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Health Care for the Whole Child

The Benefits of Comprehensive Primary Care for Youth with ASD

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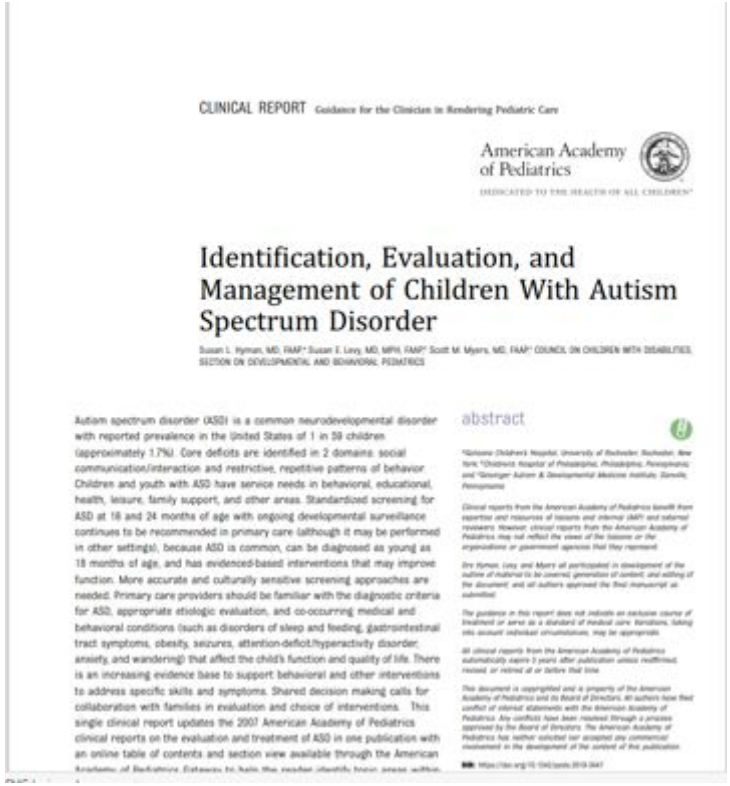
Introduction



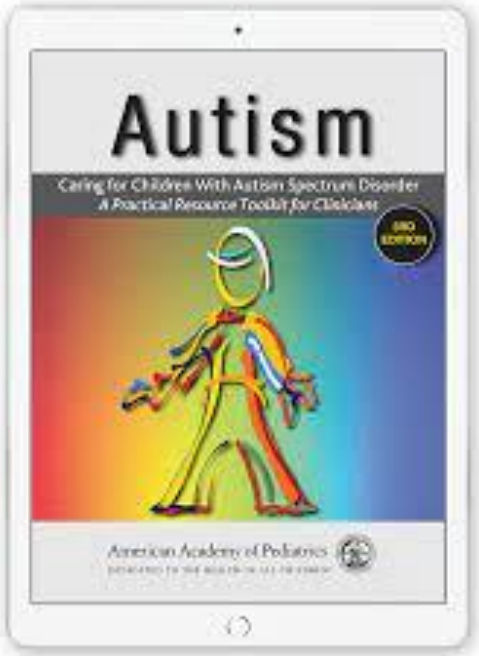
CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy of Pediatrics

Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

abstract

Autism spectrum disorder (ASD) is a common neurodevelopmental disorder with reported prevalence in the United States of 1 in 59 children (approximately 1.7%). Core deficits are identified in 2 domains: social communication/interaction and restrictive, repetitive patterns of behavior. Children and youth with ASD have service needs in behavioral, educational, health, leisure, family support, and other areas. Standardized screening for ASD at 18 and 24 months of age with ongoing developmental surveillance continues to be recommended in primary care (although it may be performed in other settings), because ASD is common, can be diagnosed as young as 18 months of age, and has evidenced-based interventions that may improve function. More accurate and culturally sensitive screening approaches are needed. Primary care providers should be familiar with the diagnostic criteria for ASD, appropriate etiologic evaluation, and co-occurring medical and behavioral conditions (such as disorders of sleep and feeding, gastrointestinal tract symptoms, obesity, seizures, attention-deficit/hyperactivity disorder, anxiety, and wandering) that affect the child's function and quality of life. There is an increasing evidence base to support behavioral and other interventions to address specific skills and symptoms. Shared decision making calls for collaboration with families in evaluation and choice of interventions. This single clinical report updates the 2007 American Academy of Pediatrics clinical reports on the evaluation and treatment of ASD in one publication with an online table of contents and section view available through the American



