

## **Autism Case Training: A Developmental Behavioral Pediatrics Curriculum Communicating Concerns: Screening and Diagnosis Results: Part IIB**

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*Visual:* “Learn the Signs. Act Early.” campaign marking

*Visual:* Autism Case Training: Video Role Plays

*Narrator:* The following video role play was staged with an actual physician and with real parents and a child with autism.

*Visual:* Communicating Abnormal Results from a Screening Tool: Part II-B

*Narrator:* In this role play, Tommy, the patient, is 30 months old. His parents are at a follow-up visit with their pediatrician. Tommy has been evaluated by a developmental specialist and the parents are questioning the diagnosis.

*Visual:* Doctor and Tommy’s mother and father are sitting in chairs in a semi-circle.

*Doctor:* Welcome back. It’s good to see the two of you again. I wanted to meet with the two of you alone so that we could review the findings from Tommy’s evaluation with the developmental pediatrician.

*Mother:* Yes, thanks, it’s a lot easier to meet when he’s not here.

*Father:* I agree. When Tommy has tantrums, it’s hard to talk around that.

*Doctor:* I’d like for us first to review the letter from the developmental pediatrician about the evaluation. I got a copy of that also and I had a chance to review it before we were meeting today. So, how did the evaluation go?

*Father:* Not very well. Tommy, he really didn’t sleep that well the night before. He was kind of cranky. I really don’t feel like the specialist really got a good feel for him. You know, Tommy wouldn’t even look the guy in the eye.

*Mother:* And they didn’t see all what he could do. And personally, I don’t think you can be diagnosed after one meeting. I mean, I don’t know, we’re just really upset about the whole thing.

*Doctor:* I hear how disappointed you both are in how that evaluation went and it’s really frustrating when kids just don’t show all of their skills in front of the specialist. It is hard to imagine that they can get a good picture of him. But the specialist, you know, they are used to this and they do understand that kids are not going to show all of their skills especially it was the first time Tommy had ever been in that office. But they know what they’re looking for and they can still look at the very specific skills, even if he’s not showing all of his abilities.

*Mother:* I just don’t understand why he wasn’t cooperative. I mean, Tommy looks at us. He wouldn’t look at the doctor and I don’t understand why the doctor couldn’t get him to look at him the way he looks at us.

*Father:* I can't believe he got a diagnosis in the first place. He wasn't at his best. We really didn't want to do this in the first place. Now he has a label. I'm not telling anybody about this.

*Doctor:* Yeah, you sound pretty angry about this at the moment. You know, you don't need to tell anyone else about this at this point and that's your decision.

*Father:* We don't want people to think that Tommy can't do anything and putting him in a classroom with kids that have more issues than he does.

*Doctor:* I completely agree with you. So I think that the work that lay ahead is really finding the appropriate intervention for him and putting that in place so that he can develop some new skills and really flourish.

*Mother:* You know... I need to talk to my sister about this. She's a teacher.

*Doctor:* You told me your sister had expressed some concerns.

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

*Doctor:* I think that's great. It's wonderful that you have someone you can talk to and provide this kind of support.

*Visual:* Tommy's mother pulls a paper out and Tommy's father reads from it.

*Father:* The specialist says that Tommy is "pervasive development disorder not otherwise specified." What did they mean by this?

*Doctor:* You know... this terminology is very confusing. When we talk about Pervasive Developmental Disorder, Not Otherwise Specified, or PDD-NOS, this falls under the umbrella of one of the autism spectrum disorders. And this involves really three areas of functioning. So, repetitive behaviors and restricted interests, sort of like when you've told me about Tommy's insistence on things always being the same, and being a bit rigid about things. And the second area is in communication. And Tommy has had some delays in acquiring language, I know he's gaining skills now, but he's had some delays. And then the third area is around social skills. And so that might speak to some of the things you had indicated, remember when you filled out the M-CHAT. That Tommy kind of prefers to play alone, doesn't really like it when other kids invade his space.

*Mother:* I don't agree that he's autistic. I mean, he knows way too much for that. He knows his shapes, he knows his colors, he knows his letters. He's not even three years old yet, I mean, we think he's ready for kindergarten.

