Web-Based Radio Show

The Misdiagnosis of Autistic Spectrum Disorders: The Most Important Signs of Progress

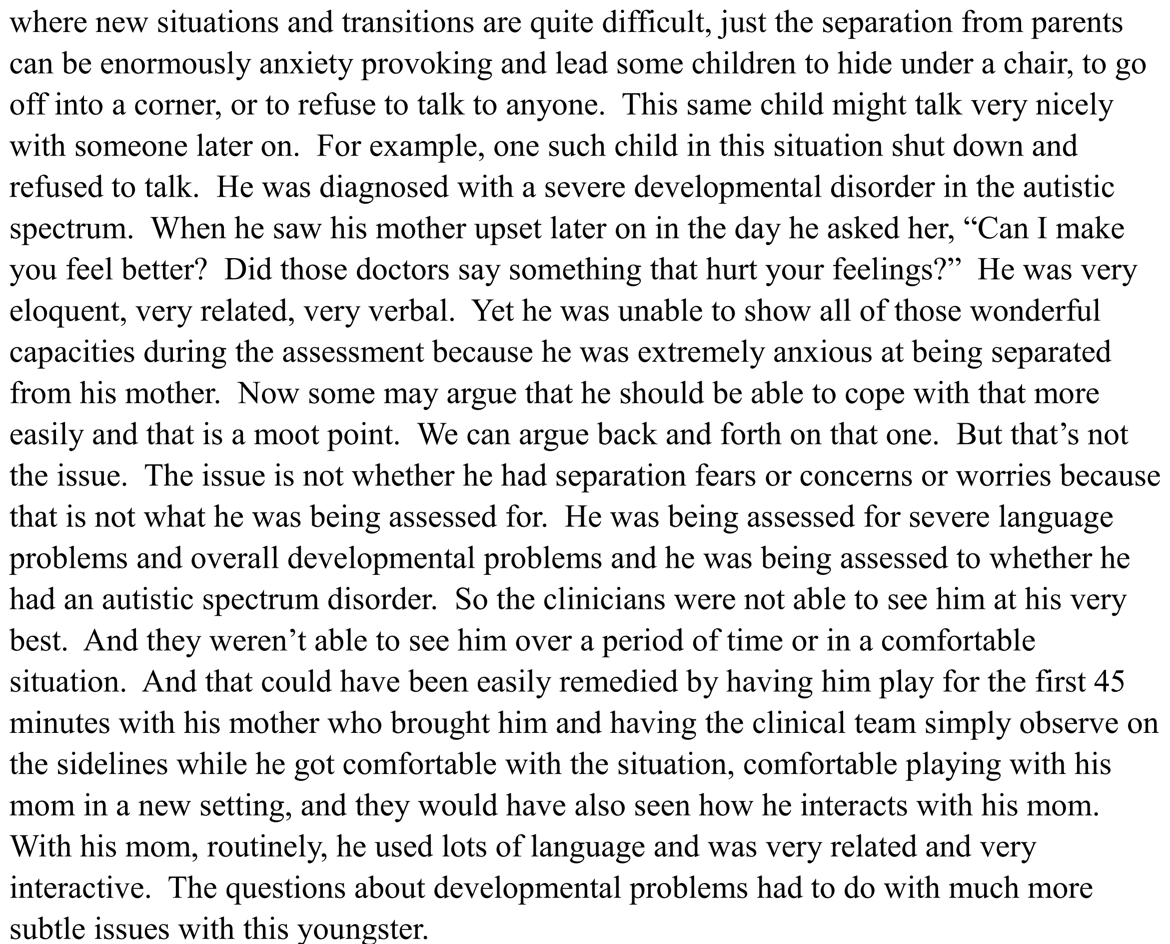
Stanley I. Greenspan, M.D.

February 26, 2004

I want to welcome you to our Infancy and Early Childhood and Families Web-based Radio Show. Today we have the distinct pleasure and honor to have a very, very important topic. The name of our show for today is "The Misdiagnosis of Autistic Spectrum Disorders" and in discussing autistic spectrum disorders we'll also be delving into not only the proper way to make a diagnoses but what to look for as we monitor progress in our children, and also what to look for more generally to know if a child is doing well in development and what to look for, for all children in terms of healthy development. If we have time we'll also touch on how to promote healthy development in children with special needs as well as children without special needs.

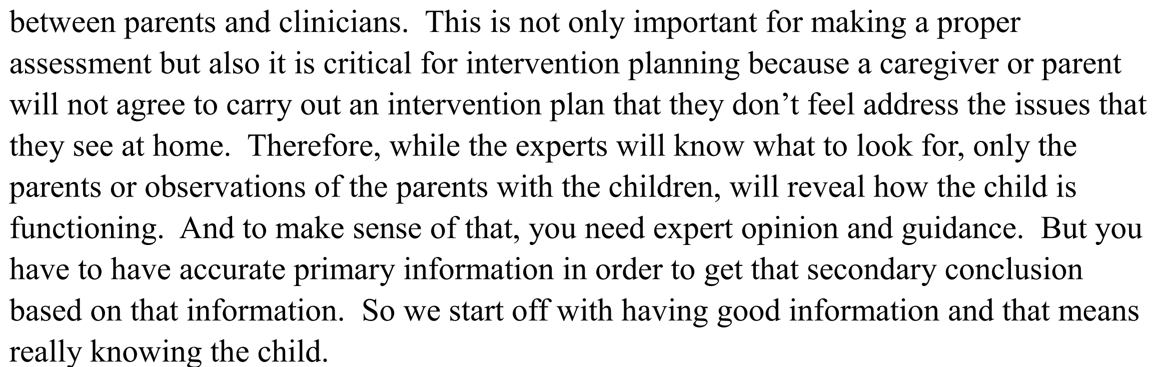
First, though, why is there a tendency, and I'm assuming some of you agree with me, to make this diagnoses for children with autistic spectrum disorders and other developmental disorders of relating and communicating? Before we even talk about the symptoms and talk about what to look for, we need to establish an agreement on a fundamental assumption. Who knows the child best? Who knows how a child is really functioning? Don't we need to really understand a child and know a child over a period of time to be able to figure out how that child is doing? So if we want to find out how a child is functioning and whether a child deserves a diagnoses of an autistic spectrum disorder or any other developmental problem, we first need to know that child quite well. Now quite often, when a parent or another caregiver is concerned about a child, the evaluation involves, number one, separating the child from the parent. That often involves very structured standardized tests. It often involves only very briefly observing that child interacting with familiar caregivers or parents and mostly interacting with new individuals, which could be the assessment team or the primary clinician in charge of the assessment team. What we are observing here is not the child at his very, very best or what his real capabilities are for intimacy and relating or even communicating. We're observing in part how a child responds to this set of new circumstances, which for some children are very stressful. For example, children who are very sensory over-reactive

4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



where new situations and transitions are quite difficult, just the separation from parents can be enormously anxiety provoking and lead some children to hide under a chair, to go off into a corner, or to refuse to talk to anyone. This same child might talk very nicely with someone later on. For example, one such child in this situation shut down and refused to talk. He was diagnosed with a severe developmental disorder in the autistic spectrum. When he saw his mother upset later on in the day he asked her, "Can I make you feel better? Did those doctors say something that hurt your feelings?" He was very eloquent, very related, very verbal. Yet he was unable to show all of those wonderful capacities during the assessment because he was extremely anxious at being separated from his mother. Now some may argue that he should be able to cope with that more easily and that is a moot point. We can argue back and forth on that one. But that's not the issue. The issue is not whether he had separation fears or concerns or worries because that is not what he was being assessed for. He was being assessed for severe language problems and overall developmental problems and he was being assessed to whether he had an autistic spectrum disorder. So the clinicians were not able to see him at his very best. And they weren't able to see him over a period of time or in a comfortable situation. And that could have been easily remedied by having him play for the first 45 minutes with his mother who brought him and having the clinical team simply observe on the sidelines while he got comfortable with the situation, comfortable playing with his mom in a new setting, and they would have also seen how he interacts with his mom. With his mom, routinely, he used lots of language and was very related and very interactive. The questions about developmental problems had to do with much more subtle issues with this youngster.

