



Sibling Support

Guide for Parents and Caregivers

The content in this section is closely adapted, with permission, from the Organization for Autism Research *Brothers, Sisters, and Autism* resource guide for parents and caregivers.

View the document in its entirety at https://researchautism.org/wp-content/uploads/2016/04/OAR_SiblingResource_Parents_2015.pdf.

Overview

For a child or teen with autism, his longest lasting relationship will likely be with a neurotypical sibling or siblings. These lifelong friends, future advocates, and potential caretakers (depending on support needs and life circumstances) need guidance and support from parents. It starts with a positive framework for teaching siblings about how autism impacts their brother or sister, teaching healthy coping skills to address difficult situations or emotions, being aware of opportunities for mutual fulfillment, encouraging bonding, and making everyone feel special.

Explaining Autism

Siblings might ask about autism if they've heard you use the term, but they're more likely to ask about what their brother or sister is doing (ie, behaviors). There is no "perfect time" for these conversations, but starting early and revising your description for age appropriateness can be very helpful.

- Siblings want to know what is going on in their brother or sister's world, so try to offer any insight that you can about motivation or purpose. For example, if your child with autism rocks back and forth, flaps her hands, or repeats noises, explain that she may do this to calm down or feel safe when there's a lot happening (lights, sounds, etc) around her.
- Younger children are likely to do better with ability-based definitions, accompanied by concrete examples. For instance, "Your brother just learns a little differently than you and me, so he needs extra help." Incorporating the term *autism* into your explanation may help older children understand what it specifically means for their brother or sister more fully.

Family Life

All families experience and must manage challenges together. These challenges can be more pronounced when there is a child who has significant support needs, but it also creates opportunities for parents and caregivers to promote understanding and acceptance.

- Recognize that perceived unfairness can seem huge to siblings when their brother or sister with autism has special teachers or toys, or perhaps even fewer or different chores.
- Show siblings that while their brother or sister with autism might require more of your active attention, it doesn't mean he receives more of your love. Try when possible to set aside alone time and remember that even small signs of appreciation and affection go a long way.
- Observe and listen to how your neurotypical children are reacting to their brother or sister with autism. Keep your expectations flexible, acknowledge and validate feelings, and remember that factors such as gender and age difference impact all sibling relationships.

Out in Public

Activities outside the home can be a source of stress for a child with autism, but also for siblings if a child's autism results in behaviors that are misunderstood or misinterpreted by friends or strangers.

- Neurotypical siblings may feel guilty or conflicted about being embarrassed by something that their brother or sister does that stems from autism. It can help to equip them with the information and confidence to explain their siblings' autism (without getting defensive) if they're comfortable doing so, or encourage them to ignore others' reactions.
- Special occasions, holidays, or outings can be tough for a child with autism that has sensory sensitivities, trouble connecting with others socially, or strict routines. If this means that any of these experiences involve fewer family members or tend to get cut short, this can make them less enjoyable for neurotypical siblings and even lead to resentment of their brother or sister with autism. Try to keep their priorities and preferences in mind when planning.
- School can be a stressful time for siblings if they feel judged for having a sibling who does "weird" things or requires special attention, so help them come up with simple, efficient



Out in Public (*continued*)

ways to have thoughtful dialogues with their peers. For playdates at home, establish clear boundaries and encourage your neurotypical children to be open with their friends about anything related to their sibling's autism they should expect.

Challenges and Feelings

Having a brother or sister with autism comes with many joys but also a host of feelings (confusion, resentment, etc) that can be difficult to process. Parents and caregivers can help by acknowledging these feelings, keeping lines of communication open, and suggesting healthy coping strategies.

- Sometimes it can help to disclose your own struggles in feelings in ways that your neurotypical children can appreciate, and remind siblings that all siblings have moments where they don't get along, fight, or can't relate to each other.
- If your child with autism has aggressive behaviors, which can be a delicate topic to address, it is important for siblings to feel that they are supported and that their safety is a priority.
- If your child with autism has significant support needs, make sure that siblings are partners in planning for the future regardless of what you hope or expect their role to be.

Relationships Between Siblings

Siblings may feel distant from their sibling with autism or wish they had the same closeness they see between siblings from other families. Parents and caregivers play a critical role in building a foundation of love that exists even when there are communication or other barriers.

- Find ways for younger siblings to play together and encourage older siblings to find shared interests, looking for overlaps even when they might not be obvious. For example, a budding scientist and a sports enthusiast can do fun experiments (like bouncing a ball to learn about energy transfer) together.
- Beyond getting involved in a club or their own activities to take a break and recharge, siblings might find it helpful to connect in person or online (using a safe platform with appropriate supervision) with others who have a brother or sister with autism.

Sibling Support Organizations and Groups

Sibling Support Project (SSP) (www.siblingsupport.org) is a national program dedicated to the concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns.

- The SSP is best known for helping local communities start **Sibshops** (www.siblingsupport.org/about-sibshops). These are curriculum-based groups that provide young brothers and sisters of children with disabilities with an opportunity to connect with other siblings, share stories and feelings, and have fun together. There are hundreds of registered Sibshops with trained facilitators at locations across the country.

Sibling Leadership Network (SLN) (<https://siblingleadership.org>) promotes a broad network of siblings who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the life span enabling them to be effective advocates with their brother and sister, and to serve as change agents for themselves and their families.

- The SLN has member chapters in more than half of the states across the country, with opportunities for siblings to get engaged and/or resources to start their own chapter in a state without one. They also host an annual 2-day conference with rotating locations.

Siblings with a Mission (www.siblingswithamission.org) provides siblings and family members an opportunity to share their stories, offer suggestions, and make friends with others who understand. They spread awareness and offer support through story columns, a resource database, monitored video conversations, Web chat forums, sibling workshops, and family conferences.

- This organization hosts virtual support groups for brothers and sisters of people with several different disability diagnoses, including autism, as well as those grieving the loss of a sibling.

Sibling Support Selected Resources

Here are **autism sibling support resources** (<https://researchautism.org/how-we-help/families/sibling-support>) from the Organization for Autism Research.

- *Brothers, Sisters, and Autism: A Parents' Guide to Supporting Siblings* is a reference tool that addresses opportunities and challenges while also offering practical strategies.



Sibling Support Selected Resources (*continued*)

- *Life as an Autism Sibling: A Guide for Teens* uses a Q&A format to provide tips and advice on how to handle challenging situations in productive ways, with testimonials from actual teens.
- *Autism, My Sibling, and Me* is a colorful workbook that helps elementary-aged children learn what autism means for their brother or sister, answer questions, and think about fun ideas for activities to do together.

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities (www.amazon.com/Sibling-Survival-Guide-Indispensable-Disabilities/dp/1606130137)

- This book is edited by experts in the field of disabilities and sibling relationships and focuses on the topmost concerns identified in a survey of hundreds of siblings; it offers a sense that you're not alone, tips on how to talk to parents about plans for your sibling, and a crash course in guardianship, medical and legal issues, and government benefits for those in caregiving roles.

