

Lesson 2 Transcript  
Introduction to Autism  
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I'm just going to give you a quick overview of autism. We all know pretty much what it's like because we all have kids in our programs but I am going to try to put a new perspective on it. I love this poem. This poem was written by a mother who put this together during that time that she and her family were going through the initial diagnosis. Things were pretty tough and her perspective on things is that autism does not have to be awful. "It can be a journey, a caravan of faith, love, commitment, growth, and tears of laughter, tears of pain. Autism does not have to be thunder. It can be a rainbow. It can brighten your world with rays of knowledge and tears of laughter, tears of pain. Autism is awesome. It can demolish, or it can construct. It can be taught, and it can teach. In a mother's life it will often rain with tears of laughter, tears of pain." Now the title of her book was titled *The Other Side of Normal* and what she said in this book that I thought was so revealing was that she loved the one thing during the day when she did laundry and she could set her dryer to the setting that said normal and it was absolutely the only normal thing she had in her life for the day. I thought that was a unique kind of healthy perspective.

The other thing that I want to start with too is that years and years ago when I was in the state of Alaska I was working in a kindergarten classroom and I was asked to go in and observe this kid and after about 15 -20 minutes I asked the teacher "Has anyone talked about autism?" The room went hush and everybody got really fearful and the school psychologist said "You know it's almost time for lunch. Judi can I take you out to lunch?" and I thought "What have I done wrong?" At lunch she said "I want to talk to you about not using that 'A' word." I'm saying, "The 'A' word? If you have an elephant on your couch, you're going to talk about it! We need to start learning about what this is and how to deal with it." At that point we brought Dr. B.J. Freeman, who was the head of Psychiatry at UCLA Medical Center who did a lot of research on autism, to the district to help us with the identification of kids to understand how to work with kids, and she was a wonderful resource. We're at that point where how much information is out there. The autism world is exploding with lots of information. We do need to talk about it and we do need to learn effective strategies for kids.

We all know what autism is. The DSM VIII diagnosed it as a Neurobiological Disorder; you didn't do anything to get it. Its present prior to age 3. It has the qualitative impairments of social interaction, communication, and those restrictive, repetitive routines. Now in 1989 Firth would tell us that Autism is primarily a cognitive disability that it is that lack of flexibility and cognitive processing that contributes to the behavioral symptomatology that we see in autism. Then in 1995, we have Baron and Colon that say it is really more a social interaction issue. It is these kids that can't interpret the social world, who can't function in the social world, the whole theory of mind concept. Then in 1996 we had another researcher that said, "No, it's not that. It's the inability to regulate your emotions. And as we look at this criteria, it certainly is a blend of all three categories of symptomatology.

Be careful, I was just last week in a program that has several kids on the autism spectrum for the first time. I observed a second grader who of course is sitting in a classroom. It

was snowing which wasn't a good thing, so she was a little agitated because she didn't like the snow, but she was watching the snowfall. Her ability to communicate her requests, wants, and needs was limited, she had no verbal language. Her behaviors were an output of that lack of communication, high aggressive rates, no social play interaction at all. Then I moved to the next classroom, another kid on the spectrum. He's in second grade. He's fully participating in the classroom. He's telling the teacher how to teach, he's telling his peers what to do, and he's controlling the entire situation. We say, remember, be careful. "If you see one child with Asperger's Syndrome or autism, you have seen one child with Asperger's Syndrome or autism." These are combinations of very unique characteristics that manifest in very individual ways. One of the most dangerous things is when school districts say, "Oh, we're going to have a classroom for all kids with autism."

We know that there is a spectrum within this disability. Dr. Freeman, when she came to Alaska, she was very instrumental in the development of the spectrum, from clients that she saw in California. She followed them up in the state of Utah where they have good genealogical records. She had family home visits and in her own words walked into the homes and said, "By God there is more than one of them, they just didn't know it." And so she said, "This is a spectrum disorder." She was very upset that previous reports that had been written said 'autistic like features.' She said, "Can you be a little big pregnant?" You either have it or you don't. What we want is for people to recognize that it is a spectrum disorder.