Part 1: Identification and Evaluation of ASD in the primary care setting

Part 2: Identification and Management of Health Issues and Coexisting Conditions

Identification and Evaluation of Autism Spectrum Disorder

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Medical Home

- What is a Medical Home?
  - It is an **approach** to providing high quality and cost-effective health care rather than a structure or health care complex
- Common Elements:
  - Family Centered - Coordinated
  - Continuous - Compassionate
  - Comprehensive - Culturally Competent
  - Accessible

Autism Spectrum Disorder

- Neurodevelopmental disorder characterized by social and communication impairment and restricted or repetitive behaviors
  - Current prevalence 1:36 children
    - Increased prevalence from 2 years prior
  - 4% of boys, 1% of girls estimated to have ASD
  - Median age for formal ASD evaluation 32 to 44 months
  - Goal is early diagnosis by 48 months
  - Barriers: girls, mild symptoms, coexisting conditions, racial disparities, language barriers, cultural differences

Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years —

Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ 2023;72(No. SS-2):1–14.

- Longitudinal, continuous, cumulative process within the setting of the medical home

- 6 components
  - Eliciting parental concern
  - Obtaining developmental history
  - Observing the child
  - Identifying risks, strengths, protective factors
  - Maintaining a record
  - Sharing opinions and finding with other childhood professionals

Surveillance

Developmental Screening

Supplements and strengthens surveillance to identify subtle risks

General developmental screening tests

- Should be done at 9-, 18-, and 30-month visits

- Autism specific screening tests
  - 18- and 24- month visits
  - MCHAT-R/F
    - 2 stage screening tool
    - 20 item parent questionnaire
    - Interview for patients deemed at risk

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MCHAT-R

M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (**FOR EXAMPLE**, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (**FOR EXAMPLE**, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (**FOR EXAMPLE**, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make unusual finger movements near his or her eyes? (**FOR EXAMPLE**, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does 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
7. 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
8. 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
20. Does your child like movement activities? (**FOR EXAMPLE**, being swung or bounced on your knee)	Yes	No

Source: CDC

Early Intervention

A "watch and wait" approach is no longer preferred

- Neural circuits are most plastic during the first 3 years of life
  - The developing brain is most capable of change
- High quality early intervention services can change a child's developmental trajectory
- In Michigan, we refer to Early On from birth through age 3
  - System for helping infants and toddlers who have developmental delays, disabilities, or are at risk for developmental delays due to health conditions
  - Works closely with families on how to use everyday activities to promote learning for each child

From the National Early Childhood Technical Assistance Center

Diagnostic Evaluation

Approved Autism Evaluation Center

- Some private insurances require evaluation through an AAEC for services like ABA to be approved
- Comprehensive evaluation by a team of experts
- Uses standardized diagnostic tools like ADOS or Vanderbilt-Tele-ASD

Psychological/Community Mental Health

- Done by an approved diagnostician- social worker, psychologist, or other medical professional
- Uses standardized diagnostic tools like ADOS or ADI-R
- Comprehensive approach that includes parent interview, direct observation, and psychological testing

Educational

- Evaluation through public school district or intermediate school district to determine eligibility for special education services
- Referred to as an educational certification rather than a medical diagnosis

TABLE 1 DSM-5 Criteria for Autism Spectrum Disorder

Domains	Criteria: Deficits	Examples
A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history; must have all 3 symptoms in this domain	1. Social-emotional reciprocity	Abnormal social approach and failure of normal back-and-forth conversation; reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions
	2. Nonverbal communicative behaviors used for social interaction	Poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language or deficits in understanding and use of gestures; total lack of facial expressions and nonverbal communication
	3. Developing, maintaining, and understanding relationships	Difficulties adjusting behavior to suit various social contexts; difficulties in sharing imaginative play or in making friends; absence of interest in peers
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least 2 of the following, currently or by history; must have 2 of the 4 symptoms	1. Stereotyped or repetitive motor movements, use of objects, or speech	Simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases
	2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior	Extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day
	3. Highly restricted, fixated interests that are abnormal in intensity or focus	Strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest
	4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment	Apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement

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). Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and ASD frequently co-occur; to make comorbid diagnoses of ASD and intellectual disability, social communication should be below that expected for the general developmental level. Specify whether: with or without accompanying intellectual impairment, language impairment or associated with a known medical or genetic condition or environmental factor. Add code 293.89 if catatonia is also present.