It may sound like this is an unusual situation, but in fact we did a review of 200 programs around the country including the very best medical centers and found that over 90% did not observe the parents or caregivers interacting with the child spontaneously and warmly in a supportive setting for more than 10 minutes. Most of the assessment was conducted with other individuals, other adults who were new to the child and the child was observed interacting with parents only as part of participating in a structured assessment or only as part of taking the developmental history. In other words it was never the primary focus for more than just a few minutes. In our way of thinking, this doesn't provide an in-depth look at the child. Also, often parents will feel that what they observe at home is quite different from what is being observed in the clinical setting. Here too it is important for the clinical team to see video tapes from the home setting or make a home visit. Or simply listen very carefully to what parents are reporting and if there is not a consensus on what is being observed, if the parents say, "Gee, the way little Johnny or Susie is behaving here is not the way they behave at home." then you have to keep observing, including multiple observations until there is a consensus reached



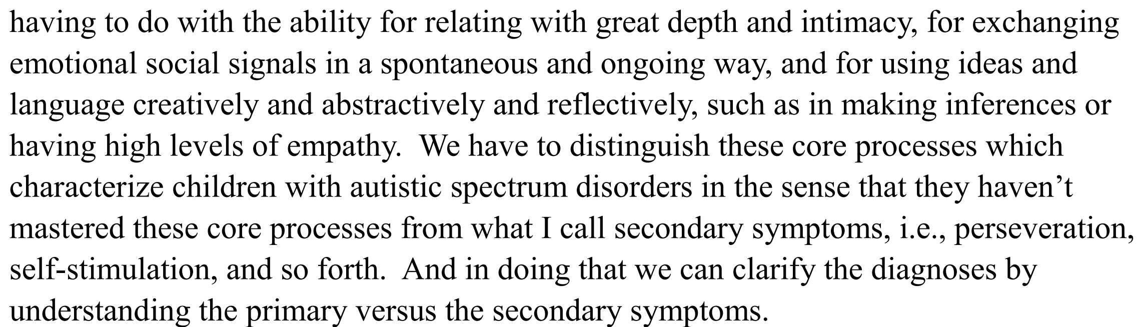
between parents and clinicians. This is not only important for making a proper assessment but also it is critical for intervention planning because a caregiver or parent will not agree to carry out an intervention plan that they don't feel address the issues that they see at home. Therefore, while the experts will know what to look for, only the parents or observations of the parents with the children, will reveal how the child is functioning. And to make sense of that, you need expert opinion and guidance. But you have to have accurate primary information in order to get that secondary conclusion based on that information. So we start off with having good information and that means really knowing the child.

Now the second question then becomes, what should we look for? What are the symptoms of autism and autistic spectrum disorders or what some like to refer to it as autism spectrum disorders? There's lots of confusion about these symptoms. Even though in the official diagnostic classification system, there are a lot of symptoms listed including inability to relate and communicate, tendency to perseverate or be repetitive, tendency to be self-stimulatory, tendency for some children to be echolalic, to have trouble interacting with peers, to be self absorbed, to be aimless, and so forth. Even though we have this list of symptoms to look for, it can be very, very confusing. Does one symptom, for example, constitute a diagnoses? Or even two or three? In the official classification system, it suggests that certain symptoms are more primary than others and if a child meets certain criteria having three out of a certain number, therefore the diagnoses will be made. But this may not be the best way of making the diagnoses. It may even lead to misdiagnoses. And one of the main reasons for misdiagnoses is not being able to clearly understand the symptoms that are specific to children with autism and the symptoms that are part of other conditions that may be confused with autism.

What are the symptoms that are specific to autism? There was a very important study done by Nancy Minshew and colleagues at the University of Pittsburgh where they looked at children with autism and children without autism who were matched for IQ scores. In other words, all the children had the same level of IQ as measured on a standardized test. And all this means is that most of the children in this sample were verbal and could participate in the test and could process the questions and respond to the questions. When they matched the children for these abilities, for some who had been diagnosed with autism and some not, they found that the symptoms that distinguished the two were not things like perseveration, or self-stimulation, or aimlessness, or echolalia. What distinguished the two was the ability for making inferences (which is a high level of abstract thinking, in other words to come up with a new conclusion to a question or a new hypothesis), the ability for reciprocal emotional cueing (to enter a back-and-forth social interaction where you're reading or responding to another person's cues and they

are reading and responding to yours), the ability for high levels of empathy (to be able to enter someone else's shoes, so to speak and understand what they are feeling and thinking and comment on it), and the ability for a deep level of trust and engagement. These were some of the characteristics that distinguished children with autistic spectrum disorders from children without autistic spectrum disorders when they were matched for IQ scores. So in other words, what we saw was the ability for high levels of abstract reflective thinking, making inferences, empathy, reciprocal emotional interactions (in other words back-and-forth social gesturing and emotional cueing), and the ability for deep and warm level of engagement. Other symptoms are important, obviously, such as the tendency to be repetitive (open and close the door many times in a row), the tendency to repeat what you hear rather than respond to it in a meaningful way, and the tendency to be self-stimulatory where you might look at a particular object moving back and forth and stare at it for long periods of time. These are all very common symptoms we see in children with autistic spectrum disorders. But what is important to know is that they are not specific to autistic spectrum disorders like the other ones I just mentioned. For example, children with language delays may repeat what they hear as another way of running the information by themselves as they are trying to process it. So children who have slow processing might repeat what they hear, and it may show very good auditory memory that they can repeat what they hear. Children with severe motor planning problems who can't sequence many actions in a row may take simple repetitive action patterns as their preference. Children who are very sensory over-reactive may do self-stimulatory activities as a way of trying to diminish the overload. So a child who is very over-reactive to touch or sound may wind up doing something repetitive or self-stimulatory as a way of trying to cope with that over-reactivity. For example, they may stare at a moving fan as a way of trying to tune out other sensory information. On the other hand, children who are under-reactive to sensation; under-reactive to touch or sound may seek sensation and do a lot of jumping as a way of keeping their body activated. Similarly, children who are under-reactive may be daredevils and do things that seem impulsive, again because they are trying to arouse their own nervous system. Again, I want to emphasize that these symptoms are seen in children with autistic spectrum disorders because children with autistic spectrum disorders have sensory over-reactivity or under-reactivity – each child will be quite different; some have delayed auditory processing; some have very outstanding auditory memory; and some have very weak auditory memory. So there is a variety of individual differences that we talked about last week. And a response to those: the children will evidence or show different behaviors. But these are found in children with sensory processing problems, with motor delays, with motor planning problems, with language delays – all which we see in children with autism but all of which we see in children who don't have autism. We just have these types of challenges in their own right. So we have to distinguish the primary symptoms,

4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



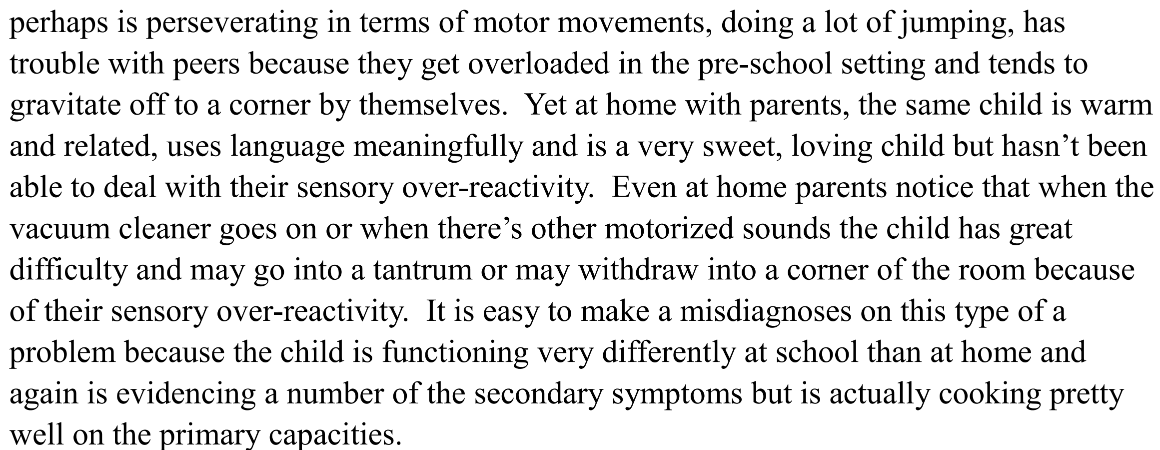
having to do with the ability for relating with great depth and intimacy, for exchanging emotional social signals in a spontaneous and ongoing way, and for using ideas and language creatively and abstractively and reflectively, such as in making inferences or having high levels of empathy. We have to distinguish these core processes which characterize children with autistic spectrum disorders in the sense that they haven't mastered these core processes from what I call secondary symptoms, i.e., perseveration, self-stimulation, and so forth. And in doing that we can clarify the diagnoses by understanding the primary versus the secondary symptoms.

