

## **A PARENT'S GUIDE TO EXPLAINING AN AUTISM DIAGNOSIS TO EXTENDED FAMILY MEMBERS**

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Superheroes Social Skills Training, Rethink Autism Internet Intervention, Parent Training,  
Evidence-based Practices Classroom Training, Functional Behavior Assessment: An Autism  
Spectrum Disorder, Evidence-based Practices Training Track for School Psychologists

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## ~ FAMILY SUPPORT MATTERS ~

When your child is diagnosed with an autism spectrum disorder (ASD), it can take time to come to terms with the uncertainties and concerns many parents face. It's important for parents and caregivers to educate themselves in order to provide the best care for their child. It's also critical for them to have a support system to help face the challenges they may encounter. If raising a child takes a village why not have your extended family be a part of that process? Family support can be extremely helpful.

However, sometimes navigating family dynamics can be difficult. Some parents may encounter family members who make uninformed comments, are judgmental, don't know how to react, or simply lack awareness of ASD making it difficult to feel supported. If you have experienced any of these responses, don't worry you're not alone. Patience is important in these situations. Introducing your child's diagnosis to your extended family is an important first step in gaining understanding and support.

Once you have explained ASD, it may be helpful to talk to your family about your child's individual characteristics, their interests, and what to expect at different family events. This will help them know how to support you and your child. This guide provides a few key points to help facilitate the discussion between parents of children with ASD and extended family members.

*“Although individual coping strategies and characteristics such as hardiness are important for parents and families of children with ASD, the enormous demands associated with raising a child with a disability also necessitate continued support from external sources.”*

*(Karst, & Hecke, 2012; Bromley et al. 2004; Khanna et al. 2011; Weiss 2002)*

## What is ASD?

Family members may not have the same background information that you have to help them understand ASD and its implications. They may have questions about the behaviors your child exhibits and the causes of ASD. Some family members may have multiple questions while others may feel overwhelmed by too much information. Explaining some of these basic points as they relate to your child may be helpful:

*It's more prevalent than they think.*

- 1 in 68 children have an ASD
- It's 4-5 times more common in boys than girls

*There are some behaviors associated with ASD.*

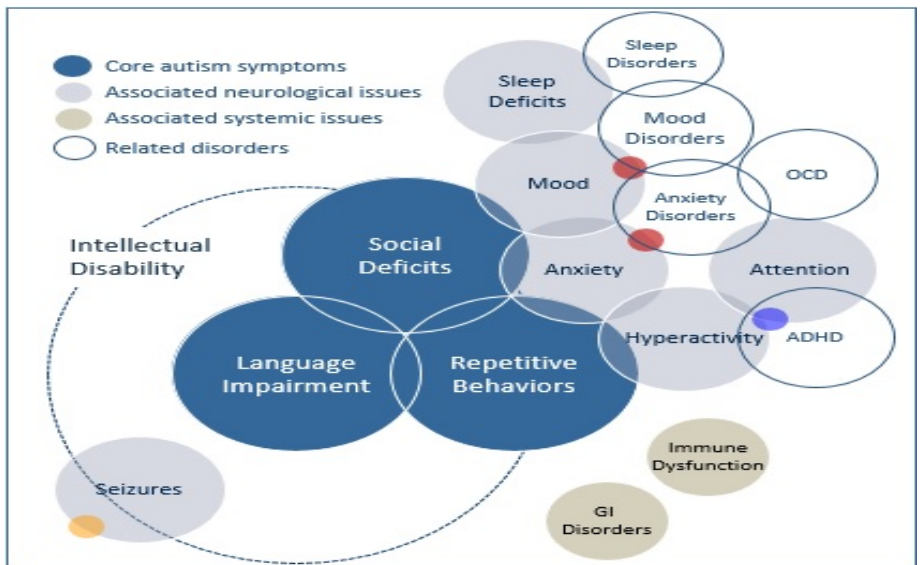
- Difficulty with social skills
- Difficulty with communication skills
- Some restricted behaviors and interests

*The causes of ASD are complex.*

- Neurodevelopmental disability
- Genetic predisposition
- Environmental factors
- Unknown factors
- NOT caused by vaccines
- NOT caused by bad parenting skills

