



Siblings Perspectives: Some 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 with an autism spectrum disorder 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 families and each member can be both strengthened and stressed from this situation. It is the degree of these conflicting effects that seem to vary from family to family and person to person. There are some factors that have been found to help strengthen families and minimize the stressors. This brief article is meant to arm you with important information and practical suggestions for helping and supporting siblings.

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).

It is also important to note from Lobato's research 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 opportunities to handle difficult situations. These opportunities also taught them confidence for handling 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 siblings 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).

There are negative experiences of having a sibling with an autism spectrum disorder that should be acknowledged and addressed. Anxiety, anger, jealousy, embarrassment, loss, and loneliness are all emotions that children will likely experience. Because of the nature of autism spectrum disorders there are barriers to the sibling bond that can cause additional stress as a result; communication and play can be difficult between siblings when one has an autism spectrum disorder. Often the sibling without the disability is asked to assume or may on their own feel obligated to assume the role of caretaker. It is best to be proactive in addressing these issues. Siblings are members of the family that need information, reassurance and coping strategies just as parents do.

Each family is unique. There are various family structures such as 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. Regardless of family circumstances, the suggestions for parents discussed here should be viewed as supportive strategies that can be considered to assist siblings in coping with having a brother or sister with an autism spectrum disorder.

Twelve 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. Parents should be alert to the need to initiate communication with their son/daughter. 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 siblings' autism spectrum disorder.**

Anxiety is most frequently the result of lack of information. Without information about a siblings' disability, younger children may worry about catching the disability and/or if 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. School aged children need to know if the autism will get worse, and what will happen to their brother or sister. Adolescents are anxious about the future responsibility and impact of the disability on their future family.
- 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 even if an accomplishment is somewhat "expected." 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 each night or a longer period of ½ hour to an hour 3-4 times a week. The important thing is to have some specific times with a parent that siblings can count on having just for them.
- 5. Siblings need to learn skills of interaction with their brother or sister with an autism spectrum disorder.**

Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings necessary play skills to interact successfully with their brother or sister with an autism spectrum disorder. It is important to go slow and generously praise the sibling for his or her efforts. Toys and activities should be chosen that are age appropriate, hold both children's interest and require interaction. The sibling needs to be taught to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2003).
- 6. Siblings need to be able to have some choice about how involved they are with their brother or sister with an autism spectrum disorder.**

Be reasonable in your expectations of siblings. Most siblings are given responsibility for their brother or sister with a disability at one time or another. Show siblings you respect their need for private time and space away from the child with the disability. Make every effort to use respite services, community recreational programs, and other available supports so that you are not overly dependent on the sibling.
- 7. Siblings need to feel that they and their belongings are safe from their brother or sister with autism.**

Some children with an autism spectrum disorder 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. Generally this would include asking a parent for help in handling the situation. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their siblings' aggressive behaviors. Thomas Powell and Peggy Gallagher offer ideas on teaching basic behavior skills to siblings (Powell & Gallagher, 1993).
- 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. For various reasons, parents sometimes do not expect their child with an autism spectrum disorder to have chores and other responsibilities around the house. Attempts should be made to make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with the autism spectrum disorder.

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 you hear what is being said. Validate the sibling's feelings both positive and negative as normal and acceptable. Repeat back what you have heard the sibling say and check for accuracy. 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, it is important to 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.** Parents should recognize the need for siblings to know that there are others who are growing up in similar family situations with a brother or sister with a disability. Opportunities to meet other siblings and/or read about other siblings are very valuable for most of these children. Some children might benefit from attending a sibling support group or a sibling event where they can talk about feelings and feel accepted by others who 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 autism spectrum disorders. Discuss solutions to possible situations. They may even benefit from carrying their own information card for friends which they can hand out as needed.

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. The information presented here highlights some of the limited research and the most significant factors influencing a positive experience for siblings of a child with a disability. As a parent of a child with an autism spectrum disorder 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 an autism spectrum disorder, siblings need you to be proactive in helping them, too.

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