



## VIDEO TRANSCRIPT

### Understanding the Diagnosis of Autism Spectrum Disorder

Families living with autism spectrum disorder often look for tips on how to handle the many different challenges that may arise. “Real Life Tips for Kids with Autism” is a series of practical videos and resources presented by the experts at Children’s Specialized Hospital.

Autism is a neuro-developmental disorder that’s characterized by impairments involving social communication and behavior that’s problematic because it’s either restricted or repetitive in nature. Typically it’s noticed from early childhood and it causes significant impairments in various aspects of daily functioning.

When we talk about autism spectrum disorder you’ll notice that the word “spectrum” is in there and that’s because there’s a wide range of functioning. So when we’re focusing on problems involving social communication, that can range from people who really are appearing to not really be interested in other people, or their play might be very solitary, to people who are very interested in making connections but really need help in building those skills. When we talk about difficulty with communications, specifically that involves both receptive and expressive language. So, again because there’s a wide range of functioning, the range could be from people who do not have any oral language but might communicate in other ways such as using sign language, using an augmentative device or picture exchange system to people who are really very articulate and highly verbal but where the difficulty with communication might be more subtle; for example, involving the give and take in a social conversation.

When we talk about restricted and repetitive behavior, it could look very different. So there might be interests that are common interests such as you might have a young boy who’s interested in trains or a young girl who’s interested in trains but the interest is very, very intense so they might be so interested in that they’re not really interacting in other forms of play, or it might really restrict how much they’re learning in other ways. Other interests might be really unusual interests so sometimes the interest can be common but over-focused and sometimes the interest can be very specific and unusual in nature.

Behaviors can be problematic in that some of the behaviors might be repetitive or stereotyped. Sometimes you’ll see people on the autism spectrum who might be flapping their hands, or have different finger motions, or walking on their toes, or be sensitive to different sensory kinds of things like sounds or touch or the feel of things. Sometimes the behaviors might be characterized by difficulty handling change or making transitions, having difficulty moderating and modulating the emotions so that there might be frequent tantrums and aggressive behaviors in that regard.

So when we talk about behavior really everyone's behavior has a function. Sometimes the function of the behavior might be related to attention, sometimes it might be related to a desire to escape from a demand, or sensory in nature, or a desire for something specific and tangible. Sometimes the behaviors really don't hurt anybody. So for example, if you have somebody who might be flapping their hands or pacing back and forth, it doesn't really hurt anybody. But sometimes the behaviors can really be problematic and you'll find some people on the autism spectrum who have self-injurious behaviors, again sometimes because of a desire to escape the situation or various situations that might lead to frustrations and really having difficult communicating what that frustration might be in a more socially acceptable manner.

While there are impairments involving socialization, it might range from mild to severe. So, on the mild level you certainly have people on the autism spectrum who have very close and meaningful and rewarding relationships. They might have spouses and they might be parents themselves. But there always might be some undercurrent of difficulty reading social cues and a real need to invest even more so in making sure that you have good communication with your partner. And it could range to something quite severe where really there's such a severe difficulty in communicating that the person does appear to be in his or her own world.

So, in all cases of autism spectrum disorder there is some degree of impairment. But the amount of support that's needed could really range from mild support to needing quite considerable support.

There's also a range in terms of cognitive skills so some people with autism spectrum disorder might have severe intellectual impairment, but other people on the autism spectrum might actually have a very high level of cognitive skills and be very functional. And similarly you could have a wide range of professions and employments. There are some people on the spectrum who have very responsible positions and are very successful in their chosen fields. And there are other people in the spectrum who will always need considerable levels of support in all aspects of life.

In terms of what's known about the cause of autism spectrum disorder, because it's a range, it's probably not one single cause. There's more and more research going on all the time to try to find more and more about the causes of autism spectrum disorder.

