



VIDEO TRANSCRIPT

Explaining the Diagnosis of Autism (ASD) to Family and Friends

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.

Explaining your child’s diagnosis of autism to family members can be a very challenging experience and can invoke a lot of fear and concern that your family may not be able to be accepted as they had in the past. I feel that honesty is usually the best policy but both parents really should work together to think through their understanding of the diagnosis and be able to share what they’re comfortable with.

With autism, because there are so many symptoms, it is often easier, especially with a young child, to say “he’s delayed” or “she’s delayed and she’s getting help for that” or “her speech is delayed and she’s getting help for that” so unless you are one hundred percent ready to share the overall diagnosis, you can break things down and that’s not an uncommon approach with families.

I think it is important to gain the cooperation and support of family members that are involved with the child on a regular basis to help improve the child’s social interaction and play skills. Grandparents are terrific at having the ability at times to spend more time with the child, getting down on the floor with them, engaging with them and having that little extra energy sometimes that a parent who’s maybe working and trying to juggle many different things could handle.

I think it’s very important to understand that today we are certainly identifying many more children with autism than we have in the past and that the children that we are identifying have much milder symptoms than it would have been perceived in the past, so parents will often say to me, “You know, I think of autism as a child who is not talking and in the corner not interacting with people, lining up toys, but my son doesn’t look like that.” And you know things that are more subtle symptoms, that parents and family members notice but they may not realize go together with that diagnosis of autism, are important to be aware of.

It’s very common nowadays for everyone to have an opinion about the child particularly therapists or teachers that are spending hours each day with the child, many times in a structured situation where spontaneous social skills are not observed or repetitive behaviors may be suppressed by the routine the child is in and many of our children are bright, they know what the routine is and they will not line up their cars or flap their hands or do other repetitive things that they may do when they are relaxed at home.

You know it doesn't mean that you shouldn't participate in family events or gatherings but you need to know my child can only tolerate such a length of time or so many people saying hi or personal space, getting in their space or some children don't want to be touched. They may not appreciate your aunt kissing them, so the parents need to be able to prep and warn family members but also the child, depending on the child's age and functional abilities. But many parents are able to integrate the children into the community with a plan and working with the child's strengths.

Family members may not understand that special types of interventions or techniques are being used with the child with autism and the concept of the early intervention program is to engage not only the child but their family and if you're able to bring in other family members into your home setting and have exposure to the therapist working with the child, that may help demystify some of the special techniques that you're using with the child.

I would take a proactive approach and turn it into something positive so that thank goodness you have family that is concerned and wants to give input but engage them in the process with professionals with you to understand directly what can be done to support the child in an appropriate manner.

I always refer parents to the Autism Speaks website. I explain to them that they've really done a fabulous job with nationwide support and committee members to provide handouts or downloads for parents and grandparents and professionals on what autism is. There are also wonderful resources that have been developed though our team at Children's Specialized at "Friends Like You, Friends Like Me" and "Make Friends with Autism" that provide support for your family members and other businesses in the community.

I think when it comes to sharing the diagnosis of autism with family members it is always best to be honest and to provide the correct information. They may not choose to believe it, they may not choose to be able to process it but again as we talked about I think they can certainly be engaged with the professionals in the home, in the school, in medical settings, in therapeutic settings and support you through your journey along the lifespan with autism and your child.



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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