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

CDC

Screening for Autism Spectrum Disorder



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-Revised with Follow-Up (M-CHAT-R/F) to screen two of her patients, ages 18 and 24 months. The resident explains the screening process to caregivers, interprets 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

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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-R 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-R Follow-Up Interview for Matthew or Handout IX: M-CHAT-R Follow-Up Interview for Claudia)

Only Have 30 Minutes to Teach? :30

Focus your discussion on the AAP Screening guidelines and administering/scoring the M-CHAT-R 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
- Optional Teaching Tools
  - PowerPoint
  - Handouts
    - Handout I: AAP Screening Guidelines
    - Handout II: Screening Tools Chart
    - Handout III: Blank M-CHAT-R Form
    - Handout IV: M-CHAT-R Form for Matthew
    - Handout V: M-CHAT-R Form for Claudia
    - Handout VI: M-CHAT-R Scoring Instructions
    - Handout VII: Blank M-CHAT-R Follow-Up Interview
    - Handout VIII: M-CHAT-R Follow-Up Interview for Matthew
    - Handout IX: M-CHAT-R Follow-Up Interview for Claudia
  - Video Library
- References

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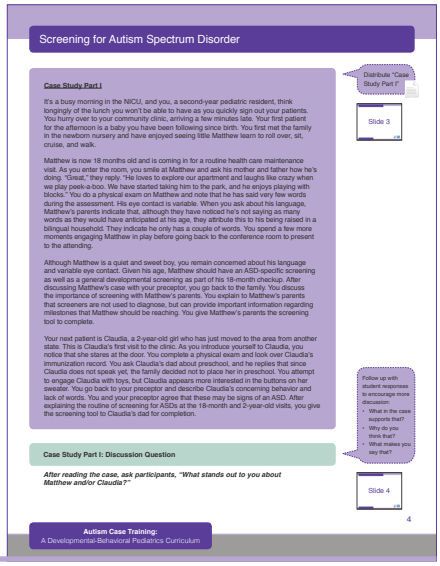
Getting Started

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
- :30 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.

Introduce the session goal and format of the case study

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.

Distribute "Case Study Part I"

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.

Slide 3

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 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.

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?

Case Study Part I: Discussion Question

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

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Case Study Part I: Potential Prompts

1.1 Discuss developmental surveillance and developmental screening. :30

1.2 When should we start screening for ASD? Why?

1.3 What screening tool should be used? :30

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?

I. AAP Screening Guidlines

Supporting Information for Potential Prompts :30

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., aversive to sounds or textures or extreme 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, little interest in others, prefers to play alone), lack of joint attention (e.g., pointing to indicate interest, showing objects of interest, looking at an object then back at the parent), lack of response to name, more interest in objects than people, repetitive behavior or play patterns, lack of creative or imaginative play (appropriate to developmental level)
- **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 supported 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?

:30

II. Screening Tools Chart

In *Identification and Evaluation of Children with Autism Spectrum Disorders*, 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.

III. Blank M-CHAT-R

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 Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R) can be administered and scored as part of a well-child care visit, and also can be used by specialists and other professionals to assess risk for ASD. The M-CHAT-R

is valid for screening toddlers between 16-30 months of age. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many children with ASD as possible. Therefore, there is a high false-positive rate, meaning that not all children who score at risk will be diagnosed with ASD.

To address this, the authors developed the Follow-Up questions (M-CHAT-R/F). The Follow-Up questions help clarify answers and obtain additional information for at-risk items. The Follow-Up questions improve the ASD detection rate and reduce the number of screen positives when compared to the M-CHAT alone. The estimated sensitivity of the M-CHAT-R with Follow-Up is 85% and specificity is 99%.

Even with the Follow-Up questions, a significant number of the children who score at risk on the M-CHAT-R will not be diagnosed with ASD. However, these children are at higher risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive.

The M-CHAT-R has been translated into numerous languages and translation materials can be found at www.mchatscreen.com.

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 24-36 months old, which may also be informative in children 12-23 months. (Sensitivity and specificity 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. One in 6 children ages 3-17 have some type of developmental "issue" (this includes everything from mild speech problems to more significant disorders like ASD and Intellectual Disability).
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, 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 needed to determine diagnosis and help develop intervention catered toward individual strengths and challenges.