When we talk about early red flags for autism some of the things that we're looking at include: no babbling by 12 months, no single words by 16 months, not combining two words by two years of age, not responding to one's name certainly by a year, not pointing or gesturing by a year. And then there's other behaviors or developmental milestones that are red flags no matter when they might occur. So loss of skills, especially loss of language at any age, is a red flag and something that should be brought to the attention of a health care provider. Some other things that we look at as possible red flags are poor eye contact, not sharing enjoyment. So when you're a little kid, let's say you're really excited about something that you see or some interest, typically what you would do is you would point to show the person what you're excited about or use words to tell them what you're excited about, or at least look at that item and then look back to check back to make sure that the person shares in what you have seen. The failure to do that is referred to as not having shared enjoyment or a lack of joint attention. That is something that is an important red flag of possible autism spectrum disorder. It is important to know that while these different things are important red flags there is no single behavior or lack of developmental milestone characterizes autism spectrum disorder.



There's a lot in the news and on the internet about autism spectrum disorder and while it's great that there is so much awareness and outreach out there, the issue is that not everything you read is really legitimate or has science behind it and that's one of the reasons why we're making this series of videos is to make sure that people have credible information that not only provides some real life tips to hopefully help them in the real world, but also has evidence and science behind it.

Just like any other impairment or condition, you can have more than one thing. So it's possible to have autism spectrum disorder as well as what's called a co-morbidity. Common co-morbidities with autism spectrum disorder might include anxiety or other mood issues, attention deficit hyperactivity disorder. Many people on the autism spectrum have difficulty with sleep. Many have difficulty with gastrointestinal issues or other allergies. So it is possible to have more than one thing.

There are many different ways that people might end up with a diagnosis of autism spectrum disorder. In some cases the health care provider or the pediatrician is the first person to express a concern. The American Academy of Pediatricians encourages all pediatricians to specifically screen everyone in their practice for autism at 18 and 24 months whenever a parent or a family member has expressed a concern. Many times it's the parent or family member who is the first person to become concerned and then he or she is strongly encouraged to discuss that concern again with their health care provider or with their preschool, their day care or their school district. Sometimes kids come to the concern of the day care provider, and one of the things we're really trying to do is to encourage all day care providers to specifically screen the kids in their program for development and specifically for autism.

It's important to get a diagnosis and one of the reasons why it's important is to better understand what's going on, also to communicate with others about what's going on. Having a diagnosis helps to link you to other people and helps to link you to other services that are needed. It helps you to realize that you're not alone, and while it might be difficult when somebody first is concerned that somebody might have autism. It's difficult to make that next step and seek out an evaluation, to seek out a diagnosis. It's really important because really that's what starts a whole process in making sure that the person is getting appropriate intervention and through the appropriate intervention being able to reach his or her full potential.

One of the reasons why it's so important to diagnose people who have autism spectrum as soon as possible is to make sure that they're getting early intervention that is appropriate and targeted to what they need. It helps many people to reach their maximum functioning and anybody can seek early intervention. It's from ages birth to age 3. The first step would be to contact the agency in one's state to set up an early intervention evaluation. You don't need a diagnosis in order to potentially qualify for early intervention services. So I really encourage anybody who has a child between 0-3 who is at all concerned about aspects of the child's development and behavior to look into that to see if the child might be able to qualify and benefit from early intervention.

People on the autism spectrum tend to learn very well using applied behavioral analysis as one form of treatment. And the reason why that's so successful and so effective is because it really breaks down behaviors into small steps.



What's important throughout the age span is to make sure that the person has as positive of quality of life as possible, and it's really important in order to really encourage that quality of life to be involved in the community. Whatever one's community is, we really want to promote meaningful inclusion. And that means not just what skills and behaviors the person with autism spectrum needs to have, but what are the skills and supports and attitudes that the rest of the community needs to have in order to support that person, the person's family and one another. So it really does take a village.

When we talk about autism spectrum disorder, we talk about it being a journey. That this is something that is not just, ok you've got this diagnosis and you're done. This is a journey that's going to be lifelong and at Children's Specialized Hospital we really want to join with you on that journey to partner and to make sure that the person is getting all of the services and support that he or she needs. So, not only are we there for you at the time of diagnosis, but we also are here for you at the time of various services and here for the whole family to support the whole family to continue on this journey together.



Through a partnership with Kohl's Cares, Children's Specialized Hospital is improving access to care for children with special health care needs.



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