



Communicating Concerns: Screening and Diagnosis Results

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



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Abstract

Tommy is a 2-year-old boy with an M-CHAT screen indicating concern that he might have Autism Spectrum Disorder (ASD). He was the full-term product of a vaginal delivery to a 42-year-old gravida 2 para 2 mother. His developmental history is notable for delayed onset of speech, an intense interest in geometric shapes, and a tendency to hum, grunt, and flap his hands when he is excited. Family history is notable for a paternal uncle with a history of speech delay and a first cousin with learning disabilities.

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 potentially complicated and difficult 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.

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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Key Learning Objectives of This Case

1. *Discuss with parents a screening result that indicates need for further evaluation. (Video Part I)*
 - a. Know how to describe the difference between a concerning screen and a diagnosis to a parent. (Prompts 1.4, 1.9 and Handout II: Talking with Parents About a Concerning Developmental Screen)
 - b. Identify reasons why parents may be reluctant to pursue a diagnostic evaluation after a concerning ASD screen. (Prompt 1.6)
 - c. Describe some important techniques that a physician should include when discussing a concerning screen with different families. (Prompts 1.3, 1.7, 1.8, 1.10)
2. *Understand how to support a family when their child has been diagnosed with ASD. (Video Part IIA and/or IIB)*
 - a. Describe specific techniques a physician can use to support a family whose child has been diagnosed with ASD. (Prompt 2.1 and Handout III: Steps for Delivering Difficult News)
 - b. Recognize the important features to assess when observing a child's behavior.
 - c. Identify various emotional responses parents may have after receiving an ASD diagnosis. (Prompt 2.2)
 - d. Name the stages of grief parents often experience when their child is diagnosed with a disability. (Handout IV: Stages of Grief)

Only Have 30 Minutes to Teach?

:30

Focus your discussion on principles of diagnosis and the diagnostic approach. Use:

- Handout II: Talking with Parents about a Concerning Developmental Screen and Handout III: Steps for Delivering Difficult News
- Videos: "Part I" and "Part IIA" OR "Part IIB"
- Potential Prompts: 1.3, 1.8, 2.1, and 2.2

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 with Embedded Videos (available on CD)
 - Handouts (available in Facilitator's Guide and on CD)
 - Handout I: "Learn the Signs. Act Early." Autism Spectrum Disorder Fact Sheet
 - Handout II: Talking with Parents About a Concerning Developmental Screen
 - Handout III: Steps for Delivering Difficult News
 - Handout IV: Stages of Grief for Parents Learning of a Disability in Their Child
 - Video Library (available on CD)
- References

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Note: This case focuses on verbal and nonverbal communication between a physician and parents of a child. Videos demonstrating this conversation are provided to enhance learning and discussion. It is strongly suggested to use these videos in lieu of the written dialogue.

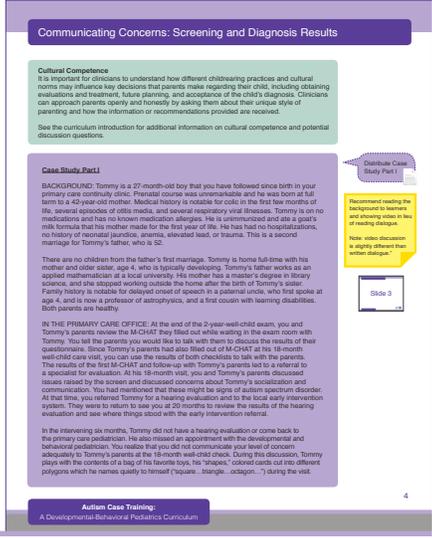
Communicating Concerns: Screening and Diagnosis Results

Getting Started

This case is designed to be an interactive discussion of a scenario residents may encounter in their practice. 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'



The screenshot shows the main content page of the case study. It includes a title bar, a 'Cultural Competence' section, a 'Case Study Part 1' section with a 'BACKGROUND' paragraph, and a 'IN THE PRIMARY CARE OFFICE' section. Callouts from the legend are overlaid on the page: a call-out bubble points to the 'Cultural Competence' section, a note icon points to the 'Case Study Part 1' section, a slide icon points to a 'Slide 3' box, and a filmstrip icon points to a video player area.

Why is This Case Important?

A key part of the screening process includes communicating results of the screening tool to parents. This can be a highly emotional experience, particularly if the screener has detected concerns. Good communication skills are essential to help parents understand the concerns and ensure their child sees appropriate specialists to determine if there is a developmental delay. This case provides a sample situation a physician may encounter and provides potential approaches to respond to parent reactions and concerns.

Introduce the session goal and format of the case study

This case was written before release of the DSM-5 in May 2013. The child in this video was diagnosed with PDD-NOS, which is no longer a diagnosis found in the DSM. Most children who previously would have been diagnosed with PDD-NOS or Aspergers fall under the new category of Autism Spectrum Disorder in the DSM-5. The discussion the parent has with the physician in these videos is still very relevant as discussion about ASD screening and diagnosis can still be challenging for both physician and families. *If you use the video version of this module, please refer to the written text as an example of how this conversation might change given the new criteria.*

Slide 1-2

Special note: If a person was diagnosed with Asperger syndrome before May 2013, his or her diagnosis stays the same, but can be considered ASD when seeking services and supports.

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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

BACKGROUND: Tommy is a 27-month-old boy that you have followed since birth in your primary care continuity clinic. Prenatal course was unremarkable and he was born at full term to a 42-year-old mother. Medical history is notable for colic in the first few months of life, several episodes of otitis media, and several respiratory viral illnesses. Tommy is on no medications and has no known medication allergies. He is unimmunized and ate a goat's milk formula that his mother made for the first year of life. He has had no hospitalizations, no history of neonatal jaundice, anemia, elevated lead, or trauma. This is a second marriage for Tommy's father, who is 52.

There are no children from the father's first marriage. Tommy is home full-time with his mother and older sister, age 4, who is typically developing. Tommy's father works as an applied mathematician at a local university. His mother has a master's degree in library science, and she stopped working outside the home after the birth of Tommy's sister. Family history is notable for delayed onset of speech in a paternal uncle, who first spoke at age 4, and is now a professor of astrophysics, and a first cousin with learning disabilities. Both parents are healthy.

IN THE PRIMARY CARE OFFICE: At the end of the 2-year-well-child exam, you and Tommy's parents review the M-CHAT they filled out while waiting in the exam room with Tommy. You tell the parents you would like to talk with them to discuss the results of their questionnaire. Since Tommy's parents had also filled out the M-CHAT at his 18-month well-child care visit, you can use the results of both checklists to talk with the parents. The results of the first M-CHAT and follow-up with Tommy's parents led to a referral to a specialist for evaluation. At his 18-month visit, you and Tommy's parents discussed issues raised by the screen and discussed concerns about Tommy's socialization and communication. You had mentioned that these might be signs of autism spectrum disorder. At that time, you referred Tommy for a hearing evaluation and to the local early intervention system. They were to return to see you at 20 months to review the results of the hearing evaluation and see where things stood with the early intervention referral.

In the intervening six months, Tommy did not have a hearing evaluation or come back to the primary care pediatrician. He also missed an appointment with the developmental and behavioral pediatrician. You realize that you did not communicate your level of concern adequately to Tommy's parents at the 18-month well-child check. During this discussion, Tommy plays with the contents of a bag of his favorite toys, his "shapes," colored cards cut into different polygons which he names quietly to himself ("square...triangle...octagon...") during the visit.

Distribute Case Study Part I

Recommend reading the background to learners and showing video in lieu of reading dialogue.

Note: video discussion is slightly different than written dialogue."

Slide 3

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YOU: Let's have a look at the developmental questionnaire you filled out.

Mother: Yes, I remember we filled out something similar on the last visit. I think he has made a lot of progress since then. He certainly has more words than he did then.

YOU: And that is really terrific. A growing vocabulary is something we really like to see, but there are some answers that concern me.

Father: Like what?

YOU: For example, on both occasions you answered that Tommy doesn't seem interested in other children.

Father: That's true – he isn't. He prefers to be alone, or to be with adults. Other children are unpredictable and he doesn't like that. He likes things to be a certain way, and other kids don't always understand that.

YOU: That's somewhat unusual for his age. Most 2-year-olds are social, and even if they don't play with other children, they are interested in being around other children, and other people in general. It's how they learn about the world.

Father: Well, most of my family is pretty anti-social or really shy, especially my brother. I think he is more like my side of the family.

