

# *Siblings of Children with Autism: A Guide for Families*

by Sandra L. Harris, Beth A., Ph.D. Glasberg

NOTES FROM THE BOOK:

## Explaining Autism

Parents can engage in frequent and open conversations with their children, taking care to present information in a way that best matches their children's developmental level. By creating an environment in which open dialogue about autism is ongoing, siblings will be more likely to share ideas, questions, and comments as they arise.

### Questions for Siblings:

1. Have you ever heard of the word "autism"? Tell me about it.
2. How do people get autism?
3. You've told me a lot about autism. How does having autism make your sister's / brother's life different than it would be without autism?
4. When she/he grows up, how will autism make your sister's/brother's life different than it would have been without autism?
5. How does having a sister/brother with autism make your life different than it would have been if she did not have autism?
6. When you grow up, will having a sister/brother with autism make your life different than if you had a sister/brother without autism?

### Tips for the questioning process:

- Hear your child out through his/her whole explanation before correcting any errors.
- Stay neutral, regardless of what you hear – remember not to judge your child's answers.
- Be sure to praise your child for sharing his/her feelings with you and acknowledge that you understand where any misconceptions about autism may have come from.
- Keep in mind that you want your child to feel comfortable speaking with you again.

- Be prepared for your child to share intense emotions ranging from sympathy to guilt to anger. Again, be sure to remain neutral. Your demonstration that she is entitled to whatever feelings she has may prevent her from judging herself about these feelings. Keep in mind that as your child is provided with opportunities to communicate with you, her feelings are likely to grow more positive.
- Consider the following example of how a parent might get a conversation like this started: “I realize that we’ve never spent much time talking about Janie’s disability. Since Janie is so important to both of us, I thought we should make sure that we learn about each other’s thoughts and feelings about it. Do you know what her disability is called?”

## **Suggestions For the Young Child:**

1. Keep the explanations simple.
  - You can’t catch autism.
  - It is nobody’s fault.
  - He hasn’t learned how to talk yet.
  - I will keep you safe.
2. Teach your children to deal with emotions.
3. Keep your children safe.

## **Suggestions for Middle Childhood:**

1. Encourage Independence.
2. Give more detailed explanations.
  - Autism happens before a person is born or is a tiny baby.
    - It is a problem in the brain.
  - It causes problems with talking, playing, understanding other people’s feelings.
    - People with autism can learn, but it takes a lot of work.
    - If your brother is aggressive, it is MY job to help him, not yours.
    - You can help him by playing and by showing him how to do things.
    - If your friends have questions, I can help you figure out what to say.

3. Help your children fit it.
4. Acknowledge that you are human.

## **Suggestions for Adolescence:**

1. Teach your adolescent to help with behavior management, without placing too much responsibility or putting them in harms way.
2. Answer questions about the future.
3. Continue to encourage independence.

## **COMMUNICATION, COMMUNICATION, COMMUNICATION**

**Create an atmosphere for communication – Between husband and wife AND between children.**

Teach the skills for communicating:

- Rule 1: Find the right place and the right time.
- Rule 2: Provide feedback and affirmation.
- Rule 3: Be open about your OWN feelings.
- Rule 4: Accept the other person's feelings.

***Family Conferences are a good tool for opening up the lines of communication.***

Rules for Family Meetings / Conferences:

1. The whole family should be present.
2. The television is turned off and the telephone answering machine is turned on.
3. No company.
4. Everyone who wants to talk gets a turn to talk.
5. Everyone listens while on person talks.
6. People should do their best to share their thoughts and feelings.
7. It is not fair to make fun of someone else's thoughts and feelings.
8. If the family cannot agree, parents have the final word.

## **OTHER TIPS FOR FAMILIES:**

Take time together.

Avoid embarrassment.

Choose the right activities for your family.

Create a private space for siblings to retreat to.

Use resources.

## **Helping Children Play Together**

To teach your typically developing child to become an effective teacher/playmate for his brother or sister with autism, you should follow a series of three steps:

- First, remember to go slowly, do just a little each day, and be liberal in your praise of your children and your pride in yourself.
- Second, create the setting for teaching.
  1. Select appropriate activities
  2. Schedule play sessions
  3. Model play skills
- Third, teach three basic skills:
  1. How to give clear, simple instructions
  2. How to reward good behavior
  3. How to give help when the child needs a prompt in order to respond

Being an effective parent includes such qualities as:

- Conveying respect, warmth, and love,
- Being consistent in one's expectations and rules,
- Setting clear limits on children's inappropriate behaviors, and
- Providing predictable but flexible childhood routines.

