Screening for Autism Spectrum Disorder

Endorsed by the American Academy of Pediatrics and the Society of Developmental and Behavioral Pediatrics

Developed in partnership with Health Resources and Services Administration Maternal and Child Health Bureau
Abstract
In the course of a typical primary care clinic, a pediatric resident performs a screening for autism spectrum disorder (ASD) as recommended by the American Academy of Pediatrics (AAP). She uses the Modified Checklist for Autism in Toddlers (M-CHAT) to screen two of her patients, ages 18 and 24 months. The resident explains the screening process to caregivers, learns to interpret the results, and determines the next steps.

Case Goal
Early identification of ASD and referral for subsequent specialized developmental services greatly improves long-term outcomes for children with ASD. The American Academy of Pediatrics (AAP) recommends ongoing developmental surveillance at every visit, developmental screenings at 9, 18, and 24 or 30 months, and ASD-specific screening at 18 and 24 months. After completion of this module, learners will be able to:

1. Perform ASD-specific screening as recommended by the AAP
2. Develop an appropriate management plan based on ASD screening results

Three Steps to Prepare - In 15 Minutes or Less!

1. Read through the Facilitator’s Guide and make copies of the case and learner worksheet for distribution.
2. Identify the key topics you wish to address. Consider:
   • Knowledge level of learners
   • Available time
   • Your familiarity with the subject
3. Select and prepare the optional teaching tools you wish to use. Each case provides a variety of optional materials to enhance the learning environment, support facilitator style, focus on different themes, or accommodate different time limitations. These materials are optional for facilitators to use at their discretion.
   • Handouts: Select any you wish to use and make copies for distribution
   • PowerPoint: Decide if you wish to use and confirm necessary technical equipment
   • Video: Review embedded video and video library, decide if you wish to use, confirm necessary technical equipment, and conduct test run

The following case was developed by the authors. It does not necessarily reflect the views or policies of the Department of Health and Human Services (HHS) or the Centers for Disease Control and Prevention (CDC).

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Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum
Key Learning Objectives of This Case

1. Perform ASD-specific screening as recommended by the AAP.
   a. Review the AAP guidelines on screening for ASD (Prompt 1.1 and Handout I: AAP Screening Guidelines)
   b. Discuss the importance of screening for ASD as part of developmental surveillance (Prompt 1.1)
   c. Choose an appropriate screening tool (Prompt 1.3 and Handout II: Screening Tools Chart)
   d. Administer and score a screening tool correctly (Case Study Part I: Activity and Handout VI: M-CHAT Scoring Instructions and Prompt 2.2)

2. Develop an appropriate management plan based on the results of screening for ASD.
   a. Interpret screening results correctly (Case Study Part I: Activity)
   b. Explain the results of screening to parents (Prompt 1.4)
   c. Formulate an appropriate plan of care based on screening results (Prompt 2.1 and Handout VIII: M-CHAT Follow-up Interview for Matthew or Handout IX: M-CHAT Follow-up Interview for Claudia)

Only Have 30 Minutes to Teach?:

Focus your discussion on the AAP Screening guidelines and administering/scoring the M-CHAT screener and follow-up interview. Focus on Matthew or Claudia and use:

- Handout I: AAP Screening Guidelines
- Potential Prompts: 1.1, 1.3, and 2.2
- Case Study Part I Activity for Matthew or Claudia: Handout IV or V
- Case Study Part II Activity for Matthew or Claudia: Handout VIII or IX

Materials Provided

- Case Worksheet for Learners
- The Case Study: Part I, II, and III (available in Facilitator’s Guide and on CD)
- Optional Teaching Tools
  - PowerPoint (available on CD)
  - Handouts (available in Facilitator’s Guide and on CD)
    - Handout I: AAP Screening Guidelines
    - Handout II: Screening Tools Chart
    - Handout III: Blank M-CHAT Form
    - Handout IV: M-CHAT Form for Matthew
    - Handout V: M-CHAT Form for Claudia
    - Handout VI: M-CHAT Scoring Instructions
    - Handout VII: Blank M-CHAT Follow-up Interview
    - Handout VIII: M-CHAT Follow-up Interview for Matthew
    - Handout IX: M-CHAT Follow-up Interview for Claudia
  - Video Library (available on CD)
- References

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Getting Started

This case is designed to be an interactive discussion of a scenario residents may encounter in their practices. Participation and discussion are essential to a complete learning experience. This Facilitator’s Guide provides potential prompts, suggestions for directing the discussion, and ideas for incorporating the optional teaching tools. It is not designed as a lecture.