Now frequently many colleagues of mine will not always make this distinction as much as I wish they would. And parents who read or look on the Internet about autistic spectrum disorders may not always make these distinctions, and nor should they. They aren't easy distinctions to make. But if we can make these distinctions between the primary and the secondary, we won't make the diagnoses of autistic spectrum disorders unless these primary symptoms are present. And if the secondary symptoms are the only ones present, we can consider alternative diagnoses. So a child who is very related and warm and interactive, for example, and a child who can use even a few words creatively and meaningfully and can exchange signals but is very sensory over-reactive and therefore is overloaded and tends to jump a lot or stare off in space sometimes or often craves sensation and therefore likes to touch everything in a repetitive way, this type of pattern in a child who is related interactive would not be confused with autism, even though we see those symptoms in children with autism rather we would say, "let's understand that child's sensory system more fully."

Now we have developed a parent questionnaire called the "Functional Emotional Assessment Scale Parent Questionnaire." A preliminary version of the types of questions that are in that questionnaire is available on our websites, www.floortime.org and website www.icdl.com. But I want to let everyone know that we will have a systematic questionnaire that has been field tested and is showing excellent reliability and validity be available in September from the Psychological Corporation. It will also be part of the new Bayley Scales that won't be out until a year after this September. But this September, this parent questionnaire on the Functional Emotional Assessment capacities of children will be available and that questionnaire will focus in on these primary capacities that when they are present suggest healthy development and when they are absent suggest that there may be a developmental challenge that requires a further evaluation and assessment.

Now what are the most common errors that are made when we don't distinguish the primary from the secondary symptoms well enough? One example I gave you before – a child presents who is very sensory over-reactive and perhaps is repeating words,

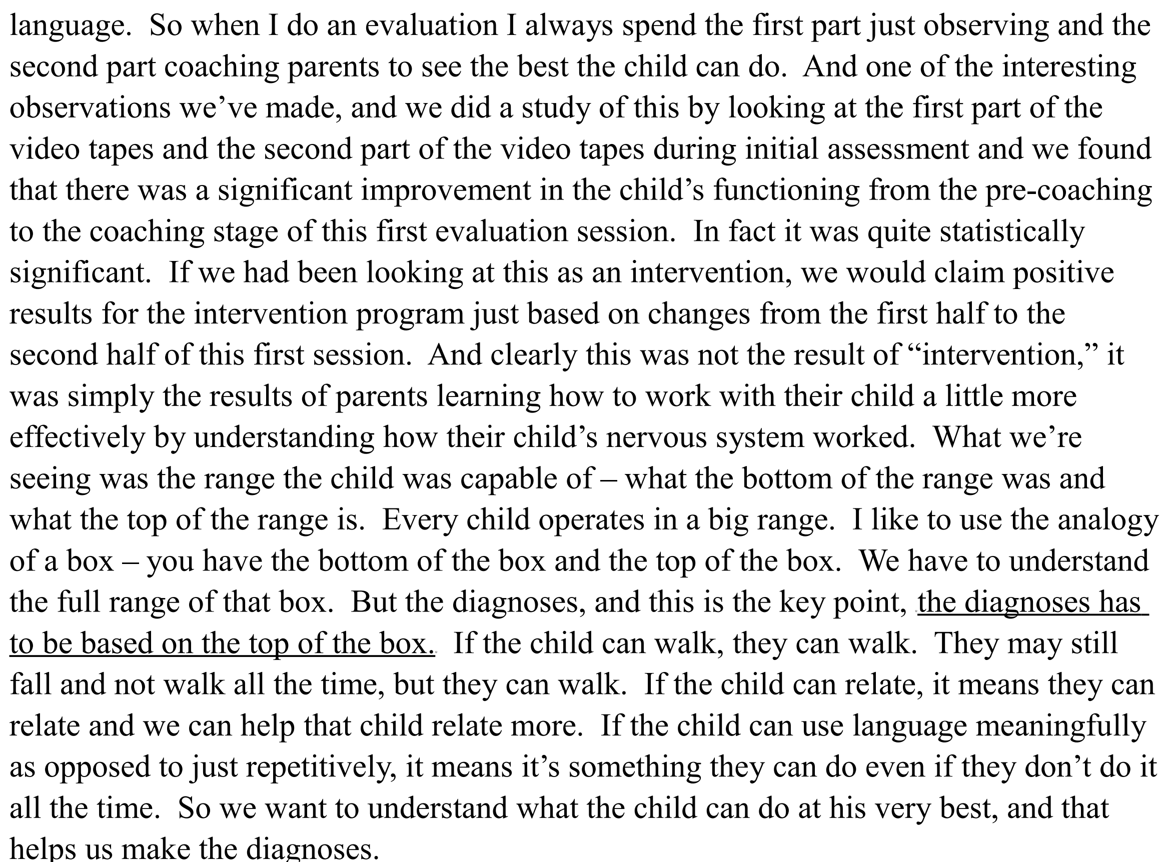
4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



perhaps is perseverating in terms of motor movements, doing a lot of jumping, has trouble with peers because they get overloaded in the pre-school setting and tends to gravitate off to a corner by themselves. Yet at home with parents, the same child is warm and related, uses language meaningfully and is a very sweet, loving child but hasn't been able to deal with their sensory over-reactivity. Even at home parents notice that when the vacuum cleaner goes on or when there's other motorized sounds the child has great difficulty and may go into a tantrum or may withdraw into a corner of the room because of their sensory over-reactivity. It is easy to make a misdiagnoses on this type of a problem because the child is functioning very differently at school than at home and again is evidencing a number of the secondary symptoms but is actually cooking pretty well on the primary capacities.

Another common type of error is for the child who is very under-reactive, who is self absorbed in a busy daycare center because no one is really engaging the child. But at home, when grandma plays with him, it pulls him it, he gives big smiles, he is warm and loving, very interactive, and begins to use some words meaningfully. So here, too, we may see a difference in the observations of the child and the interpretation of what the child is showing, but this difference can often be attributed to the primary versus the secondary symptoms or signs. So we should keep an eye on the primary symptoms and understand the secondary ones, they require work also. We want our child who is not able to function at school to be able to function at school. So we want to develop an intervention program for that child too, but we don't want to base it on a misdiagnoses which ignores many of the child's strengths. So in order to understand the child's strengths, we have to always understand how that child functions at home as well as at school and in other settings. We also have to be able to do something that I call "bringing out the best in the child," we have to support the child and bring out that best that the child is capable of to see what the child is really able to do. Now this comes back to another issue that helps us separate the primary from the secondary symptoms. During the clinical assessment process, it is very important for the assessment team to actually coach the parents on how to interact with that child a little bit better than perhaps they may understand on their own, particularly if the clinical team can figure out how that child's nervous system works. What sensations is the child sensitive to or over-reactive to? What sensations is the child under-reactive to – are they over-reactive to sound or under-reactive to sound? Are they over-reactive to touch or under-reactive to touch? Do they use vision or sound to orient themselves in the world. How well do they plan their actions? Can they carry out 3 or 4 or 5 step interactive patterns? In other words, clinicians can help parents work with their child's unique nervous system to pull that child into an optimal interaction pattern, and only then do you see whether that child can engage, can exchange social signals, can use ideas meaningfully if they have some

