



Michael Margolis: Welcome, everybody, to today's live teleconference with Dr. Marilyn Monteiro, author of the new book *Autism Conversations: Evaluating Children on the Autism Spectrum through Authentic Conversations*. I'm your host, Michael Margolis from Western Psychological Services, a leading publisher of autism and psychological assessments, and the publisher of Marilyn's new book *Autism Conversations*.

Marilyn, I'm so thrilled to have you on this teleconference today, and to discuss your thinking, and to answer questions from your readers.

Marilyn Monteiro: Well hello, Michael. I'm delighted to be here.

Michael Margolis: Hey Marilyn. How are you today?

Marilyn Monteiro: Hi. I'm just delighted to be here to discuss really just my favorite topic, which is dealing with individuals on the autism spectrum, and all the issues involved with evaluations.

Michael Margolis: Well, I really appreciate you taking the time for us to talk, and to answer some of the questions from your readers recently. And I thought maybe just to get us started, can you tell us a little bit about why you decided to write a book like this? It seems like a little bit of a departure from some of the other books and sort of tools in the field.
0:47 min.

Marilyn Monteiro: Well, this book, Michael, sort of grew organically out of my work with evaluating children on the autism spectrum, and having conversations with children, and with their parents, and with my evaluation team members.

I've been evaluating kids in Texas since 1983. And when we first started out – when I first started evaluating children, I was using more traditional assessment methods, and talking about the diagnosis in terms of sort of more clinical, sterile ways of talking

about it. And what I found was that I really was missing something.

So I began to develop just a more natural approach to interviewing parents, by talking with them, encouraging them to share their stories, and in talking with the children, being able to figure out: what's the best entry point to get children to just open up, and really relax, and be themselves, instead of being quite as preoccupied with giving them a task to do, and observing how they did on that task?

So I found that as I was doing that approach, people started asking me to teach them how to do it. And as a result of teaching people how to do it, the book evolved.

Michael Margolis:
2:18 min.

And so it goes without saying, your book really is centered around this notion of conversation. Can you tell us, or explain to us, a little bit more the importance of this idea? And really, sort of more as a practitioner, what's the real power or breakthrough that you've found from bringing sort of that frame to mind, as people think about autism diagnosis?

Marilyn Monteiro:

That's a great question. One of the things that really is at the heart of this whole sort of approach to evaluating children on the spectrum is really respecting and coming into the point of view of looking at the child and the family and the situation in individual, unique terms. And so only through having a conversation with someone can you make that sort of connection.

So, for example, in interviewing parents, rather than having a more formal approach of starting from birth, and then going all the way through all of the developmental steps – all of that information is important to get, but what's more important is to have a conversation with the parent of, say, a two-and-a-half-year-old or three-year-old or a five-year-old whose parents are beginning to worry or suspect that maybe the child has some differences in their development.

What's on their mind is what's happening right now with their child. So to have a conversation that starts out with the parent by saying, "Tell me what's on your mind. What are you most concerned about right now?" And including in that conversation

some things like asking the parents: “Tell me three words to describe your child.”

I’ve never yet had a parent describe their child as having autism. They describe their children as funny, caring, humorous, creative, intelligent, and exasperating sometimes. But they come up with words that describe the child as a unique individual.

So only in having a conversation, as opposed to giving parents checklists of behavior, are you able to really get that bond and conversation going. And it really helps parents go through the process of describing their child, so that by the time they get to the diagnosis, it isn’t quite as emotionally devastating.

The conversation with children evolved from the fact that as a consultant going into schools, I had a limited amount of time that I got to spend with children. So I was finding that to get children kind of comfortable during the time that I was spending with them and my multidisciplinary team, I would bring sensory toys, or I’d start out with the topics they were interested in, just to get them sort of comfortable. And then we’d go into the more formal assessment instruments.

And what I found, over time, is that the children loved having the conversations where they could have someone encourage them to kind of show their world view. And we got so much more rich and detailed information about the individual child that, again, Michael, when we sat down with the parents and said, “Let us describe your child. This is what we experienced. This is how we saw him see the world,” parents are much more likely to be less overwhelmed by the actual diagnostic label. Because we’re presenting them with an understanding of a child that makes sense to them.

*Michael Margolis:
15:44 min.*

Yeah. Well, it’s interesting, Marilyn, because that was one of my sort of learnings when I reviewed your book, in seeing that it was not just written for the practitioner. But it seems that while it was coaching practitioners on how to engage parents in that dialogue, and in the process, it almost – it really seemed that you’ve also written this, in many ways, for the parent as well.

What does a parent get from reading a book like yours, which I know, at times, gets into some of the real diagnostic process – but

from this approach, as you describe, that is more about conversation and really stepping into the world view of a child?

Marilyn Monteiro: You're really bringing up sort of a key point of the book, which is: I really wrote it for not just professionals, but also for parents. Because when parents are going through that diagnostic process, they are looking for a description of: "What is this whole thing gonna be like?" and "How do I make sense out of autism?"

