Autism Spectrum Disorder In Primary Care

Julia Marian, MD, FAAP
Assistant Professor of Pediatrics
Lake Erie College of Osteopathic Medicine, Bradenton
Sunflower Assessments LLC

Disclosures

No conflicts of interest to report

Learning Objectives

- Definition
- Epidemiology
- Etiology
- Clinical Criteria
- Screening and Assessments
- Management in Primary Care
- Follow up in Primary Care
- Future Considerations
- Resources for Primary Care Physicians

Definition

Autism spectrum disorder (ASD)
- neurodevelopmental condition
- complex, lifelong
- persistent social communication difficulties, restricted interests and repetitive behaviors.

Patients with a DSM-IV diagnosis of autistic disorder, Asperger's disorder or pervasive developmental disorder not otherwise specified, should be given the diagnosis of ASD

Epidemiology

At least 1 in 6 children are estimated to have a developmental disability

1 in 31 children are estimated to have autism spectrum disorder

ASD is 3x more common in males than females

Autism costs approximately $60 000 per year through childhood

Over 50% of adults with autism are unemployed

Etiology

Idiopathic

Genetic factors: contribute to up to 80% of ASD risk, changes reported in over 1000 genes

Gastrointestinal abnormalities, gut dysbiosis

Chronic inflammation and immune imbalance

Other environmental factors

DSM-5-TR, 2022:

Criterion A: Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following:

Deficits in social-emotional reciprocity: abnormal social approach, failure of normal back and forth conversation, reduced sharing of interests/ emotions/ affect, failure to initiate or respond to social interactions

Deficits in nonverbal communicative behaviors used for social interaction: poorly integrated verbal and nonverbal communication, abnormal eye contact and body language, deficits in understanding and use of gestures, total lack of facial expressions and nonverbal communication

Deficits in developing, maintaining, and understand relationships: difficulty adjusting behavior to suit various social contexts, difficulties sharing imaginative play or making friends, absence of interest in peers

DSM-5-TR, 2022:

Criterion B: Restricted, repetitive patterns of behavior, interests or activities, as manifested by at least two of the following:

- Stereotyped or repetitive motor movements, use of objects, or speech: simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases
- Insistence on sameness, inflexible adherence to routines, ritualized patterns of verbal or nonverbal behavior: extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route, eat same food
- Highly restricted, fixated interests that are abnormal in intensity or focus: perseverative interests
- Hyper- or Hypo- reactivity to sensory stimulation or unusual interest in sensory aspects of the environment: indifference to pain/temperature, adverse response to specific sounds or textures, excessing smelling or touching of objects, visual fascination with lights or movement

DSM-5-TR, 2022

Criterion C: Symptoms must be present in the early development period: may not become fully manifest until social demands exceed limited capacities, masked by learned strategies in life

Criterion D: Symptoms cause clinically significant impairment in social, occupational or other important areas of functioning

DSM-5-TR, 2022

Criterion E:

These disturbances are not better explained by:

- Intellectual developmental disorder
- Global developmental delay

Severity Levels

- Level 1: Requiring support (noticeable impairment without support)
- Level 2: Requiring substantial support (marked deficit with noticeable impairment even with support)
- Level 3: Requiring very substantial support (severe deficits and impairment)

Associations

40% of people with autism are non-verbal

Association with intellectual disability:

- 39.6%: IQ < 70 (intellectual disability)
- 24.2%: IQ 71-85% (borderline)
- 36.1%: IQ > 85

