

What Do I Do?



Helping Your Kids Understand Their Sibling's Fetal Alcohol Spectrum Disorder



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Division of Knowledge Application and Systems Improvement, Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration, 1 Choke Cherry Road, Rockville, MD 20850

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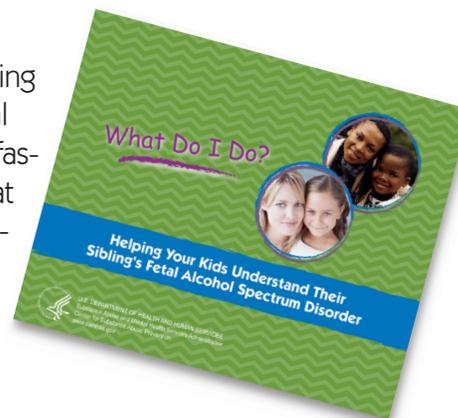
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What's This Booklet About?

Raising children is a tough job for parents. Parents raising a child with fetal alcohol spectrum disorder (FASD) need special help.

This booklet provides guidance on understanding sibling relationships when an FASD is involved. It answers questions you might have and suggests ways to help your children cope with their sibling's disorder. A list of resources is also provided if you need further information or support.

If you have specific questions or are interested in getting other materials, visit the Web site of the SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence at fasdcenter.samhsa.gov. You can also contact the Center at 866-STOPFAS (866-786-7327) or via e-mail at fasdcen-ter@samhsa.gov.



What Are Fetal Alcohol Spectrum Disorders?

“Fetal alcohol spectrum disorders” (FASD) is an umbrella term describing the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not used as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, and alcohol-related birth defects.



People with an FASD can have a range of disabilities from mild to extreme. More information is available on the SAMHSA FASD Center Web site, such as the fact sheet entitled “What You Need To Know: The Language of Fetal Alcohol Spectrum Disorders” (fasdcenter.samhsa.gov/grabgo/factsheets.cfm).

Is Having a Sibling With an FASD Different Than Having a Sibling Without an FASD?

Every child is unique, but FASD presents some challenges that many siblings don't face. People with an FASD can have qualities that make them different, such as:

- Being very unpredictable.
- Being moody, making forming a close relationship hard.
- Having trouble functioning in a typical environment.
- Having memory lapses.
- Showing behavior problems.
- Not understanding ownership. Your child may complain, “I've told him a million times to leave my stuff along and he just won't listen.” You can help by explaining that the child with an FASD isn't refusing to listen or pay attention. He or she doesn't remember being told to leave other people's things alone.

Despite the challenges, the relationship between siblings can be a very important part of anyone's life. A sibling's disabilities may change the nature of the relationship but do not prevent your kids from establishing a good one. Siblings share similar family experiences and can form special lifetime bonds.

At times, your children may act like typical siblings, arguing over the remote or blaming each other for breaking household rules. It's important to let the relationship develop in its own way at its own pace.

Many things will affect your children's relationship with each other. FASD is not the only factor. Your kids might have personality differences or nothing in common. That can make a relationship difficult. Family situations, such as divorce, can also affect the way a sibling relationship develops. Some siblings become close and remain so into adulthood, while others never get close or grow apart as they get older.

You can teach your kids not to snub their siblings because they have an FASD. You can guide your children, but don't force them to be friends. Children shouldn't be expected to stifle their feelings or to cut their sibling some slack. FASD does not excuse bad behavior. Your children may resent you if you let the child with an FASD "get off easy."



Is My Child Afraid To Tell Me That He Doesn't Like His Sibling With an FASD?

Kids might hate the problems associated with an FASD but still love their siblings. FASD can be confusing because your child may not look disabled. He or she might have a typical IQ but have emotional and behavioral problems. People with an FASD often misinterpret social cues. They might say their sibling is angry with them when there's nothing wrong. Your children might wonder what their sibling's problem is or why he or she can't just "get it together."

Other feelings siblings might have include:

- **Jealousy or anger** about all the attention the child with an FASD gets. They may see a sibling with an FASD getting attention for having problems and act out to get attention.



They might pretend to have problems with their schoolwork or complain of illness so that they can get attention too.

- **Anger about being different** from other families. Your children might be upset that your family does not do things other families do.
- **Isolation and loneliness** or feeling that no one else has the same feelings or experiences. Because of the stigma associated with FASD, your children's friends might be uncomfortable hearing about it and might not want to talk about it.
- **Guilt** for feeling angry or resentful or for not having a disability. Some siblings may feel they are to blame for their brother or sister's disability.
- **Embarrassment** about the sibling's behavior or appearance. Siblings who do not have an FASD might avoid contact with their brother or sister or not invite their friends home.

