## Web-Based Radio Show

# The Misdiagnosis of Autistic Spectrum Disorders

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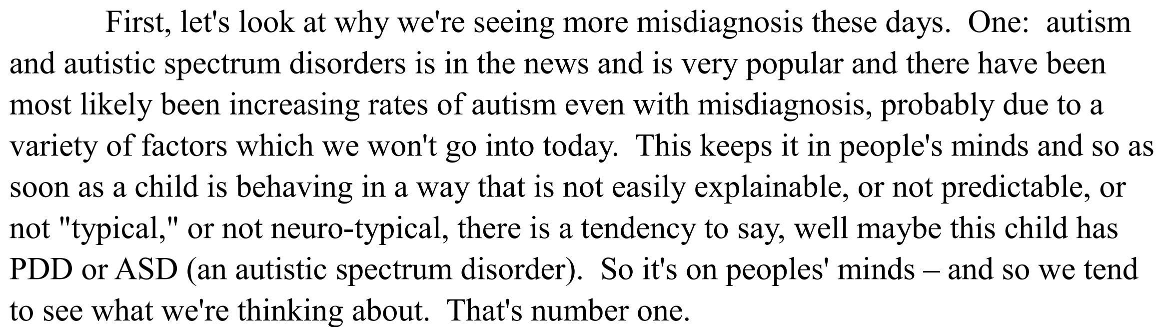
Good morning. Welcome to our Web-Based Radio Show. Today's show we are going to entitle the Misdiagnosis of Autistic Spectrum Disorders.

More and more, in my clinical practice and from talking to colleagues, I have encountered families where children have been given a diagnosis of an autistic spectrum disorder, or PDD or frank autism and when I studied the child carefully, observing parents and children interacting for long periods of time and do a little bit of what we call coaching on helping the parents interact even more effectively with their children, we observed that the child really does not deserve the diagnosis of autism and is really not on the "spectrum." The child often has what we call a series of processing differences – maybe over-reactive to sound or touch, or very under-reactive; they may have low muscle tone; or severe motor planning or sequencing problems where it's hard for them to carry out many actions in a row; they may have difficulty with language or comprehending what they hear – perceptive language and certainly often expressive language; and they may have difficulty with comprehending what they see. They may have a good visual memory in terms of memorizing what they see but have a hard time making sense out of what they see. Seeing the forest for the trees, so to speak.

So they have a range of individual differences in the way they process experience, and they may have a variety of symptoms – but the symptoms alone shouldn't be, although they often are, the basis for making a diagnosis. Now, in order to help correct this problem of the misdiagnosis of autistic spectrum disorders, we have to identify what we should term primary criteria and secondary criteria.

We have to separate, in a sense, the forest from the trees – what are the main features of autism and what should be the basis of the diagnosis? And also, related to this, how should we think about autism? Should we think about it in a two or three year old or even a 15 month old as a fixed entity or as a dynamic process where the child can still have lots of room for developing healthier functioning? That, too, is part of this important question on the misdiagnosis of autistic spectrum disorders.



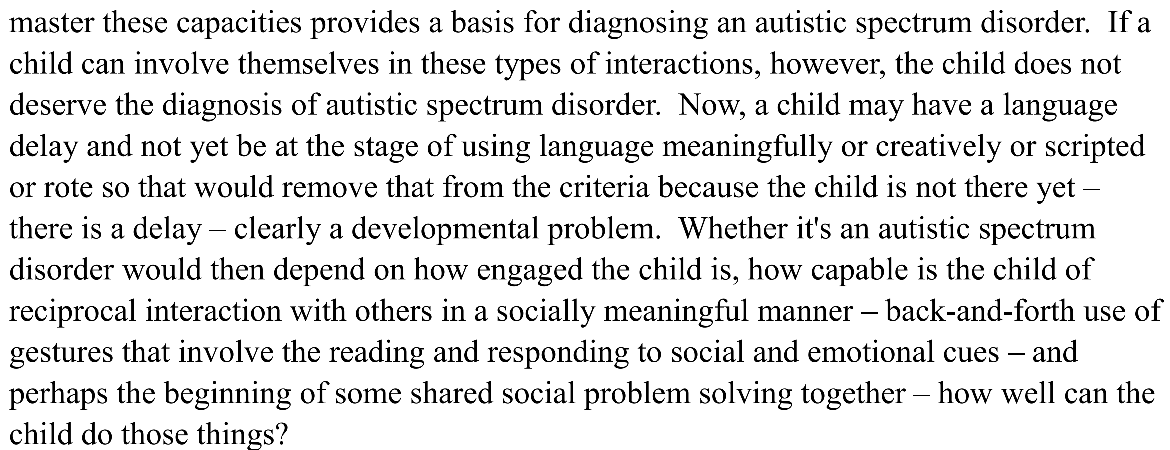
First, let's look at why we're seeing more misdiagnosis these days. One: autism and autistic spectrum disorders is in the news and is very popular and there have been most likely been increasing rates of autism even with misdiagnosis, probably due to a variety of factors which we won't go into today. This keeps it in people's minds and so as soon as a child is behaving in a way that is not easily explainable, or not predictable, or not "typical," or not neuro-typical, there is a tendency to say, well maybe this child has PDD or ASD (an autistic spectrum disorder). So it's on peoples' minds – and so we tend to see what we're thinking about. That's number one.

