AUTISM SPECTRUM DISORDERS

Symptoms, Diagnosis and Treatment Implications for School Nurses

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Objectives
- Recognize symptoms of Autism
- Explain how behavior exhibited by children with autism may be communication of sensory, social / emotional and physical needs
- Identify treatments for ASD
- Explain the role of various team members working with children who have autism
- Communicate strategies that teachers, school nurses, administrators and families can use to increase social engagement and to meet the needs of students with disabilities

What is Autism Spectrum Disorder?
- Developmental disability
- Characterized by Impaired social/communication deficits
  + Fixed interests and repetitive behaviors
- Symptoms must be present in early childhood (even if not fully seen until older)
- Symptoms together limit and impair everyday functioning

Autism Spectrum Disorder (DSM-5)
- A single diagnosis that represents the whole spectrum
- No longer Autistic Disorder, Pervasive Developmental Disorder-NOS, Asperger’s Syndrome or Childhood Disintegrative Disorder
- Change was because research did not show true differences between the separate diagnoses (same person may have been given different diagnosis, depending on the clinician)

DSM-5 also includes level of severity (1, 2, or 3) depending on amount of support needed
- Level 1 - “requiring support”
- Level 2 - “requiring substantial support”
- Level 3 - “requiring very substantial support”
Common Features

- More common in males than females (4:1 ratio)
- Most not diagnosed until after the age of 4
- Many persons show improvements in functioning over time
- People with autism are expected to live a typical life span
- Issues change over time with development

How Common is ASD?

- National estimate based on record review
  1:68 1:42 boys 1:189 girls
  (CDC 2014, based on 2010 data)
- New Jersey 1:45 1:28 boys
  (CDC 2014, based on 2010 data)
  → increase from last report in 2009
- National estimate based on parent report on phone survey 1:50
  (National Health Statistics Report, 2013, based on 2011-12 data)
  → 70% increase from 2007

How is ASD Diagnosed?

- Parent may raise concern
- Professional may raise a concern
- Clinical diagnosis based on observation and history
  (no existing lab test, or scan specific to ASD)
- Diagnosis made by MD, Licensed Mental Health Professional, or Advanced Practice Nurse
- Tools that provide data: M-Chat-R, ADOS, ADI-R, STAT, other rating scales

Other Skills to Assess

- Cognitive skills / Learning (helps guide level of goals)
- Adaptive behavior (self help skills)
- Processing
- Attention and shifting
- Basic Social Behaviors
- Interaction with the environment

Why is the Prevalence Increasing?

- broader definition
- better detection (better tools, more places to get diagnosis)
- increased community, provider awareness, and acceptance

Progression

- Some describe regression in skills occurring in toddlerhood
- Typically considered lifelong
- Some 3-25% lose diagnosis and function within normal limits for cognitive, adaptive, social and class placement
- Most kids with ASD improve functioning, especially with intense intervention
  Helt et al, 2008; Billstedt et al, 2007
What Causes Autism?

- Probably no single cause > 90% of etiology is unknown
- Genetic component
  - some genes may make person more likely to have ASD (Fragile X, Neurofibromatosis, Downs Syndrome)
  - some genes may make person more vulnerable to environmental trigger (traffic pollution? chemicals?)
- Parental age? Assisted fertility? Pollution?
  - Diabetes, lupus, etc. in mother?
  - Certain meds during pregnancy?

What Does NOT Cause Autism?

- Vaccines
- Parenting style

Why do children need a diagnosis?

