

Web-Based Radio Show

The Misdiagnosis of Autistic Spectrum Disorders – Improved Version

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Welcome to our Web-based Radio Show. We are going to continue our discussion of the misdiagnosis of autistic spectrum disorders. We are going to try to summarize and also elaborate on what we talked about last time.

In summary, the misdiagnosis of autistic spectrum disorders is often based on a difficulty in separating what might be termed the primary characteristics of autistic spectrum disorders from secondary characteristics which can be found in many types of challenges, including what we call “regulatory challenges” or another way of putting it is simply “uneven processing of sight, sound, and other sensations.”

The primary characteristics of autistic spectrum disorders are when a child has severe difficulties in a number of fundamental capacities that are part of healthy development. That has to do with:

- (1) The ability to engage with others with warmth and intimacy easily
- (2) Difficulty in engaging in back-and-forth interactions and reciprocal communication patterns. Usually this occurs first with gestures and usually with emotional gestures – smiles, frowns, smirks, moving of the arms or legs – in response to a parent’s smile or sounds or movements. So you get this nice back-and-forth dance of reciprocal interactions and that is hard for children with autistic spectrum disorders to do in a continuing way. You may get a few, but you don’t get that easy flow of back-and-forth gesturing; sounds to sounds, smiles to smiles, frowns to frowns, movement to movement.
- (3) What we call “shared social problem solving” and also sometimes referred to or even more popularly referred to by Mundy and others as “shared attention” and “multiple frames of shared attention.” This is where the child is doing things such as taking mom by the hand and walking her to the toy area, pointing to the toy that they want, vocalizing to be picked up so that they can reach for the toy, and mother is responding back with a gesture so that we are getting a continuing flow of back-and-forth gesturing, all geared to solving a problem. It also shows up in the joint attention when a




child is playing with a toy and looking at mommy and maybe pointing at mommy “Mommy you do this to the toy and I’ll do that to the toy” and they are interacting with the toy together and the child is both attending to the toy and mommy or daddy or grandma or another caregiver at the same time.

(4) Severe difficulty with using ideas in a creative and meaningful way. If language is present or emerging – it may be scripted where the child just repeats what they hear or may be just memorized where they are repeating from a book that has just been read to them – they may have a very good memory but not meaningful and creative use of language. For example, you may not see pretend play where the child has the dollies kissing and hugging and when mommy says she wants a bigger hug with her doll (speaking through her doll), the child gives her doll yet a bigger hug. When this isn’t forthcoming where the child is either repeating something they saw on TV or not getting into pretend play at all, or just using language by just repeating random phrases or reciting a book they have just heard, then that is a sign of non-meaningful use of language.

Now it should be clarified that a child may have a language delay, may have motor delays, or other delays, but may still be mastering the fundamentals of healthy development, i.e., the ability to engage, interact, get involved in shared social problem solving, and therefore not evidence signs of an autistic spectrum disorder even though there are signs of a language delay.

Now what about the secondary symptoms – hand flapping, staring at a fan, jumping up and down, moving the legs and arms in a discoordinated, excited fashion in response to what seems like a minimal stimuli such as a noise; toe walking, difficulty with forming peer relationships or in the preschool going off into the corner and holding one’s ears, doing funny or silly things with peers – what about these difficulties that often perplex parents. What about the child who is very active and seems to go off chasing all kinds of stimulation, who comes too close and almost on top of you, who is touching everything, touching people, or who is impulsive and aggressive, or who is overwhelmed easily in a busy or noisy environment or gets frustrated and falls to the floor and throws tantrums. These are all symptoms, certainly, and these are all challenges, but do they constitute an autistic spectrum disorder? What if they are present where there are language delays and motor delays and all kinds of irregular patterns of sensory reactivity where the child is overwhelmed easily by sights or sounds, bright lights, or high pitched or low pitched noises like an oil burner going off or any other motorized sounds.

These secondary characteristics are also found in children with motor delays, with what we call regulatory sensory processing challenges where there is an uneven




processing of sights, sounds, and movement patterns. But being over reactive or under reactive or sensory seeking to different sensations or having motor delays or an immature motor system where excitement leads to all kinds of discoordinated movements or being fascinated by a fan and fixing on it. These specific behaviors, while of concern and often part of uneven development of the ability to process sensations, in of themselves do not constitute an autistic spectrum disorder unless the child is also having difficulty in engaging, interacting with others in a reciprocal manner, involving themselves in shared social problem solving, and if they have language, unable to use language meaningfully and creatively. So we want to make sure that we focus on the primary characteristics, not just the secondary characteristics which are part of a number of different conditions.

