

SUPPORT for the NEUROTYPICAL SIBLINGS of Children Impacted by Autism Spectrum Disorder

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Children with autism spectrum disorder (ASD) face an array of challenges. However, the challenges that face a sibling of a child with autism spectrum are less commonly considered. According to the Centers for Disease Control (CDC), one in every 54 children born in the USA will be diagnosed with autism by the age of eight years old.[1] Each of these children may have one or more siblings who might also be on the spectrum, or have some autistic-like traits. A recent article published in JAMA Pediatrics found that a sibling who is born after a child diagnosed with ASD is 30 times more likely to be diagnosed with the same condition when compared to later-born siblings of non-diagnosed children.[2] Siblings may be neurotypical in their development but have large responsibilities and burdens in assisting their parents with caring for the special-needs sibling. They may also have a genetic susceptibility that puts their future children at risk for being on the spectrum. As such, there are multiple layers to this issue and hundreds of thousands of children with challenges that must be addressed.

As a developmental psychologist and the Executive Director for the Center for the Developing Mind in Los Angeles, California, I often assist siblings and families of a child with autism. I help strengthen and support siblings with their individual difficulties. Although the issues vary, some of the more common difficulties are outlined in the examples below.

An Older Brother With Autism

A family has two children. The older child is 17 years old and has high-functioning autism, epilepsy and mental illness. The younger brother is 12 years old and longs to have a relationship with his older brother. He would like his older brother to play basketball with him, to help him with his homework and to treat him in a loving, thoughtful way. The older brother is unaware of his younger brother's loneliness and desire for a relationship. The younger brother recognizes that the majority of the family's attention goes to his older sibling. The older brother's epilepsy is severe, and the younger brother is often required to medically support his older brother during seizure episodes. The roles of the brothers are often reversed, as the 12-year-old brother often navigates the world for the 17-year-old. The 17-year-old understands enough to recognize this, and the parents need the assistance of the younger brother to constantly monitor the 17-year-old. There is a large degree of unwanted responsibility on the younger brother.

In this family, the difficulties lie in the younger brother's loneliness, role-reversal and unwanted responsibilities. The parents rely on the younger sibling's support for the older brother. This is common in families where there is a child with autism since parents are often overwhelmed and exhausted themselves. It is also common in situations like these for there to be a confusion of rules, as the rules for one brother are often different than the rules for the other brother.

The Middle Child Syndrome

A family has four children. The oldest daughter has high-functioning autism. She has social barriers typically seen in children with autism. The second child in the family, a boy, also has autism and is non-verbal and highly aggressive. His aggressive outbursts can be very frightening for everyone in the family. The two younger siblings are developing neurotypically and are often victimized by their aggressive, non-verbal older brother.

This family faces many challenges. First and foremost, the parents are concerned about the aggressive son. He is very tall, large and strong for his age. Recently, in the midst of a temper tantrum, the older boy smashed a sliding glass door with his fist. The parents and the other children were frightened and realized, in that moment, that his violence could put him and the other members of the family in real danger. Devastated and overwhelmed after years of trying to cope with aggression and violence in their home, the parents are now facing the decision of whether or not to institutionalize their son. Of particular concern is the youngest sister, who is most often the "victim of choice" for the aggressive brother. He regularly pulls his sister's hair and appears to randomly antagonize her with little or no provocation. The parents are extremely concerned that as their daughter ages, and enters into romantic relationships of her own, she may seek abusive partners. How will the abuse she encounters today impact her future?

The burden and responsibility of care for this severely impacted sibling have even fallen on the youngest child, a three-year-old, who the father refers to as "the smartest person in the family." There is often a confusion of roles as the younger sibling must help manage the older brother or sister. In this case, the three-year-old son has been seen trying to help toilet train his older brother. This is a lot of responsibility for a very young child.

Living in this constant chaotic environment is another challenge for the entire family. The parents are at a loss and feel helpless. Although they recognize the problems, the solutions are not obvious. They do not feel they can keep their children safe from the aggressive brother. They are exhausted from years of disrupted sleep patterns. They are constantly monitoring and managing the children with autism and have little time and energy left to attend to the needs of the younger children.

SOLUTIONS

Parents facing these kinds of challenges need to know that there is help. There are professionals who can give children and families the tools they need to succeed and thrive, and strategies to use that can improve relationships, family environments and outcomes. The following are some important starting points.