- Helps to understand the child
- Suggests a road map for intervention
- Helps access needed services
- Gives understandable term that helps communicate with others
- Links with other families for support and information

Role of the School Nurse

- Clinician
- Educator
- Advocate
- Counselor
- Liaison
Pellets for the School Nurse

- Preschool
  - General developmental delays vs. symptoms of ASD

- Elementary school
  - Often undiagnosed, may have difficulty in school setting

- Middle school
  - Child may have managed academically in ES but with less structure in MS – may have more difficulty

- High school
  - Puberty may cause more difficulties

-- GET ACQUAINTED WITH THE SCHOOL NURSE --

- Regular visits at the beginning of the school year so child will know where your office is and not be surprised if they need to see you
- No procedures should be done during this time
- Walk the child through step by step process in your office
  - Sit in a particular area in the office
  - Wait in the chair to be seen then you will greet the child
  - Show the child different instruments used (thermometer, scale, BP cuff, eye chart, etc.)
  - Familiarize child about future visits (screening, med dosing, illness)

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**Associated Features**

- Impaired receptive or expressive language
- ADHD symptoms
  - Hyperactivity
  - Short attention span
  - Impulsivity
  - Self injurious behaviors
- Tantrums/Meltdowns

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**Possible Associative Features**

- Hyperlexia
- Sensory defensiveness or seeking
  - Sound
  - Touch
  - Light
  - High pain tolerance
  - “Always on the move”
  - Seeks rough, crashing play

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**Possible Associated Features**

- Eating problems
- Sleep problems
- Lack of fear
- Abnormalities of mood or affect (giggling/weeping for no reason)
- Anxiety or depression
- Intellectual disability
- Seizure disorder
Pharmacologic Treatment Goals

- Maximize functional independence
- Improve quality of life
- Alleviate family distress
- Facilitate development and learning
- Promote socialization
- Reduce interfering maladaptive behaviors

There are no pharmacologic agents with FDA approved labeling to correct the core deficits of ASD

The Pharmacologic Treatment Dilemma: To treat or not to treat?

- Risk of behavior/medical condition
- Potential benefits of medication
- Behavioral strategies tried
- Potential risks of medication
- No behavioral strategies tried
- School modifications?

Target symptoms:
- Sleep, aggression, anxiety, self-injurious behavior, agitation, depression, inattention, hyperactivity, impulsivity, tics, obsessive-compulsive symptoms

Psychotropic Medication

- SSRI (antidepressants)
  - Zoloft
  - Prozac
  - Celexa

- Atypical antipsychotics
  - Risperdal
  - Abilify
  - Guanfacine
  - Seroquel

ADHD Medications

- Stimulants (short-acting or long-acting)
  - Methylphenidates
    - Ritalin
    - Concerta
    - Metadate
    - Daytrana
  - Amphetamines
    - Adderall
    - Metadate
    - Evekeo
    - Vayarin (medical food)

- Non-stimulants
  - Guanfacine (Intuniv, Tenex)
  - clonidine (pill/patch, Kapvay)
  - Strattera
  - Vayarin (medical food)
- **Anticonvulsant mood stabilizers**
  - Valproic Acid
  - Tegretol
  - Trileptal
  - Lamictal

- **Sleep agents**
  - Melatonin
  - Clonidine
  - Guanfacine

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**Pearls for the School Nurse**

- Have a complete list of medications for each child
  - Need an order to give medications in school
  - Know why prescribed
  - Know how used
  - Any special precautions
  - How to store

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**Speech / Language Pathology**

- Evaluation
- Diagnosis
- Treatment

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**Play**

There are different stages of play:

a. Random & Exploratory 0-8 months
b. Cause and Effect 9-14 months
c. Purposeful/Functional 15-18 months
d. Representational/Symbolic 3 years
e. Constructive 4 years
f. Imaginative/Themed 4-5 years

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**Speech / Language pathologists work on these skills**

- Pre-linguistic skills
- Play
- Functional Communication
- Language Development
- Feeding
- Sensory

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**Develop individual health plan for student**

- Educate teachers about medication desired effects as well as side effects to be monitored during school

- Disruptive behavior is common – however, new onset of behaviors may have a medical component and needs to be investigated
  - Dental pain, otitis, headache, GI, bone fracture, menstrual pain, allergies
  - Children with ASD may not know how to tell you what is wrong
**Functional Communication**

- Goal is not perfection, but functional
- Establish mode(s) of communication
- Often negative behaviors are diminished
- Positive social interaction

