



Autism Spectrum Disorder: An Overview
Four-Part Professional Development Series
Moderated by Stacey DeWitt
Co-Founder and President, Connect with Kids Education Network

Module One
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Introduction

In the backyard, children play on a trampoline. One of these boys is autistic... but which one? The child with autism is Graham Nelson, who is now 19 years old. His mother is JoJo. David is his dad. Little David is his younger brother, who is now 17 years old. Like many parents, right after Graham was born, his parents bought a video camera so they could document his growing up. We also interviewed the Nelsons over a period of several years.

Hello, I'm Stacey DeWitt, co-founder and president of Connect with Kids Education Network, a company focused exclusively on providing evidence-based multi-media programs to students, teachers and parents nationwide. In this four-part professional development program you will get to know the Nelsons and many others who are living with Autism Spectrum Disorder or ASD.

Through their stories, interviews with experts, and research-based information, we hope you will gain a better understanding of how to identify and support social, communication and behavioral challenges associated with ASD. So what is Autism Spectrum Disorder? That turns out to be a complicated question for children, parents, and even the experts.

Autism is a description of children who are disconnected from the people around them. Language development is delayed. They can repeat behavior, hand movements, for example, over and over... they often get obsessed with one thing: an idea, a toy, a spinning fan. The Centers for Disease Control and Prevention describes Autism Spectrum Disorder as a group of developmental disabilities that can cause significant social, communication and behavioral challenges. Graham Nelson's description of autism is pretty simple:

"Basically it's all just anxiety... (Nervousness?) Yeah. (Worried about... what?) Like if I didn't do well at something. I was worried that people would think I wasbad at it... no good at it."
-- Graham Nelson

David Nelson might describe his son with autism a little differently...

"Graham is a gift. But it's like a gift ... like a gift somebody gives you for Christmas... some sort of erector set and the directions are missing and so you open it up and it looks really complex and really frustrating and you don't even know where to start and you just have to start doing it ... and along the way."
-- David Nelson, Graham's Father

Experts admit that the way we look at autism – and certainly its diagnosis – has changed significantly in recent years.

"When autism was first identified and named as a disorder it was not only very often considered a mental disorder... a mental illness that these people have. It was blamed on the parenting

style...the ‘refrigerator mom’ was kind of an early term that they used, that these children were cold and not attached because their mothers did not attach with them. So obviously that had a pretty significant stigma placed on them – on the parents, more specifically, the mom.

“Now, especially with autism being more known in the mainstream media, as well as in the schools. We have lobbyists that are working on a lot of insurance bills; we are seeing it not so much as a mental disability or a mental disorder so they are not mentally ill. On the other side of that is the vast amounts of research that are being done, looking at autism and the causes of autism and what it truly is. So knowing that it’s a neurological disorder is taking some of the stigma as well where it’s not being blamed on a parent. This is a neurological, medical disorder.

“The autism spectrum, as it’s becoming known, spans from children who have a diagnosis of autism so they do have poor deficits in language communication and social skills across all areas of the spectrum. However, kids who are under what we call the lower functioning end of the spectrum also have co-morbid levels of intellectual disabilities that are along with their autism symptoms, so their cognitive levels are lower. We also have, on the other end of the spectrum, we have everyone in between... we see children who are functioning or adults/people with autism who still have deficits in the communication and social skills and social functioning but have average or above average intelligence in cognitive scores. And that exists across all ages, as well. So we see young kids across the whole spectrum and we see adults across the whole spectrum.”

Dana T. Zavatkey, Ph.D.
Program Manager, School Consultation Program
Marcus Autism Center, Atlanta

Autism Spectrum Disorder presents a broad definition and sometimes an even broader diagnosis. So let’s try to break it down. In May, 2013, the American Psychiatric Association released the fifth edition of the **DSM**, the **Diagnostic and Statistical Manual of Mental Disorder**. Prior to the release of this new edition, there were four accepted types of autism spectrum disorders:

Autistic Disorder, which usually indicates language delays, social and communication challenges, intellectual disabilities, and unusual behaviors and interests.