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, bilingual 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 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 excels in, 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-R Screener :30

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

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm should be followed:

- LOW-RISK: Total Score is 0-2; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
- MEDIUM-RISK: Total Score is 3-7; administer the Follow-Up questions (second stage of M-CHAT-R/F) to get additional information about at-risk responses.
  - If 2 or more Follow-Up questions indicate ASD risk then the child has screened positive for ASD. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention.
  - If 0-1 Follow-Up questions indicate ASD risk then the child has screened negative for ASD. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
- HIGH-RISK: Total Score is 8-20; it is acceptable to bypass the Follow-Up questions and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

IV., V., and VI. Cmpleted M-CHAT-Rs for Matthew and Claudia and Scoring Template

Case Study Part I: Discussion Question

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

Distribute "Case Study Part II"

<u>Case Study Part II</u>

Matthew's parents complete the questionnaire and give it back to the nurse. The nurse scores the M-CHAT-R and determines that he has scored a three, putting him at Medium-Risk for ASD. You discuss Matthew with your preceptor, and together you decide to refer to an audiologist and administer the Follow-Up questions to get additional information about at-risk responses on the M-CHAT-R and then determine the appropriate referrals.

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-R, you note that Claudia scored a nine, plus two "unsure" responses, putting her at High-Risk for ASD. You tell Claudia's dad that some of his responses about Claudia's behavior raised concerns about her development. You explain that you would like to ask him or Claudia's mom some questions to clarify his responses.

Case Study Part II: Discussion Question

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After reviewing the M-CHAT-R 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-R 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?

VII. Blank M-CHAT-R Follow-Up Interview

If the M-CHAT-R Total Score is in the High-Risk category for ASD (total score of 8-20 points), refer for a comprehensive diagnostic evaluation and eligibility evaluation for early intervention or conduct the Follow-Up Interview to gain clarity on at-risk responses.

If the M-CHAT-R Total Score is in the Medium-Risk for ASD (total score of 3-7 points), conduct the Follow-Up Interview. The Follow-Up Interview is a semi-structured interview administered to a caregiver of any child who failed an M-CHAT-R 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, or if the child fails any two items on the Follow-Up, referral for comprehensive evaluation is warranted.

If the M-CHAT-R Total Score is in the Low-Risk for ASD (total score of 0-2 points) AND the provider and parents have no concerns, then **continue developmental surveillance** at all subsequent health supervision visits.

Case Study Part II Activity: M-CHAT Follow Up Interview :30

Matthew failed three M-CHAT-R items, putting him at Medium-Risk for ASD. Claudia, on the other hand, failed nine items plus two "unsure" questions, putting her at High-Risk for ASD. A Follow-Up Interview is warranted for both children.

VIII. and IX. M-CHAT-R Follow-Up Interview(s) for Matthew and Claudia

Even with Follow-Up Interviews, a significant number of children who fail the M-CHAT-R/F screener will not be diagnosed with ASD. However, these children are at risk for other developmental disorders or delays and require follow-up, evaluation, and appropriate intervention.

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2.2 What is the value in doing a Follow-Up Interview after the initial

M-CHAT-R questionnaire? :30

The Follow-Up questions help clarify answers and obtain additional information for at-risk items. The Follow-Up questions improve the ASD detection rate and reduce the number of screen positives when compared to the M-CHAT alone. The Follow-Up questions can also be viewed as a starting point for active and repeated discussion regarding parental concerns. A Follow-Up Interview should be done

- any time a child scores 3-7 total points on the M-CHAT-R.
- when a child scores 8-20 total points on the M-CHAT-R AND either the parent or provider is unsure of responses.

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 Follow-Up questions are designed to help clarify questions and responses. Providers can help illiterate or low-literacy parents complete the paper form.
- Completing the M-CHAT-R 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 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 some ASD symptoms, 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 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 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.

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 for a comprehensive evaluation and to early intervention.

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-R Follow-Up Interview with her mom and dad. You were concerned by Claudia's results on the M-CHAT-R, 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 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-R 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.

Distribute "Case Study Part III – Epilogue

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 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 ASD