YOU: He may be, but a couple of other items also suggest something more than a family trait. For example, the fact that Tommy doesn't point with his finger to indicate something of interest, or follow your point with his eyes when you would like to point something out to him.

Mother: I think he is just in his own little world, but now that he talks a little, he is more communicative. If he wants something, he'll just pull me to it so I know what it is. He can get very frustrated when we don't understand what it is that he wants, but mostly we can figure it out.

YOU: One other item that you checked is that he doesn't really respond to you when you call his name. Can you tell me more about that?

Father: Well, we don't really agree on that one. He does, if I really get down close to him and touch him. But if he is across the room, he will not look at you when you call his name.

YOU: Hmmm. Remind me, is he in daycare or preschool during the day?

Mother: We tried preschool for a few weeks, but it was a disaster, and we decided to keep him at home. He is much happier at home by himself than he is with other children.

YOU: What exactly do you mean by "disaster"?

Mother: They told us he wasn't ready. He was too rigid and wasn't interested in the other children. He got upset when they got too close to him or wanted to change something he was playing with. They didn't think he should spend so much time playing with his shapes. I think it just wasn't a good fit for him.

Slide 4

:30

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YOU: That's possible, but it is unusual to have such a difficult time in a preschool, so we should keep that in mind as we talk. Let's look at the screening form. This is meant to help us understand children whose development is not typical in one way or another. It doesn't make a diagnosis, but helps us see when a child is not developing as we would expect. Your answers suggest that there are a few areas where Tommy is lagging behind other children his age, and that's why I think it's important for Tommy to see a developmental specialist. I wonder if I communicated this to you well enough at Tommy's last visit.

Mother: Yes, but we were uncomfortable with the idea that there is something wrong with him, and didn't really know what you meant by an "evaluation." And now he is making progress. Do you still think we need to do this?

YOU: Yes, I do. There are things we can do to help him, and the sooner we do it, the better. This questionnaire doesn't give a diagnosis, but it does tell us that we need more information through a more thorough developmental assessment.

Father: What will they do? They aren't going to put him on meds or anything are they?

YOU: Not at all. It's a play-based evaluation, where the doctor uses toys in a very specific way to see what Tommy will do, how he communicates, that sort of thing. For a child Tommy's age, you can be there throughout the visit.

Mother: All right, it sounds like you really want us to go through with this.

YOU: I do, and I am here to talk to you about it afterwards. The specialists will do the evaluation and make recommendations about what they think might help him, but I will continue to be his pediatrician, and we will follow him along together. It's what Tommy needs right now. I'm so glad that you were both able to attend today and would like to invite you both back so I can hear both of your perspectives.

Father: Okay, doc. We'll do it.

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Case Study Part I: Discussion Question

After reading the case, ask participants, “What stands out to you about this case?”

Slide 5

Case Study Part I: Potential Prompts

- 1.1 What is known about how parents prefer to hear news about developmental delays?
- 1.2 How would you approach parents who are overly concerned?
- 1.3 What elements of this interaction are especially important? :30
- 1.4 What should you take into account when making referrals? Should there be variability based on individual families?
- 1.5 How would you respond to the family’s mention of the father’s brother?
- 1.6 What do you think contributed to the parents’ reluctance to follow through with the initial referral to a developmental-behavioral pediatrician?
- 1.7 What are the important messages, including statements and tone, that you heard in this sample conversation?
- 1.8 What does this sample dialogue teach us about how to address the parents’ reactions? :30
- 1.9 After a concerning screen, what language would you use with parents? Would you use the words “autism spectrum disorder?” Would you use the word “failed?”
- 1.10 It sometimes takes a long time to talk with parents about results from a concerning screen. Is it possible to bill for this time? What codes would you use?
- 1.11 What are the child’s strengths?

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?

Supporting Information for Potential Prompts

1.1 *What is known about how parents prefer to hear news about developmental delays?*

There is no one way to present information about developmental concerns. Most parents prefer a non-alarmist approach to communicating concern about a possible developmental delay. Some parents will want a very direct approach, including an answer to “what do you think it could be?”

Most parents who bring up the possibility of developmental delays want to be heard, not just reassured that their child is normal. (See article by Sices and Egbert, 2009.)

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1.2 *How would you approach parents who are overly concerned?*

- Most parents want to be heard if they raise concerns, not just be reassured that their child is “normal.” (See article by Sices and Egbert, 2009).
- Assess parents’ knowledge of child development and what resources the parent has or uses to learn about child development.
- Explore why parents appear to be overly concerned. For example, is there a family history of learning problems or autism spectrum disorder?

1.3 *What elements of this interaction are especially important?*

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- Explaining “screening” as distinct from diagnosis and as a first step in sorting out what the child’s developmental needs may be.
- The pediatrician’s patience in trying to join with the parents and understand their concerns, even when they have failed to follow the pediatrician’s recommendations in the past.
- The pediatrician’s willingness to ask in a non-judgmental manner if the communication strategy that she used regarding referral to the developmental specialist was clear.
- The pediatrician offering to be available for questions, and reassuring parents she will continue to be the child’s doctor.
- The pediatrician’s referral to early intervention services following initial concern despite lack of a definitive diagnosis and again following diagnosis.
- The pediatrician’s close follow-up to determine if recommendations are being followed or if they need to be adjusted.

1.4 *What should you take into account when making referrals? Should there be variability based on individual families?*

- Assess family’s readiness for evaluation. If parents seem to be concerned about moving forward, it is important to continue to support the family.
- Families can be overwhelmed by hearing difficult news as well as with all the tasks that they are asked to follow through on. If this occurs, it might be necessary to give one task to follow through on, such as getting a hearing test or calling the early intervention agency. The family should have frequent follow-up appointments with the primary care doctor soon so they can be supported and continue to work through other tasks that need to be addressed.
- How much can a family handle at each interaction?
- Assess family support structure and family strengths.
- Individual family needs should always be considered.

1.5 *How would you respond to the family’s mention of the father’s brother?*

Scientific evidence shows that ASD has a genetic component. It is not unusual to have a report of a family member with similar characteristics. Some families choose to explore an ASD diagnosis in adult family members, but this is generally not discussed at time of diagnosis or referral for the child.

1.6 *What do you think contributed to the parents’ reluctance to follow through with the initial referral to a developmental-behavioral pediatrician?*

Fear or anxiety about a possible diagnosis can sometimes cause such strong anxiety or fear that parents do not follow through with recommendations for an evaluation. Comments from other family members that a child “is just going through a phase” or “is just like his uncle when he was a child, and he turned out fine” may discourage parents from pursuing further evaluation. Financial considerations can also play a role.

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1.7 *What are the important messages, including statements and tone that you heard in this sample conversation?*

- Recognizing the parents' fear of the evaluation and their desire to normalize the unusual behaviors they have observed
- Noting that there may be some differences in each parent's levels of concern
- Leaving room for a variety of possible outcomes
- Explaining that the screening tool (M-CHAT) is just that, and does not make a diagnosis
- Reassurance that this will be a team effort
- Helping parents anticipate what the experience will be like for them and their son

1.8 *What does this sample dialogue teach us about how to address the parents' reactions?*

- The pediatrician:
 - Meets with both parents together
 - Leaves space for questions, and matches affect to that of the parents
 - Is honest about the limits of screening in his or her office
 - Is open to hearing parents' reactions to his or her suggestions
 - Recognizes that family history is critical to the couple's understanding of their child's differences
 - Mentions Tommy by name, and comments on his strengths, as well as his weaknesses

1.9 *After a concerning screen, what language would you use with parents? Would you use the term "autism spectrum disorder?" Would you use the word "failed?"*

:30

- It's important that families understand what you are screening for without overly alarming them.
- Talk about the difference between a screening and diagnosis.
- Reassure parents that even if a child is diagnosed, he or she is the same child they know and love, with or without that label, but that the diagnosis may make it easier to get the child the supports he or she needs.
- "Failed" is a common medical term, but can be alarming for parents. Use words such as "concerning" to reflect the importance of results without unnecessarily increasing anxiety.
- Talk about specific concerns, like how the child's trouble expressing what he wants and needs results in a lot of frustration for him and the parents. Identifying concerns like this will help lead to ways of addressing these challenges.
- "Autism" and "autism spectrum disorder" can be alarming for some parents at this phase of the process, while other parents may directly ask you about these terms. Use your knowledge of this family to determine if you should use these terms.
- Reflect on your relationship with the family and use the strengths you know about this child as you discuss concerning results.

