

## 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. \_\_\_\_\_

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

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

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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.

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

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

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

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### 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.

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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

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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 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

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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?

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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.

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### 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](http://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](http://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

# Communicating Concerns: Screening and Diagnosis Results

## 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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# 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

# Communicating Concerns: Screening and Diagnosis Results

## **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

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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](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](http://www.aap.org).

Delivering Difficult News. Available at [www.aap.org](http://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>.

Greenspan SI, Brazelton TB, Cordero J, et al. Guidelines for early identification, screening, and clinical management of children with autism spectrum disorders. Pediatrics. 2008; 121:828-30.

Gupta VB, Hyman SL, Johnson CP, et al. Identifying children with autism early? Pediatrics. 2007;119:152-3.

Johnson CP, Meyers S. Council on Children with Disabilities. American Academy of Pediatrics Clinical Report: Identification and evaluation of children with autism spectrum disorder. Pediatrics. 2007;120:1183-215.

Zwaigenbaum L, Bryson S, Lord C, et al. Clinical assessment of toddlers with suspected autism spectrum disorder: insights from studies of high-risk infants. *Pediatrics*. 2009;123:1383-91.

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