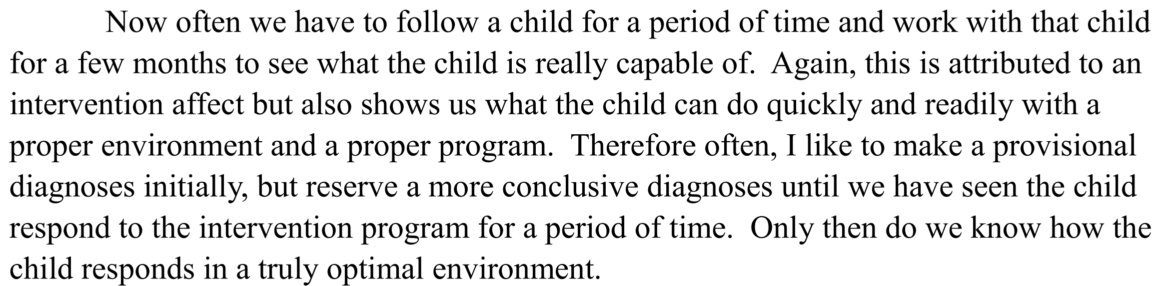
4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



language. So when I do an evaluation I always spend the first part just observing and the second part coaching parents to see the best the child can do. And one of the interesting observations we've made, and we did a study of this by looking at the first part of the video tapes and the second part of the video tapes during initial assessment and we found that there was a significant improvement in the child's functioning from the pre-coaching to the coaching stage of this first evaluation session. In fact it was quite statistically significant. If we had been looking at this as an intervention, we would claim positive results for the intervention program just based on changes from the first half to the second half of this first session. And clearly this was not the result of "intervention," it was simply the results of parents learning how to work with their child a little more effectively by understanding how their child's nervous system worked. What we're seeing was the range the child was capable of – what the bottom of the range was and what the top of the range is. Every child operates in a big range. I like to use the analogy of a box – you have the bottom of the box and the top of the box. We have to understand the full range of that box. But the diagnoses, and this is the key point, the diagnoses has to be based on the top of the box. If the child can walk, they can walk. They may still fall and not walk all the time, but they can walk. If the child can relate, it means they can relate and we can help that child relate more. If the child can use language meaningfully as opposed to just repetitively, it means it's something they can do even if they don't do it all the time. So we want to understand what the child can do at his very best, and that helps us make the diagnoses.

Now what do we see then the child is at the bottom of his box, under conditions that are less optimal where there may be noise in the room, or there may be a stranger, or there may be challenges, or parents or other caregivers aren't engaging the child according to the child's nervous system or according to what the child needs? That's important information. That helps us with the diagnoses as well. But that doesn't make the diagnoses. That helps us understand the child's individual differences; their unique patterns. And by understanding both the top of the box and the bottom of the box we may make a diagnoses of autistic spectrum disorder if the top of the box shows these primary symptoms that we're talking about, or we may say, gee the child can relate and communicate and think creatively and abstractly but they can't do it in a noisy environment and therefore what we have is what we call a regulatory disorder where they can't regulate the nervous system very well and they lose capacities under certain conditions of stress or challenge. And that's a very different diagnoses than an autistic spectrum disorder. It still requires work, but here we're fine tuning our understanding of the child by understanding what to look for. So the biggest errors have to do with confusing primary and secondary symptoms and not observing the child long enough or with coaching to bring out the best in the child.

4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



Now often we have to follow a child for a period of time and work with that child for a few months to see what the child is really capable of. Again, this is attributed to an intervention affect but also shows us what the child can do quickly and readily with a proper environment and a proper program. Therefore often, I like to make a provisional diagnoses initially, but reserve a more conclusive diagnoses until we have seen the child respond to the intervention program for a period of time. Only then do we know how the child responds in a truly optimal environment.

What I want to do now is take a question because we have one caller who promised to call before she has a meeting and she has a very good question, and then we're going to return and talk for a few more minutes about the issue of mis-diagnoses, then we'll take more calls from our audience. So we can line up our first caller and as we do, though, I'm going to say a few more words about the diagnoses.

When we make a correct diagnoses, it inevitably leads to the ability to select the proper intervention program because the intervention program needs to work on what the child's primary concerns are. If we have the intervention program, for example, working on interfering with perseveration, when the child's primary concern is how do I relate to another person or how do I get into a back-and-forth kind of social signaling, we may be focused on the wrong issue. So by understanding the primary symptoms and the secondary symptoms we can focus in on what the correct issue is for the intervention program. Often, for example, perseveration or repetition will be secondary to the inability to have a back-and-forth communication.

Now let's take our first call. Hello?

Caller: Hi.

SG: Hi, how are you?

Caller: Good, how are you doing?

SG: Good, welcome to our Web-Based Radio show, and I understand you have a wonderful question for us.

Caller: Yes, thanks for speaking with me, Dr. Greenspan. I have a beautiful 2-½ year old son. He has been diagnosed with moderate autism. He is a very warm and affectionate little boy but he does have the usual autistic behaviors. He hardly says any words and he doesn't really have good eye contact and he doesn't have play skills. I have been doing Floortime with him with good success for two months.

SG: What are you noticing?

Caller: New words, not used consistently, but used sporadically. And he comes and gets me to play with him.

SG: Oh, that's terrific because the coming to initiate social interaction with real warmth and pleasure is a cornerstone for all future progress.

Caller: Good! That's good to hear. He's picking up a few new play skills but not too many.

SG: So you're saying some improvement in his relatedness and warmth and seeking you out and some new words.

Caller: Right. Anyway, Floortime feels right to me, I like the approach. The situation I have here is in southern New Jersey is that I'm very much in a pro-ABA (Applied Behavior Analysis) area. And I'm getting a lot of strong resistance to my use of Floortime from family members – extended family members and from every professional that I've spoken to here - all of the therapists, the neurologist, and the school psychologist.

SG: They all want a very structured approach.

Caller: Yes, they have a full time ABA preschool that they want me to put Jason in, they seem to be concerned that I won't do a good job or that I'm going to mess up.

SG: They don't trust mommy.

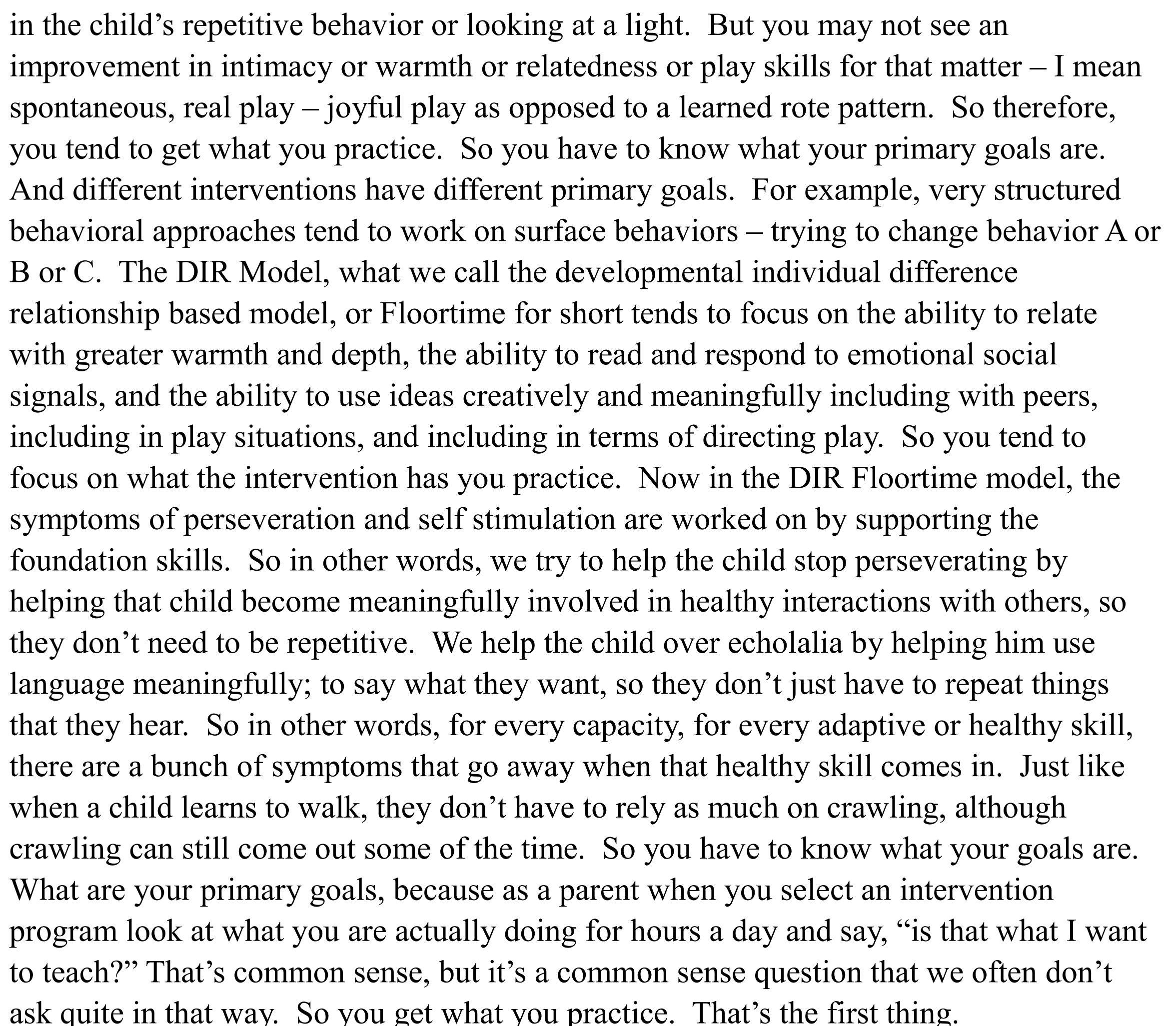
Caller: They don't trust mommy. They keep pushing that that's the way I should go, and they say that ABA is the only scientifically validated therapy. I guess I would like some advice on how to handle them and what studies I can read about that do support Floortime.