Presently, we see lots of children who have been given a diagnosis of an autistic spectrum disorder, some PDD-NOS which is another way of talking about an autistic spectrum disorder where the child doesn't show all the classic symptoms of autism, but shows some of the characteristics. But the fundamental issue is the child's capacity for engagement and intimacy and back-and-forth interaction and the child's ability to take initiative in these and to enjoy them because if the child has these capacities, the child shouldn't be thought of by parents or others as having autism. They should be thought of as having the kinds of challenges that they do have. They are not necessarily given a clean bill of health, depending on their language problems or their motor problems or their sensory processing difficulties.

But it is important for another reason or many other reasons in addition to giving parents an accurate picture of what challenges their child. The intervention program recommended may differ considerably depending on the type of diagnosis being made. Interventions for children with clear characteristics of autism may involve an autism class or a special needs class where the child is interacting mostly with caregivers in a one-on-one way, and depending on the intervention offered, this interaction will have different qualities to it.

On the other hand, a child who is seen as having sensory processing difficulties or motor challenges or language challenges may be involved in a different type of program – a language based program in a typical preschool with a helper. Not that children with autistic spectrum disorders won't have these interventions also; they may, but there is a better chance if there is an accurate diagnosis.


Also, along with the family having an accurate picture, the professionals working with the child having an accurate picture is very, very important because expectations will differ. A child who is thought of as capable of intimacy and warmth and engagement and interaction is more likely to be challenged to do more of that by their caregivers,



whether the caregivers are the educators or the parents or the grandparents, there is more likely to be natural emotional interactions and exchanges of affect and expectations in that direction. Obviously this is very healthy and useful for children with autistic spectrum disorders as well, but it is a little easier to do when the diagnosis is a proper one.

Now the third question is, why this diagnoses are being made so frequently and so easily; why are misdiagnoses being made? There are two primary reasons, I believe. One is that the difference between what we are calling the primary characteristics – the ability to engage, interact, and communicate meaningfully – is often not separated sufficiently from the secondary characteristics – things such as hand flapping, toe walking, staring at a fan, inability to play with peers, being over reactive to sounds, and so forth. This lack of clarity makes it easy to focus on a tree and not the whole forest. This isn't so much a problem of the diagnostic criteria which often focuses on the primary characteristics, but because ASD has become such a popular diagnosis in recent years and are increasing rates independent of the misdiagnosis, it is being looked for. It is like any sign of spring means spring is here, any one or two signs make it likely that a diagnosis will be made. Just like a fever doesn't mean you have pneumonia – even though it is found in pneumonia – similarly here, even though many of the secondary characteristics are found in autistic spectrum disorders as indicated, they are also found in many other challenges, such as regulatory sensory processing challenges, motor delays, an immature motor system, or children with primary language problems, and children with other developmental challenges.


The second and perhaps the even more important reason why misdiagnoses are made is the way in which evaluations are conducted. Often they are driven by a battery of tests – standardized tests – because the center or the clinic or the practitioner wants to have a clear way of making the diagnoses. So there is a checklist being used for symptoms, there are standardized intelligence tests and language tests and motor tests being used. But in a typical fashion, a child goes to a major medical center and this is an example from one case but it is characteristic of hundreds if not thousands of cases I have seen where a history is taken from parents, there is some interaction observed around the history taking, but there is not a long period of just watching the mother or father or both play with the child for a prolonged period of time – 30, 40, 45 minutes – there's no looking at videotapes of interactions at home, there is no home visit, there is not a secondary visit to see if there has been a change with some recommendations, and there is no coaching during the playtime. Instead, after the history, the child is separated from the parents, and even if the parents are in the room, a strange (strange to the child) examiner comes in and basically challenges the child with the standardized tests, to



answer questions or perform certain tasks whether it's motor tests to pile blocks or moving in a certain way. This is almost always a bit stressful for a child. A child who is a very good copier may handle these challenges very well, but a child who is over reactive to sound, for example, who finds new environments difficult, who finds warming up to strangers difficult or who is a bit shy may be overwhelmed and quite anxious by all of these demands being placed on them, particularly with all of these new individuals they are being exposed to, plus a new environment. As a consequence, the child may hide under the table, may retreat into their own world, may start jumping and flapping, and the examiner may see a lot of characteristic behaviors that are suggestive of an "autistic spectrum disorder."