Follow up after diagnosis

- After a diagnosis of Autism is made, can follow up with your primary doctor to go over recommendations
  - What services were recommended
    - Speech, OT, PT, ABA, Early On, Special Education
  - Any other medical referrals are needed
    - Neurology, Ophthalmology, Audiology, Behavioral Health, Genetics, Case Management
  - Autism Alliance of Michigan
    - MiNavigator

Etiologic Evaluation after Autism Diagnosis

Genetic testing

- Most often requires referral to pediatric geneticist or pediatric neurogeneticist
- Chromosomal Microarray (CMA)
  - Looks for extra or missing chromosomes
- Consider Fragile X analysis
  - Looks for mutation in FMR gene on X chromosome
  - Intellectual disability, autism, large ears, long face, friendly
- If female, consider evaluation for Rett syndrome, MECP2 testing
  - Progressive loss of skills

Neuroimaging

- Not routinely indicated unless there is atypical regression, large head size, small head size, seizures or abnormal neurologic examination

Metabolic testing

- not routinely indicated unless hypotonia, dysmorphic features

- Motor delay should have testing with creatinine kinase and thyroid testing

- heavy metal testing (besides lead test) not indicated

EEG

- children with ASD are at increased risk for seizures

- baseline EEG not recommended

- consider if there are suspicious symptoms or atypical/late loss of language

Identification and Management of Coexisting Medical Conditions

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General Considerations in the Primary Care Setting

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The ideal annual physical for children with ASD

- Checking height, weight, blood pressure
- Vision and hearing screening recommended for children beginning at age 3
- Review medical problem list
- Review specialist visits for those medical problems
- Review medication list, growth chart
- How are you eating? How are you sleeping? Any problems voiding or stooling?
- How is school? Do you have an IEP or 504?
- What therapies are you receiving?
- Discuss new problems and identify gaps in care
- Physical Exam
- Immunizations
- Blood work if needed

Meeting the needs of children with ASD during the primary care visit

- Consider an introductory visit
  - Let your doctor know about triggers that might lead to problem behaviors, and what techniques may keep your child calm
- Prepare in advance with a social story or visual schedule
- Consider scheduling the visit for extra time or with extra staff, at the beginning of the day or right after lunch to minimize wait times
- During the physical exam- complete an easy request before a difficult one
  - Provide distractions
  - Physical restraint is the last resort

Vision & Hearing

Vision screening

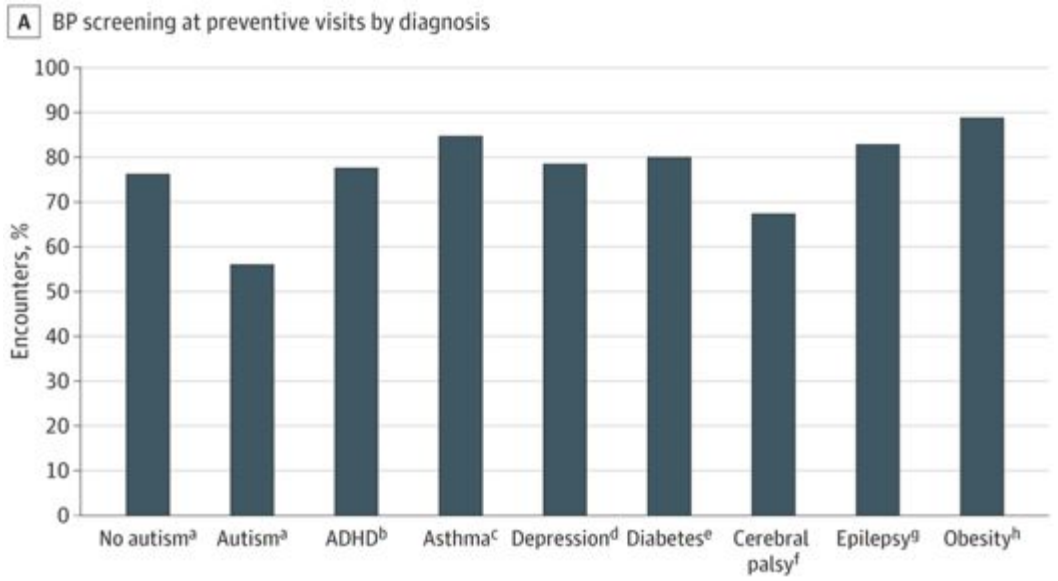
- If unable to complete in-office vision screen, follow up with ophthalmologist at least once every 2 years

