

Web-Based Radio Show

Myths of Autism

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Welcome to our Web Based Radio Show. This is Stanley Greenspan. Today's show is going to focus on myths regarding autism and autistic spectrum disorders. Also I want to let you all know we're going to have a special feature on today's show. Usually we take calls from a variety of listeners after the beginning part where I chat a little bit about a particular topic. Today we are going to be doing something a little bit different. We're going to have a particular center, The Institute for Infant and Preschool Mental Health, which is the largest provider of social services for children in New Jersey with 90 programs in 35 cities, it's called the YCS, Institute for Infant and Preschool Mental Health, and we'll be talking with the staff from the institute and they'll be asking questions. So we'll have all the questions coming from one center, but also a variety of individuals. I want to thank Dr. Gerry Coster, a dear colleague, who is at the institute for helping create this wonderful opportunity. Now before beginning, I just want to say we're going to have our talk for about 25 minutes or so, then go to questions from the Institute for Infant and Preschool Mental Health.

Now the talk for today is "Myths of Autism." Now the first myth I want to focus on is perhaps the most important one. And that has to do with a long-standing assumption that was made having to do with whether or not children with autistic spectrum disorders can, in fact, love. Can they form loving relationships? Way back when autism was first identified as a disorder in the 1940's, it was thought that autism had to do with an "autistic aloneness," that the fundamental problem in autism was an inability to form intimate, warm, nurturing relationships. And Leo Kanner, the in a sense, "Father of Autism" in a sense of having authored some of the first systematic descriptions of children with autistic spectrum disorders, formulated that as part of his theory. This concept of a fundamental deficit in the capacity to form intimate bonds or warm loving relationships has persisted in all the subsequent definitions of autism. In the Diagnostic and Statistical Manual of the American Psychiatric Association, the notion of fundamental problems or challenges or deficits in the ability to relate is to be found in all the versions, up to the current version. And the question is, is this fundamental

assumption correct? Or, is there clarification that needs to be made that will help bring this assumption into the light of modern understanding?


First let's examine what we mean by the ability to form an intimate relationship. What do we mean by the ability to feel a sense of love and warmth and intimacy and to be in love with another person? And do we really have evidence that children with autism are less able to do this or are unable to do it? Some may argue that whereas initially it was thought that the children couldn't do it at all and they had this autistic aloneness now it seems to be a continuum of varying degrees of ability where some children can do it a little bit and some a little bit more and some perhaps not at all. But the notion still persists, unfortunately, that even though some do it a little bit or do it a lot, don't do it as fully or as richly or as deeply as a "child without an autistic spectrum disorder." And that's what I'm focusing on. And if I seem to be a little repetitive or underlying this thesis, I'm doing it on purpose because it's at the heart of many of the assumptions that we make about autistic spectrum disorders that are what I believe, incorrect. And here is where I believe we have to make an important clarification. On the one hand is the ability to love, to be comfortable in an intimate relationship. This has to do with the ability to feel an internal sense of warmth and closeness and intimacy; the ability to experience pleasure in the emotional closeness with another person. So when we see a baby smiling gleefully at his mother or father at age four months with a big beautiful smile and they just seem to glow from one ear to the other ear, we assume that reflects a deep, warm sense of engagement that will grow into more and more love and intimacy over the course of the next number of months. But similarly when we see a child who is showing patterns of autistic spectrum disorder, a 2 ½ year old, and he gets scared and he runs into mommy's arms and gives her a big hug and holds on for dear life, is that any less a sign of love or warmth or intimacy? When we see a 2 year old who has been diagnosed with an autistic spectrum disorder, who loves to have his back rubbed by mommy and gives a big warm smile when mommy applies deep pressure to his back, is that simply mommy as an object? As simply a back rubber and it could be anything or anyone or a stranger or a plastic back rubber? Or is there a real warm sense of intimacy and loving and caring and that it's very important that it's mommy?

Well we have lots of evidence from the children we work with that there's that personal warmth, that personal sense of love, that personal caring because often daddy or other adults won't be perceived. They won't get that same warm look in little Johnny or Suzie's eyes. They won't be comforting in a time of fear or need. Often children show a lot of separation anxiety, not only not having that sense of aloneness, but if anything, parents have complained that the children are "too dependent." "They won't let me go!" But from a variety of observations, a warm deep smile may be only momentary to a



holding on for dear life in a time of fear to just enjoying the cuddle or firm pressure or the back rub, or gleefully jumping together with a parent as the two are enjoying the child so what seems like a self-stimulatory activity such as jumping, the parent jumps rhythmically with the child, often we'll see the child hold the parent's hand and they dance together in a joyful escapade of shared pleasure. We see all of things with these kinds of patterns with children with autistic spectrum disorders. Also what we find is when we apply our DIR Floortime approach, where we follow the child's lead to focus on the child's natural pleasures and build interactions off the child's pleasures, even if they seem to be perseverative or self-stimulatory, but use that as the point of entry into the child's world, when we do that, we see that the first element that responds is not language, it's not even communication more broadly, but it's that sense of relatedness. That sense of relatedness in the shared smiles and shared joy and shared pleasure and the deep sense of mutual belonging to one another comes in very, very quickly, often within the first 6-12 months of our treatment programs. So even for children who haven't been showing a lot of this capacity, the fact that it emerges so quickly suggests to us that it's there and maybe even existing in more obscure or less obvious forms, even when we didn't see it right away.