*Not all individuals with ASD are alike.*

- Different severity levels
- Can have comorbid disorders
- Have unique skills and abilities



### Personalize the Discussion

When discussing your child's diagnosis with family members it's important to emphasize that autism is a spectrum disorder; not everyone is the same. Discuss your child's difficulties as well as their strengths. For example, if your child has difficulty with social reciprocity, you could explain that your child isn't trying to be rude when responding inappropriately to family members' interactions. Let them know that making eye contact is also difficult for your child and that he or she may not know how to carry on a conversation. It's important for your child to be included in social situations even though these skills may be difficult. Emphasize that this is a skill your child may need assistance with and that family members can provide a safe place for your child to practice social interaction skills.

### Prepare for Family Events

Preparing your child with ASD is important when it comes to attending family events. It's also important to notify family members of potential problems your child may experience. Don't be afraid to ask for help! Although not every event can be catered to the needs of your child, having a discussion with family members about how your child might react to a large crowd, food they don't like, or other difficulties can help them be more understanding and supportive.

### Teach them Strategies

If you have family members who want to help at family gatherings or even babysit your child while you get a much deserved night off, teach them strategies that will make the experience more positive (e.g., Use a visual schedule to help your child prepare for bed).

### Encourage Questions

It may be difficult at times to disclose your child's diagnosis to others. It may require a great deal of patience especially if a family member has his or her own views of ASD. It's important to keep the dialogue open so that these individuals, as well as more supportive ones, can ask questions to better understand your child. Allowing as much open communication as you're comfortable with can strengthen the support system for you and your child.

### Emphasize Strengths

Remember to mention your child's strengths! Emphasize that he or she has many talents and abilities.

### Seek Extra Support

You don't have to be alone in the process of raising your child. Extended family support can help alleviate stress. It can also provide a place for your child to generalize skills and form relationships with family members. Seeking support from individuals outside your family can also be helpful. Friends, neighbors, and teachers can be a source of strength for you and your child. There are also support groups available. It's important to stay connected with other parents who have had similar experiences. Sharing stories, advice, and resources can be helpful whether it is online or in a group setting. Seek support wherever you can. It will help you and your child to accomplish even more!

## EXPLAINING ASD TO KIDS

Explaining ASD to adults is one thing, but including kids in the conversation is another matter altogether. Your child's siblings, cousins, and others can also be a source of strength. Kids can also be brutally honest. Be patient and understanding during these times and help them understand the different behaviors your child may exhibit. One of the ways you can explain your child's ASD is by using *The Gaming System Analogy*, which is appropriate for elementary-aged kids. A website called [whattoexpect.com](http://whattoexpect.com) explains it like this: "Autism parent blogger Four Sea Stars had a successful experience talking to her autistic son's 4<sup>th</sup> grade class. She asked them what would happen if they took a game meant for one game system and put it in another. That's all it took. Today's children understand operating systems. It led to lots of good questions from the class, and her son got an opportunity to share his unique experience with his friends who are now better able to understand him."

Let kid family members know what interests your child and that including him or her in activities is important. They may even have a fun time and discover that they have a lot in common!

Help other kids in your family know they can model different skills for your child. Let them know that they have much to offer, and so does your child!

*"Positive intergenerational alliances between grandparents and parents can also encourage involvement of other family members for constructive advocacy on behalf of the child. Successful relationships in these family teams can potentially lay the groundwork for long-term, successful integration of the child living with autism into school, work, and social spheres."*

*(Kahana, Lee, Kahana, Goler, Kahana, Shick, Burk, Barnes, 2015)*

## Resources for Families

The following websites provided on *childrens-specialized.org* may be helpful for your extended family to increase their understanding of ASD:

- **10 Ways to Make a Difference for Your Grandchild with Autism**  
<http://www.autismspeaks.org/sites/default/files/kruminsarticle.pdf>
- **A Friend's Guide to Autism-Autism Speaks Family Support Tool Kit**  
[http://secure.autismspeaks.org/site/c.8hKPL7NMLpJ4G/b.7809541/k.3B22/Friends\\_Support\\_Tool\\_Kit\\_Download\\_Request/apps/ka/ct/contactus.asp?c=8hKPL7NMLpJ4G&b=7809541&en=ajlJI XMDJ9JSI7OGI8LOI9NXXkIMKYNEIeIRL3MSJtK9E](http://secure.autismspeaks.org/site/c.8hKPL7NMLpJ4G/b.7809541/k.3B22/Friends_Support_Tool_Kit_Download_Request/apps/ka/ct/contactus.asp?c=8hKPL7NMLpJ4G&b=7809541&en=ajlJI XMDJ9JSI7OGI8LOI9NXXkIMKYNEIeIRL3MSJtK9E)
- **Friends Like You. Friends Like Me.**  
[www. www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)
- **A Grandparents Guide to Autism-Autism Speaks Family Support Tool Kit**  
[http://www.autismspeaks.org/sites/default/files/a\\_grandparents\\_guide\\_to\\_autism.pdf](http://www.autismspeaks.org/sites/default/files/a_grandparents_guide_to_autism.pdf)
- **Grandparent's Guide to Autism Spectrum Disorders: Making the Most of the Time at Nana's House** Nancy Muckow; AAPC Publishing; ISBN 1937473066
- **Make Friends with Autism**  
[www. www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)
- **A Siblings Guide to Autism-Autism Speaks Family Support Tool Kit**  
[http://secure.autismspeaks.org/site/c.8hKPL7NMLpJ4G/b.7809685/k.3B7C/Siblings\\_Support\\_Tool\\_Kit\\_Download\\_Request/apps/ka/ct/contactus.asp?c=8hKPL7NMLpJ4G&b=7809685&en=8hI FKRMvG7IOK1MyH6LKI3OPLiIJSNwGeLXJaOPIrK5G](http://secure.autismspeaks.org/site/c.8hKPL7NMLpJ4G/b.7809685/k.3B7C/Siblings_Support_Tool_Kit_Download_Request/apps/ka/ct/contactus.asp?c=8hKPL7NMLpJ4G&b=7809685&en=8hI FKRMvG7IOK1MyH6LKI3OPLiIJSNwGeLXJaOPIrK5G)



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## References

- 100 Day Kit For Newly Diagnosed Families of Young Children. (2014). Retrieved from [https://www.autismspeaks.org/docs/family\\_services\\_docs/100day2/100\\_Day\\_Kit\\_Version\\_2\\_0.pdf](https://www.autismspeaks.org/docs/family_services_docs/100day2/100_Day_Kit_Version_2_0.pdf)
- Data & Statistics. (2016). Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>
- Explaining the Diagnosis of Autism to Family and Friends. (2014). Retrieved from <https://www.childrenspecialized.org/Content/Uploads/Childrens%20Specialized/KohlsAutism/Autism/Tip%20Sheets/Real-Life-Tips-for-Kids-with-Autism-Explaining-Diagnosis-Autism-ASD.pdf>
- Kahana, E., Lee, J. E., Kahana, J., Goler, T., Kahana, B., Shick, S., . . . Barnes, K. (2015). Childhood Autism and Proactive Family Coping: Intergenerational Perspectives. *Journal of Intergenerational Relationships*, 13(2), 150-166. doi:10.1080/15350770.2015.1026759
- Karst, J. S., & Hecke, A. V. (2012). Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Clinical Child and Family Psychology Review Clin Child Fam Psychol Rev*, 15(3), 247-277. doi:10.1007/s10567-012-0119-6
- Sharing an Autism Diagnosis With Family and Friends | Child Mind Institute. (n.d.). Retrieved from <http://childmind.org/article/sharing-an-autism-diagnosis-with-family-and-friends/>
- Symptoms. (n.d.). Retrieved from <https://www.autismspeaks.org/what-autism/symptoms>
- What to expect. (n.d.). Retrieved from <http://www.whattoexpect.com/wom/family-life/how-to-explain-autism-to-typical-kids-and-lots-of-others-while-you-re-at-it.aspx>
- When Your Family Doesn't Understand Autism. (n.d.). Retrieved from <http://www.snagglebox.com/article/autism-family-acceptance>