So what's on the overhead is the current spectrum with what syndrome and childhood designation disorder, for kids that are functioning at the lower end. These are kids that have typical, normal development until about age three or so, then have a rapid degeneration of skills. These are kids that tend to, no matter what interventions, function at the lower level of the spectrum. Then we have the autism right underneath the middle of the umbrella, the stereotypic view that we all have of autism. Then leading up the scale is pervasive developmental disorder, not otherwise specified, and Asperger's Syndrome. So that's the continuum of autism spectrum disorders. Kids fall within the continuum.

Now, depending on which psychologist you go to, which medical doctor you go, who does the diagnosis, have you not had kids' kind of switch categories? They will say, "It's PDDNOS" or "this is Asperger's". Tony Atwith says it very clearly. When asked the question what's the difference between Asperger's and high-functioning autism. He gets very serious in his video and says, "Oh there's a huge difference, they are spelled different." The important thing is that we want to identify the symptomatology that we are going to be dancing with through instructional programming, not necessarily the exact label and the placement on the spectrum, because it changes. We also know that kids that start off in the middle of the spectrum with good early intervention move on up the scale.

So the critical features of autism: complex diagnosis based on "cluster" of behaviors, difficulties in social skills pervade all diagnoses in Autism Spectrum Disorder, uneven development in skills/abilities, life-long effects in socialization, communication, learning, personal care, community participation, and prognosis improves with early identification and intensive intervention. So that's just kind of a summary about what we do know about the disorder.

Now, there's a lot of things going on of the increased prevalence of autism. Is it an epidemic? These are the facts from the Centers for Disease Control (CDC) as written as recent as February 2007, which may be old information by now because of the way things are moving. The prevalence in the United States is 1 in every 500 for autism, and that's autism in the middle of the spectrum. The prevalence for an Autism Spectrum Disorder (ASD), including all of those, is 1 in every 150. That has increasingly been rising each time they take a look at it. Now, keep in mind that when they do these prevalence figures, previously it was based on, I think, Atlanta, Georgia. They would study an area of the country, then make the assumption that what's happening in that area is happening across all areas, and they come out with their prevalence. These new statistics were done, I think, across six different communities across the United States, so they might be a little bit more accurate. Think about that, 1 in every 150 for Autism Spectrum Disorder. The school that I was just in has a total school population of 276 and they have 6 kids with an ASD. As you look at your schools you may say, "Hmm it's a little higher even in our reality base." There has been a tenfold increase in the last 2 decades. We have 4-5 times more boys with autism. We have 10 times more boys with Asperger's. There are 560,000 individuals under the age of 21 in the U.S. with ASD. It's the 6<sup>th</sup> most common disorder. Somebody went to a work shop, and I haven't seen this in print, but said in this next year there will be more people identified with an ASD, than with AIDS or some of the other disabilities combined. So eligibility in Idaho that data we do control and we know exactly. You can look at the progression, 293 students in 1999-2000, and this last year 1077 students, so it's been a gradual, dramatic increase in the number of kids we are serving in our educational programs.