I. Autism Spectrum Disorder



1.10 *It sometimes takes a long time to talk with parents about results from a concerning screen. Is it possible to bill for this time? What codes would you use?*

Yes, you can usually bill for this time. This scenario typically falls under the Prolonged Services codes. This is a code series defining prolonged services by: Site of Service, Direct or Without Direct Patient Contact, and Time. It's reported in addition to other physician services, including E/M services at any level. It includes the total time for a given date, even if the time is not continuous. The time must be of 30 minutes or more.

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Counseling parents about concerns following results from a screen would likely be a preventive care visit. Consider the following codes:

:30

Face to Face	99354 first 30-74 min
Face to Face	99355 each add 30 min>75
Before or After Face to Face	99358 first 30-74 min of non-face to face
Before or After Face to Face	99359 each add 30 min>75 min

II. Talking with
Parents About
a Concerning
Developmental
Screen.



Note: Billing and coding rules can change. Please check to ensure you are using the most current codes and guidelines.

1.11 What are the child's strengths?

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.

- Asking a family what a child is good at and what his positive traits are allows you to frame recommendations for intervention and treatment in the context of these strengths.
- Asking about a child's 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.

Some strengths shown by Tommy include:

- A growing vocabulary
- A devoted, involved family

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Optional Activity: Possible Scenarios for Roleplay:

1. Parents openly disagree about whether to pursue the evaluation. Assign roles to:

- Mother: Wants to pursue the evaluation and is worried that Tommy will turn out like his uncle.
- Father: Resists the idea of evaluation, is proud of how smart Tommy is, and is not at all concerned that he is not a sociable child.
- Pediatrician: Tries to help both parents voice their concerns, yet advocate for the child, who is the patient. It is important for the pediatrician to review why the evaluation is important. It is often helpful to state the obvious, that there is not agreement between the parents and recognize this dilemma. It may be helpful to note that it is common for parents to process these types of events differently and at their own pace. If the disagreements are strenuous or the parents are divorced, one might suggest that counseling can be helpful to try to resolve these types of disagreements. It may be helpful for the pediatrician to alert the family of the timeliness needed to resolve this dilemma/dispute.

2. Mother cries. Father consoles. Assign roles to:

- Mother: Cries, states she has been worried about Tommy for a long time, afraid to say anything. Worried that she was too old to have a second baby, that they “should have quit while they were ahead” after the birth of their first child.
- Father: Consoles mother, reminding her that other family members have had similar stories and have “turned out okay.”
- Pediatrician: Notes that many parents place blame on themselves for a child’s disabilities. It is important to address it in a way that is credible and not dismissive. Compare: “It’s not unusual for parents to feel what has happened is somehow their fault and this is often very painful. It sounds like you have had worries about Tommy for a long time and have carried a feeling of guilt. Tommy’s problems are complex. You have been caring parents and are not responsible for causing these problems,” with “Don’t worry, you didn’t cause this.”

Consider having residents do a roleplay of different outcomes in the clinic visit.



Recommend showing video of discussion in lieu of reading dialogue.

Note: Video discussion is slightly different than written dialogue. Use written dialogue to address changes given changes associated with the DSM-5.

Attention Facilitator:

You can use either or both of the following Part II cases, based on your preference and available time. You can brainstorm other possible scenarios with the group.

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Case Study Part IIA

Three months later, in the PCP's office after the evaluation...

YOU: Welcome back, Tommy, it's good to see you. I have some toys here for you to play with.

Mother: He's brought his shapes along; he'll be fine if we set him up with the shapes.

YOU: Great, let's do that then. I wanted to see you to review the letter from the developmental and behavioral pediatrician, which I know was sent to you as well as to me. Before we get down to that, how did the evaluation go?

Father: I think they got a pretty good picture of him after he warmed up. He wasn't too cooperative at first, but eventually he was able to interact with him.

Mother: I don't think they saw him at his absolute best, but he pretty much showed the doctor who he is.

YOU: Well that's encouraging. Children can be different from day to day, like all of us, and it's good they got a reasonable picture of who he is.

Mother: We brought the letter with us. Do you agree with this diagnosis? And what does it mean? Autism Spectrum Disorder makes it sound like he is delayed in everything, but he isn't. In some areas, he is advanced. Even the specialist said that. And what does "Level 2" in social communication and interaction and "Level 1" in restricted behaviors mean? I just don't understand it.

YOU: The terminology can be confusing. Let me explain as well as I can. All children with ASD share challenges interacting and communicating with other people and have unusual interests or behaviors. The levels refer to how much support he needs to function like other children his age. Level 1 in "restricted behaviors" means he does need support to, for instance, put down his shapes and play with other types of toys. Level 2 in social communication and interaction means that he needs even more support to, for example, interact with other children and get his wants and needs met. Tommy did not score Level 3 in either area, but Level 3 means a person requires very substantial support. Levels can fluctuate over time. The amount of help Tommy needs may also change over time, so deciding how much support he needs in any particular area will be a measure of ongoing progress. You are absolutely right that Tommy is not delayed in all areas. He has some real strengths, like his memory and his ability to identify shapes. However, he also has a hard time telling you what he wants and seems overly focused on shapes. He's also not pointing to show you what he wants.

Mother: So what does this mean for Tommy? Why did this happen? Do you think it's because I had the flu when I was pregnant with him?

YOU: It sounds like you are wondering if there was anything you did that may have caused Tommy to have ASD. Most of the time, we don't know why a child like Tommy develops ASD. Often the specialists order genetic tests, because in a small percentage of children there is a genetic difference we can find with a genetic blood test. We do know that when one child in a family is diagnosed with autism spectrum disorder, there

Distribute "Case Study Part IIA"



:30

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is an increased chance that another child will also have it. There are a lot of theories out there that you might have heard about, but unfortunately, we don't have a lot of answers yet about ASD.

Father: Does that mean his sister could get this?

YOU: We expect to see symptoms of ASD before children turn three years old. Since she is four years old and really seems to be typically developing in her language and her social skills, I am not worried about her in this regard.

Father: Will he outgrow it? If we help him now, could he possibly be normal when he gets older?

YOU: We expect that with strong early intervention and appropriate therapies, children with ASD will make advances in social communication and interactions and improve in the area of restricted behaviors. We think of these conditions as lifelong, but we just can't predict what that will mean for Tommy in 5 or 10 or 15 years. He has a lot of strengths to build on, and with the right kind of help, he will definitely gain more skills as he grows up.

Father: I think we just have to sit with this for a while. I don't like the idea of Tommy being labeled.

YOU: It's a lot to think about, and you are right to take a little time to digest it all. (Pauses and sits quietly with parents). While you are processing the information, let's start to think about what's next.

Mother: And what is that?

YOU: The next step is Early Intervention, which could include various therapies. There are good programs in the neighborhood that I have worked with for years.

Mother: Wait a minute. Since he is obviously making some progress on his own, does he really need Early Intervention?

YOU: It can help a child who is having difficulty, especially in the social and communication areas. Depending on the program, he is likely to be offered some speech and language therapy, and some help with his social skills in small groups with other children. All the children in the group will be under three. A child with a diagnosis of ASD may be able to receive more hours of help than children with some other diagnoses. The Early Intervention program also helps children transition into appropriate preschool programs when they turn three.

Father: Then what?

YOU: Because of his developmental differences, he will likely qualify to continue receiving services, such as speech and occupational therapy, provided by your local public school in a preschool setting with other children his age. Optimally, in addition, services will include early intensive behavioral intervention to help Tommy learn new skills.

Mother: When he was in preschool it was a disaster. He was basically kicked out. I am worried about sending him to school before he is ready.

Communicating Concerns: Screening and Diagnosis Results

YOU: Children with ASD often have a hard time in a regular preschool program, but can do well in a program that integrates typically developing children along with children with ASD. That way the children can learn from their peers, while at the same time getting some extra help from staff that are trained to work with children with ASD. But let's not get ahead of ourselves. Tommy has six months before he turns three, and a lot can happen in six months. Let's get the Early Intervention started first.

Mother: How do we do that?

YOU: I will give you the telephone number of the local program. You can call yourself to get started. Then they will request some information from me, and I will send it along. It's always a good idea to keep a folder with all of Tommy's records as you visit different specialists.

Father: Why do you think this is so important?

YOU: It's one of the things we know for sure can make a difference.

Mother: Doctor, this is hitting us pretty hard. We thought he was just a quirky kid, and would grow up to be fine. Now you and the specialist are telling us to see him differently.