So if they go on the ever increasing number of websites to look at information about autism, many parents report to me it's very confusing. It's very overwhelming. Because there are lots of lists of behavior, and sometimes their child, as an individual, has maybe two or three, but not all of the things. And so they get confused about it.

In writing the book, I really wrote it so that parents, as well, would have a book that they could read. For instance, in the chapter about interviewing parents, the chapter about discussing the diagnosis with parents, they're actually able to read a live interview – an interview with a parent.

And many parents who've read the book, at this point, have said they could really relate to that, and they could really see their own experience, in reading the book. So my goal was to help parents of newly diagnosed kids, and also parents whose children have already had a diagnosis to better understand, and have a vocabulary to talk about this really unique point of view that people on the spectrum bring to life.

And I use a lot of language in the book that is non-technical, but specific. Because I think the language we use in talking about individuals is really important. So instead of talking about a restricted range of interests, for instance, which is what the terminology is for the DSM-IV-TR, the diagnostic manual – instead of talking about that, I really talk about how the particular individual child has a passionate interest in a particular topic.

And you can see how that language makes a difference, in terms of how people perceive the individual child, how they perceive their abilities, and what we can do to use that. So if it's a restricted range of interest, then of course the way we think about it is: "Well, we have to stop them from spending all their time thinking

about Legos, or figuring out which are the most amazing dinosaurs from the late Cretaceous Period, as opposed to the Jurassic Period. We want to interrupt that, because it's restricted, and broaden out their interests.”

So that is a different approach than the language of saying, “Let's look at this child as having a passion for dinosaurs, or a passion for building things.” And then we can begin to look at: how can we use that passion as a bridge to widen their interest in the social dynamics of life? So I really feel like the book was written for parents, to help them with the language, but also for professionals.

Michael Margolis: Yeah.

Marilyn Monteiro: What's been missing in the field, I think, is really an ability to have a conversational approach, where we talk about individual children, as we're evaluating them, as exactly that – individuals who have differences in their development, as opposed to a disorder or a condition. And that just humanizes the whole process.

Michael Margolis: I'm curious. You brought up this dimension of sort of humanizing the process. I know having myself spent some time talking with a lot of autism practitioners, it seems that the diagnosis process around autism is a very emotionally charged process, and one where not only parents, but it seems like also teachers and administrators have a hard time really understanding. They're not really prepared to work with autistic students or children.

And those were certainly some of the questions that we received from some of your readers. I'm curious. Since you're doing so many diagnoses all the time – you've done thousands of these, through the years – what are you seeing as the climate right now? And do you have any suggestions for a practitioner on how they manage the emotional dimensions, both with parents and, say, teachers and administrators?

Marilyn Monteiro: Yes. That's a really important point. Because what's happening is as the incident rate of autism is increasing substantially from, say, 10 or 15 years ago – the current statistic is 1 in 110 individuals – four times more common in boys than girls – but 1 in 110 individuals is thought to have some form of an autism spectrum disorder.

So it used to be relatively rare, or low incidence, and now it's something that's really – every practitioner who's in schools – a psychologist in private practice is going to have to become more skilled at working with individuals on the autism spectrum, and, specifically, being able to go through the diagnostic process.

So there are so many levels of training that are needed for individuals, that one level of training that we go to first, as practitioners, is really to know how to use the best practices instruments. And that means the standardized test measures, like the ADOS or the PEP-3, the checklists, like the CARS-2 and all of the SRS – the **BASC** – all sorts of checklists that require some training, and really are designed to help us really get familiar with: what are the behavioral profiles we're trying to measure on the child?

So that's a level of training. But sometimes we're so caught up – practitioners, I find in my experience – in training, many practitioners – is that once you get past that level of: "I know how to administer a test," you have to go to the next level, which is really understanding how to talk about that child as an individual.

And standardized tests really direct us to looking at reducing all of this rich qualitative data about a child into some scores. They either meet a cutoff score, or they don't meet a cutoff score. What gets lost in that, Michael, is an ability to really stop and be able to describe the child and, in functional terms: what does this mean?

If we sit down with a parent or a teacher, as a practitioner, and say, "This child meets the diagnostic criteria for autistic disorder or PDD-NOS (Pervasive Development Disorder) or Asperger's Syndrome," then what they hear is that label. And that label is attached in everyone's mind to something different.

Because it depends on what they know about it, who they've met like that. I've talked to many teachers who say, "Well, he's not anything like the other student I had who had autism, so maybe he doesn't have autism." So what happens is we get – we really don't have a dialogue about the individual child, if we talk about the label.

But if we go in and talk about the approach that is in the book, and also in the MIGDAS – the protocol test that I’ve developed – what we are doing is describing the child first, and then talking about the diagnosis. So if we describe the child in terms of: how are they showing us differences in their development? How is their mind organizing information differently from a neurotypical child? And to what degree is that affecting their ability to participate in typical life activities?

