

Sibling Issues

Alert! Alert!

Because NICHCY's website will only remain online until September 30, 2014, most of its rich content has moved to a new home, the **Center for Parent Information and Resources** (CPIR), where it can be kept up to date.

The new address of *Sibling Issues* at the CPIR is:

<http://www.parentcenterhub.org/repository/siblings/>



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In any family, each sibling is unique, important, and special. So are the relationships they have with each other. Brothers and sisters influence each other and play important roles in each other's lives. Indeed, sibling relationships make up a child's first social network and are the basis for his or her interactions with people outside the family.

Brothers and sisters are playmates first; as they mature, they take on new roles with each other. Over the years, they may be many things to each other — teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model. This relationship can be powerfully affected by a sibling's disability or chronic illness.

What do the sibs have to say about *their* experience of having a brother or sister with a disability? Read on, because they have a lot to say.

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Brothers and Sisters, in Their Own Words

We know from the experiences of families and the findings of research that having a child with a disability powerfully affects everyone in the family. This includes that child's brothers and sisters. Many authors and researchers have written with eloquence about how the presence of a disability affects each sibling individually, as well as the relationships between siblings.

It's different for everyone | The impact of disability in the family varies considerably from person to person. Yet there are common threads that run through siblings' stories. (1) For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability. It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with special needs or to experience feelings of great joy in watching him or her achieve even the smallest gain in learning or development. Megan, age 17, says of her life with her brother who has Down syndrome:

Every day Andy teaches me to never give up. He knows he is different, but he doesn't focus on that. He doesn't give up, and every time I see him having a hard time, I make myself work that much harder...I don't know what I would do without Andy. He changed my life...If I had not grown up with him, I would have less understanding, patience, and compassion for people. He shows us that anyone can do anything. (2)

In contrast, many siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child with special needs. (3) As Angela, age 8, puts it, "[T]here are times when I sit down and think, 'It's not fair!'" (4)

And many, many siblings swing back and forth between positive and negative emotions. Helen, age 10, whose sister has severe intellectual disabilities and seizures, begins by saying that she's glad to have a sister with special needs.

- *"It has opened my eyes to a world of people I never would have known about." (5)*
- But Helen also says, *"Sometimes I wish I had special needs. I think that a lot when Martha gets oohed and aahed over and nobody even thinks about me." (6)*
- Then in the next breath, Helen says, *"Another thing is that it really makes me mad when kids slap their chest with their hands and go, 'I'm a retard!' It made me so mad!" (7)*

Age can make a difference | The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the nondisabled sibling is, the more difficult it may be for him or her to understand the situation and to interpret events realistically. Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about "catching" the disability.

As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children. (8)

Talking with your children about disability | Clearly, it is important for you to take time to talk openly about your child's disability with your other children, explaining it as best you can in terms that are appropriate to each child's developmental level. As Robert Naseef remarks, "Just as parents need information, so do siblings, on their level." (9)

If you're concerned about sibling issues, let NICHCY put you in touch with resources that can help you open up the lines of communication and address the needs of your nondisabled children. You may also find there is a support group available to your children, which can provide an "excellent outlet" for siblings to share their feelings with others in a similar situation. (10) The Internet also offers amazing possibilities for connection sharing. We've listed a few places to start below.

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Read More about Sibling Issues

What Siblings Would Like Parents and Service Providers to Know

www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know

Siblings of Children with Special Needs

http://www.aboutourkids.org/articles/siblings_children_special_needs

What About Me? — Support for the Siblings of Disabled Children

<http://psychcentral.com/lib/2006/what-about-me-support-for-the-siblings-of-disabled-children/>

Dilemmas and Advantages of Siblings of Special Needs Children

<http://www.permanente.net/homepage/kaiser/pdf/44897.pdf>

The “Other Child” With Special Needs: Understanding Siblings of Disabled Children

<http://admin.disaboom.com/parenting-and-family-general/the-other-child-with-special-needs-understanding-siblings-of-disabled-children>

Siblings of Kids with Special Needs

<http://www.med.umich.edu/yourchild/topics/specneed.htm>

When A Sibling Is Disabled

<http://psychcentral.com/lib/2007/when-a-sibling-is-disabled/>

Parenting Siblings of Children with Disabilities

<http://www.parents.com/parenting/better-parenting/teaching-tolerance/parenting-siblings-of-children-with-disabilities/>

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For the Siblings Themselves

Sibling Support Project

The Sibling Support Project is a national program dedicated to the interests of brothers and sisters of people who have special health, developmental, or mental health concerns. Find out more about holding a Sibshop and search the database of over 350 existing Sibshops and other sibling programs across the United States, Canada and beyond, all at: <http://www.siblingsupport.org/>

We the Siblings

This site helps brothers and sisters of kids who have autism to meet each other.

<http://www.angelfire.com/bc/autism/index.html>

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References

- 1 | McHugh, M. (2002). *Special siblings: Growing up with someone with a disability*. Baltimore: Paul H. Brookes.
- 2 | Meyer, D. (1997). *Views from our shoes: Growing up with a brother or sister with special needs* (p. 89). Bethesda, MD: Woodbine House.
- 3 | Lavin, J.L. (2001). *Special kids need special parents: A resource for parents of children with special needs*. New York: Berkley Books.
- 4 | Meyer, D. (1997). *Views from our shoes: Growing up with a brother or sister with special needs* (p. 21). Bethesda, MD: Woodbine House.
- 5 | Ibid, p. 41.
- 6 | Ibid.
- 7 | Ibid, pp. 41-42.
- 8 | Lavin, J.L. (2001). *Special kids need special parents: A resource for parents of children with special needs*. New York: Berkley Books.
- 9 | Naseef, R.A. (1997). *Special children, challenged parents: The struggles and rewards of raising a child with a disability* (p. 144). Seacaucus, NJ: Birch Lane Press. (A revised edition of this book was published in 2001 and is

available from Paul H. Brookes.)

10 | See references 1 and 3 above.

(Editor's note: This page is an excerpt from *The Unplanned Journey*, written for parents who've learned recently that their child has a disability.)

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