

Sibling Perspectives: GUIDELINES FOR PARENTS

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THERE IS LITTLE DOUBT THAT THOSE OF US RAISED WITH SIBLINGS HAVE BEEN INFLUENCED BY THAT RELATIONSHIP.

Living with a brother or sister on the autism spectrum (ASD) adds more significant and unique experiences to that relationship. Throughout numerous accounts of parents and siblings of children with disabilities, it becomes very clear; when a child in the family has a disability, it affects the whole family. Also clear is that each family member can be both strengthened and stressed from this situation. The degree of these conflicting effects seem to vary from family to family and person to person. Some factors, however, can help strengthen families and minimize the stressors. This article is meant to arm you with important information and practical suggestions for helping and supporting siblings.

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Though limited research has been done, a child's response to growing up with a brother or sister with a disability is influenced by many factors such as age, temperament, personality, birth order, gender, parental attitudes and modeling, and informal and formal supports and resources available. Certainly, parents have little control over many of these factors. However, parents do have charge of their attitudes and the examples they set. Research by Debra Lobato found that siblings describing their own experiences consistently mentioned their parents' reactions, acceptance and adjustment as the most significant influence on their experience of having a brother or sister with a disability (Lobato, 1990).

Lobato's research also showed that a mother's mental and physical health is probably the most important factor in predicting sibling adjustment regardless of the presence of disability in the family (Lobato, 1990). Positive outcomes that siblings frequently mention are learning patience, tolerance and compassion, and having opportunities to handle difficult situations. These opportunities also taught them confidence when facing other difficult challenges. Research by Susan McHale and colleagues found that siblings without disabilities viewed their relationship with their brother or sister with autism as positive when:

1. They had an understanding of the sibling's disability;
2. They had well-developed coping abilities; and
3. They experienced positive responses from parents and peers toward the sibling with autism (McHale et al., 1986).

Some siblings have negative experiences when their brother or sister has ASD. Anxiety, anger, jealousy, embarrassment, loss, and loneliness are all emotions that children will likely experience. Because of the nature of ASDs there are barriers to the sibling bond that can cause additional stress. Communication and play can be difficult between siblings when one has ASD. Often the sibling without the disability is asked to assume, or may on their own feel obligated to assume, the role of caretaker. These issues should be addressed proactively. Siblings are members of the family who need information, reassurance

and coping strategies just as parents do. Siblings have a unique bond with each other, which is usually life long. Having a sibling with a disability impacts this bond and will impact each sibling differently. As a parent of a child with ASD, you can directly influence and support positive relationships for siblings. Just as you have learned to be proactive for the sake of yourself and your child(ren) with ASD, siblings need you to be proactive in helping them, too.

POSITIVE OUTCOMES THAT SIBLINGS FREQUENTLY MENTION ARE LEARNING PATIENCE, TOLERANCE, AND COMPASSION AND HAVING OPPORTUNITIES TO HANDLE DIFFICULT SITUATIONS.

Each family is unique. Some family structures include single parents, multi-generational households, and households with other significant stressors including more than one member with a disability. Each family has its own beliefs, values, and needs. But regardless of family circumstances, the suggestions discussed here are supportive strategies to consider when assisting siblings in coping with a brother or sister on the autism spectrum.