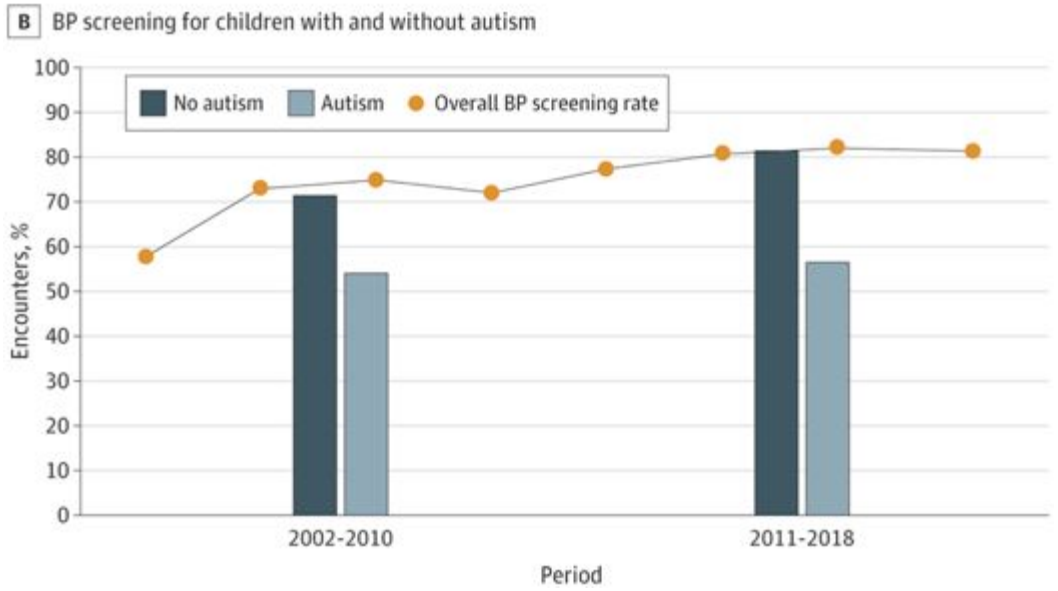
Hearing screening

- If unable to complete in-office hearing screen, follow up with audiologist once every 2 years

Blood pressure monitoring

- Adults with autism are at increased risk for hypertension and cardiovascular disease as compared with the general population
- Blood pressure monitoring recommended at primary care visits starting at age 3
- Barriers to monitoring in children with ASD
  - Sensory discomfort
- Home blood pressure monitoring may be a solution





Screening for Hypertension in Children With and Without Autism Spectrum Disorder. JAMA 2022

Dental Health

- Children with ASD commonly present with unmet dental needs
- No evidence to indicate that children with autism have more cavities
- Dental care may require sedation in some cases
  - Can discuss with pediatric neurologist or child psychiatrist
- May benefit from seeing a developmental dentist
  - Dentist who has designated themselves as being able to provide care to children with developmental disabilities

Vaccines

Overwhelming evidence supports vaccine safety

No scientific evidence to suggest that vaccines are risk factor for ASD

Large Cochrane review 2012: 1,256,407 children studied, showed no link between vaccines and autism