Then parents and teachers are all on the same page with us in saying, “Yeah. He is having trouble with reading with the social landscape. And he is really good at doing projects by himself, but group work is difficult.” Then what we’re doing is describing a child in real, dynamic terms. And when we say, “That’s what we mean by: ‘He has autism,’” then everyone benefits from that approach.

So what I’m seeing in the field is that we really still need some more dialogue about: how do we incorporate this qualitative dimension into our assessments?

Michael Margolis:
24:35 min.

And you mentioned the MIGDAS – right – which is the evaluation protocol that actually is also published by Western Psychological Services, and it’s around diagnosing high-functioning or verbal children on the autism spectrum. Where do those interview guidelines fit into the context of some of the other autism diagnosis assessment tools you just mentioned, as well as in the context of your book? How should a practitioner think about that suite of tools and how they relate to each other?

Marilyn Monteiro:

Great question. The MIGDAS, which stands for Monteiro Interview Guidelines for Diagnosing Asperger’s Syndrome – even though it has the word Asperger’s Syndrome in the title, it’s really designed to help look at high-functioning forms of autism, meaning verbal children who have autism.

And I developed the MIDGAS, because what I was finding was when I used the more standardized measures like the ADOS, which is an awesome and amazing test – but what happens is that it really has difficulty – it wasn’t designed to really look at the more verbally facile, high-functioning Asperger’s dimension kids, who are now quite a big part of the population of kids that we see during autism assessments.

So what happens with the ADOS protocol is – it is a standardized measure, so it’s a semi-structured interview, and it requires the examiner to stay within some confines of asking questions and providing tasks for the student, who then responds. And those responses are coded, and then rates as either being overall in the range of autism or not.

So for high-functioning kids, what happens with a measure like the ADOS is that high-functioning kids are really good at being prompt-dependent. So they’re able to follow the prompts and respond somewhat appropriately. So it masks, sometimes, their more subtle, nuanced areas that are neurotypical around the autism spectrum. So it doesn’t pick up on those kids.

What I was finding in my assessments, and why I did all of the MIGDAS, is when I worked with kids – as I mentioned previously, I would bring in sensory toys and topics. If a child was interested in dinosaurs, then we’d talk about dinosaurs, to begin with – or Yu-Gi-Oh! or whatever the particular area of interest was.

And I was finding that in that 20 minutes to an hour that we were discussing things together, and playing with the toys, and I was mirroring and doing what the child did, and sort of encouraging them to be themselves, if you will, instead of directing them to follow a set of prescribed tasks – what I found was that we were getting reams of information about: what gets in the way of this child’s ability to function in various settings in the classroom, at home, in the community? Those kinds of things. How rigid or flexible was the child?

So what I did was formalize that whole process. Because my teams were saying, “Wow. We’re getting more information doing this than we are doing the more standardized testing.” So one way that the MIGDAS can be used – because it does not give you a score. It’s a qualitative protocol. It’s a protocol, or method, of working with kids that does follow a pattern of: no matter what the age of the child, you are going to do a certain range of activities with them.

But what’s different is that you don’t get a test score. So if you’re going to use the MIGDAS – which I highly encourage people to

check it out, and look at using it – it is going to be – the advantage is you’re going to get kids to really enjoy the assessment process.

I have a lot of kids, where we say, “This is great. It’s time to go,” and they’re like, “Well, I’ve got a great idea. Why don’t we just stay here?” Because they’re having such a good time.

Michael Margolis: Uh-huh.

Marilyn Monteiro: So with the MIGDAS, you can use it along with some standardized checklists. I have frequently used the MIGDAS along with the SRS, or the Social Responsiveness Scale, for elementary and middle and high school students. Because that gives a nice balance between quantitative and qualitative.

And the CARS-2 High-Functioning is a really, really good standardized ratings scale measure to use along with the MIGDAS. Many teams use the MIGDAS, as well as the ADOS, in their testing. So you can use it as a compliment to that, or you can use it as a free-standing instrument, along with some of the checklists.

Michael Margolis: Marilyn, what’s the relationship then between, say, the MIGDAS and the book *Autism Conversations*? Is there a way they go hand-in-hand?
28:57 min.

Marilyn Monteiro: Yes. I developed the MIGDAS first, because it really was – I was getting a lot of requests from my teams that I work with, with all of the hundreds of assessments I do every year. They were saying, “Well, why don’t you formalize that, so we have sort of a protocol we can follow, and other people can use when you’re not on the team?”

So I developed the MIGDAS, and I was developing that, I thought, “I really want to be able to have a guidebook, if you will, for evaluators and practitioners, that is a book that really lays out: here’s how you do it, when you’re sitting there with a child who is verbal. But what about when you’re testing someone who is non-verbal?”

What about if you’re working with someone who has some good social initiation, but doesn’t have very good follow-through, which is one of the hallmarks of kids who have PDD-NOS? So the book

really expands on the protocol and the method that is laid out in the MIGDAS. So they go very well together.

Michael Margolis:
30:09 min.