YOU: I appreciate how hard this is for the two of you. Remember that Tommy is the same boy he has always been. We are just seeing him through a different lens, and we see some areas where we would like to help him. The testing shows that Tommy is bright and this gives me confidence that he will continue to make good progress.

Father: Okay doc, I think we have enough to think about for today. If you give us the telephone number, we will call the program.

Case Study Part IIA: Discussion Question

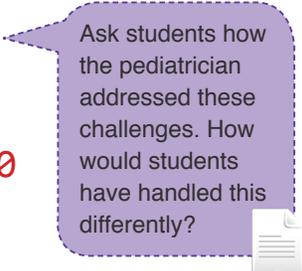
What went well in this interaction? What didn't go well?

Case Study Part II: Potential Prompts

- 2.1 What are the challenges for the pediatrician in discussing this difficult diagnosis with this family? **:30**
- 2.2 What are the challenges for the parents? **:30**
- 2.3 Did you note any jargon used by the pediatrician that might not be understood by parents?
- 2.4 It sometimes takes a long time to talk with parents about a specialist's diagnosis of autism spectrum disorder. Is it possible to bill for this time? What codes would you use?



Slide 8



Ask students how the pediatrician addressed these challenges. How would students have handled this differently?

Communicating Concerns: Screening and Diagnosis Results

Supporting Information for Potential Prompts

- 2.1 *What are the challenges for the pediatrician in discussing this difficult diagnosis with this family?* :30
- Assisting the parents in processing a potentially emotionally upsetting diagnosis
 - Explaining medical terms, such as “Autism Spectrum Disorder” and the severity levels in a manner parents will understand
 - Guiding parents to see the value of Early Intervention and overcoming fears of having their child “labeled”

- 2.2 *What are the challenges for the parents?* :30
- Acceptance: Even for parents expecting the diagnosis, having it said by an expert is shocking
 - A natural reaction for a family is shock and denial
 - Understanding complex information about Tommy’s diagnosis and next steps
 - Guilt and concern they may have “caused” Tommy’s ASD
 - Fear for Tommy’s future
 - Concern about Tommy being “labeled”

- 2.3 *Did you note any jargon used by the pediatrician that might not be understood by parents?*
- Autism Spectrum Disorder or ASD
 - Early Intervention or EI
 - M-CHAT

Special note about the video:

This case was written before release of the DSM-5 in May 2013. The child in this video was diagnosed with PDD-NOS, which is no longer a diagnosis found in the DSM. Most children who previously would have been diagnosed with PDD-NOS fall under the new category of Autism Spectrum Disorder in the DSM-5. People who received a diagnosis of PDD-NOS or Aspergers prior to release of the DSM-5 keep their diagnosis. The written script reflects the change and therefore is not an exact match to the dialogue in the video.

- 2.4 *It sometimes takes a long time to talk with parents about a specialist’s diagnosis of autism spectrum disorder. Is it possible to bill for this time? What codes would you use?*

Yes, you can usually bill for this time. This scenario typically falls under the Prolonged Services codes. This is a code series defining prolonged services by: Site of Service, Direct or Without Direct Patient Contact, and Time. It’s reported in addition to other physician services, including E/M services at any level. It includes the total time for a given date, even if the time is not continuous. The time must be of 30 minutes or more.

Counseling parents about concerns following results from a screen would likely be a preventive care visit. Consider the following codes:

This case was written before release of the DSM-5. The child in this video was diagnosed with PDD-NOS, which is no longer a diagnosis found in the DSM. Most children who previously would have been diagnosed with PDD-NOS fall under the new category of Autism Spectrum Disorder in the DSM-5, and people previously diagnosed with PDD-NOS or Aspergers keep their diagnosis. The discussion the parent has with the physician in these videos is still very relevant, as discussion about ASD screening and diagnosis can still be challenging for both physician and families. You may wish to ask learners to identify what might be different with new criteria and what remains the same. You can use the written text to discuss potential differences.

III. Steps for Delivering Difficult News

IV. Stages of Grief for Parents Learning of a Disability in Their Child

Communicating Concerns: Screening and Diagnosis Results

Face to Face	99354 first 30-74 min
Face to Face	99355 each add 30 min>75
Before or After Face to Face	99358 first 30-74 min of non-face to face
Before or After Face to Face	99359 each add 30 min>75 min

Note: Billing and coding rules can change. Please check to ensure you are using the most current codes and guidelines.

Case Study Part IIB

Three months later, in the PCP's office after the evaluation...

YOU: Come on in. It's good to see you. I wanted to have you in alone to talk about the results of Tommy's testing with the developmental and behavioral pediatrician.

Mother: Thanks. It'll be easier to talk about him when he isn't here.

Father: Agreed. He has started having tantrums when he doesn't get his way, and it's hard to talk around that.

YOU: I wanted to review the letter from the specialist with you to be sure you understand what he thinks and what the next steps should be. How did the evaluation go?

Father: Not very well. Tommy did not sleep well the night before and was cranky. I don't think the specialist got any idea of all the things he can do. He barely spoke at all and wouldn't even look at the guy.

Mother: I don't think they saw all of what he can really do. He was very clingy. I don't know how they think they can make a diagnosis after only seeing a child on one morning. We were upset by the whole thing.

YOU: It can be painful to see your child being evaluated, especially when he doesn't do things that you know he can do at home. However the instruments are designed to look at very specific things, and even if a child is having a bad day, we can often see things that we are concerned about.

Mother: I just wish he were more cooperative. He wouldn't even look at the doctor, but then again, the doctor doesn't know exactly how to get him to look at him, and we do. That's the type of thing that upset me.

YOU: I understand that. Let's talk about the letter. Do you have questions about it, anything you don't agree with or don't completely understand?

Father: I can't believe he gave him a diagnosis at all, after knowing him for such a short time, given that Tommy wasn't even himself that day. It's one of the reasons I didn't really want to do this in the first place. I don't like the whole idea of labeling kids, and now

Distribute "Case Study Part IIB"

Consider showing video of discussion in lieu of reading dialogue.
Note: video discussion is slightly different than written dialogue.

Slide 9

Slide 10

:30

Communicating Concerns: Screening and Diagnosis Results

Tommy has a label. As far as I'm concerned, no one ever needs to know this. I certainly don't plan on telling anyone.

YOU: Well, there isn't any need for anyone else to know at this point. That's a decision the two of you will make together, and you're right that there is no need for you to talk to anyone, but each other.

Mother: I would like to talk to my sister about it. She is a teacher and has a lot of experience with kids.

YOU: I remember you told me that she had expressed some concerns about Tommy.

Mother: Right, and I think she could be helpful to us.

YOU: I hope so. It's wonderful to have someone close to you who understands and can offer some support.

Father: So the specialist thinks Tommy has ASD "Level 2" in social communication and interaction and "Level 1" in restricted behaviors. (Father is reading from the letter.) What do you make of that?

YOU: Well, I thought that Tommy could possibly have a diagnosis like this, based on the screening test we reviewed the last time you were here. You may remember we discussed that M-CHAT screen that we did where he showed some signs of problems with social communication, and I was concerned that he might have symptoms of autism spectrum disorder.

Mother: We don't agree that he is autistic at all. How can a child be autistic who knows as much as he knows at such a young age? How many kids do you know who are so young and know all their shapes and letters. He is practically ready for kindergarten and he isn't even 3.

YOU: The fact is that many children on the autism spectrum have some amazing skills, skills they can build on over time. Tommy is so bright, and so clever, and so sweet. These are all great things that will help him over time.

Father: Can we talk about the diagnosis again? I still don't get it; like my wife says, how can he be autistic and practically be able to read? It just doesn't add up.

YOU: Let's back up a little and review what exactly ASD means in general and what the levels mean and then we can talk about what it means for Tommy.

Mother: Good, because I am still confused. I've never even heard of the levels.

YOU: Let's talk about the areas that children with ASD have difficulty with. The first is social communication and social interactions. This includes nonverbal communication like gestures, eye contact, pointing and following a point, that sort of thing. It also includes interactive behaviors like playing and enjoying playing with another person, having back-and-forth conversations, and sharing things he's interested in. And the other area is repetitive interests or behaviors. In Tommy's case we have some concerns in these areas.

Communicating Concerns: Screening and Diagnosis Results

Father: If you are talking about his geometric shapes, he has used those to learn so many things. He can do patterns, he knows the names of all of them, including the dodecahedron, and he has learned his colors from them.

