



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 video’s and resources presented by the experts at Children’s Specialized Hospital.

Autism is a neuro-developmental disorder that’s characterized by the impairments involving social communications and behavior that 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 the word “spectrum” is in there because there’s a wide range of functioning. So when we’re focusing on problems involving social communication that can range from can really BE 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 these skills.

When we talk about difficulty in communications, it’s specifically those that involve both receptive and expressive language. So, again because there’s a wide range of functioning the range could be from people who have no oral language but might communicate in other ways such as using sign language, using an argumentative device or picture exchange system to people are very articulate and highly verbal where the difficulty with communication might be more subtle; for example, the give and take in a social conversation.

When we talk about restrictive and repetitive behavior it could look very different. So there might be interests that are very common interests. You might have a young girl who’s in trains but the interest is very, very intense. They might be so interested that they’re not really interacting in other forms of play, or it might really restrict how they’re learning in other ways. Other interests might really be unusual interests so sometimes the interest can be over-focused and sometimes the interest can be very specific in nature. Behaviors can be problematic in that sometimes the behavior s might be repetitive and stereotyped. Sometimes you’ll see people on the autism spectrum who might be flapping their hands, have different finger motions, or walking on their toes or be sensitive to different kinds of sensory kinds of things like sounds or touch or the feel of things.

Sometimes the behavior might be characterized by difficulty handling change or making transitions, having difficulty moderating or modulating the emotions. So there might be frequent tantrums and aggressive behavior in that regard. So that when talk behavior really everyone’s behavior has a function. Sometimes the function of that behavior might be related to attention, sometimes the behavior might be related to desire to escape, from a demand, or sensory in nature, or for a desire for something specific and tangible. Sometimes the behaviors don’t really hurt anybody. So for example if you have somebody who’s flapping their hands or pacing back and forth, it

really doesn't hurt anybody. But sometimes the behavior can really be problematic and you'll find people on the autism spectrum who have self-injurious behavior and sometimes because of a desire to escape the situation in various situations that might lead to frustrations and really having difficult in communicating what that frustration might be in a more socially acceptable manner.

There are impairments involving socializations. It might range from mild to severe. So, on the mild level you certainly have people on the autism on the autism spectrum who have very close and meaningful relationships. They might have spouses and be parents themselves. But there might be some undercurrent of difficulty reading social clues and a real need to invest even more in making sure that you have good communication with their partner. And it could range to something quite severe. Well really there's such a difficulty in communicating that the person 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 ranges from needing mild support to needing quite considerable support. There's also a range of cognitive skill. People with Autism Spectrum Disorder might have severe INTER impairment, but others in the autism spectrum might have a very high level of cognitive skill and be very functional. And similarly you could have a wide range of professions and employments. There are some people 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 support in all aspects of life.

In terms about what's known about the cause of autism spectrum disorder, because it's a range, it's probably not a single cause. There's more and more research going on all the time that are trying to find out the causes of Autism Spectrum Disorder. When we talk about early red flags for autism the things that we're looking at is: no babbling by 12 months, no single words by 16 months, not combining words by two years of age, not responding to one's name by a year, not pointing or gesturing by a year. And then there's other behavior or developmental milestones that are red flags no matter when they occur. So loss of skills, for example, 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 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 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 least look at them and then look back to check back to make sure that the person has shared in what you have seen. The failure to do that is referred to not having shared enjoyment or a lack of joy. That is something that is an important red flag of possible autism spectrum disorder. It is important to know that although all these things are important red flags there is no single behavior or lack of developmental milestone that characterizes Autism Spectrum Disorder.

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 had science behind it and that one of the reasons we're making this series of videos is to make sure that people have credible information that not only real life tips to hopefully help them in the real world, but also have evidence and science behind it. Just like any other impairment or condition you can have more than one thing. It's possible to have autism spectrum disorder as well as a co-morbidity. Common co-morbidities with Autism Spectrum Disorder might include anxiety or other mood disorders, attention deficit disorder. Many people on the 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 ways that people might end up with a diagnosis of autism spectrum disorder. In some cases it's the health care provider or the pediatrician is the first person to express concern. The American Academy of Pediatrician encourages all pediatricians to specifically screen everyone in their practice for Autism Spectrum Disorder at 18 to 24 months whenever a parent or a family member has expressed a

concern. Many times it's the person or family member who is the first person to express a concern and then he or she is strongly encouraged to discuss that concern with their health care provider or with their preschool, day care or 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 really encourage all day care provider to specifically to screen all the kids in their program for development and specifically for autism.

It's important to get diagnosis and one of the reasons it's important is to better understand what's going on and also to communicate with others what's going on. Having a diagnosis helps you to link with other people and link you to other services that are needed. It helps to realize that you're not alone, and while it might be difficult when somebody is first concerned that somebody might have autism. It's difficult to make that first step and seek out an evaluation to seek a diagnosis. It's really important that's what starts a whole process in making sure that the person is getting the appropriate intervention and through the appropriate intervention reaching his or her full potential. One of the reasons it's important to diagnose someone with autism spectrum disorder as soon as possible is to make sure that they're getting early intervention that is appropriate to get what they need. It helps to get many people their maximum functioning. Anybody can seek early intervention.

The first step would be to contact the agency in the state to set up an early intervention evaluation. You don't need a diagnosis to potentially qualify for early intervention services. So I really encourage anybody who has a child 0-3 who is at all concerned with 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 breaks down behaviors into small steps. What's important about 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 encourage that quality of life is to be involved in the community.

Whatever one's community is, we want to encourage meaningful inclusion. And that means not just what skills and behaviors the person with autism needs to have the skills, supports, attitudes 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. This is something that is not just ok. Yes, you've got this diagnosis and you're done. This is a journey that's going to be lifelong. At Children's Specialized Hospital we really want to join with you on the 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 at the time of diagnosis, but we're also here at the time of various services and here to support the whole family to continue on this journey together.

For more real life tips on children with autism spectrum disorder visit www.childrens-specialized.org/KohlsAutismAwareness.



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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