**Functional Communication**

- “The ability to receive or to convey a message, regardless of the mode, to communicate effectively and independently in a given environment” (ASHA)
- ASHA- American Speech-Language Hearing Association

**Why is Functional Important?**

- The goal is to help the child to be able to communicate
- The child should be able to express a variety of needs and messages in different environments with different people
- Communication during activities of daily living

**Language Development**

There are three areas of language:

- Receptive Language
- Expressive Language
- Pragmatic Language

**Modes of Communication**

- Verbal (using spoken words)
- Augmentative/Alternative Options such as PECS (picture exchange communication system)
- Low tech boards/high tech devices (icon boards, Mac switch, Dynavox)
- iPAD / iTOUCH (Apple Corporation)
- Possibly signing/manual communication
- Pragmatically Organized Dynamic Display (PODD)

**Pragmatic Language Skills**

- Social use of language
- Most children on the spectrum have difficulty with this area
- Involves 3 major skills:
  - Using Language
  - Changing Language
  - Following Rules
Pragmatic Language Tips

Using Language:
- Ask questions or make suggestions
  - “What did you do..?”/“Tell me about..”
  - “Tell your friend..?”/“Does your friend..”
  - “Ask me..?”/“Ask your friend..”
- Respond to intended message
- Take advantage of natural occurring situations

Changing Language
- Role play conversations
- Encourage use of persuasion
- Discuss different ways to present a message

Pragmatic Language Tips

Following rules:
- Help interpret non verbal cues for the child
- Provide visual cues for them to help storytelling or sequencing
- Encourage rephrasing “Did you mean..?”
- Provide labels for feelings

Pragmatic Language Tips

Following rules:
- Pragmatic language therapy follows the philosophy of functional skills.
- Child is taught skills and then asked to generalize in naturalistic settings
- Recommendation may include transitioning to social skills group

Pragmatic Language Tips

Feeding

Various feeding problems can occur with children with ASD including but not limited to:
- sensory
- oral-motor
- behavioral

VISITS TO THE SCHOOL NURSE

- poor communication is a chief limitation for ASD children

  Ask Specific questions, “Does your tummy hurt”, instead of “what hurts you”
  Avoid touching the child unexpectedly
  Allow the child to manipulate instruments and materials
  Use a slow pace
  Use visual cues and supports, pictures is necessary
  Use reinforcement for appropriate behavior
  Develop a routine if possible
  Have rules concretely outlined
  When administering medications, state “You will need to swallow this pill with water”. Do not say, “take your pill”. 
What is Occupational Therapy?

A health profession that focuses on supporting health and participation in life through engagement in occupation.

**Occupation** refers to how one occupies their time.

**OT** provides methods of treatment that are theoretically based and clinically effective.

How does OT work?

- **Evaluation:** OTs gather information about what is contributing to the child’s level of function.
  - Medical history
  - Parent and teacher reports
  - Assessments
  - Observations

- **Treatment Planning:** Develop goals and time line for therapy

How does OT work?

- **Treatment:**
  - Improve the child’s skills
  - Adapt the environment
  - Modify task demands
  - Therapist models and instructs parent in strategies to assist the child
  - Collaborate with family, medical professionals, school staff.
  - Make recommendations and referrals

Assessment

- Fine and gross motor skills
- Visual motor/perception skills
- Self care skills
- Sensory system function
- Challenges in any of these areas may be impacting the child’s ability to participate in daily roles, routines, and tasks (i.e. play, self-care, social interactions)

What is Sensory Integration?