YOU: His interest in shapes has certainly been a help to him in some ways. This interest can also help me explain how the levels work. The levels refer to how much support he needs to function like his peers. Level 1 in “restricted behaviors” means he does need support to, for instance, put down his shapes and play with other types of toys. Level 2 in social communication and interaction means that he needs even more support to do things like interact with other children and to get his wants and needs met. You’ve noticed how that Tommy doesn’t share the shapes with anyone; he isn’t interested in enjoying them together with other people. Tommy did not score Level 3 in either area, but Level 3 means a person requires very substantial support. Levels can fluxuate over time.

Father: So what do you think caused it? He was never exposed to any vaccines, as you know, and my wife was so careful when she was pregnant. She wasn’t sick, didn’t drink any alcohol, and was completely healthy. Our daughter is completely fine.

YOU: We are quite sure that vaccines do not cause ASD.

Mother: Don’t you think we are over-diagnosing it? It’s all you read about. Everyone seems to have a child with ASD now. Why is there such an increase? There must be something in the environment.

YOU: It’s not clear that there really is an increase. The way of describing children has changed, and a lot of children would have been called something else 20 or 30 years ago.

Father: So what’s going to happen to Tommy? Should we be putting him on a special diet or extra vitamins?

YOU: In my experience the special diets haven’t helped very many children, and there is no good medical evidence to support it. Since Tommy has a pretty restricted diet to begin with, I would be worried about his getting enough nutrition to grow and be healthy. If you do decide to pursue this, I would urge you to consult with a nutritionist to be sure he is getting adequate nutrition and calories for growth and well-being.

Mother: What about vitamins? Can you do a test to see if he has a toxin in his system like mercury or lead?

YOU: A regular children’s multivitamin is fine, especially in a picky eater, but I would be careful about using high-dose vitamins. There isn’t enough known about the effects in young children.

Father: Do you think we should have him tested for mercury?

YOU: There is not a standard for measuring mercury in children, so it’s impossible for me to interpret. I don’t recommend it.

Mother: I am still worried about it because I have read about kids who are autistic because of an overload of mercury in their blood.

Communicating Concerns: Screening and Diagnosis Results

YOU: There is very little evidence to suggest that this is the case. There is evidence to support Early Intervention or EI. We know that can help. Tommy is likely to really enjoy it, and you will learn from it as well. The EI specialists are experienced in working with children and families, and it's almost always a positive experience for everyone. It's the best thing to start helping Tommy.

Case Study Part IIB: Discussion Question

What went well in this interaction? What didn't go well?

Case Study Part III: Potential Prompts

- 2.1 What are the challenges for the pediatrician in discussing this difficult diagnosis with this family? :30
- 2.2 What are the challenges for the parents? :30
- 2.3 Did you note any jargon used by the pediatrician that might not be understood by parents?
- 2.4 It sometimes takes a long time to talk with parents about a specialist's diagnosis of autism spectrum disorder. Is it possible to bill for this time? What codes would you use?



Ask students how the pediatrician addressed these challenges. How would students have handled this differently?



Communicating Concerns: Screening and Diagnosis Results

Supporting Information for Potential Prompts

2.1 *What are the challenges for the pediatrician in discussing this difficult diagnosis with this family?*

:30

- Assisting parents in processing a potentially emotionally upsetting diagnosis
- Explaining medical terms, such as “Autism Spectrum Disorder” and the levels in a manner parents will understand
- Parent concerns that child wasn’t accurately evaluated
- Parental disagreement with the diagnosis
- Parental questions about causes of ASD and over-diagnosis or “labeling” of children
- Guiding parents to see the value of Early Intervention and assisting them in making wise choices about alternative therapies and testing

2.2 *What are the challenges for the parents?*

:30

- Understanding complex information about Tommy’s diagnosis and next steps
- Fear for Tommy’s future
- Differentiating evidence-based medical information
- Concern about Tommy being “labeled”

III. Steps for Delivering Difficult News



2.3 *Did you note any jargon used by the pediatrician that might not be understood by parents?*

- Autism Spectrum Disorder or ASD
- Early Intervention or EI
- M-CHAT

IV. Stages of Grief for Parents Learning of a Disability in Their Child



This case was written before release of the DSM-5 in May 2013. The child in this video was diagnosed with PDD-NOS, which is no longer a diagnosis found in the DSM. Most children who previously would have been diagnosed with PDD-NOS or Aspergers fall under the new category of Autism Spectrum Disorder in the DSM-5. The discussion the parent has with the physician in these videos is still very relevant as discussion about ASD screening and diagnosis can still be challenging for both physician and families. *If you use the video version of this module, please refer to the written text as an example of how this conversation might change given the new criteria.*

Special note: If a person was diagnosed with Asperger syndrome or PDD-NOS before May 2013, his or her diagnosis stays the same, but can be considered ASD when seeking services and supports.

2.4 *It sometimes takes a long time to talk with parents about a specialist’s diagnosis of autism spectrum disorder. Is it possible to bill for this time? What codes would you use?*

Yes, you can usually bill for this time. This scenario typically falls under the Prolonged Services codes. This is a code series defining prolonged services by: Site of Service, Direct or Without Direct Patient Contact, and Time. It’s reported in addition to other physician services, including E/M services at any level. It includes the total time for a given date, even if the time is not continuous. The time must be of 30 minutes or more.

Counseling parents about concerns following results from a screen would likely be a preventive care visit. Consider the following codes:

Communicating Concerns: Screening and Diagnosis Results

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Note: Billing and coding rules can change. Please check to ensure you are using the most current codes and guidelines.

Case Study Part III – Epilogue: Discussion Questions

How would you apply the information in this case?

What did you learn through this case?



Potential Next Case: “Making an Autism Spectrum Disorder Diagnosis”

Case Goal

The diagnosis of autism spectrum disorder (ASD) is made on the basis of detailed information obtained from the child’s caregivers, careful observation and assessment of the child, and the use of standardized tools designed to aid in the diagnosis of ASD.

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

- Be familiar with the basic principles regarding the diagnosis and epidemiology of ASD.
- Understand the diagnostic approach to evaluating a child with suspected ASD.

Case Worksheet for Learners

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 potentially complicated and difficult discussion with the child's family.

Key Learning Points of This Case

1. *Discuss with parents a screening result that indicates need for further evaluation.*

a. Know how to describe the difference between a concerning screen and a diagnosis to a parent. _____

b. Identify reasons why parents may be reluctant to pursue a diagnostic evaluation after a concerning ASD screen.

c. Describe some important techniques that a physician should include when discussing a concerning screen with different families. _____

2. *Understand how to support a family when their child has been diagnosed with ASD.*

a. Describe specific techniques a physician can use to support a family whose child has been diagnosed with ASD.

b. Identify various emotional responses parents may have after receiving an ASD diagnosis. _____

c. List the aspects of the physical exam that are of particular importance when evaluating for ASDs. _____

d. Name the stages of grief parents often experience when their child is diagnosed with a disability. _____

Case Study Part I

BACKGROUND: Tommy is a 27-month-old boy that you have followed since birth in your primary care continuity clinic. Prenatal course was unremarkable and he was born at full term to a 42-year-old mother. Medical history is notable for colic in the first few months of life, several episodes of otitis media, and several respiratory viral illnesses. Tommy is on no medications and has no known medication allergies. He is un-immunized and ate a goat's milk formula that his mother made for the first year of life. He has had no hospitalizations, no history of neonatal jaundice, anemia, elevated lead, or trauma. This is a second marriage for Tommy's father, who is 52.

There are no children from the father's first marriage. Tommy is home full-time with his mother and older sister, age 4, who is typically developing. Tommy's father works as an applied mathematician at a local university. His mother has a master's degree in library science, and she stopped working outside the home after the birth of Tommy's sister. Family history is notable for delayed onset of speech in a paternal uncle, who first spoke at age 4, and is now a professor of astrophysics, and a first cousin with learning disabilities. Both parents are healthy.

IN THE PRIMARY CARE OFFICE: At the end of the 2-year-well-child exam, you and Tommy's parents review the M-CHAT they filled out while waiting in the exam room with Tommy. You tell the parents you would like to talk with them to discuss the results of their questionnaire. Since Tommy's parents had also filled out of M-CHAT at his 18-month well-child care visit, you can use the results of both checklists to talk with the parents. The results of the first M-CHAT and follow-up with Tommy's parents led to a referral to a specialist for evaluation. At his 18-month visit, you and Tommy's parents discussed issues raised by the screen and discussed concerns about Tommy's socialization and communication. You had mentioned that these might be signs of autism spectrum disorder. At that time, you referred Tommy for a hearing evaluation and to the local early intervention system. They were to return to see you at 20 months to review the results of the hearing evaluation and see where things stood with the early intervention referral.