In fact, we just did a study where we looked at the first part of the session with the children, in our very first meeting, and the second part. And these were all children who were diagnosed with autistic spectrum disorders, and we were able to see significant differences in their relatedness from the first part of the session to the second. Now what we did in the two parts of the session is when we did some coaching where we helped the parents read the child's signals better and tune into that child's nervous system. So if the child is hypersensitive to touch and sound, we help the mommy or daddy become more soothing. If the child was under-reactive and required more energy in the communication, we helped the parents energize up. If the child was showing a unique pattern of self-stimulation, we may have shown the parents how to enter the child's world and make it a shared activity so it's no longer just a self-stimulation, now it was a shared interaction. But in providing this type of coaching we often saw a child who seemed to be self absorbed and seemed to be looking a little apathetic or without pleasure, brighten up, get what we call the gleam in the eye, and show enormous, deep, robust pleasure and even in that first session, by the end of the session, we saw the child seeking out the parent for closeness, warmth, and intimacy. So whether it was at the first session, or over the course of the first 6-12 months, observing the quickness with which this growing intimacy emerged as the parent became better able to understand the child's nervous system led us to an important conclusion that the capacity for intimacy is present in most children with autistic spectrum disorders. Our job is to help the child find a way to express it so that the parents will understand it. Then the two, the child and the parent



together, can build that intimacy and can bring it to new and higher planes, not so much higher planes in terms of the depth of the pleasurable, warm, and intimate feelings, but higher planes in terms of their understanding of one another and the way they communicated to one another. So they can build it into more complex interaction and communication patterns. But we believe from watching the quickness with which this system comes in that it's present. When we talked to the parents about the children at home, not just what we observed in the office, almost all the parents tell us about these wonderful, warm, intimate moments. They would like more of them. And they would wish the child could verbalize their love and warmth. But again, most of the children provided lots of examples through their parent's reports, of wonderfully, intimate, pleasurable moments. What we are helping the parents do is simply create those moments more frequently by helping the child communicate more effectively through our understanding of the child's nervous system and how it works.

So our conclusion is that love and relating is not the primary challenge in children with autistic spectrum disorders. That is present as a potential and is present in varying degrees in terms of its expression, but the depth of their feeling is likely there in the child and in the parent most of the time in many situations.


Now where then is the problem and why was there this confusion? We believe the primary challenge that most of the children who are diagnosed with autistic spectrum disorders have, is in the communication of their emotions, and as we discussed on prior shows, the primary challenge is in the rapid back-and-forth signaling with emotional cues. Typically in development at about 4-10 months, children are learning to be purposeful two-way communicators, a smile leading to a smile; a frown leading to a frown; a little smirk leading to a smirk; sounds leading to sounds. We get back-and-forth interactions around emotional expressions, through sounds and through body posture and facial expression. This reaches a nice complex pattern by around 12-16 months in children who don't have challenges where they are flirtatiously coming up to mommy or daddy and reaching their arms out, grinning, making flirtatious sounds, maybe even a word or two, getting picked up, giving giggles and smiles, maybe playing with mommy or daddy's nose and so forth and so on. But this type of rapid exchange of emotional signals is much harder for children with autistic spectrum disorders. We believe it's harder because we believe that one of the primary biological challenges that children have is in connecting their affect or their emotions to their motor systems or what we call motor planning. So it's hard for them to carry out complicated actions like taking mommy by the hand and walking her into the toy area and point to the toy they want, or having a big flirtatious interaction with mommy or daddy. We believe that's hard for the children because they can't sequence their actions under the guidance of their emotional




intent or their desires. So they can have the desire for closeness but they can't figure out how to translate that into an action plan. And then later on, even if they can memorize some words or repeat some words, it's hard for them to invest those words with that feeling and say, "I love you" or "Mommy give me a big hug" because again, it's hard for them to connect the emotion or the affect to the verbal symbols. So we believe that that's the primary challenge in children with autistic spectrum disorders. But also as we've talked before, we don't believe that's a permanent limitation, we believe that the main highways are biologically blocked, but that side pathways can be developed to varying degrees and the vast majority of children with autistic spectrum disorders. As we develop these side pathways to varying degrees, we see varying degrees of progress with some children making such enormous progress that they become fully verbal and creative and interactive with their emotional signals and become very empathetic and excellent at reading the emotional signals of others. And we'll talk about that in just a moment in terms of their capacities for developing a theory of mind.

So we believe the challenges are in the rapid back-and-forth communication of emotions, not in the experience or feeling of warmth and intimacy. And that's a big distinction because we would summarize that distinction in saying we believe that children with autistic spectrum disorders can love as deeply as any other child and many can love even more deeply than most children because if they are in a proper program, we're providing them a lot of warmth and love and a lot of interactive opportunities, even more than the average child gets. So we believe that the capacity for love and intimacy is there, but that the capacity for rapid back-and-forth signaling with emotions needs work and needs extra practice and needs approaches which are geared to the child's nervous system which understands how the child may be over or under-reactive to different sensations such as touch and sound and understands where the child's strengths are in terms of visual spatial processing and auditory processing and motor planning. So when we can tailor the approach to the child, we can get improvement in the communicative capacity for the child where we believe the primary challenge is. So the key is to make a distinction between the ability to love and the ability to communicate that love and other emotions rapidly and quickly early in life. The second part requires lots of work and effort, the first part we just have to help it emerge comfortably as part of the communication system so the child and parent can understand what they already feel.