SG: Ok, that's a very good question. Thank you for asking it. Stay on the line while I answer it so you make sure I answer it well, so you can ask a follow-up if I don't.

Caller: Ok.

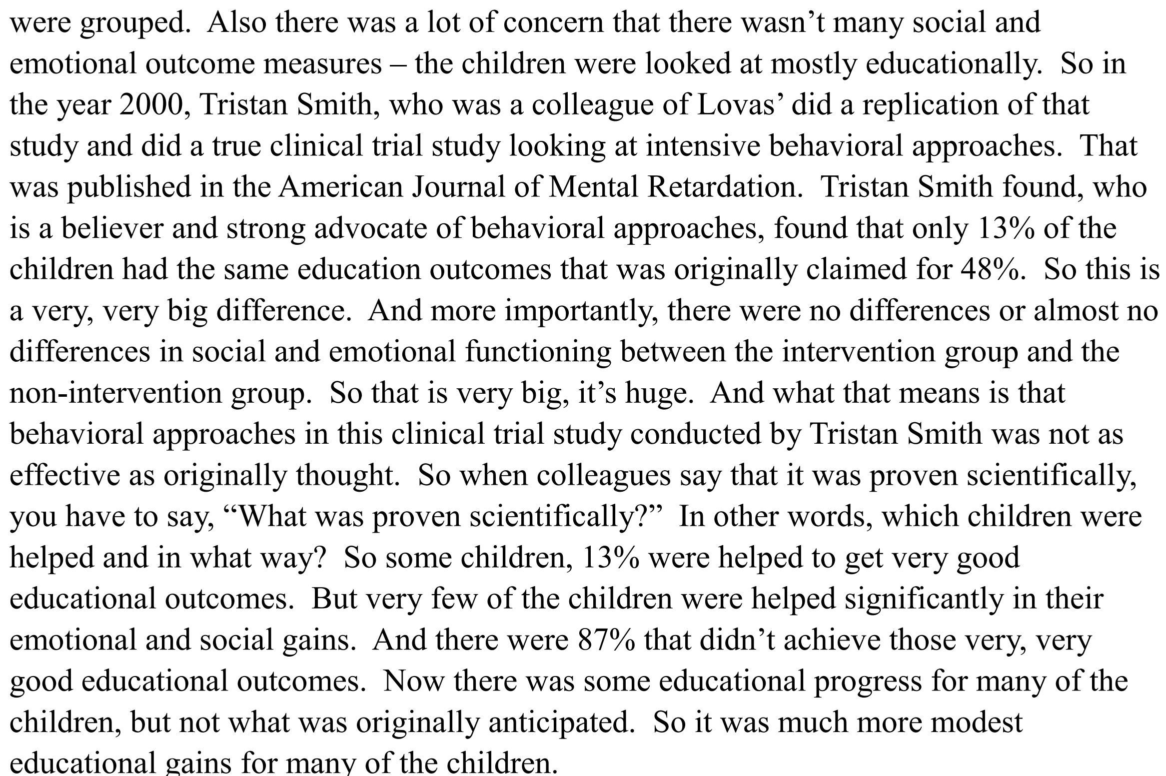
SG: The first part – there will be three parts to the answer. The first part is that you get what you practice. So in other words, when you select an intervention program, you have to be clear as to what your goals are because the child will respond to what you're doing in the intervention. So for example, as we were just talking a minute ago before we took your call, if your goal is to interrupt the child's repetitive actions, perseveration, or to stop the child from staring off at a light, then if you have a good intervention, you may get a reduction in that symptom. You may actually get a reduction

4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com



in the child's repetitive behavior or looking at a light. But you may not see an improvement in intimacy or warmth or relatedness or play skills for that matter – I mean spontaneous, real play – joyful play as opposed to a learned rote pattern. So therefore, you tend to get what you practice. So you have to know what your primary goals are. And different interventions have different primary goals. For example, very structured behavioral approaches tend to work on surface behaviors – trying to change behavior A or B or C. The DIR Model, what we call the developmental individual difference relationship based model, or Floortime for short tends to focus on the ability to relate with greater warmth and depth, the ability to read and respond to emotional social signals, and the ability to use ideas creatively and meaningfully including with peers, including in play situations, and including in terms of directing play. So you tend to focus on what the intervention has you practice. Now in the DIR Floortime model, the symptoms of perseveration and self stimulation are worked on by supporting the foundation skills. So in other words, we try to help the child stop perseverating by helping that child become meaningfully involved in healthy interactions with others, so they don't need to be repetitive. We help the child over echolalia by helping him use language meaningfully; to say what they want, so they don't just have to repeat things that they hear. So in other words, for every capacity, for every adaptive or healthy skill, there are a bunch of symptoms that go away when that healthy skill comes in. Just like when a child learns to walk, they don't have to rely as much on crawling, although crawling can still come out some of the time. So you have to know what your goals are. What are your primary goals, because as a parent when you select an intervention program look at what you are actually doing for hours a day and say, "is that what I want to teach?" That's common sense, but it's a common sense question that we often don't ask quite in that way. So you get what you practice. That's the first thing.

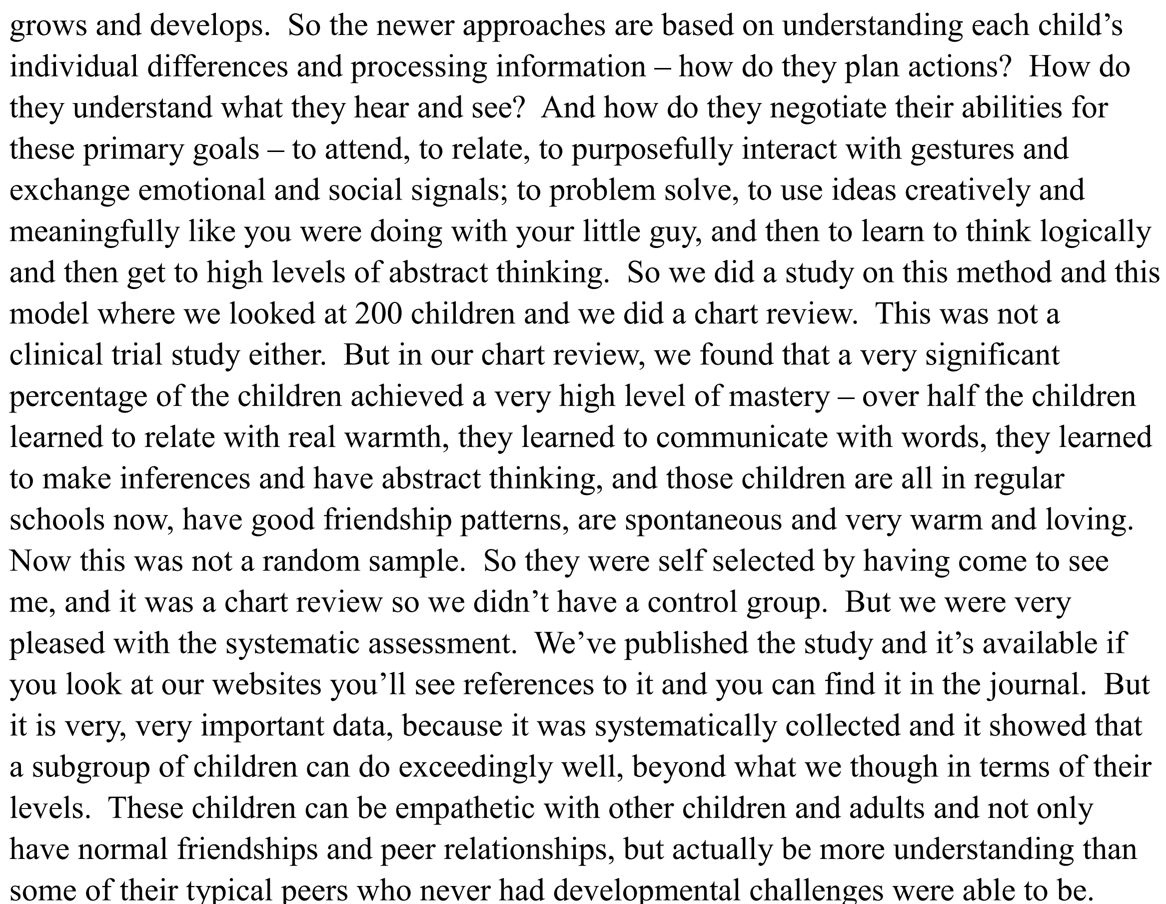
Number two: The structured behavioral approaches have a long history to them. They were among the first approaches offered to children with autistic spectrum disorders that provided some hopefulness, going way back decades ago. For that I am tremendously grateful to the intensive behavioral approaches because they said, "gee we can do something to help children with autistic spectrum disorders learn." But now we have modern approaches that can go beyond what the behavioral approaches pioneered. And that's what is important to recognize now. The behavioral approaches like to cite data. And there was an original study done by Ivar Lovaas claiming a very high rate, as much as 48% of children, it was a select sample who were chosen who were already functioning reasonably well, but could be integrated in regular schools. There were a lot of concerns from other professionals about the methodology of that study. For example, it wasn't a clinical trial study. Children were not randomly assigned to an intervention group and a non-intervention group. People were concerned about bias in how children



