify for special education under IDEA:

- 1. The child must have a qualifying disability as defined by the IDEA regulations;
- 2. The disability must have an adverse effect on the child's educational performance;
- 3. The child must need specially designed instruction in order to access and make progress in the general education curriculum.

## Multidisciplinary Team Players

- Behavior Specialists (Board Certified Behavior Analysts (BCBA))
- Developmental Pediatricians
- Mental Health Therapists/Psychologists
- Occupational Therapists
- Physical Therapists
- Psychiatrists
- School Nurses
- School Psychologists
- Skills Trainers
- Special Education Teachers
- Speech & Language Pathologists

### **Gastrointestinal**/Dietary Issues

- Children with ASD experience GI dysfunction and distress at a rate 4 times that of other children
  - Chronic constipation, diarrhea, heartburn, and abdominal pain are most common
- Children with ASD are 67% more likely than peers to have Irritable Bowel Disease
- Children with ASD have a difficult time articulating and describing abdominal pain and symptoms
- Underlying inflammation and Gi issues are <u>not</u> caused by picky eating
- Eating issues may be related to:
  - Insistence on sameness
  - ASD-related sensory aversions
  - Low muscle tone
  - Undeveloped chewing skills

Doshi-Velez F. *et al.*, (2015). Prevalence of Inflammatory Bowel Disease among individuals with autism spectrum disorders. *Inflammatory Bowel Disease*. 21, 2281-2288.

### Enuresis/Encopresis

- School Nurses may be on the front lines of these concerns
- Refer to rule-out medical concerns
- Advocate for a Functional Behavioral Assessment/Behavior Intervention Plan (FBA/BIP)
  - The information you keep will be hugely beneficial to inform this process
- Encopresis is typically the result of chronic constipation

## Sleep Concerns

- 50-80% of children with ASD experience insomnia
- Children with ASD are two to three times more likely to experience insomnia than their typically-developing peers
- Research suggested that children with ASD who got less sleep had more severe social difficulties, compulsive rituals, and challenging behaviors
- Evidence supports overlapping neurobiological and genetic underpinnings
- Children with autism may have a more difficult time transitioning between being awake and being asleep
- Healthy sleep habits include:
  - Create a calming and predictable bedtime routine
  - Keep the bedroom dark
  - Remove caffeine from the child's diet
  - Set bedtime limits for screen time- at least 1 hour before bedtime
  - Individualize for what is best for each unique child

Veatch, O. J., et al. (2017). Shorter sleep duration is associated with social impairment and comorbidities in ASD. *Autism Research*. Veatch, O. J., Maxwell-Horn, A. C., Malow, B. A. (2019). Sleep in autism spectrum disorders. *Curr Sleep Med Rep.* 1(2), 131-140.

No psychotropic medications specifically treat the core symptoms of autism spectrum disorder: (1) Deficits in social communication and social interaction (2) Restricted, Repetitive Behaviors

> Medications are being used to treat conditions associated with autism, such as anxiety, hyperactivity, and aggression. Common medications include:

### Medications

- Stimulants (Ritalin and Adderall)- for co-occurring ADHD
- Non-stimulants (Strattera and Intuniv)- for co-occurring ADHD
- Atypical Antipsychotics (Risperidone and aripiprazole)- can relieve some irritability
- Selective Serotonin Reuptake Inhibitors (fluoxetine and sertraline)- can help with mood, anxiety, or obsessive thoughts and compulsive behaviors
- Naltrexone (Revia)- eases repetitive and self-injurious behaviors

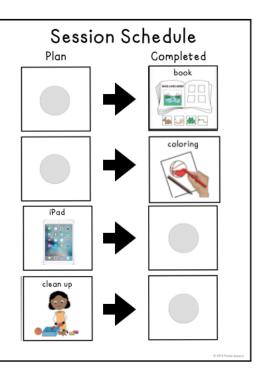
### Implications for a School Nurse

- Establish a therapeutic relationship
  - Build trust
  - Develop rapport
  - Make a connection
- Be creative!!
  - Work with the child's strengths
  - Enter into their world
  - One size does not fit all

# **Common Behavioral Supports**

- Routine/Consistency
  - Transitions
  - Social Stories
- Breaks
  - School health office may be used as a quite break space detailed in IEP
- Support Sensory Needs
  - May dislike ice packs or bandages
- Visual Schedules
- Reinforcement Systems
- Support generalization of skill





# **Reinforcers**







# Language/Communication Supports

- Delays in functional communication mean that School Nurses will have to use different/creative assessment tools
  - Use of pictures and modeling
  - Augmentative and alternative communication (AAC)
- Maintain communication with parents and teachers
- Monitor for signs of increased anxiety or bullying
  - Often "communicated" or seen as avoidance behaviors
- Use the child's interests to create analogies that are meaningful to them

#### Language Characteristics of Autism Spectrum Disorder (ASD)

| Term                 | Definition   | Example  |
|----------------------|--|--|
| Echolalia            | Children repeat what has<br>been said to them either<br>immediately or after some<br>period of time.       | Parent: "Do you want a drink?"<br>Child with ASD: "Do you want a drink?"<br>Child with ASD repeats question<br>instead of providing an answer.   |
| Contact gestures     | Children use other people<br>as a tool to get what they<br>need or want. The ges-<br>ture is not symbolic. | Child with ASD grabs adult's hand with-<br>out making eye contact and drags to<br>the television to get the adult to change<br>the channel.  |
| Pronoun<br>reversals | Children use first (I, me)<br>and second pronouns<br>(you, he, she) incorrectly.                           | Child with ASD: "You want to go to the park."<br>TD child: "I want to go to the park."   |
| Neologisms           | Children assign meaning<br>to a word or phrase that<br>is not the socially accept-<br>ed meaning.          | Child with ASD is given popcorn during<br>a movie about a dog named Rebel.<br>The next time the child wants popcorn,<br>he/she asks for "Rebel." The word<br>Rebel is a neologism for popcorn. |

Sources: Helfin & Alaimo, 2007; Noens & van Berckelaer-Onnes, 2005; Notbohm, 2006.

# Questions?

Thank you!