Yeah. So the follow-up question that's probably on the minds of a lot of folks – because it came up in some of the questions that were submitted – is sort of this notion of: how does one go about discriminating between normal and neuroatypical levels of behavior, especially with children who find themselves on that spectrum? And, as you said, children that oftentimes – sort of verbal behavior – and sort of – are acting in a certain way that perhaps doesn't fall into the hard and steadfast conventions?

Marilyn Monteiro:

Well, that's also a really good question. When we look at autism evaluations, and we talk about people who have the differences in development that fall on the autism spectrum – especially the milder end of it, where we're talking about high-functioning autism, high-functioning PDD-NOS, or Asperger's Syndrome – oftentimes, we're really talking about being able to get a sample of behavior – elicit a sample of behavior from the student or the child that shows us where are those neuroatypical differences in development, as opposed to neurotypical kids who –

For instance, in the area of language and communication, a neurotypical child who's age five is going to ask questions, is going to comment and respond when you talk. But a neuroatypical child who's verbal may initiate a conversation with you, but they're gonna initiate a conversation in a much more restricted way, and they don't really engage the listener, or really look for cues from the listener.

So with the MIGDAS and the approach that's laid out in the book *Autism Conversations*, I encourage evaluators to go through a three-step process. The first step is really starting out the conversation with a neuroatypical approach, meaning that you start it in the middle, by talking with the child about the child's interests, or sharing toys with the child.

So instead of starting your evaluation by going into the situation and saying, "Hello. We're gonna work together today. Blah, blah, blah," you go in, and you start asking them comparison questions. "So, is the Velociraptor the better dinosaur – the most fierce dinosaur? Or is the T-Rex the most fierce dinosaur? Is the Giant Squid more interesting than the Great White Whale?"

So you start asking them those questions, and they immediately relax and begin to share with you their world view, and talk with you about the things that they're interested in. And keep in mind that neuroatypical kids on the spectrum, for the most part, are constantly being told in their lives, "You're talking about that too much," or "Stop playing that way. Come do this. Come be neurotypical." So when they're actually specifically invited to be themselves, they love it. They enjoy it.

So you start out with that. That's the first step. The second step then is to introduce some more neurotypical conversational topics, like asking about friends, asking about feelings, asking: "If you had three wishes – how to describe yourself" – those types of things. So then you get a sense of: how does their language or their social behavior change when you try to shift them from their agenda, their beloved topics, to what you want to talk about?

And then the third part is to do some social play back and forth with younger children, playing catch and doing something that's a little bit more physical, to kind of get a sense of how they do in that environment. So that's kind of the layout of the method.

Michael Margolis: Well, it's a really great distinction in both acknowledging how often children end up being on that atypical end of the spectrum, and sort of showing, I think, through your book, how one sort of – in these three steps – can go through that process. I want to be sensitive to, and really acknowledge some of our readers who have submitted some questions.

So I've got a few questions here that I thought we might sort of try to run through, and see if we can't try to cover a whole series of different questions that have been submitted, if you're game for that, Marilyn.

Marilyn Monteiro: Great. Great.

Michael Margolis: Okay. So I've got a question here from **Jeanie Sim**. And she says, "What do you recommend for a diagnostic workup, beyond just what the school team provides?"
34:25 min.

Marilyn Monteiro: In terms of Jeanie's question, it depends on what – there's such a variety between what a school district does provide, that it's hard,

without the context of: what, exactly, is her perception of what school districts provide?

In terms of a good workup for an individual who has a child, who has a suspected autism spectrum disorder, again, I think that looking at – in addition to collecting information through quantitative checklists and measures of that sort, using the GADS, the CARS-2, those types of measures, where parents fill out checklists, and teachers fill out checklists, and using a more standardized test, like the ADOS or the PEP-3, it's really important that the practitioner sit down and work directly with the parents, in terms of having a conversation – that they work directly with the teachers, or the caregivers, in having a conversation with them, and that they meet and have a dynamic, as opposed to a static, exchange with that child.

And when I talk about dynamic, it's all the things that I was talking about before, where they engage the child in it. Now also important is to get cognitive and achievement measures for children who are five years old and older. Because what that will help you with is being able to see that many children who have high-functioning, or even more involved forms of autism, classically have uneven patterns of development, meaning that oftentimes, there are – being able to have a formal measure of cognitive functioning and achievement functioning will tell us a lot of information.

For instance, with kids who have autism or PDD, many times you'll see, typically, a profile on a cognitive measure where verbal skills are less developed than their perceptual reasoning skills, when they don't have to use language, but they can figure things out visually and manipulatively. That's important information to know for planning for a child.

For children with Asperger's Syndrome, oftentimes you'll see they have great skills on standardized tests, both for cognitive achievement and even language tests – language pragmatics tests. A speech therapist might find – “Wow. They're in the average range with all their pragmatic skills.”