A theory developed by Dr. A. Jean Ayres - OT & educational psychologist

Explores how the nervous system translates sensory information from the environment & the body into action

- “organization of sensation for use”
- Sensory integration provides the foundation for participation in meaningful activities

Sensory Systems

- Smell
- Taste
- Hearing
- Vision
- Tactile
- Proprioceptive
- Vestibular
**Tactile System**

**Sense of touch** - How our skin informs us about our world
- Light touch vs. deep pressure
- Temperature
- Pain
- Vibration
- Tactile discrimination
- Spatial attributes of objects

**Over-responsive to Tactile:**
- Avoids being touched or play with messy textures (i.e. paint)
- Avoids certain food textures
- Possible toe walking, more when bare foot or on different textures (sand, grass)
- Avoid wearing certain cloth textures
- Resists self care tasks more than peers (i.e. clipping nails, cutting hair, baths)

**Under-responsive to Tactile:**
- You might see a child that feels pain less than others
- Touches everything in sight
- Don’t notice when face and hands are messy
- Leaves clothes twisted on body
- Craves touch/rough play, bumps and pushes others with no malicious intent

**Proprioceptive System**
- Receptors in muscles and joints
- Provide information on the body / limbs position in space
- Amount of force needed for task
- Acts as a filter of the other senses
- Frequently called “heavy work”

**Vestibular System**
- Receptors located in the inner ear
- Provide information related to head position and movement
- Impacts:
  - Balance
  - Postural responses
  - Muscle tone
  - Coordination of eyes
  - Coordination of head movement
  - Alertness
Vestibular System

Over-responsive:
- Fear of falling/heights,
- Distress when feet leave the ground or changes in head position

Under-responsive:
- Seek movement such as spinning, twirling
- Excessive risks with movement—climbing, enjoys being upside-down, stares at spinning objects

Functional Relevance of Sensory Integration

- Accurate processing of sensory information results with appropriate responses to daily demands
- However, when sensory information is not processed correctly, this can impact the following areas:
  - cognition / academics
  - emotions / behavior
  - motor skills

Cognition and Academics

- attention problems
- organizational problems
- sequencing and spatial problems
- communication difficulties

Emotions and Behavior

- Social skill challenges
- Difficulty tolerating changes in routine
- These children may present as irritable, impulsive, controlling, easily upset, have poor frustration tolerance, are difficult to calm, are aggressive or passive

Motor Skills

- gross motor and/or fine motor difficulties
- perceptual challenges
- lack of independence in self-help skills
- clumsy, they easily forget new tasks, and are slow to learn new skills.
- some don’t like to move, while others are constantly on the go...

Sensory Integration Treatment

The intent is to improve the efficiency with which the nervous system interprets and uses sensory information for functional use. Therefore, occupational therapy is aimed at promoting underlying capabilities and minimizing abnormal function.
Pearls for the School Nurse

Awareness of behavior triggers
- Maintain good communication with teachers, parents, and therapists in the school
- Noises bothersome to children can lead to behavior challenges
- Season changes with increased clothing needs may contribute to behavior issues for children with tactile sensory issues
- Stay alert for self-injurious behaviors
  - Head banging, scratching, hair-pulling, biting oneself – often occur when a child is frustrated, fatigued or over-stimulated

Always maintain a safe environment in your office
- Remove items from exam area that could be used for self-injury or aggression
- Be cognizant of children with sensory issues and keep in contact with families
- Sensory under-reactivity including decreased reaction to pain
  - If agitated with bandage to cover wound – is liquid bandage alternative?
  - Is child sensitive to cold? – ice pack may not be option

MANAGING BEHAVIOR

Preventing Behavior Problems
- Decrease/eliminate stressors for child permanently or temporarily
- Read child’s cues/signals and react before inappropriate behaviors occur
- Use activities to reduce stress before inappropriate behaviors occur
- Utilize breaks cautiously and prior to inappropriate behaviors.