Now there is another big myth that surrounds our understanding of autistic spectrum disorders, and that is that the children who have autistic spectrum disorders can't learn the fundamentals of relating, communicating, and thinking, and the best that we can hope for them is that they can change their behaviors. This is just simply untrue. We have found from our studies of children with autistic spectrum disorders that we can




teach the fundamentals of relating, thinking, and communicating and we can do far more than just change surface behaviors. For example, we can help children learn to be solid and competent at exchanging rapid emotional signals, entering into what's called technically "reciprocal interaction patterns." We can help them understand the feelings of others. For many children, not all, we can help them communicate with their words, not just things they are interested in a book but deep feelings and negotiate friendships. So children can learn the fundamentals. In prior talks we talked about the ability to attend, relate with warmth, exchange simple emotional signals, get involved in co-regulated social problem solving, use ideas creatively, and use ideas logically. In our study of 200 children we showed that a high percentage can master all 6 of these fundamental milestones. What we find, interestingly, is as you help a child master each of these milestones, the surface behaviors that are symptomatic such as perseveration or self-stimulation or echolalia or aggression or mood instability, tend to recede because each foundation piece not only helps you develop a strength and a foundation for healthy development, but also helps you offset a particular symptom. So once a child can relate with warmth and intimacy and express that warmth and intimacy all the time, they don't need to get self-absorbed or withdrawn. Once a child can communicate meaningfully with gestures, they are less repetitive, and so forth and so on. So they thought the limitations of approaches that just worked on surface behaviors, the biggest limitation of those approaches which includes obviously the more systematic behavioral approaches, is that they don't focus enough on the foundations for healthy functioning. And I believe that while the early goals of behavioral approaches were very laudatory, i.e., to show that you could help children with autistic spectrum disorders with intensive one-on-one approaches. I believe the more modern version of those approaches has to begin embracing the foundations of healthy functioning. Work on the foundation capacities of relating, communicating, and thinking, not just the surface behaviors. And in fact, lots of behavioral approaches are moving in this direction, toward more naturalistic interactions, using more naturalistic reinforcers. And we talked about that in other of our talks. And in fact, the most recent study of intensive behavioral approaches that focuses on mostly just on surface behaviors, the ABA discrete trial approach, studied in the year 2000 by Tristan Smith, published in the American Journal of Mental Retardation, showed that only 13% achieved the educational outcomes originally thought to apply to a much higher percentage and even more importantly there were no differences in emotional and social functioning between the intervention group and the control groups. Again, emphasizing the importance of focusing on the foundation, not just the surface behaviors. Again, many of the newer behavioral approaches are focusing on these foundations which is, I believe, an excellent development and obviously our DIR Floortime model has made this the centerpiece of their goal – to work on the foundation pieces.



Related to this is also the myth that children with autistic spectrum disorders can't learn abstract thinking, make inferences, can't learn theory of mind. We found this not to be true. While not all children are capable of getting to the level of abstract thinking because it requires a lot of language capacity and cognitive capacity, we have a subgroup of children who when we worked on the foundation pieces and when we worked on emotional signaling and cuing, do learn to make inferences, have empathy, be capable of mastering theory of mind tasks. And so this myth is just not true. The approach you use to work with the child will determine, in part, whether they can master these higher levels. Again, not all children can master these high levels, even with the proper approaches, but some can. The only way we know is to provide the proper approach for the child and then follow them over time.

Also, there is a myth that children can't read the emotions of other children or other adults. There is some research showing that the children couldn't process the facial expressions and there were brain imaging studies done where the children were thought to not to be able to process at the level of brain functioning, the faces of other people. But then colleagues, Morton Gernsbacher and colleagues at the University of Wisconsin in Madison showed that in those brain imaging studies, the children simply weren't looking at the faces of others. When they were encouraged to look, the areas of the brain that process faces, lit up. They were able to process the facial expressions in the way that other people without autistic spectrum disorders process them. In other words, it was a product of not looking rather than having different brain physiology. In fact, when these children looked, they got anxious, showing that looking was hard for them but not impossible. So Gernsbacher and colleagues at the University of Wisconsin in Madison have done a great service in clarifying the misinterpretation that could have occurred about the fundamental central nervous system ability of children with autistic spectrum disorders. In fact they can process emotions of others, but it's just harder for them.

Now when all is said and done, what we are advocating here as this correction of myths, is that we think of autistic spectrum disorders including Asperger's Syndrome as a dynamic process where it's not a fixed disorder and you either have it or don't, but rather you have certain challenges such as the inability for reciprocal affect cuing or the tendency to self-absorb and become withdrawn or the difficulty with using ideas creatively and meaningfully to varying degrees. And as we help you and as we help the child interact more with affect cuing and invest their emerging symbols with real feelings and intent and meaning, we see the children move in an entirely different direction. We should see this as a dynamic process. To be sure there are varying degrees of progress possible depending on the amount of neurological impairment children have, but we should not assume a fixed disorder, but rather a dynamic process with many, many



components to it where each child is unique and different – some over-reactive, some under-reactive, some stronger visually, some stronger more with words and sounds.

In conclusion, the correction of these myths suggests that the potential of each child should be defined by the child's progress, not by a diagnostic label. With that thought, we now want to turn to our first call. Again, we are delighted and honored to have our calls coming from the YCS Institute for Infant and Preschool of Mental Health. We are now going to open our lines to them and their staff and go into their questions. Hold on just one second. Hello?