*Doctor:* You're right, Tommy is such a bright and clever little boy. When we talk about the autism spectrum disorders these days, we're talking about a very broad spectrum of children. And, Tommy has so many abilities; he knows his shapes, he knows his colors, he's learning his letters. These strengths will really continue to serve him well as he grows.

*Father:* Can we talk about the diagnosis again? Like my wife said, it just doesn't add up.

*Doctor:* Yeah, let's take a step back and let's review what Autism Spectrum Disorder means and then we can figure out what this really means for Tommy.

*Mother:* Good, because I'm still confused.

*Doctor:* OK, so remember, there are three areas that we really focus on when we're talking about Autism Spectrum Disorders. So the first is communication, and remember, Tommy had some delays in acquiring language. And the second area is around social interaction and you've told me about how Tommy often prefers to be alone, to play alone, and doesn't really like it so much when kids start to invade into his space. And then the third area has to do with repetitive behaviors and restricted interests so some of that is about what you've talked about Tommy not really liking to have his routine interrupted and sometimes he kind of spends a lot of time sorting things and organizing things. So when we talk about an Autism Spectrum Disorder, children are affected in all three of these areas. And I think I've given you some examples to help you understand what those might be for Tommy in each of those areas.

*Father:* If you're talking about shapes, he's used them to learn things.

*Doctor:* Oh, you're absolutely right, Tommy really has learned a lot by using his shapes. But at the same time, those shapes tend to preoccupy him also, which means that he uses those sometimes to the exclusion of other things. And then he gets kind of stuck on that. And you both told me about how he tantrums sometimes when you try to get him to move on to using other things. And you know, Tommy doesn't always seem to be very open to other people's interests either.

*Father:* So what caused this? He wasn't exposed to any vaccines. My daughter is fine.

*Doctor:* There's an awful lot we still don't know about what causes autism. But the research suggests that vaccines do not cause autism.

*Mother:* Don't you think we're over diagnosing? I mean, that's all you read about. I mean, why such the increase? You think it's something in the environment?

*Doctor:* Well, we do know that there is an increased number of children who are being diagnosed with an Autism Spectrum Disorder but this could be due to a number of different things. So, for example, the criteria that we are using to diagnose children has become broader and the age we're diagnosing kids is, we're doing a better job of picking kids up earlier. And in the past children may have been given a different diagnosis instead of an autism spectrum diagnosis. Or it is possible that there is actually an increase in Autism Spectrum Disorders.

*Father:* What's going to happen to Tommy? Should we put him on a special diet, or vitamins?

*Doctor:* You know I think what you're going to find is that you're going to see a lot of different kinds of recommendations on the internet, when you talk to other parents, and friends and family and in the books that you read.

*Mother:* Are vitamins safe? And, I mean, should we have him tested for lead?

*Doctor:* I think it's a really good idea to have Tommy tested for lead. And if you choose to use a vitamin, use only a regular children's multivitamin.

*Father:* Should we have him tested for mercury?

*Doctor:* There's really no standard way to measure mercury in kids, I really don't recommend this, I think it's really important to make sure that the things that we're doing for Tommy are safe and some of the treatments that are out there for kids are actually harmful.

*Mother:* You know, I'm still worried. I've heard about mercury causing autism in kids.

*Doctor:* There's no evidence at this time for a role for mercury in causing autism. What we do know, is that the standardized treatments today that have been shown to be effective are early intervention. But it's really difficult for parents to try to sort through all of these different treatments that are out there and try to make sense of it and I'd like to be available to you to help you to try to understand some of these things as you kind of go down this road. You know, it's really okay that we don't have all the questions sorted out today, but I'd like to stay in touch with you about this and I'd like to follow up with you in a few weeks just to continue to hear how things are going and I really want to thank you for coming in and just talking so openly and frankly about how you're doing with hearing all of this and going through the evaluation. And I really appreciate that you went through this evaluation even though you had a lot of reluctance to do that. So, thanks for coming in today. It was good to see you.

*Visual:* Doctor and Tommy's parents shake hands.

*Visual:* Pediatrician played by: Carol Weitzman, MD, FAAP, Yale University School of Medicine; Parents played by Thomas and Nicole Moore

*Visual:* Producer/Director: David Hughes Duke; Camera Operators: Scott Bynum and John Duke; Video Editor: David Porter; [www.livingstories.tv](http://www.livingstories.tv)

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