Number two – there are certain behaviors that are very common in children with autism. Toe walking, hand flapping, self-stimulatory behavior, becoming overloaded by noises or sounds and holding one's ears and therefore becoming disregulated or throwing tantrums, delayed language development, often aimless behavior involved in seeking out lots of sensations, lots of self-stimulatory behaviors – staring at a fan, moving a lot around a room but not, as I mentioned before, in a purposeful way but in a more aimless way. When we see these behaviors, even one or two of them, there's a tendency to diagnose autism or wonder about an autistic spectrum disorder.

It is fine to wonder about it but making a diagnosis is a more complicated matter. If we take a developmental approach and look at the primary criteria for an autistic spectrum disorder, we quickly observe that there are a few fundamental features that are part of healthy development and that are derailed in children with an autistic spectrum disorder. This also emphasizes the related principle that if we use the background for the context of healthy intellectual, emotional, and social functioning as our framework, we are more likely to make correct and proper diagnoses.

So the primary features of autism have to do with the ability of the child to engage with others; to develop a pattern of deep intimacy; to enter into a reciprocal back-and-forth interaction with others – that's two-way communication using gestures and involving reading and responding to emotional signals of the other person, so looking at the smile and smiling back, making different sounds, conveying different emotions in a back-and-forth way with a caregiver, for example; the ability for complex social interaction that we call shared social problem solving that are also referred to as joint frames of shared attention where the child is playing with a toy and the caregiver at the same time and the inability to do that; and the inability to engage in creative and meaningful language, but instead if language is learned at all, it tends to be learned in a scripted or memorized way.

So if we look at these features – the ability to engage, to interact socially, to problem solve socially and to use language creatively and meaningfully – the failure to



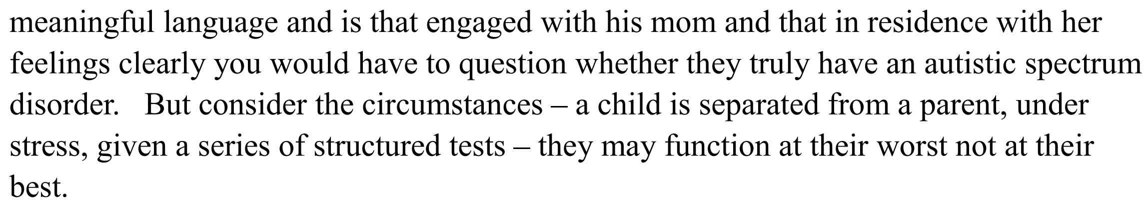
master these capacities provides a basis for diagnosing an autistic spectrum disorder. If a child can involve themselves in these types of interactions, however, the child does not deserve the diagnosis of autistic spectrum disorder. Now, a child may have a language delay and not yet be at the stage of using language meaningfully or creatively or scripted or rote so that would remove that from the criteria because the child is not there yet – there is a delay – clearly a developmental problem. Whether it's an autistic spectrum disorder would then depend on how engaged the child is, how capable is the child of reciprocal interaction with others in a socially meaningful manner – back-and-forth use of gestures that involve the reading and responding to social and emotional cues – and perhaps the beginning of some shared social problem solving together – how well can the child do those things?

Here's what I often observe. I observe a child who has many self-stimulatory behaviors, some perseverative behaviors, may repeat some words that they hear – but at the same time, they can engage warmly – when they're upset they come over and they sit in mommy's lap, they seek her out; they give daddy big hugs. They may play with a toy in a repetitive way or seemingly self-stimulatory way – moving a car back and forth; they may walk on their toes; they may flap their hands; they may stare at a fan – but they are nonetheless easy to engage, easy to involve in a back-and-forth interaction, and they'll take you by the hand and walk you to the door and try to get you to help them open the door.

Now, it becomes a qualitative clinical decision how well they are able to do these things so that's where the coaching comes in. We will coach the parents to see if we can bring out the "best" in the child. How well can they do these key or core or primary behaviors? How strong are these capacities? And herein lies the secret then to making a proper diagnosis.

So the key to proper diagnosis and misdiagnosis is focusing on the primary developmental capacities that all healthy children, children who are healthy emotionally, socially, and intellectually master, and to see to what degree the children who have developmental challenges are capable of even partial mastery of these capacities. If one focuses on these capacities rather than the symptoms of self-stimulation or perseveration, then one has a better chance of making a proper diagnosis.