were grouped. Also there was a lot of concern that there wasn't many social and emotional outcome measures – the children were looked at mostly educationally. So in the year 2000, Tristan Smith, who was a colleague of Lovas' did a replication of that study and did a true clinical trial study looking at intensive behavioral approaches. That was published in the American Journal of Mental Retardation. Tristan Smith found, who is a believer and strong advocate of behavioral approaches, found that only 13% of the children had the same education outcomes that was originally claimed for 48%. So this is a very, very big difference. And more importantly, there were no differences or almost no differences in social and emotional functioning between the intervention group and the non-intervention group. So that is very big, it's huge. And what that means is that behavioral approaches in this clinical trial study conducted by Tristan Smith was not as effective as originally thought. So when colleagues say that it was proven scientifically, you have to say, "What was proven scientifically?" In other words, which children were helped and in what way? So some children, 13% were helped to get very good educational outcomes. But very few of the children were helped significantly in their emotional and social gains. And there were 87% that didn't achieve those very, very good educational outcomes. Now there was some educational progress for many of the children, but not what was originally anticipated. So it was much more modest educational gains for many of the children.

So what this tells us is that behavioral approaches have been the most well studied of all the approaches because they have been around the longest and there has been the most research on them. But what the current data and the current research shows is that the approaches tend to help more with very structured educational goals. And that's what you practice. If you look at how it's done, the strict behavioral approaches of sitting the child at the table, involving the child in very structured paths, so children tend to be able to do those kinds of tasks in similar settings. But what's been found by clinicians all around the country and parents, it doesn't generalize as well as we would like. In other words, they are unable to take that same task and then do it in another setting or do it spontaneously with peers. That is what the challenge is. Again, the results were not as good as originally thought. So there is some positive benefit - they have been well studied and measured. So the question remains, is this the best we can do? Because again, we have an approach that has been well studied but only has very modest help for the vast majority of kids with this diagnoses. So is this what we're going to settle for?

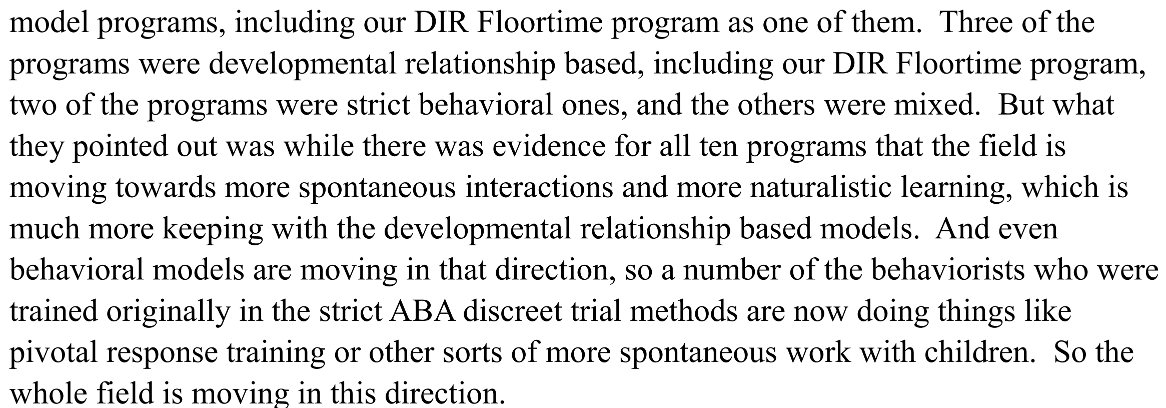
The newer approaches, and again I want to be very respectful to the behavioral approaches because historically they were very, very important, but decades later we've got to be improving things. We can't be doing the same things we were doing 20 years ago. Now the newer approaches come from newer information about how the brain



grows and develops. So the newer approaches are based on understanding each child's individual differences and processing information – how do they plan actions? How do they understand what they hear and see? And how do they negotiate their abilities for these primary goals – to attend, to relate, to purposefully interact with gestures and exchange emotional and social signals; to problem solve, to use ideas creatively and meaningfully like you were doing with your little guy, and then to learn to think logically and then get to high levels of abstract thinking. So we did a study on this method and this model where we looked at 200 children and we did a chart review. This was not a clinical trial study either. But in our chart review, we found that a very significant percentage of the children achieved a very high level of mastery – over half the children learned to relate with real warmth, they learned to communicate with words, they learned to make inferences and have abstract thinking, and those children are all in regular schools now, have good friendship patterns, are spontaneous and very warm and loving. Now this was not a random sample. So they were self selected by having come to see me, and it was a chart review so we didn't have a control group. But we were very pleased with the systematic assessment. We've published the study and it's available if you look at our websites you'll see references to it and you can find it in the journal. But it is very, very important data, because it was systematically collected and it showed that a subgroup of children can do exceedingly well, beyond what we though in terms of their levels. These children can be empathetic with other children and adults and not only have normal friendships and peer relationships, but actually be more understanding than some of their typical peers who never had developmental challenges were able to be.

So we're very excited with these results, but all we can say now is that this is true for this subgroup of kids. We don't know what the percentage would be in the real population when it's randomly selected. We're now trying to replicate this study in a true clinical trial study. But here is the other piece of it. All the children in our 200 case study became warm, related, interacted, and more spontaneous. And their symptoms all reduced. And almost all developed some degree of language. So we were very pleased with the overall progress of everyone.

Now the third point is about the research. Ours is not the only relationship based model. The DIR is the most systematic and the only one that has really showed these gains in high levels of empathy and reflective thinking. But there are lots of relationship-based models now available. And they are all showing very positive results. We have a literature review of these that are available on request so if you write me I'll send you a copy of the article. It showed that there is mounting evidence for developmentally based relationship approaches. Also the National Academy of Sciences issued a report in the year 2001 called, "Educating Children with Autism" and they cited ten programs as



model programs, including our DIR Floortime program as one of them. Three of the programs were developmental relationship based, including our DIR Floortime program, two of the programs were strict behavioral ones, and the others were mixed. But what they pointed out was while there was evidence for all ten programs that the field is moving towards more spontaneous interactions and more naturalistic learning, which is much more keeping with the developmental relationship based models. And even behavioral models are moving in that direction, so a number of the behaviorists who were trained originally in the strict ABA discreet trial methods are now doing things like pivotal response training or other sorts of more spontaneous work with children. So the whole field is moving in this direction.

So maybe you can work on helping to educate some of your professional colleagues or parents in New Jersey because we need to be doing things better. In other words, we have to appreciate what the behavioral tradition has done and the history of this movement, but now we need to go beyond that. So this is a long-winded answer to your very good question, but I'm glad you asked it because these issues need to be articulated very clearly.

Caller: Well, I definitely feel armed with evidence now to go back out there and speak with some of these people about the proven definite benefits of Floortime.

SG: And keep up your excellent work with your youngster and make sure it's guided by good professionals in your area.

Caller: I sure will. Let me ask you one follow-up. Do you see mixing ABA and Floortime as a valid approach at any point?