But then when they try to have a conversation with that child, the child isn't able to read the cues in the natural environment and apply that information. So the standardized testing is helpful,

because it lets us know what skills the child or doesn't. I would say a whole battery of tests is important.

Michael Margolis: Great. So I've got a few more questions here, Marilyn. I'd love to try to hit as many of these as we can, with the time that we have left. So another question here is from Patrick Murphy, who's in California. He loves your book. He's dog-eared it. He's highlighted passages.

Marilyn Monteiro: Awesome.

Michael Margolis: But one of the things that he's struggling with, as he's describing here, is that most of the evaluations he does are solo, with minimum collaboration from other professionals. And he really liked the team approach that you described in the book.

But he's wondering if you ever had the need to use this approach alone, without a team. And his sense is – he doesn't feel he can really change the system to get a team together. So what might be your thoughts on a situation like that?

Marilyn Monteiro: Well, Patrick brings up a good point, and that is if you're in a situation, as a psychologist or a practitioner, and you don't have access to a multidisciplinary team, and yet you're requested, by parents or school districts, to do evaluations, then I would really – my encouragement would be to use this approach, in addition to doing some of your standardized testing.

Because what it's going to give you is a very powerful tool. And people are going to be much more likely to use your results that you get from the student, if you're able to really provide a description that's really compelling about how the child thinks and operates in the world.

So my comment to Patrick would be yes. But what you lose by not having a team approach is: you don't have your multidisciplinary colleagues to also corroborate what you're seeing. But if you use the MIGDAS and the approach in the book, what you're going to have is a description of the child, that when a parent reads your report, or sits down and talks with you, and you're delivering the diagnosis – or when that teacher reads the report that you've written, they're going to say, "Wow. This describes the child I work with."

And if you don't include this approach, as a solo practitioner, what happens is you really are limiting yourself. Because you're going to be providing a report that has much more of a numbers basis, and isn't going to be as descriptive of the individual. So _____, Patrick.

Michael Margolis:
39:24 min.

Yeah. So here's the kind of related question, which was also submitted, which is: how do you coach other team members, which may have a limited knowledge and understanding of what autism is, and how it affects children in a multitude of ways?

Marilyn Monteiro:

This is a question that really gets to heart of one of the team issues that I deal with every day in coaching people. And that is because autism is an area that many people are expected to have expertise in, and have some interest in, you'll find sometimes, on teams, that people will have a good textbook understanding of autism spectrum disorders. They've been to lots of workshops. They understand the terminology and how to talk about it.

But when it comes to actually being able to interact with individuals who are on the spectrum, to really engage with them and have a personal experience, as opposed to an observation of the child, things break down. And so using this approach, one of the things the MIGDAS does – and the book, in Chapter 1 especially, and Chapters 5 and 7 – it really describes individual children, and then links that to the visual framework that I use to – and the vocabulary to talk about kids.

So for teams, what I find is that there's a lot – there's a shaping process, if you will, Michael, that goes on for team members, in terms of the language they use, and the way that they begin to – instead of looking at the child and instantly saying, "Oh, he has autism," and not really thinking about the description of that individual child, and how autism affects him or her, with this method, they tend to spend much more time describing their experiences with the child, describing the child's behavior, and then talking about the diagnosis. So it tends to help teams come to consensus more cohesively.

Michael Margolis:
41:21 min.

Here's actually another related question. Oftentimes, part of that team, in many ways, ends up being the teacher in the school with the children. And so many times, teachers are not trained or

prepared for working with autistic students. And are there any good reference materials you can recommend, so that teachers can create or locate specific materials relevant to autistic students?

Marilyn Monteiro: Well, I think actually in the field of education now, my experience is that more and more teachers are receiving in-service training, and receiving lots of supports too. Because you can't be a teacher in a school nowadays, and not have a child on the spectrum in your class.

Really, my experience of teachers is that, for the most part, they're very open to learning more about autism, and applying the experiences that they have – adopting and accommodating for these kids in the general ed classroom, when they're capable of being in there.

So in terms of references for teachers – I encourage teachers to go to any in-service that's offered on autism. In Texas – I think this is true in other states as well – there are oftentimes online courses teachers can take. There are lots of good resources there. In terms of actual teaching and testing materials, school psychologists across the country and behavior specialists – often districts have autism behavioral specialists or school psychologists who are specialists in autism.

And they are wonderful resources right in the schools, for teachers to gain access to all sorts of different resources. And then if you're interested in further resources, on my website – and then I'll be blogging about it on the *Autism Conversations* website, looking at different resources that are good for actually looking at materials.

But in the scope of our conversation today, I wouldn't be able to really go into it in as much detail as I would like.

Michael Margolis: Uh-huh. Yeah. Now here's a more technical question for you.
43:28 min. Can you explain the difference between willful and autistic noncompliance?

Marilyn Monteiro: Yes. I think that when you talk about language – earlier today, I talked about – in our conversation, Michael, I was talking about how the language we use is so important. And when we talk about willful, we're putting a judgment on that behavior.

