



Sibling Issues

Most brothers and sisters of children with autism spectrum disorders (ASDs) cope well. However, they still have challenges in learning how to deal with a sibling with an ASD. This handout can help you teach your children how to meet these challenges.

How can we explain ASDs to our other children?

Children need to understand what ASDs are all about. Tell them about it early, do it often, and be open and honest with them. When explaining ASDs, give your children the information they need in a way they can understand. For example, very young children are mostly worried about strange behaviors that may scare or puzzle them. An older child may want to know how to explain ASDs to his friends. Teens may be concerned about the long-term needs of their sibling with an ASD and the role they will play in future care. Every age has its needs, and each child has his own concerns. Your task is to listen carefully to your child's concerns at each stage. Some siblings may be hesitant to ask about ASDs. They may not know what to ask, or they may not want to upset their parents. Parents who start discussions about ASD early can help siblings be more comfortable about sharing their feelings and asking questions about ASDs.

Children need to be told about ASDs again and again as they grow up. Young children may use the words they hear their parents use but may not understand the full meaning of those words until they are much older. Don't be misled by a young child's use of words like "autism" or "behavior therapy." That does not mean the terms have real meaning for him.

What can we do to help our children form a good relationship with their brother or sister with an ASD?

It is sometimes hard for a young child to form a bond with a brother or sister who has an ASD. Some behaviors make it seem like the child with an ASD is not interested. This may discourage brothers and sisters from trying to form a relationship.

Young children can be taught simple skills that will help them to engage their sibling in play. These skills include things like making sure they have their sibling's attention, giving simple instructions, and praising good play. While many siblings will be asked to share in the responsibility for their brother or sister, parents should respect their need for some private time as well.

Siblings can play a game with their brother or sister who has an ASD. The game can be simple and should be at the developmental level of the sibling with an ASD. This teaches turn-taking to the sibling who has an ASD and can help form a positive routine for the siblings that they can both be successful with.

How can we make sure all of our children get special time?

Make sure that the child with an ASD is fully included in the family, but remember that other children in a family need time to be special too. Find some regular, separate time for the children in your family who do not have ASDs. It may be one evening a week, a Saturday morning, or even a few minutes at bedtime each night. If your child with an ASD has a home-based program or displays serious problems, you may not be able to give your other children the same amount of attention. But all of your children need to feel special to you and that they are equal partners in the family.

Some activities should be shared by the whole family, and others should not. There will be some events for which one child in the family deserves to be the focus of everyone's attention. In fact, there may be times when it may not be fair to include a brother or sister with an ASD. For example, if your child with an ASD cannot sit still for a school play, it may be better if she stays home when your other child performs.

If your child is eligible for it, find out if a special sitter or respite is available. Or talk to your child's school, your church, the doctor's office, or a local college and ask if resources can be suggested for a special respite sitter. Often parents feel uncomfortable leaving their child who has an ASD with a sitter. It is important, however, to use this time for your other children.

What issues do we need to deal with as our children reach adulthood?

Being the brother or sister of a person with an ASD does not end with childhood. The concerns of an adult sibling will be different from those of children. Young adults may focus on their own plans to have children and worry if their children are at risk for having ASDs. In some cases, young adults may also feel responsible for their brother or sister with an ASD, which makes it hard for them to leave home. Talk with your adult

children about what you expect of them in caring for their sibling with an ASD. Tell them it is OK to start their own lives as adults.

As you age, you and your children should talk about what will happen when you are no longer able to care for your child with an ASD. If the person with an ASD is not already living outside of the home, this may be a time when placement in a group home or supervised apartment is best. In families in which such care is needed, adult children and parents must figure out who will care for the sibling with an ASD when the parents are no longer able.

Are there support groups for siblings of children with ASDs?

Sometimes siblings of children with ASDs feel lonely. A way to deal with this is to connect them with others who can understand how they feel. Peer support groups for siblings of children with ASDs are becoming more available. Examples are

- Autism New Jersey (www.autismnj.org) matches siblings with pen pals around the country. Online resources are available, such as a chat room for siblings of children with disabilities (<http://autismnj.org/SiblingPenPalProgram.aspx>).
- The Sibling Support Project (www.siblingsupport.org) provides support and information to siblings of persons with disabilities while helping caregivers to understand the unique issues facing siblings.

Siblings may need opportunities to work through their feelings with understanding and guidance from their parents. If a child is having an especially hard time being the sibling of a person with an ASD, talking with a counselor might help.

Resources

American Academy of Pediatrics HealthyChildren.org:
www.HealthyChildren.org

Autism Society: Siblings: www.autism-society.org/living-with-autism/family-issues/siblings.html

Autism Speaks: A Sibling's Guide to Autism: www.autismspeaks.org/family-services/family-support-tool-kits#siblings

Autism Support Network: 12 important needs of siblings and tips to address these needs: www.autismsupportnetwork.com/news/12-important-needs-siblings-and-tips-address-these-needs-autism-22032431

Feiges LS, Weiss MJ. *Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Co; 2004

Harris SL, Glasberg BA. *Siblings of Children with Autism: A Guide for Families*. 2nd ed. Bethesda, MD: Woodbine House; 2003

Adapted from Autism Society: Siblings: www.autism-society.org/living-with-autism/family-issues/siblings.html, 800/3AUTISM (800/328-8476), and Autism Speaks: A Sibling's Guide to Autism: www.autismspeaks.org/family-services/family-support-tool-kits#siblings.

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate. Original document included as part of *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, 2nd Edition. Copyright © 2013 American Academy of Pediatrics. All Rights Reserved. The American Academy of Pediatrics does not review or endorse any modifications made to this document and in no event shall the AAP be liable for any such changes.

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