SG: Only for children who require it for certain purposes and that has to depend on the specific needs of the child. So don't just do it because you're told and you're going to reach a political compromise like having a little bit of Democratic and a little bit of Republican agenda. In other words, it should be meaningfully done. Read "The Child with Special Needs," my book.

Caller: I have read it.

SG: That will give you criteria of when you need to pull in some more structured approaches. We have a language curriculum called, "The Affect Based Language Curriculum," the ABLC, that's available from our website and that tends to use semi-structured and structured language approaches but it does it in the context of the DIR Floortime model. So that is a more useful structured curriculum to use if you want to add

some structure onto the program, but that should be determined by you and your professional helpers. Good luck to you.

Caller: Thank you Dr. Greenspan, bye bye.

SG: Bye bye. Well, we're going to take some more questions in just a minute and I think we have one right now. Let's take the next question. Hello? Oh, I think our caller got tired of waiting – we went on so long with the first call. So what I'm going to do is read some questions – oh I think we're back. Hello?

Caller: Hello!

SG: How are you?

Caller: Hi Dr. Greenspan.

SG: Thank you for calling in, and we're sorry we took so long getting to your call but let me hear your question.

Caller: Ok. My daughter Samantha is 18 months old. She was born with cataracts. She wears contact lenses now, she has sensory integration…

SG: Could you please speak a bit more loudly because we're on the Internet, and I hate to do this because you are speaking very clearly, but just a little more loudly.

Caller: Ok, she was born with cataracts. She wears contact lenses now. She has sensory integration problems. She has motor planning problems, possibly auditory processing, she has acid reflux, she now gets PT, OT, speech and a teacher. My teacher does the Floortime method which I think is wonderful. But she has given her a cognitive on the health scale of a solid 5 months, scattered to 12 months. And on her socialization she only has a solid 2 scattered to 8. She doesn't babble at all, nothing, no sounds. She makes, like sounds but nothing else. She doesn't point, she doesn't wave, she doesn't clap her hands. She walks but she's not balanced. When I try to do Floortime with her, once she sees me on the floor with her, she wants to use me to pull up and then go. So she doesn't want any interaction. I can't find a way to teach her and play with her because she wants to keep going, but she's not stable enough to really walk. She's walking, but she's going to fall. You know what I'm saying?

SG: I know exactly what you're saying.

Caller: It's so hard. I really think it's a great method and I don't know what else to do with her. She's very difficult.

SG: Well, I know that, I can hear it in your voice. Can you describe some of the interactions when you feel it goes well with her? I hear some of the frustrations. Is there anything that you do that tends to work or be helpful for her?

Caller: I can close about 10 circles when we're eating cereal. She just started giving me the Cheerios so we'll do that back and forth. She just started giving me a block just about two days ago, so she'll do that maybe 5 or 6 times. She'll do peek-a-boo, she can do hide-and-seek but there again I'm afraid she's going to fall so it has to be limited because her balance is off. She doesn't balance very well. She gets very flustered and she'll cry when she gets off balance and she can't regulate herself. So there are so many things she doesn't want to do. Once I'm on the floor with her, she just wants to pull up, and use me to pull up on because she can't get up from the floor without holding onto something so she wants to hold onto me and go. But when she's gone, I can't play with her because she just wants to go, she doesn't really want to play with a toy, she just wants to walk around the room.

SG: When she wants you to pull her up, how does she gesture or let you know that she wants to be pulled up?

Caller: She just crawls up to me – she drags one knee and uses one foot to crawl, so she drags over to me and then pulls herself up on me.

SG: Now, what would happen, as she comes over to you, you sort of go to the left so she has to change direction to get to you?

Caller: She gets very frustrated and will start crying.

SG: Not that you move away dramatically, you just move a little to the left or a little to the right. What would she do?

Caller: She gets very frustrated.

SG: Even just a tiny thing like that?

Caller: Yes, yes. She's very difficult.

SG: Now if you offer your hand to her, she pulls towards you rather than waiting for her to pull on you…will she make a sound if you kind of gesture "what do you want?" with your hand.

Caller: No. She makes like one noise like a little yell kind of. Other than that, she has no sound at all.

SG: When she pulls herself up, what does she do next?

Caller: She just wants to walk around the house.

SG: With you holding her hand?

Caller: She can walk, but she will get off balance and when she falls, she doesn't always put her hand out, so sometimes she'll just fall to the side and hit her head. She sometimes will put her hand out but not always. She's getting a lot better but…

SG: Does she like to hold your hand while she walks?

Caller: Occasionally, but not always. Occasionally.

SG: Well, here's what I would like to suggest. Now, of course any suggestions I give, you recognize that they are just possible things to consider because obviously I don't know your daughter well enough to really speak in any detail, although – where do you live?

Caller: I live in Pennsylvania, but I'm moving back to New York.

SG: Ok, because she is the kind of youngster that we have a lot of DIR Floortime trained colleagues…

Caller: That was my next question. I wanted to know about New York.

SG: Yes, we have a lot of good people in New York and if you call my office we can give you names of people in New York.

Caller: That would be wonderful.

SG: But she has the kind of profile that I love to work with because while I know she's challenging, she has a lot of stress from what you describe, and she would be both challenging and exciting to work with and I think she'd be capable of lots of progress. But let me just throw out a few ideas for you to consider. One is, is your husband frequently at home when you're working with her?

Caller: He is, but he doesn't really agree with this approach right now, so I'm trying to explain to him…he's very good with her. He can engage her and she'll constantly laugh with him and he's very good at playing. But I'm trying to really get him into this method but he's a little difficult.

SG: So if he's enjoying her and she's relating to him, and they're playing, then he's doing both the method…

Caller: I've tried to explain to him that if he wants to play with her and then he's bored he wants to change the play and I keep telling him you've got to build on what you're doing, please do it this way.

SG: Let me make one suggestion for all parents, ok? If your spouse plays a little differently than you do and even if they don't do it "perfectly" the way you think it should be done, if they are getting the goals met, if the child is engaged and happy and you're getting some back-and-forth interaction…

Caller: He is.

SG: …and the child is being more purposeful, then the advice to everyone out there in listening-land is: Don't micro-manage your spouse.

Caller: I try not to, really! I usually try not to.

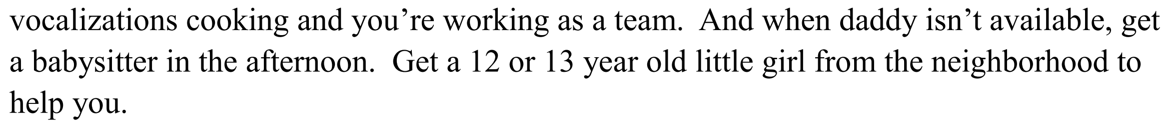
SG: And emphasize the positive. In other words, this is not your primary question but, when your spouse, who may spend less time with the child, is involved and they're "getting it cooking" – they're getting some engagement, some increase in purposefulness, some increase in communication - count your blessings. Tell him how wonderful he's doing it. Show them sometimes how you do it, and see if they want to model after you, but don't criticize and don't micro-manage and be enthusiastic because then they'll do more and feel competent. If they do it differently, it's fine because there are many ways to do it. What you do is look at the results. You look at, are you getting the engagement interaction going?

Caller: Yes, he does. He does. He does it even better than me.

SG: Then watch him do it and learn from him, ok? And let him know that. But here's a suggestion. Work with her together as a team where one of you kind of is concerned with her safety, maybe holding her hand or walking next to her. And the other is interacting with her. So for example, let's say she is up on her feet and daddy is walking next to her to just kind of offer his hand or catch her if she should fall. And you, then as she is walking, kind of get in front of her and show her things and try to get interaction going as she is walking so that you don't have to be worried about both.

Caller: We do like to play hide and seek where he'll hide.

SG: Do that kind of thing, but do it with treasure hunts, do it with finding things, you could jump out from behind a chair, you know surprise her and say, "where's mommy and daddy?" and she can try to find you. Now what is happening there is you're getting interaction, you're getting social problem solving, and you may even get more



vocalizations cooking and you're working as a team. And when daddy isn't available, get a babysitter in the afternoon. Get a 12 or 13 year old little girl from the neighborhood to help you.

Caller: She's not good with other people.

SG: No, no, no. You're missing my point. You're missing my point. To be a helper to you so that person can be the catcher just in case she falls and you don't have to be all things because it's hard to be both. It's hard to be the safety provider and be interactive at the same time. So get some help in the afternoon too.