Asperger’s Disorder, which is typically characterized by social challenges and unusual behaviors and interests but does not include the language or intellectual disabilities.

Childhood Disintegrative Disorder, in which children who appear to develop normally for the first two years of life then lose skills in areas such as language, play, and bowel control. They also manifest impaired social interaction and communication associated with "restrictive, repetitive, stereotyped" behaviors.

And **Pervasive Developmental Disorder or PDD NOS (Not Otherwise Specified)**, which is also called atypical autism and is generally used for those with some criteria of autism or Asperger’s but not all.

Now these four disorders have been replaced by a single category in DSM-5 called **Autism Spectrum Disorder** which has four characteristics:

- **Persistent deficits in social communication and social interaction.**
- **Repetitive patterns of behaviors, interests, or activities.**
- **The presence of symptoms in early childhood.**
- **Symptoms limit and impair everyday functioning.**

Behaviors in infants that are considered **autism’s “red flags”** and further define these characteristics include:

- **Not responding to your name by 12 months**
- **Not pointing at objects to show interest (point at an airplane flying over) by 14 months**
- **Not playing "pretend" games (like pretending to feed a doll) by 18 months**
- **Avoiding eye contact and wanting to be alone**
- **Having trouble understanding other people's feelings or talking about their own feelings**
- **Delayed speech and language skills**
- **Repeating words or phrases over and over**
- **Giving unrelated answers to questions**
- **Obsessive interests**
- **Flapping hands, rocking their body, or spinning in circles**
- **Having unusual reactions to the way things sound, smell, taste, look, or feel**

After someone is diagnosed with ASD – they are generally also assigned a severity level:

- **Level 1 requires support**
- **Level 2 requires substantial support**
- **Level 3 requires very substantial support**

In addition, the DSM-5 includes a new diagnosis, **Social Communication Disorder**. This diagnosis is based upon difficulty in the social uses of verbal and nonverbal communication in a natural context and low social communication abilities which result in functional limitations.

“That’s been some of the emphasis behind the change in the diagnostic criteria is that there is no set criteria for saying low functioning autism, high functioning autism...most of the time it’s correlated with the level of intellectual disability so there are cognitive scores or IQ scores that we look at. It’s sort of where we make those determinations but there is not a number...it’s not if you get an IQ of a hundred then you are high functioning. It’s about their language abilities and having more of the skills that we need...low functioning usually has an intellectual disability in accordance with the autism.”

Dana T. Zavatkay, Ph.D.
Program Manager, School Consultation Program
Marcus Autism Center, Atlanta

But even with these guidelines, for educators, medical professionals and parents alike, it’s a broad, complex and often very scary problem.

“I think we just put on a big show....I did, I just sort of acted like things were fine. I mean that was my m.o., ‘look what a good mother I am.’ I was so panicked and threatened by being perceived as not a good one and not a competent and not able, that I went all out to be appear just the opposite.”

JoJo Nelson, Mother of Graham

“I think both of us did the same with our families, there was a real need to successful at what we were doing... so we just isolated ourselves from them.... He was just typical enough to make us feel like we were not good parents, like parenting wasn’t fun, like we didn’t have a great relationship with him. But he wasn’t so disordered or wasn’t struggling so much that we immediately saw the red flags and said, ok we have to do something about this.”

David Nelson, Father of Graham

“He didn’t look disordered enough...I couldn’t look at him and say it was your fault...I thought that maybe I made a big mistake having a child ... Because there was nothing going on between us. We weren’t laughing, we weren’t giggling...I wasn’t making funny noises, and cuddling....and him laughing...”

JoJo Nelson, Mother of Graham

This is what a mother and child is supposed to look and sound like: Interaction. Connection. Little David is just a year old and she makes him smile and laugh. Another example a couple of days later.

