

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, and do it often!

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.

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 they 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 autistic 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.

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 autism. 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 each 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 when 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 autism. 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.

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 okay 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 where such care is needed, adult children and parents must figure out who will care for the sibling with an ASD when the parents die.

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

- The New Jersey Center for Outreach and Services for the Autism Community matches siblings with pen pals around the country. Online resources are also available. For example, it has a chat room for siblings of children with disabilities called SibChat. This organization's Web address is www.njcosac.org.
- The Sibling Support Project provides support and information to siblings of persons with disabilities while helping caregivers to understand the unique issues facing siblings. Its Web address is www.siblingsupport.org.

If a child is having an especially hard time being the sibling of a person with an ASD, talking with a counselor might help.

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

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