So why is this happening? You know, wouldn't you love to have the crystal ball that told you and said "It's exactly this"? What we have been told at this point is that all the research dollars that are out there trying to study the causal factors of autism are still leading to inconclusive evidence, but they have changed some of the factors about that research. The current summary is that we think of it as genetics loads the gun, so you have a genetic predisposition to the condition of autism, but environment pulls the trigger. So we have kids with genetic predispositions, where something from the environment triggers the onset. We have absolutely no idea what that is through all the research dollars. You've all heard "Is it the immunizations?" There have been duplicate studies across the United States, across international, that still have no conclusive evidence that immunizations have any kind of impact on the onset of autism. You've heard of all other kinds of things. Maybe it's those diets; maybe it's the secretin hormones. What they are saying now is that the commonality in all of this does seem to be a relationship between problems with the digestive system, problems with the immune system, and problems with brain development. The new thought is that maybe autism is not an actual brain disorder, but is more a systems disorder, that when those vulnerable genes are impacted with this condition it affects the cellular biology which has an impact on development. So they are looking at the possibility of inflammation. Is there inflammation in the digestive track? Is there inflammation that affects the immune system in the brain? So we'll see how this all turns out, but it feels like they are getting a little bit more conclusive without being able to target specifically. So we consider it maybe the new illness of the current generation. There is a growing sense that our heavily industrialized chemical-soaked environment and the way it acts on vulnerable genes in some individuals is the major culprit, but we don't know for sure. Let's talk about some of those characteristics.

If you look at this little guy, we'll call him John, on the screen, he doesn't look too happy, does he? Obviously, he is in a state of heightened arousal. His attention, when he is in this state of heightened arousal, is impacted because he's probably more inward focused, unable to attend. His affect, he doesn't look too happy. He looks a little frightened, a little rigid. The action that's produced is going to be a tantrum. When we look at these sensory characteristics, they're mutually regulatory around those 4 A's that we have to have in place for good learning to occur. If you have a student in the classroom they have to be at the right arousal state for learning to occur. They have to be able to establish attention. They have to be able to interpret the emotional regulation and information in the classroom and then have action that is productive. Disturbances in the sensory system can throw all of that off.

When we look at that sensory processing we know that it's about how they take in that information, hyper, hypo. If you're hypo reactive, it means that you have a very high sensory threshold, so literally the world can pass you by and you don't notice it. On the other hand you might have a hyperactive sensory system where small things that other people don't even notice, can cause a great disturbance and concern. So, the projector noise, the lights, the action. So if we take in that information, then we have to process it, and when you really work with these kids you start to understand how difficult processing is. We do it automatically but it's team work between sensory information, emotionally interpretation, and cognitive knowledge. When that teamwork breaks down then that processing is disturbed or disrupted, and then after you process you have to use it and you have to have some kind of output. We know that these kids have different kinds of situations that involve sequencing, motor planning. That's one of the basic difficulties of being in the classroom and learning, is how do we regulate that sensory environment and help the student regulate their sensory situations.

Now I have a good example of a little boy that I was hired to work with. His first day of first grade in the Meridian School District and he sat in the back of the classroom on the side so that the aide would have easy access to him, and so during that first day when students would raise their hand he would shout from the back, "Put your hand down, that's rude!" because the rapid movement caught his attention and felt aversive. He then proceeded to tell everybody that worked with him, including myself, that you had bad breath, so when I sent an aide out to get breath mints, brought back Altoids, he told us that he really preferred Spearmint Certs. The lights bothered him. He kept telling his teacher that her voice was too loud. He would say, "Stop shouting at us." Then when the bus drove up, even though it was a school of 750 kids in a brick building, the bus drives up and he says, "The bus is here." I thought, "How did he hear that?" All day long by the end of the day, at two o'clock, this little guy stood up and looked directly at his teacher and pointed his finger at her and said, "You're fired!" and walked out of the classroom. Now the horrible thing is that it was this teacher's very first day of teaching in the classroom, so it was like time to do some triage work. She was thinking, "It's my first day and I just got fired by one of my students." It's not going to be easy, but we can make this better because we are going to accommodate the environment to not irritate his sensory system as much. So those sensory challenges kids have, they avoid sensory input or they seek sensory input. They are unsure of body position, have poor motor planning, poor motor coordination, inconsistent motor performance, are easily distracted, and self absorbed.