- **Fear** that they might develop an FASD. Children sometimes think that disabilities are contagious. They also might think they have an FASD if they do something their sibling with an FASD does. Your children might forget their homework one day and worry that they have an FASD.

- **Pressure to achieve** in order to make up for a brother or sister's inabilities. Your child might act interested in an activity and pretend to enjoy it just to make you happy.

- **Pressure to help take care of the sibling** and resulting anger, especially if taking care of the sibling conflicts with plans with friends or becomes overly burdensome.

- **Confusion about the disability.** Siblings often are not given thorough information about why a sibling has a disability, how it affects him or her, and what the family can do to help. Talking about FASD is important, especially since it provides a good opportunity to discuss alcohol use.

Many of these feelings affect children as they grow up, but siblings often continue to have concerns as adults. They may be concerned about the future of their sibling after their parents die, especially if the sibling with an FASD still lives at home.



Is There Anything Good About Having a Sibling With an FASD?

Despite the challenges, there are several positive aspects of having a sibling with an FASD. Many adults who grew up with a sibling with special needs say that they learned a lot. What they learned made them stronger and wiser adults. They feel they are more understanding and patient than they might have been otherwise. Children in families where a sibling has a disability can also become more mature, responsible, self-confident, and independent.

Growing up with a sibling who has an FASD may instill a greater level of understanding and development in the siblings who are not disabled. They may develop greater leadership skills, especially in areas where understanding and sensitivity to human awareness issues are important. Many leaders in The Arc and other contributors to the field of mental retardation, as well as other notable people, grew up with a sibling with a disability.

Having a sibling with an FASD can also make kids more aware of the dangers of alcohol use. They might be less likely to drink. It can also lead them into careers in substance abuse prevention, disability advocacy, health and social services, and similar fields.

Beyond what they might learn from the experience, your kids can enjoy their sibling with an FASD. Kids with an FASD have many good characteristics, just like other kids. They can have a good sense of humor, creativity, caring, a love of animals, determination, musical and artistic talent, and a desire to please (see *Teaching Students With Fetal Alcohol Syndrome/Effects*, available online at www.bced.gov.bc.ca/specialed/fas/). Everyone has something positive to offer. Encourage your children to look for the good things in their siblings, rather than focusing on the problems frequently associated with an FASD.

Can My Kids Still Play Together and Have Fun?

Children with an FASD can usually participate in most activities. Try to avoid competition. It can call undue attention to your child's disability. Frustration and feelings of failure may result.

Games with lots of rules can be difficult as well. Kids with an FASD can have trouble remembering how to play the game. Find things your kids can do together that allow them to share time without pressure. Singing, dancing, painting, watching videos, going for walks, and reading together are just some ideas.

Also remember that children with an FASD may have difficulty making and maintaining friendships. The inability to make friends may be stressful. Siblings and other family members can help provide friendship. But don't pressure your children to spend time with their sibling with an FASD if they'd rather be with other friends. They might resent being their sibling's only friend.



What Can I Do To Help My Children Cope With Their Sibling's FASD?

You can help siblings adjust in several ways:

- **Give each of your children individual time without interruption.** You might need help from your spouse or partner, a friend, or a relative. But it's important for your kids to know that they don't have to have a disability to get your attention. You may want to schedule individual time with each child.
- **Assure your children who don't have an FASD that their feelings are okay.** Ask them how they feel about having a sibling with an FASD. Encourage them to express their feelings openly.
- **Help your children accept their sibling's FASD.** They can be angry about the FASD but they still have to be nice to their sibling. After all, no one chooses to have an FASD. You can teach them ways to deal with any bad feelings that arise, such as leaving the room, counting to 10, or writing about it.

Anger management skills help in any relationship.

- **Remind your child that differences make the world more interesting.** People with an FASD are different, but they aren't bad. And we're all human. A sibling with an FASD may do embarrassing things sometimes such as being clumsy or interrupting others. But guess what? The child without an FASD might embarrass his or her sibling at times too.
- **Look for ways to play up the strengths of your child with an FASD.** Try to find activities that he or she can do well. Give your children a chance to see the child with an FASD doing good things that the whole family can be proud of, such as participating in Special Olympics or helping at a nursing home.
- **If your children want to help their sibling, encourage them.** But don't pressure them to help out. Relationships between siblings should embrace friendship rather than caregiving. Treat the child who does not have an FASD as a child, not as

another caregiver. Don't ask your child to take on responsibilities for which he or she is unprepared.