12 IMPORTANT NEEDS OF SIBLINGS AND TIPS TO ADDRESS THESE NEEDS

- 1. Siblings need communication that is open, honest, developmentally appropriate, and ongoing.** Parents may need to deal with their own thoughts and feelings before they can effectively share information with siblings. Children may show their stress through their withdrawal or through inappropriate behaviors. Siblings may be reluctant to ask questions due to not knowing what to ask or out of fear of hurting the parent. While doing research on siblings, Sandra Harris found that developmentally appropriate information can buffer the negative effects of a potentially stressful event (Harris, 1994).
- 2. Siblings need developmentally appropriate and ongoing information about their sibling's ASD.** Anxiety is most frequently the result of lack of information. Without information about a sibling's disability, younger children may worry about "catching" the disability and/or whether they caused it. The young child will only be able to understand specific traits that they can see, like the fact that the sibling does not talk or likes to line up their toys.
- 3. Siblings need parental attention that is consistent, individualized, and celebrates their uniqueness.** Many families make a major effort to praise and reward the child with the disability for each step of progress. This same effort should be considered for the siblings. Self-esteem is tied to this positive recognition by parents. Remember to celebrate everyone's achievements as special.
- 4. Siblings need time with a parent that is specifically for them.** Schedule special time with the sibling on a regular basis. Time with the sibling can be done in various ways such as a 10 minute activity before bed or a longer period several times a week. The important thing is to schedule specific "alone" time with a parent that siblings can count on.
- 5. Siblings need to learn interaction skills with their brother or sister with ASD.** Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings play skills to interact successfully with their brother or sister with ASD. Go slow and praise the sibling. Toys and activities should be age appropriate, hold both children's interest and require interaction. Teach siblings to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2003).
- 6. Siblings need choices about how involved they are with their brother or sister.** Be reasonable in your expectations of siblings. Most siblings are given some responsibility for their brother or sister with a disability. Show siblings you respect their need for private time and space.
- 7. Siblings need to feel that they and their belongings are safe from their brother or sister with autism.** Some children with ASD can be destructive and hard to redirect. They can also be quick to push, bite, or engage in other challenging behaviors with the sibling as a target. Siblings must be taught how to respond in these situations. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their sibling's aggressive behaviors.
- 8. Siblings need to feel that their brother or sister is being treated as "normal" as possible.** Explain differential treatment and expectations that apply to the child with a disability. As they mature, siblings can better understand and accept the modifications and allowances made for the brother or sister with a disability. Make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with ASD.
- 9. Siblings need time to work through their feelings with patience, understanding, and guidance from their parent(s) and or a professional, if appropriate.** Listen and acknowledge what is being said. Validate the sibling's feelings, both positive and negative, as normal and acceptable. Sharing your positive and negative emotions appropriately is also important. Remember parents are important models of behavior. Help siblings learn ways to cope with and manage their emotions.
- 10. Siblings need opportunities to experience a "normal" family life and activities.** If needed, draw on resources in the community, both informal and formal. Some families are uncomfortable in asking for help. For the sake of everyone in the family, find and use resources available such as respite care services and other community programs for persons with disabilities and their families. Most families would be overwhelmed without some breaks from the ongoing demands of caring for children with a disability. Siblings and parents need opportunities for activities where the focus of energy is not on the child with special needs.
- 11. Siblings need opportunities to feel that they are not alone and that others understand and share some of the same experiences.** Siblings need to know that others are growing up in similar family situations. Opportunities to meet other siblings and/or read about other siblings are very valuable. Some might benefit from attending a sibling support group where they can talk about feelings and share a common understanding while also having opportunities for fun.
- 12. Siblings need to learn strategies for dealing with questions and comments from peers and others in the community.** Parents should help prepare siblings for possible reactions from others toward their brother or sister with a disability. Make sure the sibling has facts about ASDs. Discuss solutions to possible situations. For example, the Autism Society offers wallet-sized autism awareness cards in English and Spanish that siblings can carry (see Web site for details).

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ASD & Siblings

Addressing the Needs of Neurotypical
Siblings of Children with Autism Spectrum
Disorders: A Guide For Parents



ASD & Siblings

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April 2018
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About this Toolkit

For parents, taking care of a child with special needs can present some difficult challenges. Yet, being a sibling of a child with special needs has its own challenges, which can sometimes go overlooked. Most parents understand that having a sibling with autism can be overwhelming at times for their neurotypical (NT) child, but the immediate nature of the needs of their child with an Autism Spectrum Disorder (ASD) may get in the way of helping their NT child cope. This can sometimes lead parents to experience feelings of guilt and failure. This guide was created by siblings as a way to help parents address the needs of neurotypical siblings of children with autism.



Explaining Autism

Educating your neurotypical child about ASD can help them gain a better understanding of their sibling's needs and behaviors. If your neurotypical child is young, it may be important to explain that autism can sometimes make certain things hard for their brother or sister, and that they need help and support from everyone in the family. As your child ages, you will be able to explain ASD in more detail. If meltdowns are an issue, be sure to mention that your child with ASD may have meltdowns because they're feeling overwhelmed or frustrated. If your child with ASD is nonverbal, help your NT child to understand that behaviors can be a nonverbal form of communication. Be sure to give your child the opportunity to bring up any specific concerns or questions they may have.

TIP

"How do I explain autism to a sibling?" is an insightful article by Maureen Bennie that provides tips on discussing ASD in three stages, depending on the sibling's age. To view the article, visit autismawarenesscentre.com.