Up to 50% bolt or wander off from safety

Up to 61% have ADHD

Over 50% have chronic sleep problems

7-40% have anxiety and/or depression

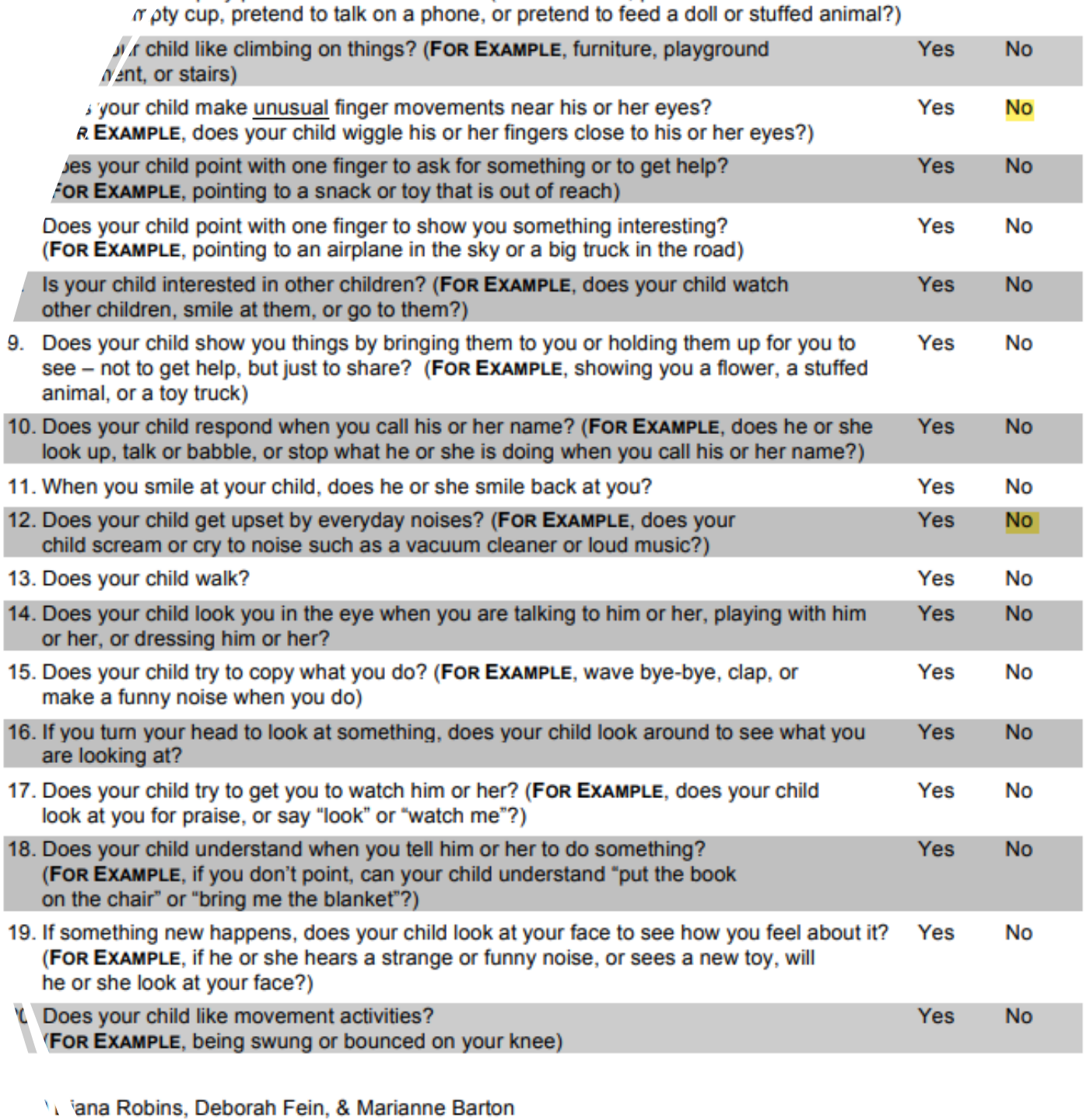
8x more likely to have chronic gastrointestinal disorders

Up to one third have epilepsy

Drowning is leading cause of death

Screening and Assessments

- M-CHAT-R
  - Performed at 18 months
  - Low risk: 0-2; repeat at 24 months
  - Medium risk: 3-7; administer the follow up/second stage of the MCHAT-R/F; if score is 2+ then refer immediately
  - High risk: 8-20; refer immediately



	...pty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)		
	...r child like climbing on things? (FOR EXAMPLE, furniture, playground ...ent, or stairs)	Yes	No
	...your child make unusual finger movements near his or her eyes? ...R EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
	...es your child point with one finger to ask for something or to get help? ...FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
	Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
	Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9.	Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10.	Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11.	When you smile at your child, does he or she smile back at you?	Yes	No
12.	Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13.	Does your child walk?	Yes	No
14.	Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15.	Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16.	If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17.	Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18.	Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19.	If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
	Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Yes	No