A telling story was a child who went for an evaluation at one of the northeast better known and most esteemed medical centers and was immediately separated from mom, given a battery of developmental tests, and the verdict came back – your child has autism. Mom was crying on the way to the car, and the child said, "Mom, did they hurt your feelings?" A child who could take that degree of empathy and have that degree of



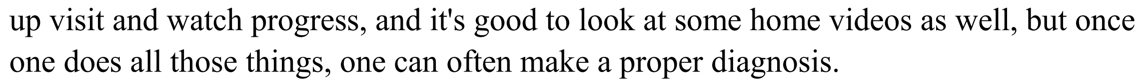
meaningful language and is that engaged with his mom and that in residence with her feelings clearly you would have to question whether they truly have an autistic spectrum disorder. But consider the circumstances – a child is separated from a parent, under stress, given a series of structured tests – they may function at their worst not at their best.

When we did a review of 200 cases, we found that over 90% of the children, who were evaluated at major medical centers around the country, were only observed with spontaneous interaction with their parents for a few minutes. Most of the observations of their interaction with parents was done during different developmental testing and they spent often large chunks of time away from parents. That creates an artificial picture of the child. We see the child at their most stressed or worst level of functioning rather than their best level of functioning.

So, in order to make a proper diagnosis we have to follow certain criteria. One: bring out the best in the child. Two: in order to do that, we have to observe the child interacting with parents for at least a half-hour, and we have to then observe the child additionally with some coaching from the professional on how to interact more effectively. Then we look for the primary or core criteria – engagement, back-and-forth reciprocal or social interaction, and if language is present, the meaningful use of language. Language delay may just be a language delay – not a sign of autism.

The key is then to look at the symptoms against this background of how engaged the child is, how interactive is the child, and if there is language, how meaningful, or in a sense, non-scripted or non-memorized it is. The reason why it's critical to look at symptoms that way is because the symptoms of let's say self-stimulation, or toe walking, or hand flapping, can all be signs of other challenges. These are challenges seen in children with autism but not itself indicative of a diagnosis of autism.

For example, toe walking may be a sign of some motor immaturity. Jumping up in the air a lot and shaking one's hands when excited and seemingly different from "other children" may be just a sign of motor immaturity. Retreating into the background and avoiding eye contact may be a sign of sensory over-reactivity to either sights or sounds in a noisy environment or certain types of touch. Babies or toddlers or preschoolers may pull away from even physical intimacy. So until one coaches parents to work with the child, take into account the child's individual differences in the way they experience sensations in the world, it's hard to understand the degree to which that child can be engaged, interactive, and use language, if they have it, meaningfully. Once you do a little coaching, even in that first or second session in that office, and it's good to have a follow-



up visit and watch progress, and it's good to look at some home videos as well, but once one does all those things, one can often make a proper diagnosis.

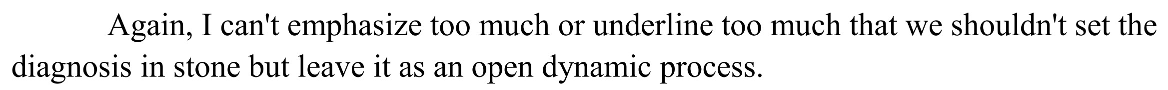
In summary, the misdiagnosis is often due to focusing on a few trees but not the whole forest. Often focusing on what I call secondary criteria like self-stimulation or perseveration or immature motor movements or social interaction under stressful conditions, rather than the primary criteria. And the primary criteria is simply the ability to engage with warmth and intimacy, the ability to interact socially with an enticing caregiver who is active in wooing the child and paying attention to the child's individual differences and how they deal with experience, and if language is present, the ability to use that language meaningfully, even if it's a single word like “hug” or “go” or “open.”

If we focus on the primary criteria and also focus on bringing out the best in the child and observe the child interacting with caregivers for longer periods of time during our evaluation with a little bit of coaching added in, we are more likely to make the proper diagnosis most of the time. The importance of following a child over a short period of time, and looking at how the child functions at home, is critical as well.

So, the reason why we are seeing a lot of misdiagnosis is because we are focusing on isolated behaviors, not on strong developmental foundations and we're not observing parents interacting with children for long enough periods of time.

It's heartbreaking to a parent to hear a diagnosis, particularly one that's not accurate. Equally important, the child is more likely to be put in the wrong type of program. The child may be put in an autism class which is organized according to behavioral principles, when the child belongs in a class with more neuro-typical kids who can engage and interact so the child can learn better and better patterns of interaction. The child may not be able to take initiative in social interaction because of the tendency to become overloaded in a sensory way, may have what we call regulatory problems, but might be able to learn that quickly in the right environment, particularly with support, with just a small group of children, and lots of play dates.

So we have to make a distinction between what we call regulatory disorders which is simply uneven processing of experience, and children who truly meet the criteria for autistic spectrum disorder. Additionally, we want to realize that particularly at early ages, and even as a child is growing older, nothing is set in stone. Children are capable of becoming more engaged, more interactive, and learning to use language more and more meaningfully. So we have to have the child in a comprehensive program and see how these patterns develop. Sometimes it takes a while to make a proper diagnosis.



Again, I can't emphasize too much or underline too much that we shouldn't set the diagnosis in stone but leave it as an open dynamic process.