Preventing Behavior Problems
- This doesn’t mean “Walk on eggshells”
- Know your child’s limits and triggers
  - Sounds, lights, new situations, time of day
  - If you find yourself saying things like, “You ALWAYS do this when…” you have found a trigger! This is what you change!
  - If these situations can’t be avoided, can you reduce the stress? (Ear plugs, hats, sunglasses, prepare an errand when there are few crowds)
- A change may need to occur – prepare yourself and your child (Have a back-up plan! Have materials ready!)
Preventing Behavior Problems

- Provide structure, routine, and predictable results (This may be shown with visuals/photos/drawings/words)
  - Activity Schedules for Children with Autism by McClannahan and Kranz
- Rehearse appropriate behavior and have your child repeat appropriate comments. Let other family members help!
- Communicate with your child about instructions when he or she is free from distractions (Communicate in simple terms)
  - The Parent’s Guide to In-Home ABA by Johnson (Get This Book!)

Basic Principles of Managing Behavior

- A behavior that is reinforced is likely to happen again
- A behavior that is not reinforced is not likely to happen again

If we like the consequences, we will repeat the behavior; if we don’t like the consequences, we won’t repeat the behavior

Teach Appropriate Related Skills

- Give choices (choice-making may need to be taught, considering saying/showing a few options rather than completely open-ended choice)
- Make statements, don’t ask… NO is a good answer to “Joseph, can you clean your room for me?”
- Provide praise often. Compete with energetic “No/Stop/Don’t!”
- Self stimulatory behavior: Modify the setting to reduce the behavior, give the child an opportunity to engage in this behavior during certain times or substitute more socially acceptable object which meet the same need (i.e. small squishy toy in pocket)

Preventing Behavior Problems

- DO NOT assume your child knows what to do! Children with ASD often have “splintered skills”
- Break down tasks:
  - If the child tantrums when asked to clean his room, ask him to pick up the papers on the floor, then put the laundry in the hamper, etc.
- Substitute tasks in which the child is skilled.
  - If he is not good at setting the table, maybe he can put the silverware in the drawer.
  - Take it slow! Stick with this step for a week or two.

How to Use Behavioral Principles

- To increase appropriate behavior
- To decrease problem behavior
- To continue appropriate behavior
- To teach a new skill
- To help a new skill generalize
The ABCs of Behavior Management

A = Antecedent
What happens immediately before the behavior occurred?

B = Behavior itself

C = Consequence
What happens immediately after the behavior occurs?

In order to modify behavior, change the A or the C

Four Reasons Why Behavior Occurs

1. Self-Stimulatory/Repetitive (Stereotypy)
   - internally or automatically reinforced
   - may occur regardless of the events or people present (e.g. spinning, hand movements, rocking, teeth grinding, vocalizations)
   - We can create attention-maintained stereotypy when we attend to automatic stereotypy.

2. Attention
   - The problem behavior will likely result in some form of attention from others (parents, grandparents, siblings, school personnel)
     Facial expressions, reprimands, attempts to soothe, laughing, etc.
   - These reactions serve to increase the behavior
   - This attention may be provided inadvertently
   - The attention provided and therefore accessed may be good/bad
   - Attention may come from adults or peers

3. Escaping or Avoiding a Non-preferred or Unpleasant Situation
   - From a difficult task
     “Take out your math homework”
   - From a person who challenges the child
     “Look Johnny, your speech therapist is here”
   - From a social situation
     “Say hi to grandma.”

4. Problem behavior results in getting a preferred item/activity
   This occurs because providing the item temporarily stops the target behavior ALTHOUGH it can increase the frequency of the behavior in the future
   - Student pushes a peer to get to the front of the line
   - A child is tantruming in a store until they receive the M&M’s® in the candy isle
   - Hitting over a shared toy

Often, behavior is multiply maintained. This means it happens for more than one reason.

Once we know WHY it happens we can help PREVENT or STOP it from happening
Causes / Antecedents

Understanding the antecedent or what happens right before the behavior can help us understand the function of the behavior.

Change the antecedent to change the behavior.

For example...

Antecedent: You say, “No”

INSTEAD...

Antecedent: Bring a preferred snack to a store, a food that is never allowed at home and provide it while waiting in the check aisle. Deliver lots of praise for appropriate behavior throughout the store. “Great job waiting,” “You’re being an awesome listener,” “It’s a shoe-shopping-Frito’s party!!!”