Gerry (Gerard Costa Ph.D., Director, YCS Institute for Infant & Preschool Mental Health): Hello.

SG: Yes, hi, Stanley Greenspan here.

Gerry: Hi, Gerry here.

SG: Hi Gerry, welcome.

Gerry: Thanks very much. I'd like to say a bit about who we are and then maybe then open up to some questions from our staff and trainees.

SG: Great. Thank you for joining us, Gerry and we would love to hear a little bit about your center and then go into your questions.

Gerry: Great. We're called the YCS Institute for Infant and Preschool Mental Health, and we are a training and consultation clinical service and research center for infants and young children birth to six and their families. We provide assessments, treatments, consultation and a growing research program and certainly the DIR work is a very important model for us in terms of our assessment and treatment. So we're thrilled to have this chance to ask you some questions and maybe we can go right to that?

SG: Great.

Gerry: Well, our first question is going to be from our developmental pediatrician. So I'm going to ask Dottie to speak up loudly.

SG: Hello?

Dottie (Dr. Dorothy Bryan, Developmental Pediatrician): Hi I'm Dottie. I've been to a number of our seminars and my question is what is your thinking of the reasons for the remarked increase of number of children who are diagnosed with PDD or autism.

SG: The question is, why are there more children being diagnosed with PDD or autism these days? It's obviously a question that's on many people's minds, and it's a complicated question because there are no simple answers to it. Some people believe that its better diagnoses and broader diagnostic categories and better early case finding. Other people believe that there are real increases occurring. Probably it's a little of both. Those that believe that there are real increases occurring are worried about a number of factors. Some of them biological factors, prenatal influences that may undermine development – exposure to toxic substances pre-natally, for example. Others worry about postnatal influences. They worry about auto-immune reactions which is a fancy way of talking about allergic phenomenon in some of the children. There is also a concern with more environmental stress and more use of technology babysitting children with early use of TV and computers, rather than personal interactions. Now obviously, no one factor seems to provide an answer. To be sure, the diagnostic criteria are broader and we're better at early finding of children with autistic spectrum disorders so that should account for part of it. But also there clearly is, in the environment, more exposure to toxic substances, PCB's, lead, endocrine disruptors etc., that were not as prevalent 30 years ago. All of these toxic substances as they effect of the system pre-natally or post-natally influence the nervous system. And the question is, in genetically susceptible children, do certain environmental toxins have a greater impact. In certain genetically susceptible people, do certain stresses in the environment due to changing educational practices or use of computers and TV as babysitters have an impact? And for each person, no one factor is going to be decisive, but my favorite model is to think in terms of cumulative risk. We're introducing the concept of a multi-path cumulative risk model, where we try to look for each child as a cumulative risk factors that may be present in that child from genetic risks up through differences in physical and biological and environmental stressors like exposure to toxic substances, and see if that helps us understand this phenomenon. My hunch is, that the genetic risk is not just one pattern but many patterns. And so that's why I think we have multiple paths for this disorder. I think the disorder itself is more of a type of follow a common pathway much like inflammatory response is where you can have many reasons for an inflammatory response. So I think if we start looking at cumulative risk and multi-path models, we'll get a better handle on all the things that might be contributing to the large increase of autistic spectrum disorders. I don't think we can make much progress if we only look at “decisive and definitive” factors because we haven't found one. We are unable to pinpoint a particular genetic pattern, although we know that genetics are very, very important and we have been unable to pinpoint a particular environmental toxic substance like PCB or endocrine disruptors or other alleged factors. But the question is, do we get cumulative risks? And so this is an open area for research. It's clear we are getting some increase. Thank you for that question.

Gerry: The next question is from one of our psychology doctoral interns here. So Beth is coming up to the phone.

Beth (Elizabeth Doppler, Doctoral Psychology Intern): Hi Dr. Greenspan.

SG: Hi, how are you?

Beth: Good, thanks. I have a case where I'm using DIR Floortime with a 6 year old boy and his mother and his younger brother often also plays, and I've noticed a powerful relationship themes emerging in the play that seems to interfere with the mother and the 6 year old stay regulated and elaborate on the play. So I'm wondering how you would address the content of the dramatic play while using the Floortime model.

SG: Give me an example, if you can.

Beth: Ok. From an early age, the mother has talked about not feeling very connected emotionally with her older son, but feeling very close to the younger son. So when they are playing together, what will often happen is the older son, the 6 year old, will build a castle. Mom's attempt to get engaged is to try to break into the castle. And they just get stuck in this repetitive play of her trying to break in and him keeping her out. So then mom will try to heighten her affect and she'll call for help from the younger son who will join her, then the two of them collaborate to continue to try to break in. So that repeats, and eventually the older boy seems to become upset and either throw his action figures across the room or he'll remove himself from the play.

SG: Now are you coaching the play, are you there with them?

Beth: Yes.

