

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).

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

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.

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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