Case study icons:
- **Call-out:** step-by-step teaching instructions
- **Note:** tips and clarification
- **Slide:** optional slide, if using PowerPoint
- **Filmstrip:** optional slide contains an embedded video
- **Paper:** potential place to distribute an optional handout
- **Digital clock:** tips if you only have '30 Minutes to Teach'

Why is This Case Important?

Early identification of autism spectrum and other developmental disorders may allow access to interventions, which may lead to improved outcomes. Formal screening of every child for autism spectrum disorder during pediatric visits has been recommended by the American Academy of Pediatrics (AAP) at 18 and 24 months. This case highlights important issues surrounding screening for autism spectrum disorder.

Cultural Competence

It is important for clinicians to understand how different childrearing practices and cultural norms may influence key decisions that parents make regarding their child, including obtaining evaluations and treatment, future planning, and acceptance of the child’s diagnosis. Clinicians can approach parents openly and honestly by asking them about their unique style of parenting and how the information or recommendations provided are received.

See the curriculum introduction for additional information on cultural competence and potential discussion questions.
Case Study Part I

It’s a busy morning in the NICU, and you, a second-year pediatric resident, think longingly of the lunch you won’t be able to have as you quickly sign out your patients. You hurry over to your community clinic, arriving a few minutes late. Your first patient for the afternoon is a baby you have been following since birth. You first met the family in the newborn nursery and have enjoyed seeing little Matthew learn to roll over, sit, cruise, and walk.

Matthew is now 18 months old and is coming in for a routine health care maintenance visit. As you enter the room, you smile at Matthew and ask his mother and father how he’s doing. “Great,” they reply. “He loves to explore our apartment and laughs like crazy when we play peek-a-boo. We have started taking him to the park, and he enjoys playing with blocks.” You do a physical exam on Matthew and note that he has said very few words during the assessment. His eye contact is variable. When you ask about his language, Matthew’s parents indicate that, although they have noticed he’s not saying as many words as they would have anticipated at his age, they attribute this to his being raised in a bilingual household. They indicate he only has a couple of words. You spend a few more moments engaging Matthew in play before going back to the conference room to present to the attending.

Although Matthew is a quiet and sweet boy, you remain concerned about his language and variable eye contact. Given his age, Matthew should have an ASD-specific screening as well as a general developmental screening as part of his 18-month checkup. After discussing Matthew’s case with your preceptor, you go back to the family. You discuss the importance of screening with Matthew’s parents. You explain to Matthew’s parents that screeners are not used to diagnose, but can provide important information regarding milestones that Matthew should be reaching. You give Matthew’s parents the screening tool to complete.

Your next patient is Claudia, a 2-year-old girl who has just moved to the area from another state. This is Claudia’s first visit to the clinic. As you introduce yourself to Claudia, you notice that she stares at the door. You complete a physical exam and look over Claudia’s immunization record. You ask Claudia’s dad about preschool, and he replies that since Claudia does not speak yet, the family decided not to place her in preschool. You attempt to engage Claudia with toys, but Claudia appears more interested in the buttons on her sweater. You go back to your preceptor and describe Claudia’s concerning behavior and lack of words. You and your preceptor agree that these may be signs of an ASD. After explaining the routine of screening for ASD at the 18-month and 2-year-old visits, you give the screening tool to Claudia’s dad for completion.

Case Study Part I: Discussion Question

After reading the case, ask participants, “What stands out to you about Matthew and/or Claudia?”

Follow up with student responses to encourage more discussion:
- What in the case supports that?
- Why do you think that?
- What makes you say that?
Screening for Autism Spectrum Disorder

Case Study Part I: Potential Prompts

1.1 Discuss developmental surveillance and developmental screening. 

1.2 When should we start screening for ASD? Why?

1.3 What screening tool should be used?

1.4 How should information be communicated to parents with regards to screening and screener results?

1.5 How would you respond to the parents attributing Matthew’s language delay to being raised in a bilingual household?

1.6 What are the strengths of this child and family?

Supporting Information for Potential Prompts

1.1 Discuss developmental surveillance and developmental screening. The American Academy of Pediatrics (AAP) recommends developmental surveillance be performed at every health supervision visit. Developmental surveillance is the ongoing process of identifying children who may be at risk for developmental delays. It is a “flexible, longitudinal, continuous, and cumulative process” consisting of five components:

1. Eliciting and attending to the parents’ concerns about their child’s development
2. Documenting and maintaining a developmental history
3. Making accurate observations of the child
4. Identifying risk and protective factors
5. Maintaining an accurate record and documenting the process and findings

Elements of surveillance relevant to ASD include:

- **Eliciting parent concerns** about hearing or unusual responsiveness, temperamental variations (irritability, passivity), unusual sensitivities (e.g., clothing, food preferences), or resistance to transitions
- **History of milestones**, particularly in the domains of communication and social-emotional development
- **Observations** of impaired relatedness (e.g., eye contact), lack of joint attention (e.g., gaze monitoring, pointing), lack of response to name, more interest in objects than people, restricted play patterns
- **Obtaining family member history**, especially siblings diagnosed with ASD, indicating a tenfold increased risk as compared to the general population

Concerns raised during surveillance should be addressed with standardized developmental screening tests. **Screening** refers to the use of measures with proven reliability and validity that are administered in a standardized way. Screening tests are recommended by the AAP at the 9-, 18-, and 30-month visits (or at the 24-month visit if a 30-month visit is not routinely scheduled).
By incorporating developmental surveillance and screening into primary care visits, the pediatrician can provide anticipatory guidance to the family to support their child’s development and to facilitate early detection of a disorder.

1.2 When should we start screening for ASD? Why?

In Identification and Evaluation of Children with Autism Spectrum Disorder, AAP also recommended administering a standardized autism-specific screening tool on all children at the 18-month well-child visit. In 2006, the recommendation was expanded to screen at 24 to 30 months of age to identify those who may regress after 18 months of age.

A standardized screening tool should be used at any point that concerns about ASD are raised by a parent. It should also be used as a result of clinician observations or if there are suspect answers to surveillance questions about social, communicative, and play behaviors.

1.3 What screening tool should be used?

The choice of a screening instrument depends on a variety of factors. Screening tests vary with respect to sensitivity, specificity, reliability, and validity.

- **Sensitivity** is the ability of a test to identify correctly those who have the disease [i.e., true positives over all positives (true positives and false negatives)].

- **Specificity** is the ability of a test to identify correctly those who do not have the disease [i.e., true negatives over all negatives (true negatives and false positives)].

- **Reliability** is the repeatability of a test; ability of a test to obtain consistent results.

- **Validity** is the ability of a test to measure a certain criterion; strength of conclusion.

Screening tests ideally should have a sensitivity and specificity of at least 85 percent to be considered acceptable. Additional factors must be considered, such as cost, availability in multiple languages, reading level required, and whether the test relies on a caregiver report or screener’s observations.

The M-CHAT is a parent-completed questionnaire that includes items from the CHAT, but covers a broader range of signs and a wider age range (16–30 months). The M-CHAT also includes a follow-up interview to be given, in which the parent is asked in more detail about symptoms identified by the questionnaire. This interview increases the specificity of the M-CHAT and is highly recommended. The sensitivity of the M-CHAT is reported to be as high as 85% (77% for the 2/6 critical item score, 92% for the 3/23 item score), but specificity is low (43% and 27%, respectively, for the two scores).
Other measures that may help detect early behavioral indicators of ASD include:

- **Infant Toddler Checklist (ITC)**, a test designed to screen for communication delays.

- **Screening Tool for Autism in Two-Year Olds (STAT)**, a tool previously designed to assess children younger than 2 years old, which may also be informative in the second year (sensitivity and specificity recently estimated at 95% and 73%, respectively, in a sample of 71 infants aged 12–23 months and at high risk). This screen requires direct observation and significant training.

- **Childhood Autism Spectrum Test (CAST)**, a 37-item, parent-completed questionnaire can be used in children ages 4–11 years old. This has a reported sensitivity and specificity of 88%–100% and 97%–98%, respectively.

1.4 **How should information be communicated to parents with regards to screening and screener results?**

Communication with parents is one of the most important tasks a pediatrician has during the visit. When undertaking screening for ASD, the pediatrician has the opportunity to discuss the parents’ concerns about their child, talk about the child’s strengths and weaknesses, and consider future steps.