So when we look at the behavior of non-compliance, I like to talk about it not so much as non-compliance, but resistance to – the child is resisting doing what you want the child to do. So in terms of: how does understanding autism spectrum disorder weigh into the way that you deal with that? Well, I'll bring up a child – I'll just give an example of a kindergartener who was getting upset in the class.

He had Asperger's Syndrome. He got upset when he sat down, and someone had moved his crayon. He would get upset if it was time to move from this activity to that activity. So in understanding him – now he's very bright, so the teacher said, "Well, you're just willful about this. Then there's going to be a consequence."

And in kindergarten, a lot of times the consequence is your little green color gets sent to the yellow color, and then your yellow color goes to the red color, and then you get a frowny face or something. So there are consequences directed to the behavior.

The assumption is, with a neurotypical child, that the child is going to want to conform to the social norm and please the teacher, and is going to then change their behavior. If we understand autism spectrum disorders and the neuroatypical way of organizing in the world, then we understand that the child is really having difficulty with the whole sensory aspect of life. They're having trouble with transitioning from their agenda to the agenda of the teacher.

So that creates resistance in the behavior. So how do we kind of help the child, as opposed to give consequences to the child? Well, one way that is very powerful with kids on the spectrum to help them with resistance to instructions is to give them predictability and a way to prepare for those.

So using a lot of visual supports that predict, beforehand – "First, we're gonna do this. Then we're gonna do that." Those types of measures can be extremely helpful. I want to get back, just for a second, to the child that I was talking about – the kindergartener.

Michael Margolis: Yeah.

Marilyn Monteiro: So he would just get very, very upset, and he'd cry, and he'd scream, and he'd disrupt the whole class. So we came up with a little index card for him that said, "How am I doing?" He had to

follow his plan of how he was gonna take a deep breath, count to 10, calm down.

And then if he couldn't do that, he'd kind of remove himself for a little while – get regrouped or rebooted, if you will – and then come back into class.

So he had his little card, and he was supposed to rate himself throughout the day on how he was doing. What we were trying to do is pair up the understanding of: “When you're getting disorganized and agitated, these behaviors happen. And they're not acceptable in the kindergarten class. So we've got to teach you and coach you on how you can kind of regroup in an effective way.”

So he does this program for a while. And then one day, he doesn't want to do something, because he's really preferring to stay on the computer. And he circles the picture on this plan that says, “I'm not doing well at all.” And he says, “I'm not doing very well, and I don't want to do very well, because then I'll have to get off the computer.”

So in that case, he was telling us, wonderfully, that he understood the consequences, and he was ready for consequences. But to start out with, he really needed the support of – “I've got to reorganize myself, before I'm ready to go on to the next activity.”

Michael Margolis:
47:22 min.

Wow. Well, we have time for just a couple more questions here, Marilyn. One that I have here is from an early interventionist. And she says that she's frequently working with parents who may, themselves, be on the spectrum.

Sometimes they don't see their child's behavior as a problem, because they were the same way as children. Others have a hard time participating in our intervention sessions. Any strategies that you can suggest that might help?

Marilyn Monteiro:

Yes. In fact, early intervention means that she's working with very young children. And one of the things that I've had the privilege of being able to do, over the years, is to work in early childhood intervention programs, where I work with young children under the age of three, and go out to their homes, and work with the families,

and help support the therapists in the work that they're doing, and also sometimes help with framing the diagnosis for parents of young children.

But the question that our colleague is bringing up, about – parents may, themselves, be on the spectrum – this is an issue that is part of the whole human element of working with children on the spectrum – is sometimes there is a genetic component, and parents may not have all of the characteristics, but have some of the characteristics. Or they may see some of the characteristics in their child that they had.

And then they're, of course, frightened by the idea that maybe there's a disorder. And what would that mean – not just for their child, but for themselves as well? So I think that she's bringing up an issue that is something that is very much a part of the culture of working with children on the spectrum.

And in terms of how to help parents come to terms with it, in the book, one of the things that I spend a lot of time laying out is how to talk about autism without saying autism. In other words, really talking about the way the child organizes and manages in the world, without saying – if we focus on the label – if you're talking to a parent of a young child, and you say, "This is the diagnosis," and then you begin to describe the child, they don't hear anything past the diagnosis.

And why not? They don't hear it, because they have their own idea, and they're reeling with – "Autism. What does this mean? I don't think he has it." So if you stop, and don't say the word "autism" with early childhood children, but you begin to talk to their parents about – "Let's watch them."

I was with a child a couple of weeks ago – a young child. The mother said, "He's just like me. And she said, "So I don't know if he has it or not. Does that mean that I have it?" She was really wrestling with these things. So we were sitting on the floor at his home, in the little play area. And this little boy, less than three years old, is not talking yet, but is beginning to say a few words paired with pictures.

But now that he's got the pictures, he's beginning to tantrum less, and he's actually going and finding the pictures of "cookie," or

“milk,” or “video.” And he’s bringing them to his mother. And she said, “You know he’s talking less now, while he’s doing that.”