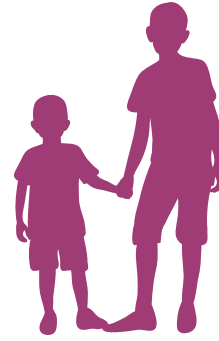
Recognizing Feelings

In addition to the love and pride a sibling often feels, it's perfectly natural for siblings to experience other feelings as well. It's important to keep an ongoing, open dialogue with your child so you can recognize these feelings and help them understand what they are experiencing, as well as how best to cope. According to siblings, these feelings can include:

Resentment: The neurotypical child may feel resentful toward their sibling, their parents, and even toward strangers. They may resent their sibling for having loud or inappropriate behaviors, or for preventing their family from living a "normal" life. They may be resentful that they cannot have friends over, sleepovers, or go on family vacations. They may feel resentful towards their parents for expecting them to watch their sibling, or for seemingly spending more time with their sibling. They may resent having to explain their sibling's behaviors to peers, or the possibility of someday having to take on the responsibility of guardianship and overseeing the care of their sibling with autism when they are older.

Guilt: Resentment can lead to guilt. They may feel guilty that they have negative feelings toward their sibling, or even harbor feelings of guilt that they are neurotypical and their sibling is not. Other times, they may feel guilty for wishing their parents spent more time focused on them instead of their sibling. It's also been said that neurotypical children may feel uncomfortable talking about their struggles because they don't want to give their parents additional worry.

Embarrassment: Siblings may experience feelings of embarrassment at times when their sibling with autism engages in difficult behavior in a public setting, or when they have friends over. They may be embarrassed when their sibling is loud, or draws negative attention through their behavior.



Anxiety: Siblings may be anxious that their brother or sister's behaviors might draw attention from strangers. They may experience anxiety relating to their perceived need to be perfect in their parents' eyes in an attempt to reduce their parents' level of stress.

Concern: Siblings may find themselves in a state of worry about the safety of their brother or sister with autism. They may worry that their sibling will not progress or that they are suffering emotionally and physically. They may also worry about their parents' wellbeing, as many children are intuitively aware of their parents' stress levels as they try to care and advocate for their children's needs.

Sadness/Despair: Your child may feel like nobody understands what they are experiencing growing up with a sibling with special needs. They may feel sad that their parents always seem busy attending appointments, talking on the phone with doctors, or researching treatments for their child with special needs. They may also feel sad that their sibling is struggling to progress, or that they may never have a "normal" relationship with their sibling.

Fear: They may fear their sibling due to aggressive or unpredictable behaviors, or be unsure of how to play with their sibling in a way that's fun, but not overly stimulating. They may fear the reactions of strangers, and the possibility of their sibling or themselves being bullied.

Addressing Concerns

Be sure to acknowledge and validate your child's feelings, and make sure they understand that it is perfectly normal to have such feelings and concerns. Let them know they are not alone, millions of other kids are going through the same situation. In fact, reiterate how proud you are of them for sharing their feelings.

If you are concerned that your neurotypical child sometimes fears your child with autism, speak to them about their fears. Reassure them that you will keep them safe. Make a plan if your child with autism experiences meltdowns, such as designating a safe place for your neurotypical child if needed.

Discuss how strangers may react to their sibling, and how to react to strangers. If they stare, mock, or bully, tell your child how you think they should react. Encourage them to educate others if possible. If they are willing, empower them to be an advocate for compassion and understanding toward not only their brother or sister, but for all people with disabilities.

Above all, make sure they know that the opinions of bullies are meaningless, ignorant, and should be ignored. True friends will always be kind and understanding.



If your child feels like they are alone, you may be able to ask their school to share your information with other families that have a child with special needs and neurotypical siblings. Your child may be able to connect with others who are experiencing the same things as them. They may feel more comfortable discussing their feelings with a peer their age.

If it applies, talk to your child about perfectionism. They may feel like they need to be perfect in order to “make up” for their sibling with special needs. Explain that they do not need to be perfect, they just need to be themselves and they are loved beyond measure.

If your child is hesitant to tell you how they're feeling, discuss with them healthy ways of dealing with emotions through activities like exercise, singing, dancing, art, sports, and talking to trusted friends and adults. Reassure them that you are always there to listen and will never judge them.