In the intervening six months, Tommy did not have a hearing evaluation or come back to the primary care pediatrician. He also missed an appointment with the developmental and behavioral pediatrician. You realize that you did not communicate your level of concern adequately to Tommy's parents at the 18-month well-child check. During this discussion, Tommy plays with the contents of a bag of his favorite toys, his "shapes," colored cards cut into different polygons which he names quietly to himself ("square...triangle...octagon...") during the visit.

YOU: Let's have a look at the developmental questionnaire you filled out.

Mother: Yes, I remember we filled out something similar on the last visit. I think he has made a lot of progress since then. He certainly has more words than he did then.

YOU: And that is really terrific. A growing vocabulary is something we really like to see, but there are some answers that concern me.

Father: Like what?

YOU: For example, on both occasions you answered that Tommy doesn't seem interested in other children.

Father: That's true – he isn't. He prefers to be alone, or to be with adults. Other children are unpredictable and he doesn't like that. He likes things to be a certain way, and other kids don't always understand that.

YOU: That's somewhat unusual for his age. Most 2-year-olds are social, and even if they don't play with other children, they are interested in being around other children and other people in general. It's how they learn about the world.

Communicating Concerns: Screening and Diagnosis Results

Father: Well, most of my family is pretty anti-social or really shy, especially my brother. I think he is more like my side of the family.

YOU: He may be, but a couple of other items also suggest something more than a family trait. For example, the fact that Tommy doesn't point with his finger to indicate something of interest, or follow your point with his eyes when you would like to point something out to him.

Mother: I think he is just in his own little world, but now that he talks a little, he is more communicative. If he wants something, he'll just pull me to it so I know what it is. He can get very frustrated when we don't understand what it is that he wants, but mostly we can figure it out.

YOU: One other item that you checked is that he doesn't really respond to you when you call his name. Can you tell me more about that?

Father: Well, we don't really agree on that one. He does, if I really get down close to him and touch him. But if he is across the room, he will not look at you when you call his name.

YOU: Hmm. Remind me, is he in daycare or preschool during the day?

Mother: We tried preschool for a few weeks, but it was a disaster, and we decided to keep him at home. He is much happier at home by himself than he is with other children.

YOU: What exactly do you mean by "disaster"?

Mother: They told us he wasn't ready. He was too rigid and wasn't interested in the other children. He got upset when they got too close to him or wanted to change something he was playing with. They didn't think he should spend so much time playing with his shapes. I think it just wasn't a good fit for him.

YOU: That's possible, but it is unusual to have such a difficult time in a preschool, so we should keep that in mind as we talk. Let's look at the screening form. This is meant to help us understand children whose development is not typical in one way or another. It doesn't make a diagnosis, but helps us see when a child is not developing as we would expect. Your answers suggest that there are a few areas where Tommy is lagging behind other children his age, and that's why I think it's important for Tommy to see a developmental specialist. I wonder if I communicated this to you well enough at Tommy's last visit.

Mother: Yes, but we were uncomfortable with the idea that there is something wrong with him, and didn't really know what you meant by an "evaluation." And now he is making progress. Do you still think we need to do this?

YOU: Yes, I do. There are things we can do to help him, and the sooner we do it, the better. This questionnaire doesn't give a diagnosis, but it does tell us that we need more information through a more developmental assessment.

Father: What will they do? They aren't going to put him on meds or anything are they?

YOU: Not at all. It's a play-based evaluation, where the doctor uses toys in a very specific way to see what Tommy will do, how he communicates, that sort of thing. For a child Tommy's age, you can be there throughout the visit.

Mother: All right, it sounds like you really want us to go through with this.

YOU: I do, and I am here to talk to you about it afterwards. The specialists will do the evaluation and make recommendations about what they think might help him, but I will continue to be his pediatrician, and we will follow

Communicating Concerns: Screening and Diagnosis Results

him along together. It's what Tommy needs right now. I'm so glad that you were both able to attend today and would like to invite you both back so I can hear both of your perspectives.

Father: Okay, doc. We'll do it.

Case Authors

- **Elizabeth Caronna, MD**, Boston University School of Medicine
- **Eileen Costello, MD**, Boston University School of Medicine

Case Study Part IIA

Three months later, in the PCP's office after the evaluation...

YOU: Welcome back, Tommy, it's good to see you. I have some toys here for you to play with.

Mother: He's brought his shapes along; he'll be fine if we set him up with the shapes.

YOU: Great, let's do that then. I wanted to see you to review the letter from the developmental and behavioral pediatrician, which I know was sent to you as well as to me. Before we get down to that, how did the evaluation go?

Father: I think they got a pretty good picture of him after he warmed up. He wasn't too cooperative at first, but eventually he was able to interact with him.

Mother: I don't think they saw him at his absolute best, but he pretty much showed the doctor who he is.

YOU: Well that's encouraging. Children can be different from day to day, like all of us, and it's good they got a reasonable picture of who he is.

Mother: We brought the letter with us. Do you agree with this diagnosis? And what does it mean? Autism Spectrum Disorder makes it sound like he is delayed in everything, but he isn't. In some areas, he is advanced. Even the specialist said that. And what does "Level 2" in social communication and interaction and "Level 1" in restricted behaviors mean? I just don't understand it.

YOU: The terminology can be confusing. Let me explain as well as I can. All children with ASD share challenges interacting and communicating with other people and have unusual interests or behaviors. The levels refer to how much support he needs to function like other children his age. Level 1 in "restricted behaviors" means he does need support to, for instance, put down his shapes and play with other types of toys. Level 2 in social communication and interaction means that he needs even more support to, for example, interact with other children and get his wants and needs met. Tommy did not score Level 3 in either area, but Level 3 means a person requires very substantial support. Levels can fluctuate over time. The amount of help Tommy needs may also change over time, so deciding how much support he needs in any particular area will be a measure of ongoing progress. You are absolutely right that Tommy is not delayed in all areas. He has some real strengths, like his memory and his ability to identify shapes. However, he also has a hard time telling you what he wants and seems overly focused on shapes. He's also not pointing to show you what he wants.

Mother: So what does this mean for Tommy? Why did this happen? Do you think it's because I had the flu when I was pregnant with him?

YOU: It sounds like you are wondering if there was anything you did that may have caused Tommy to have ASD. Most of the time, we don't know why a child like Tommy develops ASD. Often the specialists order genetic tests, because in a small percentage of children there is a genetic difference we can find with a genetic blood test. We do know that when one child in a family is diagnosed with autism spectrum disorder, there is an increased chance that another child will also have it. There are a lot of theories out there that you might have heard about, but unfortunately, we don't have a lot of answers yet about ASD.

Father: Does that mean his sister could get this?

YOU: We expect to see symptoms of ASD before children turn three years old. Since she is four years old and

Communicating Concerns: Screening and Diagnosis Results

really seems to be typically developing in her language and her social skills, I am not worried about her in this regard.

Father: Will he outgrow it? If we help him now, could he possibly be normal when he gets older?

YOU: We expect that with strong early intervention and appropriate therapies, children with ASD will make advances in social communication and interactions and improve in the area of restricted behaviors. We think of these conditions as lifelong, but we just can't predict what that will mean for Tommy in 5 or 10 or 15 years. He has a lot of strengths to build on, and with the right kind of help, he will definitely gain more skills as he grows up.

Father: I think we just have to sit with this for a while. I don't like the idea of Tommy being labeled.

YOU: It's a lot to think about, and you are right to take a little time to digest it all. (Pauses and sits quietly with parents). While you are processing the information, let's start to think about what's next.

Mother: And what is that?

YOU: The next step is Early Intervention, which could include various therapies. There are good programs in the neighborhood that I have worked with for years.

Mother: Wait a minute. Since he is obviously making some progress on his own, does he really need Early Intervention?

YOU: It can help a child who is having difficulty, especially in the social and communication areas. Depending on the program, he is likely to be offered some speech and language therapy, and some help with his social skills in small groups with other children. All the children in the group will be under three. A child with a diagnosis of ASD may be able to receive more hours of help than children with some other diagnoses. The Early Intervention program also helps children transition into appropriate preschool programs when they turn three.

Father: Then what?

YOU: Because of his developmental differences, he will likely qualify to continue receiving services, such as speech and occupational therapy, provided by your local public school in a preschool setting with other children his age. Optimally, in addition, services will include early intensive behavioral intervention to help Tommy learn new skills.

Mother: When he was in preschool it was a disaster. He was basically kicked out. I am worried about sending him to school before he is ready.