So as we played with him and worked with him, rather than talking about does he have autism, or doesn’t he, we really began to talk about: “Look at how he is beginning to really master this idea of: ‘Communication involves another person. I take the picture up to them.’”

And she said, “But he’s not talking as much.” And I said, “But let’s look at this – that he’s tantruming less, and he’s putting a lot of effort into finding you, handing this to you, waiting for your response. That involves a lot of social dynamics for him. And he’s going to begin talking a little bit more, once he’s mastered that.”

And sure enough, I did a follow-up about a month later, and he’s beginning to vocalize and use his words a lot more. But in talking about all of this, we played with him. We saw. We established a context of consensus. We see the same thing as she sees it. And then we’re able to talk, with the triangle that’s depicted in the book – talk about the child’s profile, and then talk about autism.

One last comment I want to make on this question is if you are really thinking that the parents have some of the same sorts of more literal thinking, less flexibility in thinking, less social engagement, then really think about using more visuals in the way that you depict things. Put things into terms of: “We’re gonna do this in two steps or three steps.”

Because the more that you are sort of predictable, and use the same techniques with parents that you use with students, the more successful you’re going to be in having them relax and work with you.

*Michael Margolis:
52:08 min.*

So Marilyn, in hearing you describe so much of your approach, and sort of evolving and reframing the conversation, it seems to me like there’s a deeper creative tension here between – because some of the questions that we also received were typical, expected questions, like – “Can you differentiate between the various forms of high-functioning autism and Asperger’s? Can you discuss the variability of the disorder among children?”

There's this need and desire within the pedagogy of diagnosis, which is about specificity. It's about understanding really: what is the diagnosis? Where is this child? How are they behaving? And yet, so much of what you're saying and articulating is that we need to expand our notion that this is about context. Quite literally, we're talking about where children exist on a spectrum.

And so there is gonna naturally be this sense of variability. And yet, of course, within the medical community and within the school system, there's still a desire and expectation around: "Well, we need to know: where is the child on that spectrum?"

Marilyn Monteiro: Right.

(Crosstalk)

Michael Margolis: Any closing thoughts about that creative tension – of like the pragmatic reality of the environment that practitioners are working in, and then sort of this deeper nuance that you're bringing to the surface, that's clearly the way to get in touch with parents, and a way to really better humanize and help people to have a better relationship and connection to an individual with autism?
53:27 min.

Marilyn Monteiro: Yes. There's a paradox that's really in play when you're doing the diagnostic work with children on the autism spectrum, and trying to determine and tease out – especially with higher-functioning kids. Is it best? Is it the most compelling way to describe the child – as having an autism spectrum disorder?

And if so, which specific aspect is better emphasized? Asperger's? PDD-NOS? Or high-functioning autism? So if we're looking at that question, really the method that I'm talking about, and the tools and techniques that I'm coaching people to use in the field, when they're doing diagnostic work – if they are able to really take this approach of really getting to know the child's world view, and describing that – eliciting that behavior sample, if you will, Michael – what happens is that it becomes much more clear to all parties involved that, oh, this really does fit better under Asperger's, or better under PDD-NOS.

I'll say this in closing for this question – in particular, the area of PDD-NOS is very loosely defined in the diagnostic criteria. And yet, there is a compelling need to really describe some of these sort

of ADHD kids who are sort of quote, unquote, “quirky,” really describing all of this behavioral way of looking at the world, difficulties that these kids struggle with. Sometimes talking about them as having a pervasive developmental disorder really makes a lot of sense.

But if we start with describing the child, using these methods and techniques that are described in *Autism Conversation*, along with other tools, what we’re able to do then is to back into the diagnosis, and be much more accurate and confident in our description of individual children.

So it really is, I think, adding something to the field, in terms of helping people have a real practical tool to be able to better tease out those differences and nuances along the spectrum.

Michael Margolis:
55:58 min.

Wow. I love that, Marilyn. In our conversation today, I think you’ve really helped to connect the dots in some really meaningful ways. I know as we were talking, just a little bit earlier –

I was wondering if you might just share your experience, just recently, with one of your presentations. What was your experience with a nine-year-old in the room, and the conversation that you had on this topic?

Marilyn Monteiro:

Oh, I had a lovely experience. I was invited to do a training for a group where there were about 130 teachers, and also parents and their children in the audience. And it was really talking about looking at: what are some of the challenges facing children on the spectrum, as they become adolescents and then young adults, and look at making that transition from high school to college?

Well, as is often the case when I give a talk, the audience is very varied. In other words, it wasn’t just people who were adolescents, or had adolescents that were going into college. There was a nine-year-old with his mom in the audience.

So at the end of the talk, I was asking for questions. And it was a large group, so they were collecting cards that people had written their questions on. But while we were waiting for the cards to be collected, I just said, “Does anyone have any questions?”