“It’s such an image something that simply never happen with Graham... and it’s a little piece where David comes in and cuddles and nestles in my neck, ...kind of a cuddling thing (on the kitchen floor)... that sort of physical, nuzzling, cuddling connection... didn’t happen with Graham.”

JoJo Nelson

The problem, in a phrase, is feeling emotionally connected. And that, perhaps, is how you diagnose this disorder. It seems backwards, but it’s not just how a child with autism thinks or acts or feels. It’s how you feel about him or her.

“Isn’t that interesting? It’s the connection that I feel, as the not-autistic person, that makes me think you might be autistic... that’s one of the ways I as a clinician might think this kid might be autistic... because you know I don’t feel connected with him.”

Kathleen Platzman, Ph.D., Child Psychologist

“A lot of the indication of what was wrong with Graham was what was in my heart because...in Graham’s case and this is not true of every kid but in Graham’s case it wasn’t as much about the behavior you could see as much as it was about the relationship that wasn’t happening. And therefore the biggest signal was how bad it felt inside...the biggest signal of what was wrong was my heart felt so bad...”

David Nelson

Finally, when Graham was three years old, a psychologist talked to them and to Graham, and then said this boy has autism.

“There was a lot of pain that came in the days later and the pain was...we’ve been through three years of hell...it was...almost mad at God.... not that Graham had autism, you know, it wasn’t ‘why did you give me a child with autism?’ It was why didn’t you let me know?”

JoJo Nelson

But that was over a decade ago. Experts in the field are now working hard to remove the stigma, doubt and guilt that often go along with a long and difficult diagnostic process. We now have a more specific working set of criteria, as evidenced by the recent change in the DSM 5 discussed earlier in this segment and we have made great strides with earlier diagnosis. Autism Spectrum Disorder can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.

Diagnosing an ASD generally occurs in two steps. There is generally a **developmental screening** which is a short test to tell if children are learning basic skills when they should, or if they might have some delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.

The developmental screening is generally followed by a **Comprehensive Diagnostic Evaluation**, which may include looking at the child’s behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.

And most important, what we also know now is that an ASD diagnosis does not have to be terrifying.

"I don't believe in that at all, I don't consider it a death sentence or a feeling of doom...although I am very sympathetic with parents because in society autism is considered incurable... but I work with children all day long who have developmental differences that are so big that they impair the quality of their social relatedness and they get better."

Kathleen Platzman, Ph.D., Child Psychologist

In 2012, **TIME Magazine** published an article called "**What Genius and Autism Have in Common.**" The article cited a study, which followed eight child prodigies – all-famous and having achieved professional acclaim by the age of 10. What were some of the main characteristics that each had in common? Most scored high in autistic traits and three of the eight had a diagnosis of autism spectrum disorder. It is now clear that those with autistic traits may have a kind of creative intelligence that many would label genius.

David Nelson became so passionate about helping children with autism and changing the way society views the diagnosis that he went back to school, changed his career, and started a school for teenagers with autism. More about that later in our training. Throughout that process he learned through his own life and many others that there is a lot of hope – that children with autism can become happy, productive adults with understanding and support:

"I think a really important principle for teachers to hang on to is that autism is an issue of development, which is to say you can facilitate change and growth in individuals. It's not a fixed condition. There may be underlying medical issues that are fixed that we can't control. I don't mean to say that all kids with autism are completely curable by any stretch but people can get better at engaging with others. They can get better at interacting. They can become better communicators and they can become better at understanding themselves and connecting with the world."

David Nelson

Executive Director, The Community School

In this first part of the program we have learned the clinical and practical definitions of Autistic Spectrum Disorder and the characteristics of that disorder. Next we'll tackle the identification of key behaviors that are often present in students with ASD, and the accompanying sensory, communication, and social and emotional issues.