## **Siblings and Autism Book and Website List**

Compiled by Baylor University's Autism Resource Center  
[www.baylor.edu/soe/autism](http://www.baylor.edu/soe/autism)

### **Books:**

*All About My Brother*  
by Sarah Peralta

*Andy and His Yellow Frisbee*  
by M. Thompson

*Autism and Me: Sibling Stories*  
by Ouisie Shapiro

*Autism Through a Sister's Eyes: A book for Children about High-Functioning Autism and Related Disorders*  
by E.B. Band and G.B. Mesibov

*Children with Autism: A Parent's Guide*  
by Michael D. Powers

*Coping when a Brother or Sister is Autistic*  
by M.S. Rosenberg

*Effects of Autism on the Family*  
by Eric Schopler and Gary Mesibov

*Everybody Is Different: A Book for Young People Who Have Brothers or Sisters with Autism*  
by Fiona Bleach

*Everything You Need to Know when a Brother or Sister is Autistic*  
by M.S. Rosenberg

*I Love My Brother!: A Preschooler's View of Living with a Brother Who Has Autism*  
by C. Sullivan

*Ian's Walk: A Story about Autism*  
by C.A. Amenta

*My Brother Has Asperger Syndrome*  
by Jacob Betts

*My Friend with Autism: A Coloring Book for Peers and Siblings*  
by Beverly Bishop

*The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs*  
by Don Meyer

*Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum*  
by Lynne Stern Feiges , Mary Jane Weiss

*Siblings of Children With Autism: A Guide for Families*  
by Sandra L. Harris, Beth A., Ph.D. Glasberg

*Sibshops: Workshops for Siblings of Children with Special Needs*  
by Donald Meyer & Patricia Vadasy

**Websites:**

Sibling Support Project: <http://www.siblingsupport.org/>

Helping Siblings Understand Autism and Encouraging Positive Relationships:  
[www.autism.ca/siblings.pdf](http://www.autism.ca/siblings.pdf)

We the Siblings: [www.angelfire.com/bc/autism/index.html](http://www.angelfire.com/bc/autism/index.html)  
Interactive website with a chat room, pen pals, bulletin boards and pictures

# Sibling Questions

1. What kinds of things were confusing or difficult to understand about your brother/sister or his/her behavior before you learned about autism?
2. How old do you think you were when you first realized that your brother/sister was different from you and most other kids?
3. How did you learn about autism? What do you think would help other siblings learn about autism?
4. What are some ways that you have tried to help yourself deal with difficult feelings?
5. What works the best or helps you the most?
6. Are there things that make you worry about your brother/sister?
7. What is your favorite memory or special time with your brother/sister?
8. Is there something you'd like to tell other brothers/sisters of children with special needs?
9. Do you have advice for parents?

# Sibling Supports Links

Forum Discussion:

<http://www.iancommunity.org/cs/discussion?discussion=/forum/forums/show/28.page>

**Halo - sibling support group:**

<http://www.specialneedskidsdirectory.com/page/6660198>

**Friday Nite Friends respite program at Custer Rd. United Methodist:**

<http://www.crumc.org/templates/cuscusterroad/details.asp?id=33399&PID=340982>

**Site:**

<http://www.siblingsupport.org/>

**NPR Story:**

<http://www.npr.org/templates/story/story.php?storyId=98012194>

Articles

<http://www.time.com/time/health/article/0,8599,1698128,00.html>

<http://ezinearticles.com/?Autism---The-Effects-On-Siblings-Of-Autistic-Children&id=1049739>

<http://abcnews.go.com/WNT/story?id=2025829>

[http://www.brighttots.com/Autism/Siblings\\_autistic\\_children](http://www.brighttots.com/Autism/Siblings_autistic_children)

[http://www.associatedcontent.com/article/1611282/raising\\_happy\\_siblings\\_of\\_autistic.html](http://www.associatedcontent.com/article/1611282/raising_happy_siblings_of_autistic.html)

[http://www.associatedcontent.com/article/57503/autistic\\_children\\_resources\\_for\\_the.html?cat=25](http://www.associatedcontent.com/article/57503/autistic_children_resources_for_the.html?cat=25)

<http://www.child-autism-parent-cafe.com/siblings-of-children-with-autism.html>

<http://www.disabilityscoop.com/2009/05/26/sibling-questions/3404/>

Life's a Beach!

<http://www.lifesabeachgrill.com/>