...ana Robins, Deborah Fein, & Marianne Barton

Screening and Assessments: Interdisciplinary Evaluation

Developmental specialist: Developmental Behavioral Pediatrician, Child Neurologist, Child Psychiatrist, Developmental Psychologist etc.
Speech and Language pathologist
Physical therapist
Occupational therapist
Audiology
Geneticist and/or Genetic counselor
School and/or teacher reports
Parent and/or caregiver reports

Screening and Assessments

The two diagnostic tools with the “largest evidence base and highest sensitivity and specificity”:

Autism Diagnostic Observation Schedule (ADOS-2)	Autism Diagnostic Interview-Revised (ADI-R)

When used in combination, accuracy is described as 80.8% in the diagnosis of ASD

Screening and Assessments: ADOS-2

Observational assessment: semi-structured, standardized

Allows specialist to observe and code: communication, social interaction, play, restricted and repetitive behaviors

Informs: diagnosis, intervention, treatment planning, educational placement

40-60 minutes to administer

Toddler module: 12-30 months, do not consistently use phrase speech

Module 1: 31 months +, do not consistently use phrase speech

Module 2: any age, use phrase speech, not verbally fluent

Module 3: verbally fluent children and young adolescents

Module 4: verbally fluent older adolescents and adults

Screening and Assessments: ADI-R

Questionnaire: administered by an experienced clinical interviewer, answered by a parent and/or caretaker that is familiar with the child

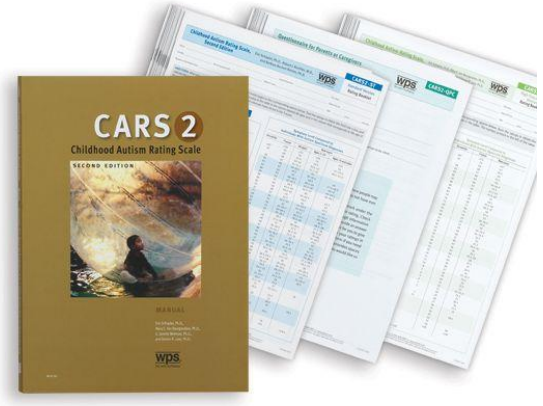
For children and adults with a mental age of 2.0+ years

Duration: 1.5-2.5 hours

Informs: diagnosis, treatment and educational planning

Evaluates: language and communication, reciprocal social interactions, restricted/repetitive/stereotyped behaviors and interests

Screening and Assessments: Other tools



Childhood Autism Rating Scale (CARS-2): questionnaire, assess autism

Sensory Profile 2: questionnaire, assess for sensory difficulties

Kaufman Brief Intelligence Test (K-BIT-2): assess verbal and non-verbal intelligence

Vineland Adaptive Behavior Scales: questionnaire, assess adaptive functioning, daily living skills

Management of ASD in Primary Care

Developmental

Refer	Refer to a specialist: Developmental Behavioral Pediatrician, Neurologist, Psychiatrist, Developmental Psychologist etc.
Refer	Refer to a geneticist and/or genetic counselor
Start	Start speech and language therapy
Start	Start occupational therapy
Start	Start physical therapy (if necessary)

Management of ASD in Primary Care

Educational

- **Start** Developmental Preschool
- **Obtain** psychoeducational evaluation by the school: autism, intellectual disability, ADHD, other developmental disorders
- **Advocate** for an Individualized Education Plan
- **Advocate** for middle or high school transition services: teach independent living skills and employment readiness
- TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children): children with autism thrive on consistency and visual learning
- Schools designed for children with autism

Behavioral: Applied Behavioral Analysis

- **Refer** to Behavioral Therapy
- Evaluation and plan of care provided by: Board Certified Behavioral Analyst (BCBA, usually specialized psychologists)
- Sessions provided by the BCBA, BCaBA (Board Certified Assistant Behavior Analyst, RBT (Registered Behavioral Technician)
- At home, school, outside, ABA centers
- One on one, or in a group
- Adapted to meet the needs or goals of each unique patient and family
- 25-40 hours per week for 1-3 years: studies show improvement in language and social skills, daily living skills, intellectual functioning, decrease problem behaviors

Social-Relational

- Floor time: follow specific interests of the child
- Relationship Development Intervention (RDI): nurture skills and interest in participating in social activities
- Social stories: learn what to expect in a social situation
- Social skills groups: practice social abilities in a structured environment

Management of ASD in Primary Care

Psychological

Cognitive behavioral therapy

Help patients cope with associated anxiety, depression, other mental health issues

Management of ASD in Primary Care

Pharmacological

No cure or treatment for the core symptoms of autism.