We strongly recommend vaccination

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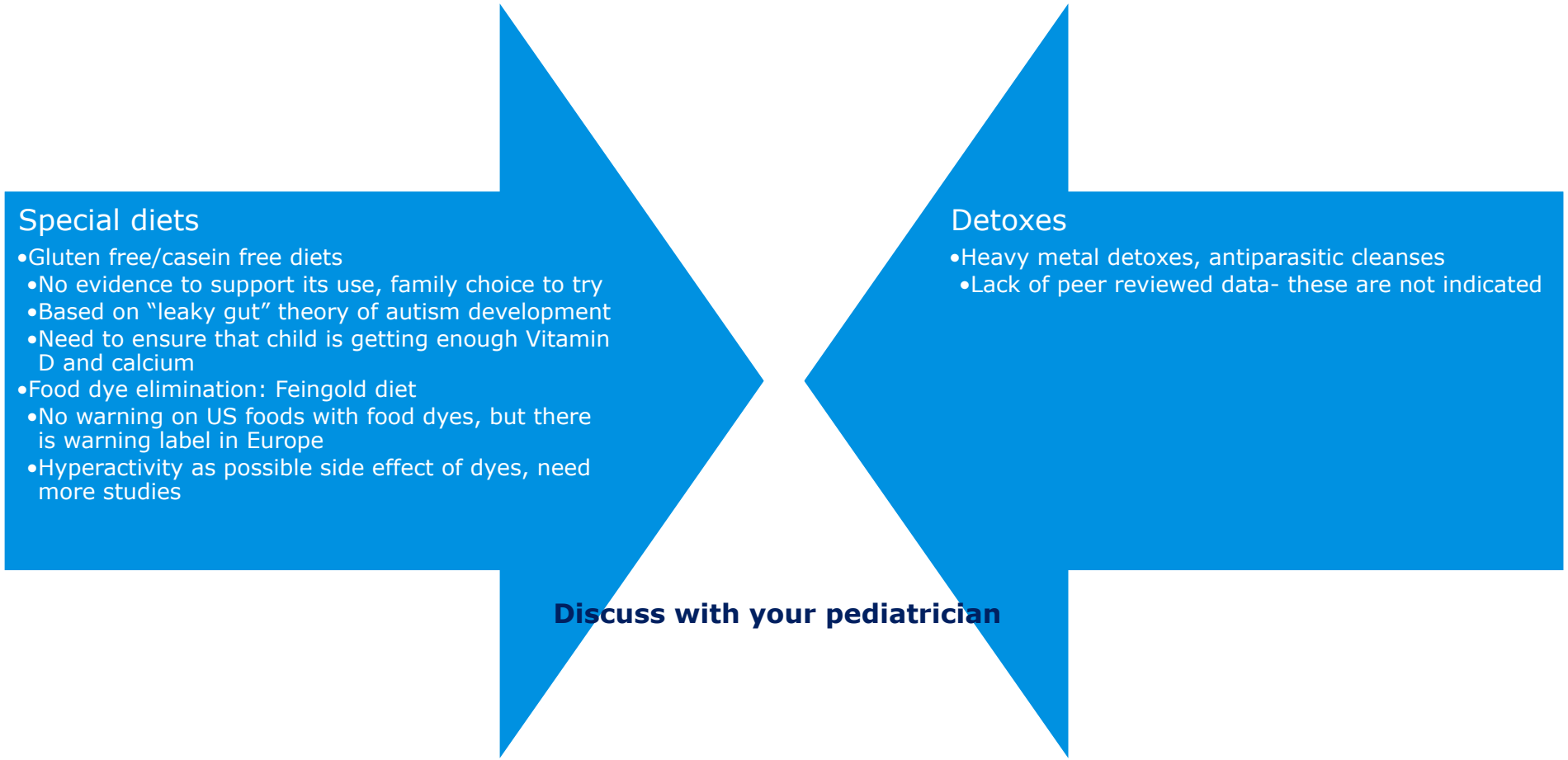
Complementary Therapies



Autism Spectrum Disorder Comorbidities

- Gastrointestinal Problems
  - Constipation
  - Diarrhea
  - GERD
  - Food Allergy
- Feeding/Eating issues
  - Restricted eating habits
  - Pica
- Sleep disturbances
- Obesity
- ADHD
- Anxiety
- Depression
- Elopement
- Motor delays