When communicating about screening for ASD, a physician may discuss the following with the parent:

1. There is a high prevalence of developmental problems in infants and young children.
2. If a developmental problem should be found, there are many potential interventions.
3. Intervening earlier in a child’s developmental course can lead to improved outcomes.
4. Screening involves using a standardized tool to identify and describe a child’s risk for developmental delay (in this case, an ASD).
5. Screening is done routinely at the 18- and 24- or 30-month visits, or when any concerns are raised during surveillance.
6. Screening is not diagnostic. A positive screening test identifies a child at higher risk than one with a negative screen, but does not provide a diagnosis. Further diagnostic evaluation is warranted.

1.5 **How would you respond to the parents attributing Matthew’s language delay to being raised in a bilingual household?**

Growing up in a bilingual household should not be used as a reason to explain away a child’s speech or language delay. Sometimes, initially, children may have a short-lived delay in expressive language, but their receptive language should not be affected by being spoken to in two different languages. The delay in expressive language should be no more than 1-2 months. It is important when assessing a child’s speech to count words in both languages to come up with the total number of words that a child is speaking.
1.6 What are the strengths of this child and family?

It is always important to explore the strengths of a child with an autism spectrum disorder or developmental delays. Parents and clinicians may become so focused on the deficits and, in some cases, the behavioral issues that a child is having, that they aren’t able to notice what the child does well.

• By asking a family about what a child is good at, and what their positive traits are, one is able to frame recommendations for intervention and treatment in the context of these strengths.

• Asking about what a child likes can be used when discussing next steps.

• Finally, in addition to exploring the strengths of the child, it is helpful to think about the strengths of the family and how these can be used when discussing options and next steps for treatment.

It is always helpful for clinicians to take the time to note and explain changes and improvements in functioning and positive features of the child to parents.

• Matthew:
  − Attained his motor milestones appropriately
  − Enjoys interactive games
  − His parents describe him as a quiet and sweet boy

• Claudia:
  − She takes some interest in other children
  − She uses her finger to point to communicate her needs to her parents
  − She responds to her name at times
  − Her parents have demonstrated appropriate concern for Claudia and have asked relevant questions

Case Study Part I Activity: Scoring the M-CHAT Screener

Distribute M-CHATs for Matthew and/or Claudia. Ask learners to score each M-CHAT.

• Note that a child fails the M-CHAT when two or more critical items are failed or when any three items are failed.

• Also note that the failing responses are listed on the scoring sheet.

• Answers matching these answers are failed items. Items in bold and italics are the critical items.
Case Study Part I: Discussion Question

Before moving to Part II, ask participants, “What would you do next?”

Case Study Part II

Matthew’s parents complete the questionnaire and give it back to the nurse. The nurse scores the M-CHAT and determines that he has three failed items. You discuss Matthew with your preceptor, and together you decide to refer to an audiologist and call Matthew’s parents for a follow-up interview.

Claudia’s dad is unsure of the answers to several questions as mom typically cares for Claudia during the day. He asks to speak with you. Upon scoring the M-CHAT, you note that Claudia failed at least four critical items on the screening tool, as well as at least six other items. You explain to Claudia’s dad that some of his responses about Claudia’s behavior raised concerns about Claudia’s development.

Case Study Part II: Discussion Question

After reviewing the M-CHAT results, how has your initial reaction changed?

Case Study Part II: Potential Prompts

2.1 If the screening shows concerns, what is your plan of care? What if it is negative?

2.2 What is the value in doing a follow-up interview after the initial M-CHAT questionnaire? :30

2.3 What would contribute to a false negative screen? A false positive screen?
Supporting Information for Potential Prompts

2.1 If the screening shows concerns, what is your plan of care? What if it is negative?

If the M-CHAT reflects concerns:
Complete the M-CHAT follow-up interview. The follow-up interview is a semi-structured interview designed as a telephone or in-person interview administered to a caregiver of any child who failed an M-CHAT screening. The interview includes a script to review all the failed items, asks for specific examples, and offers multiple examples against which to judge whether the child fails or passes the item. If the follow-up interview raises concerns, referral for full evaluation is warranted.

If screening does not reflect concerns:
• Continue developmental surveillance at all health supervision visits

Case Study Part II Activity: M-CHAT Follow Up Interview
Matthew failed three M-CHAT items (5, 10, 23). Claudia, on the other hand, failed five critical items (2, 7, 9, 13, 14) and six other items (5, 6, 8, 10, 21, 22). A follow-up interview is warranted for both children. It should be noted that the positive predictive value of the M-CHAT for children younger than 2 years old may be lower (28%) than for those older than 2 years (61%). This emphasizes the importance of repeated assessment.