Caller: Thank you, yes.

SG: So that's the preliminary suggestion. But basically this is something that would benefit from consultation and it sounds like you've got the right idea. The idea is to relax and create safe situations. Also, create a padded floor - a room with a real padded floor where it's not dangerous if she falls. And therefore, you can have more fun with her.

Caller: Right, good idea.

SG: So what you need to do is relax, try to do one thing at a time, create a safe environment, and have fun with her.

Caller: I'm trying.

SG: Ok? Good luck.

Caller: Thank you very much. Can I call your office to find out about these doctors in New York?

SG: Yes, call my office and one of my helpers will give you information about doctors in New York.

Caller: Can I ask you one more question?

SG: Yes, sure.

Caller: No babbling – have you ever heard of a child who didn't even make a sound. I mean I've never heard of that.

SG: Oh, sure, sure. But there are very excellent speech pathologists, and I'm sure you have the benefit of that.

Caller: Yes, I do.

4938 Hampden Lane • Suite 800 • Bethesda, Maryland 20814 • 301 656-2667
www.icdl.com

SG: What are you doing in terms of speech work?

Caller: Well, right now, today we did food. We played with her food and we tried to get her to move her mouth more and she tried to drink out of a cup and things like that. She's not very good with the teachers because she cries a lot when they are around, but she's getting a little better. So that's what we did today. We did food play, you know, the sensory things like that. She was good with that. That's basically all we could do with her because she doesn't, you know, we did a little two-way communication like I got her to kiss her doll today, which was a very good thing.

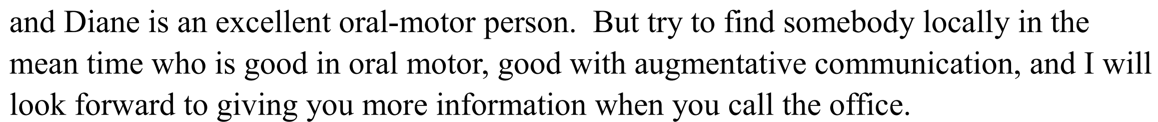
SG: You need, with a child with motor problems, you need a very good oral motor program. And you need a speech pathologist who is an expert on oral motor work, which can involve a lot of muscle work in the mouth including massage and so I recommend that you consider that. Also our book, "The Affect Based Language Curriculum" has a good section on oral motor work, but you may want to consult with the author of that book, or my co-author. But make sure you have a speech pathologist who is a real expert in oral motor work. If not, receive a referral in your area, because that is critical to get the sounds cooking so you can get language. In the meantime, try to use symbols and other means of symbolic communication until the language begins and the vocalizations start cooking.

Caller: I did do the pictures, but she eats them. She puts everything in her mouth, so I taped them to the wall. But she tried to take them off and eat them. I tried to do that with pictures of me, food, and toys, but that's been difficult too because she's very oral and everything goes into her mouth.

SG: Instead of having pictures, you could have pictures not just taped on the wall, but on blocks or something she can't eat that she could use to point to, to show you what she wants.

Caller: She doesn't point either.

SG: Well, just show you. Or otherwise show you what she wants. Like you have these big symbol boards where you have a bunch of symbols on them. There's a system called the PECS (Picture Exchange Communication System) that some parents use. So you need a speech pathologist. Also in addition in being an expert in oral motor, they need to be an expert in use of augmentative communication and that will be helpful too while we are trying to get the vocalizations cooking. So this is the situation, and if you call my office and let them know we spoke on the web-based radio show, we can try to get you on our waiting list and maybe see you and I can then try to refer you also to my colleague here, Diane Lewis, who is my co-author on "The Affect Based Curriculum"



and Diane is an excellent oral-motor person. But try to find somebody locally in the mean time who is good in oral motor, good with augmentative communication, and I will look forward to giving you more information when you call the office.

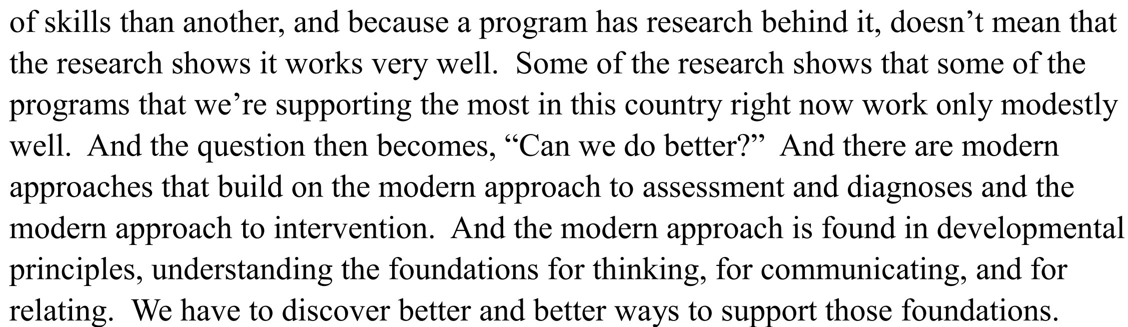
Caller: Great, thank you so much. I appreciate the time.

SG: Good luck, and thank you for your excellent question.

Caller: Thank you very much.

SG: And in just a minute we are going to be closing off today's show. I just want to summarize, and I think these last two callers really helped me finish what I wanted to talk about in terms of the issue of misdiagnoses and making a proper diagnoses. Just to review, the proper diagnoses requires understanding the primary symptoms from the secondary symptoms. So primary concerns for autistic spectrum disorders are having to do with the ability to relate, communicate with gestures and social signaling, and then communicate with words meaningfully and creatively and then eventually abstractly and reflectively. And when you focus on those issues, the secondary symptoms – perseveration and self stimulation – they tend to reduce because we are supporting foundations and strengths that make these secondary symptoms not necessary. But the secondary symptoms are not specific to autism. We find that in many problems where there are sensory processing problems or motor planning problems, so we have to separate the primary from the secondary symptoms. Also we have to make sure we know the child well and see the best that the child can do in a supportive, warm setting with caregivers. Often we have to work with the child over a period of time with caregivers to see the best that they can do.

When you understand the child's primary concerns, you also are able to then select an intervention that works with these primary concerns. Again, in the intervention selection you get what you practice. And if you do things only with surface behaviors, you may improve those surface behaviors but you may not get generalization to the deeper levels of relating, communicating, and thinking, that are part of the goal for every parent and every professional who works with children with autistic spectrum disorders and other developmental problems. So we have to select the intervention program carefully to, and be clear what our goals are because then we can, even in a common sense way, say, "Is the intervention working on the goals I hold most important?" Because if we look at the research, we see that it's not just, "Is the program effective?" But, "Is the program effective for what and which children?" And so some programs tend to teach more rote skills and surface behaviors. Other programs tend to teach more relating, communicating, and thinking. What do we want as the main goal? And when we look at data, the data also shows that certain programs tend to focus more on one set



of skills than another, and because a program has research behind it, doesn't mean that the research shows it works very well. Some of the research shows that some of the programs that we're supporting the most in this country right now work only modestly well. And the question then becomes, "Can we do better?" And there are modern approaches that build on the modern approach to assessment and diagnoses and the modern approach to intervention. And the modern approach is found in developmental principles, understanding the foundations for thinking, for communicating, and for relating. We have to discover better and better ways to support those foundations.

Now next week we are going to talk in more detail about how to select the appropriate program for a specific child. Again, each child is unique and different and there are certain criteria we can use to select the proper program. Also we'll go into more detail in looking at the research behind different programs, not just asking the global question, but asking the specific question, "What does the research show us about the specific capacities the different approaches tend to support and tend to favor?"

Thank you for tuning in and I'm sorry we couldn't take more questions today. We had some good ones and we wanted to focus on them. But those who we didn't get to today, we will take you questions for next week. Please email in additional questions. Also, many of you have asked in your letters where to get more training in the DIR Floortime approach that we talk about so much here. There is a training course that I give every spring. This spring it is April 23, 24, 25, and 26th right here in the greater Washington area in McLean, Virginia just outside Washington, DC. If you want information about our Infancy and Early Childhood training course, which will focus on autistic spectrum disorders and other developmental challenges, call 301-320-6360 and they'll send you some brochures. You can also check my website, www.stanleygreenspan.com and there will be information up on the website about this year's training course.

Again, thank you for listening and please email in your questions during the week and we'll select some for live call-in, and I hope you have a good week. Bye bye.