So this young boy raised his hand, in a very assertive way. And so, of course, I was delighted, and I called on him. And he said, “I have question for you.” And I said, “Great. What’s your question?” And he said, “You mentioned that individuals on the autism spectrum are motivated by their sensory behaviors. Explain to me what you mean by that.”

So I said, “Oh, that’s a great question.” And I said, “Are you nine-years-old?” I didn’t ask him how old he was. I took a guess. And working with lots of kids, it wasn’t that hard to guess, because I see a lot of nine-year-olds. So I said, “Are you nine?” And he said, “Yes.”

And I said, “So what do you most like to do? Do you like video games or –” And he said, “Legos.” So rather than saying, “Oh, you like Legos. That’s great,” I said, following his kind of neuroatypical way of talking, which is something that I do with kids all the time, “Oh, so you’re a Lego maniac.” Because many nine-year-olds who are on the spectrum and love Legos refer to themselves as Lego maniacs.

So when I said Lego maniac, he beamed, and he held up this intricate Lego ship that he’d made, that he happened to bring with him. So he held that up, and then he started holding up some other Legos. And his mom sort of stopped him from doing that. But what happened was –

The point I want to make is that everyone in the audience was able to really sort of resonate with this child’s ability to really kind of respond to that conversational approach. And so we had a lovely conversation about how he uses his Legos as a way to regroup, and regulate, and keep himself kind of calm, and block out some of the stressors of the social and language world, and how it does motivate him to get his homework done, when his mom says, “You can play with your Legos when you’re done.”

So that’s just an example of this whole neuroatypical conversation, and how really thinking about how we enter into the child’s way of dialoguing, how we enter into, and respect, and support their interests. Rather than looking at that as checking off a box that says, “Restricted range of interest. He must have Asperger’s,” it really helps us to then do some planning for children.

Michael Margolis: Beautiful. Well, Marilyn, it's such a wonderful anecdote to close out our conversation. And I think it really brings to light this notion of how as practitioners, and as parents, and as just individuals, the way in which we relate to individuals who are on the autism spectrum.

And that at the end of the day, it's just about seeing people for who they are. And that really is the message that I hear coming through in that example and through your book.

Marilyn Monteiro: Absolutely. Thank you for this opportunity to talk about my preferred topic, which you can tell I'm quite passionate about. And I would want to end this with: if you're an evaluator, and you're listening to this, go out there and really listen to the stories people are telling, and figure out ways to really connect with these kids, so that you really have the experience of getting to know them.

If you're a parent listening to this, tell your stories. People need to hear your stories.

Michael Margolis: Uh-huh. Beautiful. So that brings us to the close of the teleconference. We certainly have covered a lot of rich territory. And if there's one thing that's really for certain, autism diagnosis, as the topic of your book, is really a rich topic for conversation.

And we can hear that and see that just in the territory that we've explored. Now Marilyn, there's a few bonus resources related to the book that are available on the book website:
AutismConversations.com.

Marilyn Monteiro: Yes.

Michael Margolis: Both some things that people can sign up for, and there are some things that you'll be continuing to share with folks in the months to come.

Marilyn Monteiro: Uh-huh.

Michael Margolis: And I know you've started to blog there as well. So we're gonna continue to make sure that your thoughts and experiences are shared through that site. There are several questions that were submitted, which we did not get a chance to cover in the call. But

certainly I imagine those will make really great fodder for some of your future blog posts.

Marilyn Monteiro: Oh, I'd love to blog about that.

Michael Margolis: Right? And then I know, also, you're doing a lot of presentations right now. Like just recently, you were at the NASP Conference. You're also doing a lot of school district and service trainings. Where are some of the places that people can find you in the coming months?

Marilyn Monteiro: Well, the best place to kind of look at the schedule of events is gonna be on either the *Autism Conversations* website or my website – the postings of where I'm gonna be speaking. So I am doing lots of trainings, and enjoy, always, having opportunities to talk to groups, and to also do specific trainings for teams. So just look up the schedule on the calendar page.

Michael Margolis: And what is the URL for your personal website, Marilyn?

Marilyn Monteiro: MarilynMonteiro.com.

Michael Margolis: Great. And so to spell that for everybody, that's: M-A-R-I-L-Y-N-M-O-N-T-E-I-R-O dot.com.

Marilyn Monteiro: That's right. Monteiro – it's Portuguese. Yeah.

Michael Margolis: So MarilynMonteiro.com.

Marilyn Monteiro: Yeah.

Michael Margolis: And then we also have AutismConversations.com, which is the main site for the book, of course. And so with that, I just want to thank everybody for being on today's call. I hope you've enjoyed the conversation with Dr. Marilyn Monteiro.

We are gonna be sending out an MP3 audio recording of this file to all of you very soon, and we welcome your further comments and questions on Marilyn's blog, for her to know what some of the things are that are really on your mind, so she can continue to cover and elucidate for you. So with that, thanks everybody, and have a wonderful day.

Marilyn Monteiro: Thanks. Thanks, Michael. Bye.

[End of Audio]