Research indicates that the majority of neurotypical kids cope well with their experience of having a sibling with ASD. However, that doesn't mean that they do not encounter particular difficulties. While having a sibling on the spectrum is a challenge to the siblings, it is certainly not an insurmountable obstacle. Talk to your physician if you see any of these warning signs in your neurotypical children as they try to cope with a sibling on the autism spectrum:

- withdrawal (e.g., hibernating in their bedroom)
- talk of hurting themselves
- poor self-esteem
- poor concentration
- physical symptoms (e.g., headaches or stomachaches)
- loss of interest in activities
- hopelessness
- frequent crying or worrying
- difficulty separating from parents
- changes in eating or sleeping (e.g., too much or too little)

From the article, *Helping Your “Neurotypical” Children Cope with a Sibling on the Autism Spectrum*, myaspergerschild.com

Offering Support

Take Time to Connect

Time to bond and engage with your neurotypical child can be difficult to come by, but what's most important is to spend quality time together, when your attention can be focused only on them. If outings alone aren't possible, try to dedicate some time to them whenever you can, even if it's just a few minutes of reading together at bedtime or playing a game. Do something together that the child enjoys, like video games, makeovers, or sharing a favorite meal.

Give Guidance

Younger children who want to play with their sibling with autism may need guidance. Encourage fun play time for both siblings. Demonstrate play that will not be overstimulating for your child with autism. Activities like Play-Doh, train sets, Legos, coloring/drawing, video games, blowing bubbles, or playing outside on a trampoline or swing set can be fun activities for all kids. Encourage good behaviors like sharing and taking turns.

Offer Sources of Support

If you think it would benefit your child, talk to them about sibling support groups or counseling. If possible, allow them to occasionally have time away from home to enjoy a sleepover with a friend, or a stay at a family member's house for the weekend.

Always Remember

Sometimes parents worry that they do not spend enough time with their neurotypical child in relation to the time they spend with their child with special needs. This often leads us as parents to feelings of guilt. But the reality is, we can only do our best – and that is enough.



Suggested Reading

My Brother Charlie by Holly Robinson Peete & Ryan Elizabeth Peete

What About Me? A Book By and For An Autism Sibling by Brennan & Mandy Farmer

The Autism Acceptance Book: Being a Friend to Someone With Autism by Ellen Sabin

A Friend Like Simon by Kate Gaynot

A Guide for Grandparents: Answers to Common Questions & Concerns Relating to Autism Spectrum Disorders



What is Autism?

Autism Spectrum Disorder (ASD) is characterized by social-interaction difficulties, cognitive impairments, communication difficulties, and repetitive behaviors. Because autism is a spectrum disorder, it can range from very mild to very severe and occur in all ethnic, socioeconomic and age groups. In fact, because each individual can vary greatly in symptoms and abilities, there's a popular saying: *If you've met one person with autism, you've met one person with autism.* Males are four times more likely to have autism than females. Some children with autism appear to develop typically before age 1 or 2 and then plateau or suddenly regress, losing language or social skills they had previously gained. ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.

My grandchild was just diagnosed. What now?

Your adult children will need your support as they navigate their new normal. As they embark on their journey of getting appropriate services/therapies for their child, learning to help their child communicate effectively and addressing any co-occurring medical issues, remember that they are likely feeling stressed and overwhelmed. Being a trusted person they can lean on, talk to without judgment, and offering support caring for their child, will be incredibly helpful.

I'm having difficulty dealing with my grandchild's behaviors and meltdowns.

It is so important to recognize that your grandchild is not choosing to behave poorly. Many children with autism cannot communicate basic needs or wants. For example, if a child is thirsty, hungry, in pain, hot, cold, tired, wants to watch a specific show/movie, etc., they may not be able to tell you. Imagine living in a world where you cannot express yourself effectively. Many children are left feeling

A Guide for Grandparents: Answers to Common Questions & Concerns Relating to Autism Spectrum Disorders

frustrated and overwhelmed. They may also have sensory challenges making them especially sensitive to light, sound and touch. A lack of structure or predictability for the individual may also lead to the child engaging in undesirable behavior, including bolting or wandering from the environment. Helping to identify and avoid triggers is key to preventing a child from entering a "fight or flight" mode.

I don't think my grandchild's parents are getting the proper help for him/her.

Speaking openly, with a supportive tone is the best way to find out and understand what decisions your adult children are making for your grandchild. If you think they are unaware of specific rights or interventions you believe may be helpful, or if they are too consumed in getting by day-to-day, doing the research for them and presenting options in an easily-digestible way and offering to help with the logistics can be tremendously helpful. To understand more about evaluations and therapies, please download our First Signs, Next Steps toolkit by visiting: <http://nationalautismassociation.org/-first-signs-next-steps/>

How can I learn more?

For more specific issues, you can access free downloadable lectures by experts on a variety of topics on our website at nationalautism.org under the Autism Atrium WebiNAARs tab. Our website also offers free, downloadable toolkits and other helpful information.



Feeling like you need guidance and support from others? We invite you to join our Facebook support group for grandparents at: <https://www.facebook.com/naagrandparents/>