SG: Ok, I think this is a perfect opportunity to enter the play and through the play offer clarification to the mother. You could be the voice of the older child's doll or his action figures, and say, "You're trying to break in and you're scaring me! You're scaring me and you're making me mad by trying to break in. Can't you be nice to me? Why can't you try to win my approval (I can't think of a good word to use here)?" But basically raise the question which is, "Why can't you try to cooperate with me, why do you have to break into my fort? Maybe you could win my heart by bringing me some fruit or cookies or..." I'm thinking of the old days when there were wars and you could approach a new kingdom with a war and bring your troops in or approach them with all kinds of gold and goodies. So I think one thing you could say is, raise the question "Why are you attacking me only? Why can't you bring goodies to me to win my favor?" And see what the mother says that's part of the pretend. What that will do is you're kind of broadening the drama now. Whenever play is repetitive, your goal is to broaden the

drama. It's to thicken the plot. So you want to get to reasons why the characters are doing what they are doing, so your character, speaking on behalf of the older child says, "Why are you doing this?" and then you're getting the mother to reflect a little more.

Beth: Ok.

Gerry: In some ways, too, you're giving a very mild interpretation of what you think is happening between them and bringing it to the drama of the play.

SG: Exactly. You are offering your clarification or interpretation but not as you would, let's say, if you were having an adult in therapy, but through the play itself. So the characters have to be, instead of being repetitive, have to now be deeper characters. They have to consider, "Why am I doing that?" And that's also giving a little message that there is another way. Then also you let that register, then you try to have some private sessions with mom where you go into her deeper feelings about both children and why she is angry at one or the other.

Beth: That was going to be my next question.

SG: Go ahead.

Beth: No, that was my next question. You already answered it.

SG: Ok, great. You definitely have a private session with mom when you see a theme like that and ask her how she feels about each child and go through the history and try to help her see that she's been upset and felt rejected by the older child and therefore she is angry. But the way she has tried to deal with it is by intruding into his life, not by figuring out how his nervous system works, and he probably needs much more soothing rather than intrusiveness.

Gerry: Those are exactly the themes, in fact, that Beth has been seeing so that's great. The next question, we have two star interns. This is our second star intern, Matt Clark. He's a psychology intern as well. Here he is.

Matt (Matthew Clark, Doctoral Psychology Intern): Hi Dr. Greenspan.

SG: Hi Matt.

Matt: My question pertains to how do you best present the Floortime or DIR Model to parents, especially parents of children with special needs who are kind of leery about the whole play therapy approach or social service mental health practitioners in general. How do you present the model in your initial sessions with the child and with the parent?


SG: What's the orientation of the families you feel are the most resistant or have the hardest time? Will you describe them?

Matt: Describe them? Many of them are low SES who come from a different racial background than maybe the practitioner so you have racial suspicion, some SES suspicions right away, a lot of them feel that they have been burned by other social service or mental health agencies or the government in the past.

Gerry: In many cases, too, Dr. Greenspan, we're the first mental health provider that they have been connected with. They might have been in early intervention programs and worked with other disciplines, but now they have come to a mental health provider where the stigma of a mental health practice still abides and some, frankly, come not so sure the role they will play and want us to try to fix the child. So the idea of a play therapy with the child doesn't sound to them like it's a real way of helping the child. So I guess Matt's question has to do with, have you a way of trying to talk to these families who don't have a sense of the effects of play and how we may be able to talk with them about it?

SG: I think this is an excellent question because it gets at the heart of the issue, not just for families that may come with a different set of assumptions, but many families, really even if they speak a good game, even if they seem to say they understand that play is important, don't really have a good intuitive feel for it because they haven't done it yet. In some things you can only develop the feel for it after you've done it. But what we have found over the years is with families that have a hard time with intuitively grasping this notion, is the key first step – the absolute key - is to involve first the parents or whole family in the process so they can experience it with you. So see this as a multi-step process where the first step is that you begin relating to the mommy or the daddy or the grandparents or all of them, whoever approaches you or whoever is accessible. This may involve home visits as well, where you establish the first levels of our Functional Emotional Developmental Capacities with the parent directly. So you first get their attention, and you do this through shared activities. It may be breaking bread with them at their house or it may be taking a walk with them or it may be at your center. Then you try to form a relationship with them where they feel your empathy and interest by hearing about what they think is the challenges for their child and what they think is likely to be helpful. Maybe they are looking for a pill. Maybe they are looking for very concrete set of instructions where you are very tough with the child. But maybe they tried those things but it hasn't worked already. But if you listen and you are empathetic, you are giving them the first lesson in the value of empathetic listening. So you've got to form that first relationship with the parents so they learn about shared attention, they learn about engaging when someone is empathetic, and then once you're doing that you're

reading their emotional clues and you're entering into back-and-forth emotional signaling with them to follow your empathy. So it's not just simply listening but you're actually resonating with them and they are feeling the presence and benefit of back-and-forth signaling. Then you're going to help them not just signal with you but also consider new options; be creative in their use of ideas. So you're going to ask them, "Well, what's worked?" And maybe the pills haven't worked or trying to be just tough and set limits with the child hasn't worked. Or maybe trying to simply break into the child's world hasn't worked. So you're going to be asking them what else they think could work and what other suggestions have they considered. And you can throw out some ideas, well have they considered this or that? Now you're beginning to expand their horizons, get them into Level 5, Creative Use of Ideas. Then you're going to help them eventually be logical in the way they approach their child, but from a more broader, creative base. So there is no substitute for spending a couple of hours with the family at the beginning, getting a feel for them, their unique background, who they are, and letting them experience the DIR Model firsthand in the way you relate to them. Then when you point out and show them the results of your evaluation of the child, if you present it in terms of what the goals are for the child, if we have to teach the child to pay attention because the child won't listen to them unless they pay attention. We have to teach the child to want to be with them and to love them so the child will want to please them. In other words, each milestone in our DIR Model is a reason. Because the child doesn't want to please them unless they are engaged with them. The child has to be able to respond to their emotional signals so even without saying a word they can give a dirty look to the child and he'll know he shouldn't be doing that. Then they have to teach the child to speak and to speak about his feelings because without that, the child won't be able to figure out why they are angry or why they are sad, and so forth and so on. So for each milestone, we explain to them why it's important to master that, and we should explain to them how that will result in the mastery of a particular symptom. So if the child is aggressive, how being more regulated will offset the aggression. How if the child is not self-absorbed and becoming more related, it will help with the self-absorption. So that has to be explained, but also if you could refer back to the way you're interacting with them, they'll understand. And also if you observe them interacting with the child and you've done some coaching during the interaction, you can refer back to those coachable moments, saying "Remember when we did this how we got him more engaged and at that point he was less self-absorbed." What I do with a family is I show them while it's happening so right after a moment where I do some coaching and the child gets more involved and therefore is less self-absorbed and less self-stimulatory, at that moment I'll stop the action and say, "What do you think just happened?" And they'll smile broadly and say, "Well, he became more interested in me so he wasn't in his own world." Regardless of their assumptions, so what you do through the evaluation, you do two things. Number one is