Consequences

What follows the behavior:

- Positive Reinforcement
  - Depends on what child finds reinforcing
  - A snack, a prize, hug, praise, points earned towards a prize
  - Token economy helps! You get tokens to trade in!

- Negative Reinforcement
  - Remove unpleasant things/activities – the behavior improves
  - Say “Hello” to Grandma and then you can go to your room.
  - Let the child be rewarded for going past their “comfort zone”

Consequences

- Providing reinforcement increases a behavior
- Providing reinforcement after problem behavior will increase the problem behavior.
- Showing attention during a tantrum increases the likelihood that the tantrum will occur again.

This is very hard to do! If you need help, consult a behavior analyst to observe in your classroom. A BCBA can find your trouble spots, and help solve problems.

Identifying Positive Reinforcers

Not simply something tangible...

- time spent with teacher or school nurse, extra time on a preferred task, a special opportunity
- deliver these things when the child is engaged in an alternative behavior that is appropriate
  - Instead of hitting her classmate, Sophie used her words so she will get extra time to color today
  - Instead of throwing food on the floor, Nathan ate the food nicely, so he will be the line leader today
ADDRESSING SOCIAL ISSUES

Social Issues
- Why are social situations challenging for kids with ASD?
- Not necessarily true that they don’t want interactions
- Difficulty reading social cues and therefore these opportunities are difficult.
- Trouble participating in give and take of conversation
- Not sure how to make small talk

Social Issues
- Unsure if they are invited into an exchange
- Trouble reading social signals
- Others may not understand their efforts to be social
- Play may be different
- Trouble showing empathy and concern

How to Promote Socialization
- Social Skills Groups
  - Pros: teach specific skills, such as eye contact or waiting one’s turn
  - Cons: not real-life
- Exposure, exposure, exposure!
  - Formal: Clubs, religious groups, Y, classes
  - Informal: Library, playground, diner

How to Promote Socialization – lessons for parents
- Meet other parents in your child’s class
  - Compliment them when their child is accepting
- Volunteer at your child’s school to familiarize yourself with peers
- Arrange playdates
  - Brief, structured, provide lunch, outdoors, neutral place
  - Plan a craft, bake cookies – a cooperative task
- Schedule structured play time with your child
- Teach your child how to play
  - Play as if you are a child

How to Promote Socialization – Lessons for parents
- Pay attention to trends
  - Purchase popular clothing, backpack, etc.
- Parents should take child to interesting places to help promote conversation
- Go to the movies, out to lunch, playground for a playdate
- Role play
- Provide scripts and picture cues
How to Promote Socialization – Lessons for parents

- Provide prompts (can be a nonverbal cue such as zipping a lip) or verbal (it’s hard for me to hear you when you are looking away)
- Encourage problem-solving – ask your child what to do in a particular situation
- Encourage independence, so that your child will not rely on others

Pearls for the School Nurse

- Children with autism have concrete and literal understanding of language and have difficulty interpreting facial expressions and jokes. This puts them at risk for bullying.

School nurses can support a child’s social safety:
- Screen for bullying and support child and family
- Provide anticipatory guidance about bullying
- Identify high risk situations
- Provide bullying prevention resources to and school staff
- Yearly in-service to school staff about tolerance to bullying

Pearls for the School Nurse

SOCIAL SAFETY …
- Lessons to children –
  - Teach children to identify adults to whom they can turn to for questions or concerns.
  - Ensure adequate adult supervision of unstructured social opportunities
    - lunch, recess, playground
  - Assist families in identifying developmentally appropriate resources to teach child about appropriate and inappropriate touch, puberty education and sexuality education.

What can the school nurse do?
- Use Sensitivity Training with Staff
- Use Sensitivity Training with Peers
- Model Tolerance /Inclusion
- Think about ways to support differences in students
- Develop a plan to include students with differences

References

- Association for Science in Autism Treatment (ASAT)
  - www.asatonline.org
- Autism NJ
  - www.autismnj.org

Questions?
Thank You!