YOU: Children with ASD often have a hard time in a regular preschool program, but can do well in a program that integrates typically developing children along with children with ASD. That way the children can learn from their peers, while at the same time getting some extra help from staff that are trained to work with children with ASD. But let's not get ahead of ourselves. Tommy has six months before he turns three, and a lot can happen in six months. Let's get the Early Intervention started first.

Mother: How do we do that?

YOU: I will give you the telephone number of the local program. You can call yourself to get started. Then they will request some information from me, and I will send it along. It's always a good idea to keep a folder with all of Tommy's records as you visit different specialists.

Father: Why do you think this is so important?

Communicating Concerns: Screening and Diagnosis Results

YOU: It's one of the things we know for sure can make a difference.

Mother: Doctor, this is hitting us pretty hard. We thought he was just a quirky kid, and would grow up to be fine. Now you and the specialist are telling us to see him differently.

YOU: I appreciate how hard this is for the two of you. Remember that Tommy is the same boy he has always been. We are just seeing him through a different lens, and we see some areas where we would like to help him. The testing shows that Tommy is bright and this gives me confidence that he will continue to make good progress.

Father: Okay doc, I think we have enough to think about for today. If you give us the telephone number, we will call the program.

Case Authors

- **Elizabeth Caronna, MD**, Boston University School of Medicine
- **Eileen Costello, MD**, Boston University School of Medicine

Case Study Part IIB

Three months later, in the PCP's office after the evaluation...

YOU: Come on in. It's good to see you. I wanted to have you in alone to talk about the results of Tommy's

Mother: Thanks. It'll be easier to talk about him when he isn't here.

Father: Agreed. He has started having tantrums when he doesn't get his way, and it's hard to talk around that.

YOU: I wanted to review the letter from the specialist with you to be sure you understand what he thinks and what the next steps should be. How did the evaluation go?

Father: Not very well. Tommy did not sleep well the night before and was cranky. I don't think the specialist got any idea of all the things he can do. He barely spoke at all and wouldn't even look at the guy.

Mother: I don't think they saw all of what he can really do. He was very clingy. I don't know how they think they can make a diagnosis after only seeing a child on one morning. We were upset by the whole thing.

YOU: It can be painful to see your child being evaluated, especially when he doesn't do things that you know he can do at home. However the instruments are designed to look at very specific things, and even if a child is having a bad day, we can often see things that we are concerned about.

Mother: I just wish he were more cooperative. He wouldn't even look at the doctor, but then again, the doctor doesn't know exactly how to get him to look at him, and we do. That's the type of thing that upset me.

YOU: I understand that. Let's talk about the letter. Do you have questions about it, anything you don't agree with or don't completely understand?

Father: I can't believe he gave him a diagnosis at all, after knowing him for such a short time, given that Tommy wasn't even himself that day. It's one of the reasons I didn't really want to do this in the first place. I don't like the whole idea of labeling kids, and now Tommy has a label. As far as I'm concerned, no one ever needs to know this. I certainly don't plan on telling anyone.

YOU: Well, there isn't any need for anyone else to know at this point. That's a decision the two of you will make together, and you're right that there is no need for you to talk to anyone, but each other.

Mother: I would like to talk to my sister about it. She is a teacher and has a lot of experience with kids.

YOU: I remember you told me that she had expressed some concerns about Tommy.

Mother: Right and I think she could be helpful to us.

YOU: I hope so. It's wonderful to have someone close to you who understands and can offer some support.

Father: So the specialist thinks Tommy has ASD "Level 2" in social communication and interaction and "Level 1" in restricted behaviors. Father is reading from the letter. What do you make of that?

YOU: Well, I thought that Tommy could possibly have a diagnosis like this, based on the screening test we reviewed

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the last time you were here. You may remember we discussed that M-CHAT screen that we did where he showed some signs of problems with social communication, and I was concerned that he might have symptoms of autism spectrum disorder.

Mother: We don't agree that he is autistic at all. How can a child be autistic who knows as much as he knows at such a young age? How many kids do you know who are so young and know all their shapes and letters. He is practically ready for kindergarten and he isn't even 3.

YOU: The fact is that many children on the autism spectrum have some amazing skills, skills they can build on over time. Tommy is so bright, and so clever, and so sweet. These are all great things that will help him over time.

Father: Can we talk about the diagnosis again? I still don't get it; like my wife says, how can he be autistic and practically be able to read? It just doesn't add up.

YOU: Let's back up a little and review what exactly ASD means in general and what the levels mean and then we can talk about what it means for Tommy.

Mother: Good, because I am still confused. I've never even heard of the levels.

YOU: Let's talk about the areas that children with ASD have difficulty with. The first is social communication and social interactions. This includes nonverbal communication like gestures, eye contact, pointing and following a point, that sort of thing. It also includes interactive behaviors like playing and enjoying playing with another person, having back-and-forth conversations, and sharing things he's interested in. And the other area is repetitive interests or behaviors. In Tommy's case we have some concerns in these areas.

Father: If you are talking about his geometric shapes, he has used those to learn so many things. He can do patterns, he knows the names of all of them, including the dodecahedron, and he has learned his colors from them.

YOU: His interest in shapes has certainly been a help to him in some ways. This interest can also help me explain how the levels work. The levels refer to how much support he needs to function like his peers. Level 1 in "restricted behaviors" means he does need support to, for instance, put down his shapes and play with other types of toys. Level 2 in social communication and interaction means that he needs even more support to do things like interact with other children and to get his wants and needs met. You've noticed how that Tommy doesn't share the shapes with anyone; he isn't interested in enjoying them together with other people. Tommy did not score Level 3 in either area, but Level 3 means a person requires very substantial support. Levels can fluctuate over time.

Father: So what do you think caused it? He was never exposed to any vaccines, as you know, and my wife was so careful when she was pregnant. She wasn't sick, didn't drink any alcohol, and was completely healthy. Our daughter is completely fine.

YOU: We are quite sure that vaccines do not cause ASD.

Mother: Don't you think we are over-diagnosing it? It's all you read about. Everyone seems to have a child with ASD now. Why is there such an increase? There must be something in the environment.

YOU: It's not clear that there really is an increase. The way of describing children has changed, and a lot of children would have been called something else 20 or 30 years ago.

Father: So what's going to happen to Tommy? Should we be putting him on a special diet or extra vitamins?

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YOU: In my experience the special diets haven't helped very many children, and there is no good medical evidence to support it. Since Tommy has a pretty restricted diet to begin with, I would be worried about his getting enough nutrition to grow and be healthy. If you do decide to pursue this, I would urge you to consult with a nutritionist to be sure he is getting adequate nutrition and calories for growth and well-being.

Mother: What about vitamins? Can you do a test to see if he has a toxin in his system like mercury or lead?

YOU: A regular children's multivitamin is fine, especially in a picky eater, but I would be careful about using high-dose vitamins. There isn't enough known about the effects in young children.

Father: Do you think we should have him tested for mercury?

YOU: There is not a standard for measuring mercury in children, so it's impossible for me to interpret. I don't recommend it.

Mother: I am still worried about it because I have read about kids who are autistic because of an overload of mercury in their blood.

YOU: There is very little evidence to suggest that this is the case. There is evidence to support Early Intervention or EI. We know that can help. Tommy is likely to really enjoy it, and you will learn from it as well. The EI specialists are experienced in working with children and families, and it's almost always a positive experience for everyone. It's the best thing to start helping Tommy.

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Autism Spectrum Disorder

FACT SHEET

What is autism spectrum disorder?

Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. Scientists do not know yet exactly what causes these differences for most people with ASD. However, some people with ASD have a known difference, such as a genetic condition. There are multiple causes of ASD, although most are not yet known.

There is usually nothing about how people with ASD look that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.

What are some of the signs of ASD?

People with ASD often have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things. Signs of ASD begin during early childhood and last throughout a person's life.

Children or adults with ASD might:

- not point at objects to show interest
(for example, not point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone

- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled, or might cuddle only when they want to
- appear to be unaware when people talk to them, but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- have trouble expressing their needs using typical words or motions
- not play "pretend" games
(for example, not pretend to "feed" a doll)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had
(for example, stop saying words they were using)

What can I do if I think my child has ASD?