There are some questionnaires used with parents that also don't distinguish sufficiently the primary characteristics from the secondary characteristics and these checklist approaches to diagnoses don't have the opportunity as well as a clinical approach to weight the factors. So to tell you a concrete example, when I see a child and that child is wandering around the room a bit aimlessly or staring at a fan or jumping when excited, but also comes over to the parent and sits on their lap and gives them a big hug and kiss and leans into the parent, and when the parent makes an overture to the child and the child responds back with a gesture and often a loving response, I often immediately think of this child in terms suggestive of some types of processing problems; some types of uneven development but not in terms of having a primary diagnosis of an autistic spectrum disorder. The child is simply too engaged and too warm and too comfortable with intimacy and trust initially, as a parenthetical and often with intervention we can help children with an autistic spectrum diagnosis achieve this level of intimacy, so it is not out of reach of children with autistic spectrum disorders. When I see it initially it suggests a different type of diagnostic possibility than classical autism.


Years ago we did a survey of over 200 children, the majority of whom were assessed at major medical centers around the country. Over 90% of the children, when they were going through their evaluation process, had less than 5-10 minutes to interact with parents in a spontaneous and supportive manner. Literally none of the children received the benefits of the parents having some coaching on how to facilitate interaction to see what would bring out the best in the child. Typically when I see a child, I spend at least 30-40 minutes watching the child interact with the parents. I watch them first without any coaching at all to see how they interact at home and it's simply a room with toys and a friendly atmosphere and I am pretty quiet and I just ask the parents to enjoy your child as you would at home or play as you would at home or interact or communicate as you would at home. With an older child, it is simply to engage, communicate, and interact. With a younger child, it is often play.



Then, after a bit, when I see what the characteristic patterns are, I will coach the parents a little bit to try to do a little bit more of this or a little bit more of that. For example with an under reactive child, I will often suggest the parents use a little more energy in their voice. For the child who is a little avoidant, I may have the parents engage in some playful obstruction where the child is moving away and the parent gets in their way and they have to go around the parent. Or, if a child is showing over focus on a particular toy, I may have the parent take the toy and put it on their head and the child has to look at the parent and take it off their head; or hide it in their hands or in their shirt. Often this will lead to some playful interaction, some giggles, some more engagement, and we will see the child who is quite capable with a little bit of caregiver support or challenge to master the fundamentals of healthy development – that is, being engaged to be interactive and to begin communicating meaningfully. The child may have many sensory processing challenges in terms of being over reactive to sound, having difficulty making sense out of what they see, having motor planning and sequencing challenges and immature motor systems so that they do a lot of things that would worry parents that need therapeutic intervention and need a program, but the child is not evidencing an autistic spectrum disorder.

So the second big reason why I think we are seeing misdiagnoses is we are not spending enough time in the evaluation observing the caregiver; the person the child trusts and knows best, interacting with the child in a spontaneous way. Also we are not affording the caregiver the benefit of a little bit of coaching on how to work around the child's, what we call, "individual differences" – their sensory processing challenges like being over reactive to high pitched sounds so talking to them in a low pitched voice, or energizing up a bit for the child who needs a little more because they are under reactive; a little more sound because we are not affording the parents these helpful coaching hints and we are not seeing what the child can do. We are not seeing the best of the child. So we want to make a diagnosis based on the best the child can do, not the worst the child can do.

Then there are issues about why he is having trouble with peer relationships, why is he retreating in the preschool program? Why then is the child having difficulty in preschool, retreating off into a corner or not playing with peers, why is the child having trouble playing with peers or siblings at home? Why is the child throwing tantrums? Again here, there may be many different reasons – all different from having an autistic spectrum disorder. The child may be sensory over reactive, therefore overwhelmed by the noise and commotion of the preschool environment, there may be too many peers for the child to handle, all those sights of movement around them may be difficult, they may have motor planning challenges themselves where it is hard for them to move so it's




harder for them to interact with peers – there may be many specific reasons, but difficulty with peers is not the same as lack of intimacy with caregivers. We see clearly that the primary characteristic of autism is not difficulty in peer relationships; it is difficulty with the primary caregiver who you trust and know well. Almost all children who have warm and intimate relationships with primary caregivers, over a period of time we can help them become comfortable with peers if we give them enough practice, particularly in calm, supportive settings with some facilitation initially.