you show them the benefits of the DIR Model by letting them experience it in your relationship to them by letting them experience the six fundamental emotional levels. Two, as you observe them interacting with their child, you do some coaching. When they see progress right in front of their eyes and you underline it for them, then you've explained to them through that action how each bit of progress offsets certain symptoms they are concerned about. And when you do that and you take your time with it, they are ready to then embrace the model. But if you just throw out this cockamamie notion that play or fun is supposed to be helpful, they are not going to get it and even parents who say they get it won't get it. So you have to go through this process with everyone. And then you have a real colleague or ally in your work. But this requires an extended evaluation and if the parent is not getting it, you just continue the "extended evaluation" until you feel they do. In some ways it also requires a one-on-one meeting with the parent alone, which should always be for at least 45 minutes, meeting with the key family members, exploring with them what is their own kind of emotional patterns. In other words, what do they find easy or hard about their child and why. And what about their own background makes some things easier and some things harder. As they get into that, they will also become more allies into your approach.

Everybody, regardless of socio-economic background, regardless of educational background, is capable of fully participating in the process I'm describing. In fact, it's more critical for those whose backgrounds haven't given them a lot of the experiences that you want them to do with their child because then they have got to experience it with you first. So in our work with multi-problem families, many of whom have come from three or four generations of poor parenting, we had to do months and months of work with the parent before they understood what we meant by engaging their child because we had to give them the experience of being engaged with us. So for some families there was more preparatory work. But this is all part of the therapeutic process.

Gerry: That was very helpful. I wish you could be here because around the table a lot of heads were nodding, affirming what you were suggesting. Our next question is from our associate director for clinical services, Dr. Jennis Hanna (Associate Director for Clinical Services). Dr. Hanna has actually been to several of the ICDL conferences and is going to be at the DIR Summer Institute this summer.

SG: Oh, wonderful! Wonderful!

Dr. Hanna: Hi, how are you?

SG: Fine, how are you?

Dr. Hanna: Fine, thanks. We have been asked to do an evaluation of a 7 year old boy with Downs Syndrome. He was described by another practitioner in the community as having autistic features and the parents are wanting us to rule in or rule out such a diagnoses. He has the typical physical problems that come with Downs Syndrome. He has a heart murmur, he has hyper-thyroidism as opposed to hypo-thyroidism. He has abnormal EEG but not a definitive diagnoses of a seizure disorder so he's a little bit complicated. My question is this. First of all, how often do you see autism coincide with Downs Syndrome?

SG: Very frequently but not all the time. A lot of children with Downs Syndrome are obviously very warm and sweet and in fact the typical child with Downs Syndrome tends to be kind of very warm and sweet and very engaged. But I see an awful lot of children with Downs Syndrome, as well as other developmental challenges, with autistic-type symptoms because when a child has motor planning problems, as children with Downs Syndrome do, most of them have low muscle tone, that alone makes it harder to learn to communicate and relate. So when the child has language and auditory processing problems, it's harder to interact and relate. So each area of processing challenges makes it harder to master the milestones of relating, thinking, and communicating which are essential for foundations for healthy development and which we see impaired in various degrees of autistic spectrum disorders. So I think it's a testament to many parents of how many children with Downs Syndrome are warm and loving and engaging but it also tells you that any time you have developmental processing problems, you're at increased risk for also autistic spectrum type symptoms.

Dr. Hanna: In my initial assessment of this little guy, though he's 7 years old, he functions at about the 24 month level on the Bayley's. I did an FEAS (Functional Emotional Assessment Scale) but I haven't recorded it yet. He is attuned, he is engaged, he does engage in some self regulatory behaviors. How do you distinguish between the self regulatory behaviors of the kid with the sensory integration issues versus self stimulatory behaviors of the low functioning kid? Or are those the same thing?