2.2 What is the value in doing a follow-up interview after the initial M-CHAT questionnaire?
Screening for ASD may be most informative when used as a starting point for active and repeated discussion regarding parental concerns. A follow-up interview should be done following the paper screen. The positive predictive value is 11% when using the M-CHAT questionnaire alone and 65% with the telephone follow up.

2.3 What would contribute to a false negative screen? A false positive screen?
• A parent or caregiver who does not fully comprehend the items might provide responses based on experience and perceptions that may not reflect true behavior. The clinician should make sure the parent completing the M-CHAT fully understands each item so as to give an accurate answer.
• Completing the M-CHAT at an early age (younger than the recommended age) might also contribute to a false negative or false positive screen. Approximately 30% of children with an ASD show a period of typical development followed by plateau or regression, and screening too early might miss some of these later-onset children.
• A child with other forms of developmental delay or other atypical forms of development might exhibit autistic-like behavior which would result in a false positive screen. Similarly, toddlers with severe developmental delays or impairments in vision and/or hearing may have a false positive screening for ASD.
Some children with an ASD, particularly those with more intact language and intellectual development, may have more subtle symptoms at an early age. Thus, mild symptoms and even an absence of symptoms at 18 months does not “rule out” a later diagnosis of an ASD. Ongoing surveillance and follow up are essential, particularly for children who are referred as a result of early concerns, but who do not initially receive an ASD diagnosis.

The positive predictive value of the M-CHAT for children younger than 2 years old may be lower (28%) than for those older than 2 years (61%). This emphasizes the importance of repeated assessment.

Clinical judgment should be considered when assessing a child. Even if a screen is negative, if there are professional or parental concerns, the child should be referred.

**Case Study Part III – Epilogue**

Matthew’s parents return the next week for a follow-up appointment to discuss the results of the screening tool, and you conduct the follow-up interview. On the follow-up interview, Matthew passes all the items. You discuss Matthew’s development with his parents and ask them if they have any concerns. They state that they do not at this time. You provide ideas for engaging Matthew in creative play, as well as facilitating speech and language development, and you make another health care-maintenance appointment for Matthew during which you will continue to follow his development progress. Per the AAP recommendations, Matthew should have another ASD-specific screen at 24 months or earlier if the parents or physician have concerns.

Claudia and her parents also return the next week so you can obtain further history and complete the M-CHAT follow-up interview with her mom and dad. You were concerned by Claudia’s results on the M-CHAT screener, and you would like to use the follow-up interview to identify the areas of greatest need and where to focus your energies. Claudia’s parents’ responses note continued concerns regarding Claudia’s communication and social skills. For instance, Claudia takes interest in children, but typically does not respond to the presence of others. She does not engage in pretend play and does not play properly with toys, preferring to bang them on the floor. Although she uses her finger to point, she cries and whines when she wants something and does not use gestures or pointing in order to work to gain attention from others. Claudia also does not imitate others. She occasionally responds to her name, but does not respond when she is focused on a preferred activity. She also has been noted to stare at nothing and wander. Given the presence of continued concerns, you speak in depth with Claudia’s parents regarding the possible diagnosis of autism spectrum disorder based on the screening measures. Of note, although some of Claudia’s initially reported behaviors of concern are resolved on the M-CHAT follow-up interview, and Claudia’s dad is unsure of some of Claudia’s behaviors, there remain enough concerning behaviors to warrant referral for further evaluation. You address the need for a formal evaluation to clearly delineate Claudia’s symptoms. Claudia’s parents are in agreement with the concerns, but also wonder how these results are accurate based on such a short time for observation. You refer Claudia for a hearing evaluation and an assessment by an early intervention specialist. You also refer her for a complete evaluation by a developmental specialist.

You schedule a follow-up visit with Claudia and her parents in two months to continue to follow her progress and to ensure that assessments and services are underway.
Case Study Part III – Epilogue: Discussion Question

*How would you apply the information in this case?*

*What did you learn through this case?*

Potential Next Case: Communication Concerns: Screening and Diagnosis Results

Case Goal

Primary care physicians are responsible for doing developmental screening in children. If one suspects that a child might have an autism spectrum disorder (ASD), the physician must be prepared to have a discussion with the child’s family.

After completion of this module, learners will be able to:

1. Discuss with parents a screening result that indicates need for further evaluation
2. Understand how to support a family when their child has been diagnosed with an ASD