Feeding and Gastrointestinal Problems

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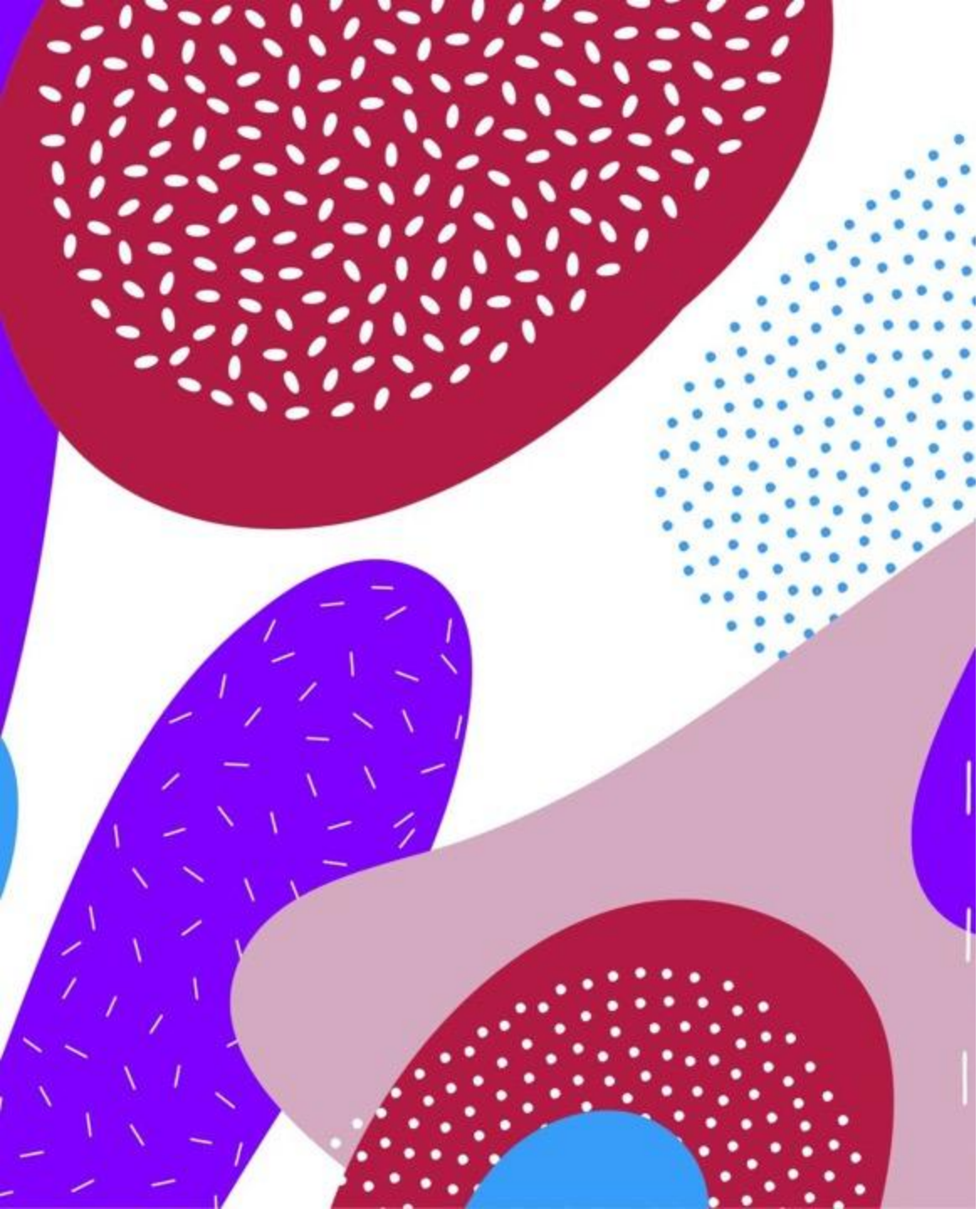