Parental Self-Care While this may seem like an impossible task, it is vitally important for the family's survival and success that parents learn how to take care of themselves. When parents are feeling rested, they can function as caregivers, rule-setters and mediators. In other words, they establish themselves as the true parental figures, which allows the children to be children. In collaboration with colleagues from UCLA, I recently conducted a research project investigating the feelings of neurotypical children who have a sibling with autism spectrum disorder. Preliminary results suggest that if parents take care of themselves, then the children in the household are able to be relaxed and function in their role as children (as reported at the American Psychological Association Annual Conference, Toronto, Canada, 2015).

Support Groups for Siblings The siblings of a child with ASD need a safe and understanding space in which to freely express themselves. They need a place where they have a voice. There is something very special about children being with peers who have similar experiences and who can truly understand the difficulties and challenges that happen when you have a sibling on the autism spectrum. It is critical for parents to seek out social support groups for the siblings of a child with autism.

Have Alone Time with Each Sibling When juggling the appointments, job requirements, other children's responsibilities and (hopefully) a little parental self-care, it is not always feasible for parents to *find* alone time with the neurotypical siblings. I understand that a full mommy-daughter spa day or a night out at the movies is not possible for many families. However, you can get around this obstacle by including your neurotypical child on your errands. Ask your neurotypical child to join you on a trip to the supermarket, and tell your child that he/she can pick out something that doesn't have to be shared with anyone else. This can be especially effective because siblings will tell you they feel like they have to share everything in their personal world and that the family focuses most on their autistic sibling. While you are running errands with your neurotypical child, be creative and find ways to connect. Tell your child a story about your favorite childhood cereal as you walk down the cereal aisle. Ask about his/her friends at school. Let your child talk. Ask what your child would like for dinner and find all the ingredients together.

Talk About Autism in Your Family Give the challenges and behaviors a name. Talk to all of the children - both ASD and neurotypical - about autism in a calm, relaxed and age-appropriate manner. I recommend that parents wait until their children ask questions about autism, and then answer them with simple answers. As they age, the explanations and answers will become more complex. Speaking about autism should be an ongoing discussion, based on the maturity of the person who is asking the questions.

SIGNS THAT A SIBLING MAY NEED HELP

Parents should constantly monitor the health and well-being of all of their children. Take note of any changes that are interfering with the child's daily functioning. Any unusual behavior and changes warrant attention and a conversation.

- Is the child playing with his/her friends?
- Have eating or sleeping patterns changed?
- Is the child overreacting to scenarios that never used to be a problem?
- Was the child who was once very social now self-isolating?

It is important to note that siblings often seek attention by mimicking the behavior of the child with autism. If needed, seek help to determine if the behaviors are aimed at gaining extra attention or if they are actual concerns.



HOW CAN PARENTS FACILITATE POSITIVE SIBLING RELATIONSHIPS?

Do Activities As a Family

I encourage parents to do as many things as possible as a family. For example, families can eat dinner together each night. Additionally, I encourage parents not to give the child with autism obvious privileges. The entire family, including the child with autism, can set the table together, eat dinner together, clear the table and do dishes together. Although the responsibilities of the child with autism may differ, the family is working together with a common goal in mind.

Find Activities That the Children Can Do Together

Whenever possible, find activities that the child with autism enjoys and then try to get the siblings to join in the activity. Water activities tend to provide enjoyment for the entire family, as the buoyancy of the water helps calm anxiety and appeals to the autistic child's sensory system. Horseback riding is another activity that I find very successful for families and siblings to enjoy together. I know one child who really loves to sculpt clay. He is an excellent sculptor and has begun to teach his neurotypical siblings how to sculpt. It's wonderful seeing how this activity is creating a bond between brothers. Parents should be excited about the strengths and abilities of their child with autism, and find creative ways to turn these interests into bonding experiences.

CONCLUSION

It is worth noting that many individuals with a sibling on the spectrum choose helping professions as adults. They tend to be very loving, thoughtful, bright and articulate individuals. They are raised to be more empathetic, more responsible and more flexible than most other people. They develop so many positive characteristics from having a sibling on the spectrum, and the world is truly a better place for having these amazing individuals in it.

References

1. Maenner, M.J., et al. (2020). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *Morbidity and Mortality Weekly Report. Surveillance Summaries* (Washington, D.C. : 2002). 69: 1-12.

2. Miller, M., Musser, E.D., Young, G.S., Olson, B., Steiner, R.D., Nigg, J.T. (2019). Sibling Recurrence Risk and Cross-aggregation of Attention-Deficit/Hyperactivity Disorder and Autism Spectrum Disorder. *JAMA Pediatrics*, 173(2):147-152. doi:10.1001/jamapediatrics.2018.4076

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