SG: Well, basically they are the same thing because what you want to think about is how does the child use their body to try to achieve some degree of self regulation and self pleasure? And there are various levels of it. So self stimulation, let's say jumping up and down or looking at a fan or repetitively doing a certain action, or touching an object over and over again – those are attempts to regulate but they may not be very adaptive attempts in the eyes of us. Although for the child they may be as adaptive as he or she feels they can do at the moment. Our job is to get them to a higher level of adaptation where we think they could be even more effective at their self-regulatory goals. So if we help a child go from self stimulating to interacting with us and playing a game where they

can, instead of just moving around and jumping aimlessly, they now are dancing with us or involved in a certain sensory integration activity collaboratively with us, where we can systematically provide them certain movement and certain vestibular and certain tactile including deep pressure input, we may feel we can show them that they can have an even better self regulatory experience through collaborating with us. So we are constantly trying to help the child get to higher levels of self regulation but I think it's healthy and useful for us to think of different levels of it and not try to say this is a "low functioning and not worthy of the sensory integration" label and this one is worthy of sensory integration because it fits our preconceived notion of what sensory integration ought to be. I think we should think of, forget the term sensory integration, even though it's valuable in one obviously for professional training purposes keep it, but in terms of thinking about the child, think in terms of the child organizing their sensory system and their motor system at different levels. We want to promote developmentally more advanced levels and so the child begins the process by just very simple sensory motor connections, then becomes involved in many more complex patterns as he goes up the developmental hierarchy.

Dr. Hanna: Thank you.

Gerry: I remember in a November ICDL conference a couple of years back, one parent stood up and said that professionals often called her child's behavior self stimulating, but she calls it self OT.

SG: Exactly, exactly. And it's a continuum. You see these things on a continuum.

Gerry: Absolutely. Next question and hopefully we'll have one more if there is time, but I'm thrilled the next questioner is up because she is one of our doctoral externs from Fairleigh Dickenson University in clinical psychology and she is about to give birth to her first child.

SG: Oh, congratulations!


Gerry: So we had a baby shower for her this morning right before this program.

SG: Wonderful.

Gerry: Laura Coraci (Doctoral Psychology Extern). So here she is.


Laura: Hi Dr. Greenspan.

SG: Hi Laura.



Laura: My question is similar to Matt's in that I'm having a difficult time convincing a parent of a child's foster parent the value of the DIR Model. She has a long history of success and she has witnessed successful use of behavioral techniques. She is a strong proponent of more behavioral types for managing behaviors and I was wondering how you would address this and try to sort of sell the concept of Floortime specifically in relation to behavioral.

SG: Again, I think what I found that is most helpful is to get to know the parent and their background. People have many important reasons – often in their own experiences there are good reasons for favoring or finding one or another approach more understandable or more intuitively accessible for them. So some people who prefer the DIR Floortime or a sort of natural relationship people, they like to think about the inner emotional life of themselves and others. Other people who favor the more at home with the behavioral approach are much more interested in changing this or that behavior, changing the symptom, less interested in the internal world of feelings and the reasons for things. So just like people have different political philosophies or different attitudes about a variety of things, people use different metaphors for understanding behavior. I'm always impressed with how people use their professional metaphors. Economists think about behaviors different from literature professors who are yet different from physicists; each one sort of applying a different model to human behavior. So you have to start off with where the person is coming from. What is their own background and history? Why do they kind of lean in a certain direction? That is critical. Once you have that, then you have a common frame of reference to speak about. Then it's important to see what their goals are for the child. Maybe they only want symptom change. Then you try to enlarge those goals. You say, "Wouldn't you also want him not just to do A but also to be more loving, wouldn't you also want him to be more creative in his thinking, not just say the appropriate response but to come up with new answers to things?" So you raise questions to try to expand their framework. And in raising those questions, obviously, you are guided by the DIR Model and our six fundamental building blocks of healthy development, so you're asking questions about logical thinking, about creative thinking, about self esteem, about the depths of intimacy, about reading and understanding other people's emotions. And if they feel these things are important, then you obviously now have a collaboration. If they feel these things are unimportant, you ask them why. Maybe they don't understand the significance of it. Then you can point out how for each new capacity like intimacy or empathy, that offsets certain symptoms, so rather than having to go symptom by symptom, you can actually offset a whole group of symptoms by getting one fundamental capacity in place. You're also getting the foundations for healthy development in place. But you're going through that in a very personal way. Then, most importantly, and the key is actually to do some coaching as they play and



interact with their child. Actually demonstrate where they are actually doing it with your coaching, that they can do it. Because when all is said and done, the biggest reason people avoid Floortime or avoid emotional interactions with their children is, down deep, often not consciously, they fear they can't do it. Often parents will tell me once we've stripped away some of the surface defenses, is "No one ever played with me this way, I don't think I can do it, I think the best I could do is try to just change his behaviors, I don't think I have it." Then my job is to demonstrate to the parent that they do have it. The only way to do that is actually getting down on the floor with them and doing some coaching and showing them that they can, in fact, do it.

So those are the steps involved. It's not just simply saying, "Do it because I say it" or "Believe in me and I'm right and everything you've heard is wrong" but the way to do it is through personal experience, exploring within their own background, their reasons, explain to them conceptually the benefits of thinking in a more expanded way and this new way and pointing out that this is new and they may have not heard it before. Then the critical piece is getting down on the floor and letting them experience it.

Laura: Thank you.

Gerry: Dr. Greenspan, do we have time for one more question?


SG: Yes we do, we have time for one more.

Gerry: This is a question of a general nature. Our clinic here is the only licensed Medicaid-approved mental health clinic in New Jersey for birth to six. While we have a pediatrician, a child psychiatrist, an analyst, a psychologist and other mental health professionals and an infant massage specialist, we are seeking funding for an occupational therapist. We're developing a statement of support for that. The question has to do with what your thoughts are and your knowledge of any research demonstrating the efficacy of occupational therapy treatments for children, generally with developmental problems, particularly with autistic spectrum problems. We certainly are profound supporters of OT services and are seeking to find a body of empirical support for that.