So while the inability to play with peers, the inability to adapt to the preschool environment, the inability to carry out a ten step action plan and instead get involved in repetitive actions, or the inability to cope with high pitched noises or a busy visual environment – yes, they are all challenges, but they are challenges of a different kind and require specific interventions. But they are not characteristic in a core manner of autism. Again, it is the ability to engage, interact, and communicate meaningfully and creatively that are the core characteristics.

When I come back to the earlier point that when we use checklists to make the diagnosis, it is hard to wait as much as we want to as we can in a clinical situation where we are using the criteria but interpreting it to that family so when we are adding up scores on a checklist, we are not going to be, necessarily, as accurate and weighting that gleam in the child's eye, the warmth, and the intimacy. Sometimes in a clinical evaluation in my office, just one little look from the child to the parent with suggestive love with just a little “look at me” with a little gleam in the eye and a smirk or a smile is my clue that we are dealing with something different here than with an autistic spectrum disorder and we have something very, very important for the child to build on.

So it is very, very important that all of our colleagues be alert to the primary characteristics of autism and it's important for parents also. Often they are the most knowledgeable about their children and they can tell you about the intimacy and about the back-and-forth communication and about the shared social problem solving and the meaningful use of language. So parents have to be educated about these primary characteristics as well.

Therefore, the misdiagnosis of autistic spectrum disorders is a big and growing problem because we are: 1) Confusing the forest for the trees and we are not focusing on the primary characteristics. 2) It is true that autism is showing up more and more and there might be a variety of reasons for this, not only changing diagnostic criteria or misdiagnoses which may be contributing factors but I think largely a variety of other factors – the physical environment has more elements in it that can be toxic to the nervous system, both prenatally and postnatally, there may be an increase in genetic




factors that predispose children to autistic spectrum disorders that we haven't yet identified all the reasons for, and it may be an interaction with the above.

So there may be cumulative risks that are mounting in our changing culture and our changing society and changing physical world that are predisposing to greater and greater numbers of autistic spectrum disorders. But because of this fact that we are seeing greater numbers of children with these types of challenges – with autistic spectrum disorders, it is even more important now than ever before to make a proper diagnosis. And as indicated, a proper diagnosis will lead to a proper intervention plan. It is a terrible burden on a family to have a misdiagnosis, and therefore if a child is enrolled in the wrong type of intervention program, it may contribute to the child's not only not improving but being further derailed from healthy development. That is why when we look at early identification and early intervention, the issue of proper identification and diagnosis is critical.

The overall arching principle overarching all of what I just said is that we need to use a healthy developmental framework. In other words, we need to understand the building blocks of healthy development for infants and young children; the ability to share focus and attention, to be calm, to be engaged, to be interactive and take initiative, to get a continuous flow of back-and-forth interaction going, to be engaged in shared social problem solving such as taking the parent by the hand, pointing, and showing, and to use language creatively and meaningfully. As we focus on these healthy foundations, we see that it is the derailing of these healthy foundations that is the cornerstone of an autistic spectrum diagnosis and that secondary symptoms may involve some of the specific behaviors we described earlier but in of themselves may be more characteristic of what we call regulatory sensory processing problems or other types of developmental challenges but not an autistic spectrum disorder.

So having a framework of healthy development is critical. Also this becomes critical in our intervention programs where the goal must be the facilitation of healthy foundations for development rather than just changing specific behaviors. Then even if we make a misdiagnosis, we are unlikely to enroll the child in an intervention program, particularly if it is early diagnosis or an early identification program where we are undermining development rather than helping the child. For example, if we are working with a child who is staring at a fan just to change the child's behavior, and losing sight of the importance of developing engagement and intimacy and warmth with that child, and a nurturing relationship, we may be undermining rather than helping that child.



So proper diagnosis is important, it leads to proper intervention, and both need to be part of a framework of understanding the foundations of healthy social, emotional, and intellectual functioning.

Thank you for joining us today and we will have more next time.