Let me go on to cognitive characteristics, and here's where we get to the real meat of it. This is the tough stuff. In order to cognitively process you have to interpret the language, social, and emotional messages and make sense out of that, so what do these messages mean. With kids with autism, they see details of parts of things, which lead to fragmented information, which often leads to a very rigid schema and view of the world. Cognitive characteristics would be a challenge of kids on the Autism Spectrum. So when we look at the cognitive trait of attention we know that over selectivity and focused attention lead to that narrow view point, that's the tendency, so the weakness is any flexibility in thinking patterns and that attention shifts. We look at perception. The tendency is to attend to the visual spatial. When you have visual spatial that's constant, guess what? You get more time to process it. So, it's constant in its nature so processing can be easier, but how much of the information that we give kids, and even in this workshop today, auditory transient, harder to absorb. Information processing is one piece at a time. It's very concrete and very much a Gestalt idea about that small piece.

For example, I had a little student, and it was actually here in your district, that was moving from Moscow to Coeur d'Alene. He definitely had some behavior issues that were going on, and we were meeting and looking at his transition. The Coeur d'Alene team was down here and we were doing a great job of communicating information, and when we come out, he looks at me and says, "I hope you weren't talking about getting me a friend, because I had one once. His name was Tony and it didn't work." See, his whole schema and ideas were very narrow, but very Gestalt image. That friend, Tony, was the only friend that didn't work, so he didn't want friends anymore.

Memory. Rote memory. You all know kids that can rattle off all the commercials, and movies, the jingles, but aren't as good at the recall. Then the social recognition, being concrete, versus that concept of theory of mind. Again, theory of mind is that concept that looks at can you interpret the emotions and the perceptions and the feelings and reactions of somebody else, and process them to have an impact on your own behavior. So the best example, and sometimes that's hard to understand, because we do it so automatically. You don't think about everything that you're processing when I'm looking at you. Are you attending? Are you liking it? Do you look okay?

So an example is on the theory of mind test, there is an item, a test item, that John, it was his birthday and he was so excited for his birthday because he had wanted a rabbit and he just couldn't wait to get this rabbit. He just knew he was going to get the rabbit. On his birthday morning he pops out of bed, he runs down the stairs, and on this big table sits a box and he thinks, "Oh this is my rabbit!" He's just excited. So he tears off the wrapping paper and he opens it up and it's a box of encyclopedias, and John looks at his parents and says, "Oh thank you very much, that's just what I wanted!" The question on the test is, "Why did John say that?" So somebody tell me, why would John say that to his parents? The most typically developed children will say something like, "Well he didn't want to hurt their feelings." Right? A child with an Autism Spectrum Disorder will usually answer it with something like, "I don't know. It must have had an R in Rabbit and I like Rs. Maybe he also wanted an Encyclopedia so he can also read about rabbits." They can't conceptualize why you would fabricate your response to protect the emotions of somebody else.

So we see that when kids tell us blatantly what we do and don't do correct, you think, "Whoa. That's rude." I had one kid the other day who categorizes people into two groups so in the past I've always been mom. When I walked in he said, "Oh, grandma." I thought "It's time to get my hair done or something done."

We look at core communication skills. That non-verbal interaction, the tendency is to respond to others, eye gaze, gestures, brief turn taking, regulating others, so pulling others in to get what you want them to do versus interacting, perseverative interactions. The weaknesses are initiating interactions, combining eye gaze and gestures, reciprocal interactions, sharing and flexible interactions. We look at imitation, pretty good. Tendencies to imitate a motor act, weaknesses to imitate a sequence of motor acts. We're going to be looking at a lot of these elements in our programming techniques to help counter what the weaknesses are in learning processes.

Reciprocity, the tendency is inconsistent eye gaze and response to others. The weakness is joint attention and initiating. Functions, pretty good at varying levels of request, a tendency for Echolalia. The weaknesses are comments and general novel messages. Conversations, routinized interaction, perseverative topics, and self-directed, reciprocal interactions, flexible discourse, and shared interactions. So talking yes, but on my topic, on my subject.