SG: I think it's a very, very good question. In the Clinical Practice Guidelines put out by the Interdisciplinary Council for Developmental Learning Disorders (ICDL), which everyone can access through www.icdl.com...


Gerry: We actually have that here too.

SG: Yes, there is a chapter, I think it is by Elizabeth Tsakiris that looks at the evidence for all the different components of the DIR Model including language therapy



but also including occupational therapy and physical therapy. And there is a considerable body of empirical evidence for the importance of working with these parts of the nervous system – motor planning, sensory reactivity, etc. – in children with autistic spectrum disorders and children with learning difficulties and children with language disorders and in children with emotional disorders. Also, in our DC 0-3 Diagnostic System, we have a category called, “Regulatory Disorders” which we also have a chapter on in our ICDL Clinical Practice Guidelines. In there, a group of experts have come together to establish the criteria for what we call Regulatory Disorders. Basically these are disorders where there are emotional or behavioral challenges, but where there is a very, very strong contribution from underlying sensory processing, motor, or sensory regulatory challenges. There’s a lot of emerging evidence from the OT literature for the contribution of these variables - motor planning, sensory modulation, sensory processing - for a variety of behavioral and emotional disorders including ADHD, including conduct disorders, etc. Sometimes it’s referred to in this Tsakiris article, others I have a bibliography available that I can send you if you drop me a note for more recent things that have come out since our Clinical Practice Guidelines came out.

The way to argue this is on two fronts. One the one hand, we argue on the point of view of empirical support that we can show now that taking these variables into account is very important in a comprehensive treatment program and there is studies of efficacy to show that working with these variables does change the child. The other way of arguing it, however, is that a comprehensive program has to deal with all components of the problem. It will be varying degrees of empirical support for different parts of a comprehensive program, but you can’t hold one component of a comprehensive program hostage just because there is less research done on that component because there was less research done. That would be like trying to approach heart disease and saying we have good evidence for diet, we have emerging and some evidence for exercise, but because the evidence for exercise isn’t as strong only because we haven’t done as much research on exercise, therefore we’ll leave it out of our program. Well, that’s foolish because we know that from basic muscle physiology, that exercise is important. We have basic animal research showing exercise is important in healthy functioning, we just don’t have clinical trial outcome studies on exercise as much as do on diet, for example. But when we know that it’s a part of that system, we’ve got to do the best approach available, given current research. So the standard is not clinical trial efficacy for every variable, because in medicine we simply don’t have that. We don’t hold hostage comprehensive approaches in general medicine because of lack of clinical trial studies if we know from other studies, more basic research that that part of the system is important. We simply do the best we can. The same thing has to happen here. You can’t not work with the family because you don’t have evidence that family systems work. It’s important if you have a



child with problems with aggression, for example. You know from a variety of studies that the family is an important part of child development, especially the child with problems with aggression, for example. You know from a variety of studies that the family is an important part of child development. Any more than if you didn't have evidence that sleep was important to a child, you would deprive a child of sleep. Some things you know, from basic physiologic studies, are important contributors, even though you don't have clinical trial studies. So you can't buy into that, what I call insurance company or even state or county manipulation. It's simply a concrete manipulation to try to avoid funding for certain critical services. So you are arguing on two fronts. You argue it first and foremost that conceptually you have to have a comprehensive program. You do the best you can in each area if you do have evidence contributors to the problem. We know that motor planning is part of the problem. We have enormous evidence of that. So once we know its part of the problem, we have to treat it. Then the best treatment available, based on the evidence available, is the treatment that should be used. But there too, we have to realize that for some types of approaches, we don't have as many studies as we'd like to have, but they may show more promise than studies we have more research on but it shows only modest help. So you've got to interpret your research skillfully. So you can't let the other people who are less knowledgeable than yourselves determine these important policies in a mindless kind of way. So hang in there, and present your case very forcefully.

Gerry: That's very helpful. I hope in a couple of months we can tell you we're a mental health clinic with an occupational therapist. We'll send you a copy of what we have developed as our proposal.


SG: That would be terrific.

Gerry: Thanks so much, Dr. Greenspan. I wondered if I could just give our phone number here for people to contact us?

SG: Sure, talk right into the phone.

Gerry: Its 973-395-5500 and we're the YCS Institute for Infant and Preschool Mental Health. We were thrilled to have the chance to do this with you.

SG: Well, we're honored to have you be our first institutional caller. Others out there who would like to set up a similar kind of institutional consultation as Dr. Costas was able to do with the YCS Institute, please drop us an email or give us a call and we'll try to do the best we can to set it up for you also.



Thank you all for listening today and we'll see you next week. Next week we're going to focus on one of the most fundamental issues when we talk about the DIR Model and Floortime. We always talk about tailoring to the child's nervous system and engaging the child. What does it really mean to engage the child? How do we follow the child's lead? Does following the child's lead mean doing what the child does? Or does it mean challenging the child by taking your cues from the child? So the question for next week is going to be, "In the DIR Floortime approach, how do you follow the child's lead and can you challenge the child while following the child's lead?" That will be the topic for next week. I will look forward to speaking with you then.

Gerry: Take care, Dr. Greenspan.

SG: Thank you, bye bye.