



# What About Me?

Becoming in tune with the needs of siblings of children with autism.

*by Jennifer Fortier, L.C.S.W., R.P.T.-S.*

Raising a child with Autism Spectrum Disorder (ASD) can place extraordinary demands on parents and families. Parents have many adjustments to make in order to adapt, but the siblings are often the ones in the family who spend the most time with the child with ASD and therefore live the moment to moment struggle to adapt with far more limited resources as they are still young, less mature beings. They have their own concerns, frustrations, worries, opinions and needs that deserve to be acknowledged, and in some cases may cause enough disturbance for them to warrant professional support outside of the home. Here are some of the challenges typical siblings struggle with routinely that are important to be aware of as parents, and some suggestions for how they can be addressed.

## **Understanding the Disorder**

Research indicates siblings of children with ASD often do not understand or have inaccurate information about their brother or sister's disorder. Education starting from a young age is helpful, including bringing the sibling to some of the doctor's appointments to become more aware of the facts of the child's condition. Keep in mind that sharing and interpreting information geared toward the child's current developmental level is important, and continuing to adjust the level of information according to their age and maturity level will be necessary. This includes giving many reminders over time. It will also help children to explain the disorder to others they encounter throughout their lives.

## **Forming a Relationship Bond**

This is tricky considering the nature of autism. In response to their natural attempts to play with their brother or sister with autism, siblings may experience indifference, being rebuffed, or meltdowns arising over their efforts to interact together. Children naturally become discouraged and seek relationships elsewhere when this occurs repeatedly. When parents help them find common ground, this can make a difference. Find simple activities they both share such as blowing bubbles, or when they each enjoy being tickled by a parent and share laughter together. It can be explained that "Josh doesn't enjoy some of these games you like to play because they are not comfortable to him. That may change as he grows, but for now these are some things you can do with him." Parents can also help by teaching the methods of getting the child with ASD attention, giving simple instructions that work best and how to praise/encourage him or her for positive engaging behaviors as they interact.

### **A Lack of Fairness**

This becomes the reality for the sibling of a child with ASD, as hard as you work as parents to offer the kids more equal amounts of time, attention or special accommodations. Siblings frequently feel jealousy as they quickly cue in to this aspect of being part of the family. They may exaggerate their reactions and expressed needs over typically minor scenarios such as skinning a knee, feeling ill or needing help with a task. Creating special time with the child without autism will help minimize this. Designating special times where parents have 1:1 outings with them, and time spent doing tasks such as a trip to the store, cooking or gardening together that need to be accomplished anyway are ways to offer this too. Bringing the sibling to their special school concert or school play alone if that would be necessary for an uninterrupted performance and experience is also important.

### **Fear of Aggressive Behavior**

Many siblings have dealt with beyond their share of this as much as parents would like to protect them from being on the receiving end of physical aggression. Kids may feel like they need to walk on eggshells to prevent the outbursts that frighten them. They can feel traumatized by witnessing the other child lashing out towards their parents or destroying property. While parents can't prevent every outburst, it's important that there are clear rules the kids are aware of, reasonable consequences that will be used consistently in fairness to both, and a safety plan for the child to follow to become removed from the situation and get help. A safe haven such as the child's room (if the sibling has his or her own room), or if not another designated corner or room of the house should be made up as a comfort zone to retreat for respite and peace as needed.

### **Mixed Emotions and Social Isolation**

I mention these together because these challenges for siblings can reinforce each other, creating a feeling of helplessness or sense of being trapped. They may feel confused about the autistic child's behaviors and Mom or Dad's response to them. They may feel angry or embarrassed to the point of wanting to avoid public encounters or having friends come to the house, and resentful that they can't have a "normal" family situation. They vacillate between feeling wary of bringing "outsiders" into their lives for fear of exposing the roller coaster they live on at home, and feeling overprotective fearing their sibling with autism will be misunderstood or mistreated. At the same time, the siblings often feel guilty about all of their resentful and embarrassed feelings because they love their family and care deeply for the child with ASD.

It's important to recognize these kids have a constant emotional struggle to be the one to remain calm, rational and level headed. It's helpful for parents to encourage them to identify, express and acknowledge all of their feelings as neither good nor bad but healthy and natural, being careful not to come to the rescue or defend the child with the disorder so much of the time.

Learning to develop and use a sense of humor regularly within the family is also of great importance if this is not something that has come naturally to the family. It will help the sibling to cope and receive the affirmation with exchanged looks or words that suggest “It's crazy sometimes, right?! But we're in this together!” Also, encourage honesty with regards to the situation. Siblings can benefit from dealing with stares, comments, or questions from outsiders not only with humor but with honesty, such as responding, “That's my brother, yes! Looks like he's gotten your attention. He has special needs. Do you have any questions?”

### **Becoming a “Parentified” Child**

This development may be the coping mechanism of a sibling who tries hard to make up for the perceived deficits of his sibling with ASD, or the pressure he or she feels to move into this role to help out with overwhelming situations for his family. Siblings are aware of how stressed their parents can become and will want to fix the problems. Kids can be helped with firm clear limits that will allow them to feel safe and that the adults are in charge, even when they feel challenged to be. The siblings can be assured that the desire to help is appreciated, but that they are also a child or young person and the parents are responsible for caring for both of them, so they don't need to act as the Mom or Dad of the child with autism. Siblings need to be given age-appropriate chores and responsibilities around the house instead, just as any child needs to feel capable and become independent. It may be necessary to seek outside help from trusted babysitters, family members, friends and neighbors to watch the child with autism to give necessary breaks for parents. If the siblings in the family are also young enough to require some child care, than they should also be included at these times under the trusted sitter's care. It's important not to put that burden of being in charge when the parents are out onto a sibling who may appear to be mature enough able to handle it.

### **Gaining Support**

This can be challenging to access, and as mentioned earlier, the feeling of social isolation can become a real challenge. Siblings need chances to have play dates, go to the movies, attend peers' birthday parties and have age-appropriate plans with other kids on their own outside of the family. In addition to this, they also benefit greatly from the support of those who can relate to their situation so they feel even less alone.

### **Resources Available for Support:**

HeartLight Healing Arts: Play therapy helps children using play-based interventions to engage and interact more successfully with their sibling with autism. It offers emotional support and improves coping skills for the sibling during his or her own individual therapy time. Therapy can also help siblings showing concerning signs of being withdrawn, depressed, overly anxious, fearful, or having problems sleeping, in social situations, or with school.



Adolescents can be helped with talk therapy, art and sand play to express their feelings and problem solve solutions. There are any number of troublesome symptoms that could be observed that may relate to or directly correlate with the demands of living with a child with ASD. Our office can be contacted if you have further questions or are interested in an assessment for your child who may be exhibiting behavior that concerns you.

**The Kennedy Krieger Institute in Baltimore:** This agency offers “Sibshops” which are fun workshops geared towards letting the siblings know they're not alone, and playing games that encourage developing problem solving skills to deal with their sibling with autism and with peers.

**The Autism Society:** The Autism Society can be contacted to locate a local ASD support group and to learn about more resources available in your area.

**Autism New Jersey:** This organization matches siblings with pen pals around the country and internationally.

**The Sibling Support Project of the ARC of the United States:** This project offers a range of information including reading lists for children and adults, sibling groups, meetings, and online resources.

Many demanding challenges exist for siblings of autistic children, but the good news is that these kids often turn out to be more compassionate, intuitive, and caring than average. Learning to manage the demands they face will help them build skills to become even more effective, capable and resilient adults.

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