Feeding and Nutrition

- Up to 75% of all children with ASD have problems eating
  - Texture aversion, emesis, gagging, feeding refusal, self-imposed rituals around food presentation
- Consider true medical problems
- Rare cases of rickets (vitamin D) and scurvy (vitamin C), keratoconus (vitamin A) have been reported deficiencies seen with severe food aversions
- Many deficient in fiber, calcium, and vitamin D
- Offer routine meals and snacks, eat as a family, allow child to self-feed when able
- Consider referrals to: occupational therapist or feeding therapist, nutritionist for assessment of adequacy of intake
- Consider lab work and a daily multivitamin
  - Vitamin D level, Iron studies, Total cholesterol (depending on age)
    - Individuals with autism nearly 2x as likely to have abnormal lipid testing

Pica

- The continued ingestion of non-food items
  - Associated with developmental delay- younger children mouth objects to explore
  - Obsessive behaviors or anxiety may also be associated
- May indicate iron deficiency
  - Consider checking complete blood count and iron studies such as ferritin level
- Persistent mouthing of non-food objects places child at risk for elevated lead levels as well

Obesity

- 33% children with autism are overweight, 18% obese
- Result of diet challenges, decreased physical activity, missed satiety cues, genetic vulnerabilities, medications
- Increases risk for type 2 diabetes, high cholesterol, high blood pressure, sleep disordered breathing
- Multidisciplinary approach: nutritionist, OT/feeding therapy, behavioral modification
- At home can work on healthy habits for the whole family, encouraging good sleep for child, get child involved in cooking when possible

Obesity and Autism. Pediatrics 2015.

Gastrointestinal Disorders

Presentation of symptoms

- Untreated conditions may cause significant physical discomfort, and in turn maladaptive behaviors
  - May present with behavior changes rather than with focal pain
- Discuss the need for labs such as ESR, liver function tests, thyroid function tests, celiac screen.
- Refer to gastroenterologist as needed

Constipation

- Withholding, diet, medical conditions
- Treatment
  - Dietary modification
    - Increased water and fiber
  - Stool softener- first line MiraLax
  - Stool lubricant- glycerin suppositories
    - Laxative if needed
    - Goal is pudding like stool consistency

Encopresis

- When hard stools are held in the rectum, the rectum muscles eventually relax
- Liquid stool can ooze around the large mass of stool and leak out into underwear
- Child unable to control this
- Requires cleanout and bowel re-training

GERD

- Can present as behavioral changes, irritability, oral aversion
- Can see with long eating times, excessive chewing, difficulty swallowing, burping, chest pain, frequent hiccups
  - Children with ASD may have repetitive behaviors or stimulatory behaviors that mimic these, sometimes diagnosis can be difficult
- Behavioral modifications: eat more slowly, avoid spicy foods
- Medications:
  - Pepcid (H2 blocker)- decreases stomach acid production, can lose efficacy over time
  - Omeprazole (PPI)- turns off stomach acid production, has side effects that need to be monitored
- If severe reflux, unexplained symptoms, need for PPI- likely needs follow up with gastroenterologist

Sleep and Movement Problems

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Sleep Disorders

- 50-80% of children with ASD have sleep problems
  - Sleep onset
  - Sleep maintenance
  - Sleep phase
- Preschoolers need 10-13h sleep per day
- School age children need 8-11h sleep per day
- Consider medical problems (OSA, seizures, GERD, restless leg syndrome), mental health conditions (ADHD, anxiety), primary sleep disorder
- Consider testing like lab work, sleep study, EEG
- Melatonin can be helpful
- Other medication options from child psych/neurologist

Motor delays

Gross motor delays can be seen in children with ASD

- Mild hypotonia or ligament laxity

- Reduced motor coordination often defined as developmental coordination disorder
  - Bike riding, catching, throwing, kicking may be difficult
  - Children may be less likely to engage in physical activity as a result of this delay

Fine motor delays can be seen in children with ASD

- handwriting, feeding, dressing, brushing teeth

Toe walking

- transiently seen in typically developing children, should resolve by age 2
- if persistent may be associated with achilles tendon contracture- orthopedics/PMR evaluation

Academic Functioning

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School Problems

- Should be discussed with your pediatrician!
- Section 504 plan
  - Structured plan for extra help in the regular classroom
- Individualized Education Program (IEP)
  - Comprehensive evaluation for children who need help outside of a regular classroom
    - Resource room or special education classroom
- Least restrictive environment
- Learning disabilities
  - Neuropsychology evaluation