- **Help your children learn to communicate with their sibling with an FASD.** People with an FASD may have trouble understanding long sentences with many parts. They also may have difficulty following multiple directions. Remind your kids to use short words and sentences and to break things into steps. For example, if you want the child with an FASD to come downstairs for dinner, go upstairs and say that it's dinnertime. Then lead the child to the table.
- **Suggest positive reinforcement.** Tasks that we take for granted can be difficult for someone with an FASD. Even a simple "thank you" can mean a lot. Encourage your children to praise their sibling with an FASD if he or she gets something right or does something well.
- **Provide siblings with choices and include them in decision-making.** Discuss family matters with your children, especially if it affects them personally. Don't make assumptions. You might think that your children won't want to go to the mall because their sibling with an FASD might get overstimulated and act out. They might surprise you and say they don't mind. Also talk with older children, teens, and young adults about the future. For example, who will take care of the



child with an FASD if something happens to you? Provide your children with available resources and let them know they do not have to take on this responsibility alone.

- **Provide your children with information about FASD.** Answer their questions and respond to their concerns in a simple but precise manner. Explain the cause of FASD and let them know that they can't catch it. Siblings may also benefit from the support of a person outside the immediate family. A relative, trusted friend, or other resource people such as coaches and counselors may be helpful.

What If My Kids Ask Me a Really Hard Question, Like Why Their Sibling Has an FASD?

Kids are curious about FASD. That's why the SAMHSA FASD Center has a booklet for siblings to help them learn about FASD and get answers to their questions. The booklet is entitled "My Sibling Has a Fetal Alcohol Spectrum Disorder.

Can I Catch It?" You also might find it helpful to talk to other parents of kids with an FASD. Some questions may require outside help from a family counselor, therapist, or other professional. For example, if you drank when you were pregnant, your children might ask why. They might ask if you drank while you were pregnant with them and why they don't have an FASD like their sibling. These are difficult questions. Your answer will depend on your child's age and maturity and your relationship with him or her. It's okay to tell your child that you need to think about it and set up a time to talk later.



Where Can I Get Help?

Many organizations have support groups, such as The Arc's Sibshops. Sibling groups provide a forum where siblings can discuss their experiences, share ideas, and give each other support. Other sibling services include seminars and meetings that address topics of interest to siblings such as future planning (guardianship, alternative living arrangements, etc.). Programs that provide family support, such as respite care, also include siblings in the planning process or provide services in integrated settings where all siblings can participate.

You may also want to contact the National Organization on Fetal Alcohol Syndrome (NOFAS) for information about additional resources available in each State, including support groups. Visit their Web site at nofas.org or call 202-785-4585. See the next page for additional resources. Remember, you are not alone.

Additional Resources

The Arc, 1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910, 301-565-3842, fax 301-565-3843 or 301-565-5342, www.thearc.org.

FAS Community Resource Center, www.come-over.to/FAS.

FAS Family Resource Institute, PO Box 2525, Lynnwood, WA 98036, 253-531-2878 or in Washington, 800-999-3429, vicky@fetalalcoholsyndrome.org, www.fetalalcoholsyndrome.org.

Lobato, D.J. 1990. *Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children With Chronic Illnesses and Developmental Disabilities*. Baltimore: Paul H. Brookes Publishing Co.

Meyer, D., and Vadasy, P. 2000. *Living With a Brother or Sister With Special Needs: A Book for Sibs, Second Edition, Revised and Expanded*. Seattle: University of Washington Press.

Minnesota Governor's Planning Council on Developmental Disabilities. 1999. *Siblings: Brothers and Sisters of People Who Have Mental Retardation*. Silver Spring, MD: The Arc, www.thearc.org/faqs/qa-siblings.html.

National Family Empowerment Network, University of Wisconsin Medical School, Department of Family Medicine, 777 South Mills Street, Madison, WI 53715, 800-462-5254 or 608-262-6590, fax 608-263-5813, fen@fammed.wisc.edu, www.fammed.wisc.edu/fen/index.html.

National Organization on Fetal Alcohol Syndrome, 900 17th Street, NW, Suite 910, Washington, DC 20006, 202-785-4585, 1-800-66NOFAS, fax 202-466-6456, e-mail info@nofas.org, www.nofas.org.

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence, 866-STOPFAS, fasdcenter@samhsa.gov, fasdcenter.samhsa.gov.

SAMHSA National Clearinghouse for Alcohol and Drug Information (NCADI) 11420 Rockville Pike, Rockville, MD 20852, 1-800-729-6686, <http://ncadi.samhsa.gov/>.

Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way, NE, Seattle, WA 98105, 206-527-5712, e-mail dmeyer@chmc.org, www.chmc.org/departmt/sibsupp.

Stop Underage Drinking, www.stopalcoholabuse.gov

Stop and think. If you're pregnant, don't drink.
For more information, visit fasdcenter.samhsa.gov or call 866-STOPFAS.
www.stopalcoholabuse.gov



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