Talk with your child's doctor or nurse. If you or your doctor thinks there could be a problem, ask for a referral to see a developmental pediatrician or other specialist. At the same time, contact your local early intervention agency (for children under 3) or local public school (for children 3 and older), even if your child does not go to that school. To find out whom to speak to in your area, contact the National Information Center for Children and Youth with Disabilities by logging onto **www.nichcy.org**. In addition, the Centers for Disease Control and Prevention has links on its Autism Spectrum Disorder Web page to information for families (**<http://www.cdc.gov/ncbddd/autism/links.html>**).

Don't wait. Acting early can make a real difference!

www.cdc.gov/actearly

1-800-CDC-INFO



Handout II: Talking with Parents About a Concerning Developmental Screen

:30

- Explain in advance that all children of a certain age are screened for developmental concerns.
- Be sure parents understand that screening is not a diagnosis; it gives the pediatric provider information about parental concerns and is a starting point for discussion.
- Discuss screening results in person, not on the phone. If only one parent is present, offer to meet again with both parents or another support person identified by the parent.
- Referral to Early Intervention may be the first step. Be able to explain what Early Intervention is, and make parents aware that Early Intervention provides developmental services based on established eligibility criteria such as language delay, not based on a diagnosis. Early Intervention providers do not typically provide diagnoses, though they may or suggest that a child be evaluated by a specialist in order to determine a diagnosis.
- If a referral to a specialist is indicated, be sure that the parents understand your concerns in addition to their own.
- Use language that leaves room for parents to anticipate possible results of a more detailed evaluation: e.g., the child “may be behind other children her age in this area,” or “seems to be having more difficulty than we would expect in a couple of areas,” or “The specialist has a lot of experience helping children, and will make recommendations for us to follow over time.”
- Provide information about accessing Early Intervention as soon as concerns are raised. If possible, identify someone in the office (social worker, nurse, etc.) to help parents make appointments. This is especially important for non-English speaking parents.
- Try to get a sense of whether the parents are likely to follow through with your recommendations. Arrange a follow-up visit in several weeks if you are concerned.
- Be available to parents as questions arise, and let them know you will remain the primary care doctor for their child.
- Ask if they want information about support groups in your area.

Adapted from the Section of Developmental and Behavioral Pediatrics of the AAP Newsletter, Fall, 2007

Handout III: Steps for Delivering Difficult News

1. Set up the interview:
 - Use a quiet exam room without distractions
 - Ask parents if they are comfortable having the discussion with the child present
 - Sit down with parents
 - Keep interruptions to a minimum and allow parents to ask questions
 - If possible, let parents know in advance that you have news they may not want to hear alone, so they have the option to bring along a support person; this is especially important for single parents.
2. Assess the parents' perceptions:
 - Ask parents if they have read materials on the Internet or talked with friends or family members about their child; this can determine where parents are in their own thinking about their child.
3. A "warning shot," then the news:
 - Let parents know you have difficult news
 - Use appropriate level of vocabulary
 - Get to the point as quickly as you can, so there is time for questions, and to repeat anything that might be confusing
4. Address parental emotion with empathy:
 - Expect affect from parents and respond when appropriate, recognizing that they are hearing difficult news
 - Anticipate possible reactions: silence, disbelief, tears, denial, or anger
 - Four parts of empathic response:
 1. Observe the response
 2. Identify the emotion to yourself (sadness, anger, etc.)
 3. Identify the reason for the emotion (ask the parent, even if it seems obvious, it may be related to previous experience with the diagnosis, or another life stressor that makes this news more difficult)
 4. Acknowledge and validate the emotional reaction, be as warm and thoughtful as possible; families remember this
5. Be prepared to discuss your honest opinion about their child:
 - Explain where "on the spectrum" their child lies
 - Do not prognosticate: children on the autism spectrum have a wide variety of outcomes and it is not possible to predict outcome for one child
 - Leave room for hope and stress that the child will make forward progress with appropriate intervention
 - Acknowledge the difficult aspects of an uncertain prognosis

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6. Assess Understanding:

- Ask parents how they will explain what you have told them to their family members; that will help you understand what message they have taken from you, and provide you an opportunity to clear up any misconceptions
- Offer a follow-up meeting to review the news a second time, perhaps with another family member present

7. Next Steps:

- End session with a clear plan for referrals and follow up
- Write steps down for parents, so they can leave with something to refer to later

The Physician's Experience of Delivering Bad News:

Definition of "Bad News," Information which adversely and seriously affects an individual's view of his or her future," or in this case, their child's future.

Physicians experience stress when delivering bad news, especially when the patient is young or the prognosis is poor.

In one survey, 57% of physicians ranked: "How to be honest with patient and not destroy hope" as most important stress in giving bad news.

Physicians who are comfortable delivering bad news experience less stress and burnout.

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Shonkoff JP, Yatchmink YE. Helping Families Deal with Bad News; *Developmental and Behavioral Pediatrics-Handbook for Primary Care*, Parker S, Zuckerman B, Augustyn M, Lipincott, Williams and Wilkins, 2005.

Handout IV: Stages of Grief for Parents Learning of a Disability in Their Child

- *Shock and distress at hearing bad news:* parents need to feel comfortable expressing their emotions to provider. If parents are embarrassed to express their emotions, they are less able to attend to the information.
- *Denial:* Can be a useful defense mechanism for parents mastering the new information. However, prolonged denial impedes adaptation.
- *Anger:* A natural response to loss of the expected typical child, parents ask “Why is this happening to us and our child?” It is important parents are provided an outlet to express anger, rather than turn it inward. Be aware that anger may be directed at you as the messenger, and try not to take it personally.
- *Bargaining:* The hope that parents have that with lots of intervention, their child will be “normal.” Parents often think that they can cure their child of ASD if they engage in certain therapies, and sometimes are willing to spend lots of resources to ensure they bargained effectively.
- *Grief:* Begins when parents start to worry about the child’s development. Grief for parents of children with ASD is cyclical: renewed grief can occur with each developmental milestone that is not met and with each life event that does not go as the parents had expected (e.g. the first day of kindergarten, the day the child would have been confirmed in a religious faith, etc.) Chronic grief occurs over time as the demands of raising a child with a disability mount.
- *Acceptance:* Most parents will eventually make some kind of peace with their child’s disability, but grief and acceptance can alternate over time. Acceptance does not imply that parents are not bothered by their child’s disability, but that they accept it as a reality of their lives.

These stages are not necessarily linear, and parents will move from one to another. Two parents may not be in the same stage at the same time. These stages have been adapted from those of Elizabeth Kubler-Ross, who described stages of grief in dying persons. In this case, parents are grieving the loss of their expectation of raising a typical child. Salient differences for families who have a child with a diagnosis of an ASD include:

1. There is no “end,” as there is in a terminal illness
2. There is much uncertainty for each child with ASD, creating stress for parents
3. Most parents receive the diagnosis when the child is relatively young, and they cannot anticipate what the future holds for them
4. There is not always a clear-cut treatment modality that is known to work in all cases
5. In the case of a child with a developmental disability, grief is more likely to become chronic

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Suggestions for Parents When Faced with a New Diagnosis of a Disability:

1. Accept the child's disability
2. Manage the child's condition on a day-to-day basis
3. Meet the child's normal developmental needs
4. Meet the developmental needs of other children in the family
5. Cope with ongoing stress and periodic crises
6. Assist family members to manage their feelings
7. Educate others about the child's condition
8. Establish a social support system

References:

The Challenged Family: Issues and Insights. Chapter 17, Primary Care Pediatrics
Green-Hernandez C, Singleton JK, Aronzon DZ, Lipincott, 2001.

Kubler-Ross E, Kessler D. On Grief and Grieving: Finding the Meaning of Grief through the Five Stages of Loss, Scribner, 2007.

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Other Useful Resources

Websites for Parents:

American Academy of Pediatrics

<http://www.aap.org/healthtopics/autism.cfm>

Centers for Disease Control and Prevention

<http://www.cdc.gov/ncbddd/autism/>

<http://www.cdc.gov/vaccinesafety>

Autism, Asperger, and PDD website

<http://www.autism-help.org>

Autism Speaks 100 Day Kit

http://www.autismspeaks.org/community/family_services/100_day_kit.php

First Signs

<http://firstsigns.org>

For Providers:

Explaining the results of a “failed” screen. AAP Section on Developmental and Behavioral Pediatrics Newsletter, Fall 2007. Available at: www.aap.org.

Delivering Difficult News. Available at www.aap.org.

Sugar-Coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care; Sices et.al. Pediatrics. September 2009.

From the AAP:

Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians. Available for purchase at <http://www.aap.org/publiced/autismtoolkit.cfm>.

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“Understanding Autism Spectrum Disorders Booklet” available for purchase at the AAP Online Bookstore.