Behavioral Problems

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Irritability and Severe Disruptive Behavior

- Acts of aggression, self-injury, property destruction
  - May serve as way of communication to escape a demand
  - New onset aggression should have evaluation for underlying medical problem
- Functional behavioral analysis and implementation of behavioral strategies as initial step
- Behavioral health referral often indicated if ongoing
- May consider medication: atypical antipsychotic
  - Risperidone
  - Does have side effects, considered if other interventions have failed

Elopement

- 50% of children with ASD have had significant wandering incident
  - At risk for traffic related injury or drowning
- Elopement should be added to medical problem list
- Big Red Safety Box (National Autism Association)
  - Caregiver checklist
  - Family wandering emergency plan
  - Window and door alarms
  - RoadID bracelet/shoe tags
  - Child ID kit from National Center for Missing and Exploited Children

Create community awareness, identify triggers, teach self help

https://nationalautismassociation.org/wandering-quick-tips/

Mental Health Problems

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Attention Deficit-Hyperactivity Disorder

- Approximately 50% of children with ASD may also qualify for ADHD
- Many different ways to make this diagnosis: pediatrician, neuropsychologist, psychiatrist, psychologist
- Educational modifications
  - 504 plan
- Behavioral strategies
  - Breaking down tasks into units, taking breaks
- Consider medications
  - Stimulant medications generally first line
  - Children with ASD more prone to side effects

Anxiety & Depression

- 40-66% of school aged children and adults with ASD have a co-occurring anxiety disorder
- Core symptoms may decrease ability for person with ASD to interpret social cues, leading to constant heightened state of anxiety
- Cognitive behavioral therapy (CBT) is most proven therapy for school age children with ASD and anxiety

- 12-33% of school aged children and adults with ASD have co-occurring depressive disorder
- May be related to neurobiological factors and chronic stress
- Attempted suicide also occurs more frequently in adults with ASD
- Lifetime diagnosis of bipolar is 9% in people with ASD, compared with 1% in general public

Transitioning to Adulthood

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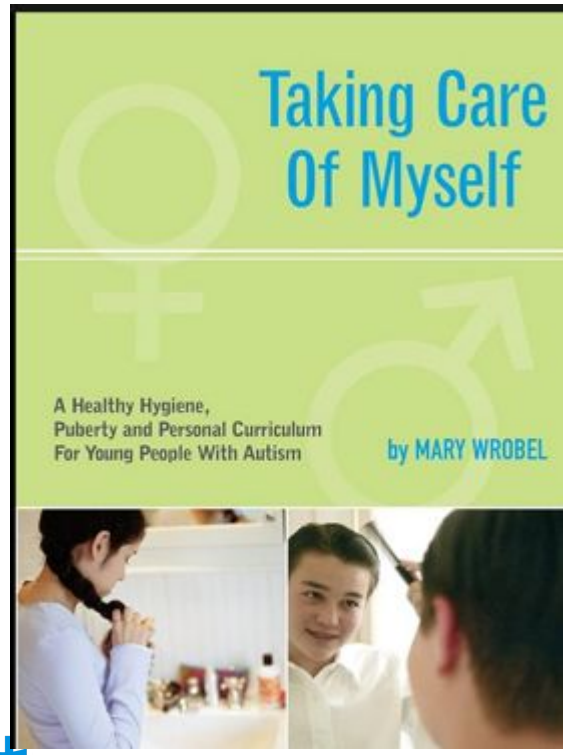
Teenagers with ASD

- Discussing sexuality
  - Important piece of anticipatory guidance
  - Help adolescents understand physical and emotional changes
- Discuss typical stages of puberty
  - Tanner stages



- Encourage independence in self care
  - Difficulties with menstrual hygiene
  - Regular GYN visits after 21 years of age
- Discuss consent and respect in relationships
- Set concrete rules for internet use
  - Teenagers with ASD more likely to be exploited on the internet

Transition to Adulthood

- 6 core elements
  - Transition policy for the practice
    - 18 years? 21 years?
  - Tracking and monitoring transition
  - Assessing transition readiness
  - Actively planning details
  - Transfer of care
  - Transition completion
- Guardianship issues
- SSI benefits
- Workforce, secondary education, housing

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