

# parenting plus

## Siblings Need Support Too



By Laura Nelson

### Editor's Note:

This article first appeared in the 2004 Southwestern edition of Celebrating Special Children.

In 1958, I became the three-year-old big sister of a little brother with profound cerebral palsy. Parents, naturally, have their own story of what it means to care for a child with severe disabilities, but a sibling has unique perspective. During the 25 years of my brother's life, I developed a thick skin, a fiercely protective nature and a strong sense of empathy. Some of my most eloquent childhood memories are of teaching my friends (and anyone else within earshot, including well-meaning but misguided grownups) not to make fun of, not to be afraid of, and most of all, not to pity my brothers or others like him.

I'd like to say that I was the perfect big sister to my brother, but of course I wasn't. For every time I chastised (and sometimes beat up) a neighborhood kid for using the word, "retard," there were times that I was resentful for having to put my own life on hold in deference to my brother's needs. For every time I was proud of my ability to be compassionate and wise beyond my years, there were times that I was jealous of the attention my brother received. Many years later, as a young adult, I spent some time in therapy sorting out my feelings. It wasn't ever that I didn't love my brother; it wasn't necessarily that I wished to have a "normal" family, but it would have been an immense relief to have had someone I could talk to at the time, someone who understood what I was feeling.

The world has changed a lot in past forty years with regards to families with children with special needs. The Individuals with Disabilities Education Act (IDEA) promises that children with every type of disability have the right to be educated in a public school setting. Further, the concept of Inclusion advocates that these children be educated in

neighborhood schools. But siblings of children with disabilities must also have the right to be more visible in the community, to have access to support and services. When I was a child, no such support paradigm existed. Now it does.

While searching the Internet for resources for this article, one word kept showing up again and again: Sibshops. In 1994, Paul H. Brookes Publishing Company published *Sibshops: Workshops for Siblings of Children with Special Needs*, written by Donald J. Meyer and Patricia F. Vadasy. These authors, one the director of the Sibling Support Project at Children's Hospital & Medical Center in Seattle, and the other a research associate at the Washington Research Institute in Seattle recognized what siblings have always known and what parents sometime overlook: siblings of children with special needs need to be able to share their thoughts, concerns and fears about their unique circumstances. Unlike their parents, who came to the situation as adults, siblings have been with siblings all their lives and may very likely bear the responsibility of guardianship for their sibling after the parents are gone.

Excerpts from the Sibshops book offer insight into the thoughts and feelings of some of these children:

"...I have a new friend, Tom. We have a lot of fun together. My problem is that when Tom is joking around, he will say things like, "Cut it out, you retard!" I hate it when he says that because my baby sister, Jamie, has Down Syndrome. How can I get him to stop using that word?" or "Just because my brother has a disability and I don't, my parents expect me to be "Superkid." They expect me to get perfect grades in school. Does that seem fair to you?"

and "I always have to babysit for my sister. She has problems and my parents say I am the only one they can trust. I want to get a job after school but I'll feel bad if I leave them empty handed."

With these children and others like them in mind, Sibshops: Workshops for Siblings of Children with Special Needs, was created with five clearly defined goals:

- Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.
- Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.
- Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.
- Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.
- Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

In order to meet these goals, Sibshops provides a very easy-to-follow format which can be used by anyone. As the Sibling Support Project website states, "Originally developed for eight-to thirteen-year-old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger and older children. It has been adapted for brothers and sisters

of children with other special needs, including cancer, hearing impairments, epilepsy, emotional disturbances, and HIV-positive status." In addition, according to the book, "Any agency that serves families of children with special needs can sponsor a Sibshop provided it can financially support, properly staff the program, and attract sufficient numbers of participants. It's most effective if agencies work together to co-sponsor a local Sibshop. [The authors] have found that Sibshops are well within the reach and abilities of most communities. They are not expensive to run, and logistically are no more difficult to coordinate than other community-based programs for children, such as Scouts."

Teachers, social workers, school guidance counselors and parents can all be facilitators of the workshop model. It's even possible that a local social services agency, school or church

near you is already holding a Sibshop workshop. In Fairfax County, the public school system periodically provides sibshop workshops. Here are some of the comments of the participants:

Hannah, a 10-year-old said, "The best parts were being with other kids who know what it's like to have a "different" brother, cooking together, and just talking." We really appreciated the availability of this program."

Parents, too, expressed appreciation of the opportunity to have their children attend a SibShop. One mother stated, "Thank you so much for the opportunity for my children to attend the SibShop class. They have felt frustration over the behavior of their brother recently diagnosed with Asperger's. His reactions and behavior often caused them to feel embarrassed and out of step with their peers. Your class provided a safe place to explore their feelings and to put some concrete

actions in place to deal with their feelings. This was a unique opportunity for them and we are so very grateful. Please encourage others to participate in this program as facilitators and as participants. Each will be rewarded."

If you can't find a sibshop in your community, bring this article to the attention of someone at your school, church or social service agency. You can help your "other" kids get the support they need by helping to start a sibshops workshop in your community. ■

*My profound thanks to Don Meyer, who gave me permission to quote information from this book and from the Sibling Support website.*

## Resources

### **Sibshops: Workshops for Sibling of Children with Special Needs**

Additional information about sibling issues, including other books and newspaper/magazine articles can be found in the appendix of the workbook.

Paul H. Brookes Publishing Co.

PO Box 10624

Baltimore, MD 21285-0624

800-638-3775

410-337-8539 FAX

[www.brookespublishing.com](http://www.brookespublishing.com)

### **The National Association of Sibling Programs (NASP)**

#### **The Sibling Support Project**

Children's Hospital and Medical Center

PO Box C5371, CL 09

Seattle WA 98105

Don Meyer, Director

### **Sibling Support Project**

#### **The Arc of the United States**

6512 23rd Ave NW #213

Seattle, WA 98117

206-297-6368

[www.thearc.org](http://www.thearc.org)

### **The ARC of the United States**

Works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community. Additional information about sibling issues, including books and newspaper/magazine articles can be accessed from this site.

[www.thearc.org](http://www.thearc.org)

### **SibKids**

A listserv where young brothers and sisters of kids with special needs can talk to each other over the Internet.

[www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)

### **Sibnet**

A listserve where adult siblings can inquire about social services for their siblings and talk with other sibs. Many adult brothers and sisters have never talked to a peer about growing up with a sib who has special needs. SibNet will be a place to share the good times, the not-so-good times, and everything in between with others who "get it."

[www.thearc.org/siblingsupport/sibnet](http://www.thearc.org/siblingsupport/sibnet)

**We the Siblings** - This site helps brothers and sisters of kids who have autism to meet each other.

[www.angelfire.com/bc/autism/index.html](http://www.angelfire.com/bc/autism/index.html)

### **Sibshop Parents Group**

Children's Hospital of The King's Daughter

"We are always interested in starting new groups, so if you have a desire to develop a special interest group, let us know and we'll be happy to share ideas."

Norfolk

757-668-7646

757-668-7932

757-668-7950 FAX

Contact:

Gail S. Cervarich, Sibshop Coordinator

[www.chkd.org](http://www.chkd.org)