I love to tell the story about two twins I had in Tillamook, Oregon, that in first grade when I first met them, I walked into the classroom and they have been previously trained on some really good social conventions. So I walk in and they say, "Hello Mrs. Hall, and welcome to our school." I'm pretty impressed and then the next question was, "What kind of a vacuum cleaner do you have?" And then, my mistake was that I said, "I think I have an Oreck." "Oh no, those are not good." And they proceeded to tell me the suction capabilities, etc. So, talking but on their topic alone.

So the paradox in the learning style and pattern is that it has to be repetitive, organized, predictable, visual and concrete. That's what kids with Autism Spectrum Disorders will have integrated into their learning. But the requirement is that you be flexible, dynamic, random, multi-sensory and social. So you can see right away the discrepancies in learning for these kiddos.

Social development and play activities. The characteristic, typical development, when you watch kids play is functionally appropriate, interactive, lots of communication going on. You know it's great when you go into kindergarten first grade programs and just watch what these kids are doing. Reciprocal interactions, it's imaginative. During their play they practice themes, roles, and scripts they've learned from another environment get translated in. They work through issues, etc. Children with autism tend to be repetitive, manipulating, obsessive, narrow-focused, aloof, and isolated. So, you can see again discrepancies building through that inability to have social play activities that are more close to the norm.

So the social challenges, social isolation. Holidays, Thanksgiving, Christmas where's the person with an Autism Spectrum Disorder? The family's over. Everything is happening. Where are they at? In their bedroom, door closed, tuning everybody out. Poor attachment. We have theory called the rubber band theory. If you're with a two or three year old in the parking lot and they run off, they only run a certain distance. The distance of a stretched rubber band is what we call it and then they come back and they reference the care giver. It's like I'm taking off and I'm watching to see where they're at. I don't want to go too far.

Then I'll come back. A child with autism is likely to keep right on going. Unaware of the social conduct. When they tell you that you have bad breath or that you look like grandma, which was actually a complement because I am a grandma. Difficulty with friendships.

I had one student, pretty impressive kiddo, he walked down the hallway from the cafeteria to the classroom and literally said every rude possible thing he could to everyone on the way. So I'm kind of observing from a distance and going, "He's got some talent. He picked out everyone's issues, called the little girl fat, etc." Then he goes into the room and does a very nice invite to play to another student to play chess. So they do another turn taking and then what do I hear? Another student says, "That's not the way we play the game, that's not the rules." The kid observing says, "They're my rules." Well, do you think that's going to facilitate friendships? Don't think so. So that altered awareness of the feeling or the needs of others.

These are kids that are driven to sameness and these ritualistic routines. Imposed to make life predictable and keep order, when novelty, chaos and uncertainty are intolerable. These routines get more rigid under times of stress and chaos. Create no opportunity for change, they become more elaborate when key people change. You know, sub comes in something doesn't happen on time, having everything be exact. So that desire, we've all experienced that. This demand for sameness has huge impact on families thrust and stability. Bed time routines turn from putting your kid into bed and giving them a hug goodnight and rubbing their back a little bit to I'm going to drive around in the car for three and a half hours and then when I pull in the garage, hope that he doesn't wake up so I can get him into bed. So that demand for sameness tends to alter the way that we as teachers as givers interact with the student. They cause major destruction of the social roles.

Then we have those attachments to objects and things and those special interests. You know, transportation cars, trucks, video game series. You know things that kids get obsessive about. We've all seen many examples of those working with our students. We had one child that was into barbeques and he'd literally leave the school or wherever he was at, run into a stranger's house, go to their backyard, and see if they had a barbeque. We don't understand where this comes from or how the obsession develops, but definitely has an impact on that student's ability.

So, a word of caution is that differences may be greater than similarities. Remember one child with autism, you've met one child. Be careful with labels and really try to understand how do these characteristics combine and manifest in your individual student that you're working with. This whole workshop is going to be working on helping you understand program elements that will help counter the negative affects of these characteristics: changing behavior, making learning easier.