Medications help with associated symptoms or comorbid conditions: ADHD, self injurious behavior, sleep disturbances, mental health conditions, seizures, gastrointestinal conditions etc.

Melatonin

Non-stimulant and Stimulant ADHD medications

Management of ASD in Primary Care

Nutrition

- Prevent obesity and malnutrition
- Parents need interdisciplinary medical and social support
- Some support for casein (milk protein) free, and gluten free diets
- Some support for low carbohydrate diets
- Healthy nutrition is proposed to improve behavioral and cognitive outcomes

Management of ASD in Primary Care

Complementary and Alternative Treatments

- Special diets and herbal supplements: probiotics, special vitamins, diets advertised as “cures”
- Osteopathic care
- Animal therapy
- Arts therapy
- Mindfulness and relaxation
- Chelation therapy: removal of heavy metal
- Magnetic e-Resonance Therapy (MeRT): “EEG/EKG-guided magnetic resonance therapy”
- Chiropractic care

Follow Up in Primary Care

- Provide patient, family, caregiver support
- Ensure the child receives the medical and therapeutic services recommended
- Help family and caregivers advocate for your patient in school meetings
- Help the patient, family and caregivers through the process of Transition from child to adolescent to adulthood
- Continuity of care into adulthood

Follow up in Primary Care

Conservatorship and Guardianship

Limited guardianship: specified by the court	Full guardianship: health, safety, support, care, place of residence
Conservatorship: contracts, property, transactions, trusts	Start talking about it at 12 years
Start collecting documents at 14-16 years	Submit at 17 years

Follow up in Primary Care

Adults

- Health insurance
- Housing
- Employment
- Social security
- Social support
- Medical care: hypertension, diabetes, hyperlipidemia, cardiovascular concerns, seizures, mental health
- Mental health care

Future Considerations

2022 article on the crisis in the developmental behavioral pediatric workforce

- Over 19 million children < 19 years have a developmental disorder
- < 750 board certified DBPs
- 29 states have < 1 DBP per 100 000 children
- Requires support from both primary care providers and subspecialists

Advocate for adult patients with autism to join the workforce

- https://www.autismspeaks.org/workplace-inclusion-now

Why Primary Care?

Primary care is the first point of contact in pediatrics, family medicine and sometimes even internal medicine

Primary care is the most accessible resource to the general population: geographical accessibility, timing of appointments, financial burden, etc

Primary care can help provide earlier screening, earlier referral, earlier intervention- consequently better outcomes

Primary care can provide optimal advocacy for the patient and their family or caregivers: not limited by timing of appointments, build a relationship with the family, educate the patient and family to advocate for themselves

Primary care can provide continuity of care across ages and stages of development

Resources for Primary Care Providers

Senate Bill 2654: Florida Autism Insurance Law (Effective 04/2009)

- All State Employee Health Plans and Fully Insured Large Group Plans
- Cover screening and diagnosis, ABA services, speech therapy, occupational therapy, physical therapy
- Diagnosed with a developmental disability at 8 years of age or younger
- Child will be covered until 18 years of age, or graduation of high school, whichever is longest
- Maximum annual benefit: $36 000
- Lifetime limit: $200 000

https://www.autismspeaks.org/health-insurance-coverage-autism

https://www.autismspeaks.org/florida-state-regulated-insurance-coverage

Resources for Primary Care Providers

Developmental Preschool:	• www.easterseals.com/florida/
Educational scholarships for students	• https://www.fldoe.org/schools/school-choice/k-12-scholarship-programs/ • Family Empowerment Scholarship for Students with Unique Abilities • https://www.stepupforstudents.org/ • https://www.aaascholarships.org/
Transition Planning	• https://www.fldoe.org/core/fileparse.php/7764/urlt/0084240-transition.pdf

Resources for Primary Care Providers

- Conservatorship and Guardianship
  - https://www.flcourts.gov/Resources-Services/Office-of-Family-Courts/Family-Courts/Guardianship
  - https://disabilityrightsflorida.org/disability-topics/disability_topic_info/turning_18_guardianship_other_options

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Thank You!

- Questions?

- Julia Marian, MD, FAAP
- office@sunflowerassessments.com